

EIGHTH INTERNATIONAL

Post-Polio ^{AND}
Independent
Living
Conference

SAINT LOUIS, MISSOURI

PROGRAM

June 8-10, 2000

Saint Louis Marriott Pavilion Downtown

SPONSORED BY

GAZETTE INTERNATIONAL NETWORKING INSTITUTE (GINI)

Coordinator of International Polio Network (IPN)
and International Ventilator Users Network (IVUN)

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**Gazette
International
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Institute**

*Coordinator of International Polio Network (IPN) and
International Ventilator Users Network (IVUN)*

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GINI thanks the presenters for providing the excellent information contained in this book.

If you share this information, we respectfully ask that you acknowledge both the presenter and that the information was disseminated at GINI's Eighth International Post-Polio and Independent Living Conference in June 2000.

GINI will incorporate the additional information presented at the conference and make the book available through its publications and www.post-polio.org.

Welcome to the Eighth International Post-Polio and Independent Living Conference ...

On behalf of the Board of Directors and staff of Gazette International Networking Institute (GINI), I welcome you to Saint Louis and to this unique gathering - our Eighth International Post-Polio and Independent Living Conference.

This meeting, although the eighth in nineteen years, represents some "firsts." For the first time, GINI circulated a "Call for Proposals." The responses were gratifying, and we built our comprehensive program around the ideas we received. Acting on feedback from previous conferences, we designed the program to offer multiple tracks of information with many interactive sessions for both health professionals and consumers. We have, with the expertise and commitment of our presenters, prepared this book. It contains abstracts, outlines, fact sheets, handouts, and "take home" material. We hope that the information about the presentations will assist you in choosing which session to attend and will provide you with quality information after you leave Saint Louis.

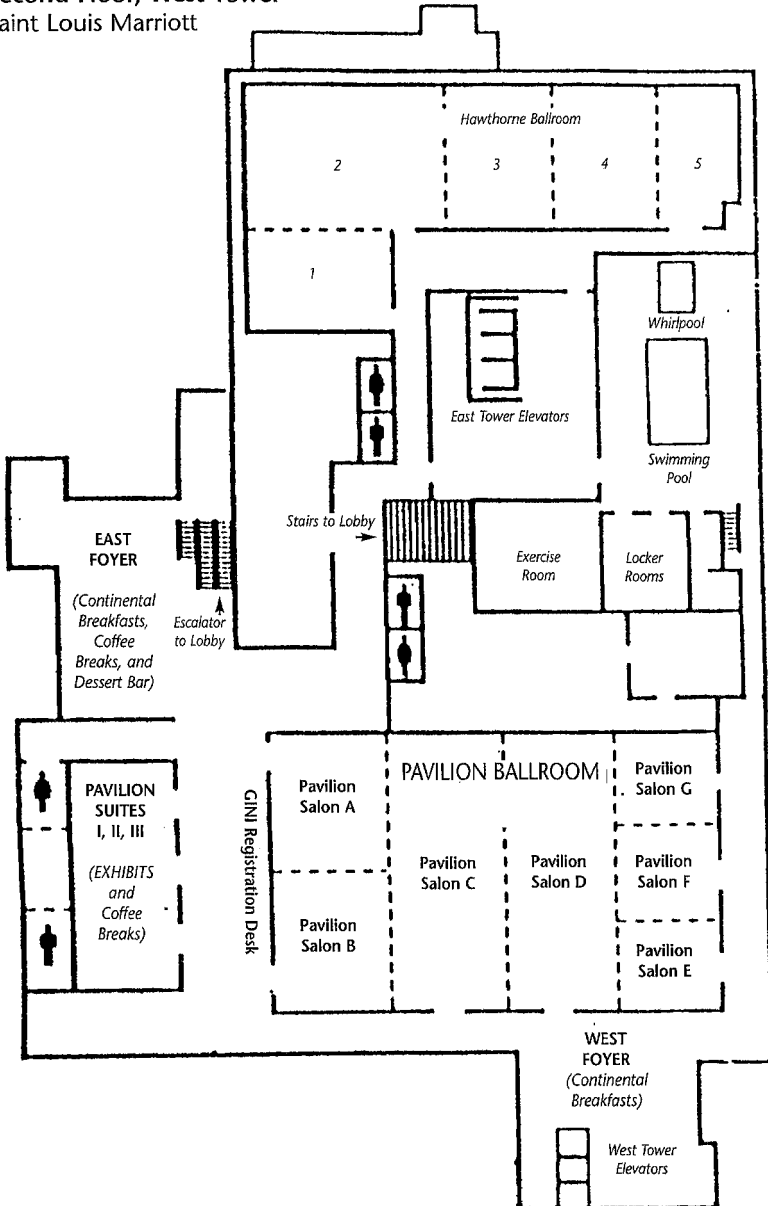
Another "first" is the concurrent seminar for occupational therapists and physical therapists. GINI is committed to providing education to health care professionals about the needs of polio survivors and ventilator users.

GINI's goal for this conference is to provide a forum that will cause you to think, offer you opportunities for interaction, and obtain answers to your questions. We want you to leave with a feeling not only of having received, but also of having participated.



Joan L. Headley
Executive Director, GINI

Second Floor, West Tower
Saint Louis Marriott



Details, details, details

Please wear your **NAME BADGE**; it is your "ticket" for the sessions.

The **TIME SCHEDULE** will be strictly adhered to because some of the sessions will be audiotaped and offered for sale at a later date through GINI's publications and www.post-polio.org. *The sessions scheduled to be audiotaped are marked in the program schedule with an asterisk.*

Prepaid **MEAL TICKETS**, including a Dessert Bar (Thursday evening) ticket, have been placed in your name badge holder.

Drs. Alba and Perry will be recognized before Thursday's luncheon in the Pavilion Ballroom. The meal tickets for Thursday's luncheon will be taken at the table. Non-ticket holders may participate in the opening (11:30-11:50 am) as space allows.

Friday and Saturday Luncheons, and Friday Dinner also will be served in the Pavilion Ballroom. Tickets will be collected at the door. Due to hotel restrictions, we cannot accept last-minute purchase of meals.

Dinner on Thursday and Saturday are "on your own." The Saint Louis Marriott Pavilion will be offering a stir fry/pasta bar both evenings in the Garden Terrace on the first floor.

CONTINENTAL BREAKFASTS (included with registration) will be served Friday and Saturday mornings in the East and West Foyers between 8:30 am and 9:15 am. Tables will be available in the Pavilion Ballroom (the same location as Friday's first session of the day).

NOTE: Continental breakfasts for the PT/OT Seminar will be served Friday and Saturday in Fort San Carlos, First Floor, between 7:45 am and 8:15 am.

COFFEE/ICED TEA BREAKS will be served in Pavilion Suites I-II-III and the East Foyer.

EXHIBITS are located in Pavilion Suites I-II-III. Information about the exhibitors and advertisements follow the program information in this book.

IN CASE OF AN EMERGENCY, call the hotel operator "O" and request that they call "911" which will alert the hotel so they can direct the emergency crew to you. The closest emergency room is BJC (Barnes-Jewish-Christian) Hospital.

To connect with others at the meeting, a **MESSAGE BOARD** has been provided near the GINI Registration Desk. Another convenient way to connect is to use the hotel voice mail system.

QUESTIONS FROM THE AUDIENCE will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Thursday, June 8, 2000

EIGHTH INTERNATIONAL
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SAINT LOUIS, MISSOURI

9:00 am - 6:30 pm	Registration (OUTSIDE PAVILION SUITES I-II-III)
2:30 pm - 5:30 pm 7:00 pm - 9:30 pm	Exhibits Open in Pavilion Suites I-II-III
11:30 am - 11:50 am PAVILION BALLROOM	GINI Honors Dr. Augusta S. Alba and Dr. Jacquelin Perry Joan L. Headley, MS; Martin B. Wice, MD
11:50 am - 1:00 pm PAVILION BALLROOM	OPENING LUNCHEON (Ticket required)
1:30 pm - 2:45 pm	SESSION I OPTIONS
PAVILION SALON D	Telling Our Own Stories: Polio Narratives Then and Now Daniel J. Wilson, PhD; Edmund J. Sass, EdD; Sally Aitken
PAVILION SALON F	Ventilator Users: Exploring the Issues – Learning from Each Other Deborah Cunningham; Audrey J. King, MA; Doris Jones
PAVILION SALON C	Managing Chronic Pain: Self-help Techniques Dorothy Woods Smith, RN, PhD, HNC
PAVILION SALON A	What the Numbers Say: Epidemiological Studies* Nete Munk Nielsen, MD, BSc; Barbara Ivanyi, MD, PhD; Linda Tompkins, MS
PAVILION SALON E	Strategies for Obtaining the Best Bracing Mark K. Taylor, MLS, CPO; Ammanath Peethambaran, MS, CO
PAVILION SALON G	Post-Polio Syndrome: The Theories Paul E. Peach, MD
PAVILION SALON B	A Multidisciplinary Team: Evaluation and Treatment of Polio Survivors* Anne C. Gawne, MD; Pima McConnell, PT, ATP; Linda Palmer, OTR/L Assessing Our Activities to Effectively Manage Our Lives* Hilary Hallam
2:45 pm - 3:15 pm PAVILION I-II-III & EAST FOYER	BREAK
3:15 pm - 4:30 pm	SESSION II OPTIONS
PAVILION SALON C	Beyond the Blues: Negotiating the Pitfalls of Depression Creatively Dorothea Nudelman, MA; Patricia Strong, MA
PAVILION SALON B	The Sleep-Bladder Connection* Mary Umlauf, RN, PhD; John McBurney, MD; Eileen Chasens, RN, DSN

An asterisk () marks the sessions that are being audiotaped.
One presentation (in Pavilion Salons D or C) each hour will be "real-timed."*

PAVILION SALON D

**Influencing Those Who Do Not “Get It ” ...
... Working with the Media**
Cyndi Jones
... Advancing Disability Studies
Karen Hirsch, PhD
... Teaching About Disability
Kathleen A. Navarre, PhD

PAVILION SALON E

Assessment of 277 Post-Polio Clinic Patients
Wendy Malisani
Nutrition for the Ventilator User
Paul Ott, RD (sponsored by Pulmonetic Systems, Inc.)

PAVILION SALON A

Strategies for Management of Arms and Shoulders*
Mary Ellen Brown, RPT; Nancy L. Caverly, OTR/L

PAVILION SALON F

**Self-empowerment and the Post-Polio Support Group:
A Conversation for Support Group Leaders**
Jeff and Linda Feinstein

PAVILION SALON G

Footwear and Care for Polio Survivors
Dennis J. Janisse, C.Ped

4:30 pm - 6:30 pm

DINNER (On your own)

A stir-fry/pasta bar is available in the Pavilion Terrace on the first floor. Information about downtown Saint Louis and its restaurants is available at the GINI Registration Desk.

6:30 pm - 8:00 pm

TWILIGHT SESSION OPTIONS

PAVILION SALON A

Writing Your Story: Getting Started
Daniel J. Wilson, PhD; Edmund J. Sass, EdD; Sally Aitken

PAVILION SALON G

Drawing Connections: Exploring Yourself Through Art
Mary St. Clair, MAT, ATR-BC, LCSW

PAVILION SALON B

Ronald's Rules for Winning
Robert J. Ronald, SJ

PAVILION SALON D

A Musician's Lesson: Listening and Learning from Our Bodies
Darwyn Apple, Violinist, Saint Louis Symphony Orchestra
Vera Parkin, Pianist

PAVILION SALON F

Expressing Intimacy & Sexuality
Linda L. Bieniek, CEAP

PAVILION SALON C

**Rejuvenating Partnerships: A Discussion for Survivors, Spouses,
and Significant Others**
Dorothea and Michael Nudelman; Jack Genskow, PhD, CRC;
Joyce Ann Tepley, LMSW/ACP, LPC

PAVILION SALON E

More Than A Best Friend
Bobette Figler, Support Dogs, Inc., Saint Louis, MO

8:00 pm - 8:45 pm

PAVILION I-II-III & EAST FOYER

GETTING ACQUAINTED DESSERT BAR
(Ticket required)

PAVILION SALON F	Breathing Devices: What's Available Augusta S. Alba, MD; Alan D. Fiala, PhD
PAVILION SALON B	Influencing Policy* Aging Issues Norma Collins ... MiCASSA (Personal Assistance Legislation) Deborah Cunningham
PAVILION SALON D	Managing Chronic Pain: Findings of a Pilot Program Dorothy Woods Smith, RN, PhD, HNC Benefits of Hot Pool Therapy Nickie Lancaster, RN
PAVILION SALON A	Spinal Problems and Solutions (Part I)* Carol B. Vandenakker, MD
2:45 pm - 3:15 pm PAVILION I-II-III & EAST FOYER	BREAK
3:15 pm - 4:30 pm	SESSION IV OPTIONS
PAVILION SALON G	Wheelchairs and Scooters: Making the Transition Linda Wheeler Donahue Funding through Medicare Robert H. Thayer Selecting the Appropriate Mobility Device Robbie B. Leonard, MS, PT
PAVILION SALON A	A Tracheostomy: What, Why, When* Edward Anthony Oppenheimer, MD
PAVILION SALON F	Advocacy It's Personal Audrey J. King, MA ... It's Cultural Neena Bhandari ... It Makes A Difference Susana Saavedra
PAVILION SALON E	Strategies for Obtaining the Best Bracing Mark K. Taylor, MLS, CPO; Ammanath Peethambaran, MS, CO
PAVILION SALON B	Finding, Nurturing, and Utilizing Local Resources* Elaine Burns Revitalizing the Support Group Membership* David A. Livingston
PAVILION SALON D	Complementary/Alternative Therapies: How to Choose S. Laurance Johnston, PhD
6:00 pm - 7:15 pm PAVILION BALLROOM	DINNER (Ticket required)
7:30 pm - 8:30 pm PAVILION BALLROOM	Presentation by The Dis-Ability Project, That Uppity Theatre Project (sponsored by AT&T)

Saturday, June 10, 2000



7:30 am - 1:30 pm Registration (OUTSIDE PAVILION SUITES I-II-III)

8:30 am - 1:00 pm Exhibits Open in Pavilion Suites I-II-III

7:45 am - 8:15 am CONTINENTAL BREAKFAST for PTs/OTs

FORT SAN CARLOS (1ST FLOOR)

8:15 am - 12:00 noon SEMINAR FOR PTs/OTs (PT/OT Program follows Main Schedule)

FORT SAN CARLOS (1ST FLOOR)

8:30 am - 9:15 am CONTINENTAL BREAKFAST

EAST & WEST FOYERS

9:15 am - 10:15 am **SESSION I OPTIONS**

PAVILION SALON G **Spinal Problems and Solutions: Surgical Options (Part II)**
Lynne Breakstone; Carol B. Vandenakker, MD

PAVILION SALON F **Activities of the Parents' Association of Children with Ventilators in Japan**
Yoichi Sakakihara, MD
Options for Ventilator Users in Denmark
Lotte Mortensen; Grethe Nyholm Olsen, RNP

PAVILION SALON A **Health Care Advocacy Strategies***
Robert J. Provan; Patricia Strong, MA

PAVILION SALON E **Why Do Some People Thrive?**
Joyce Ann Tepley, LMSW/ACP, LPC
Succeeding in a Wellness Program
Sunny Roller, MA

PAVILION SALON C **Maximizing the Efficient Functioning of the Musculoskeletal System**
Todd Holmes, MD

PAVILION SALON B **Anesthesia Concerns for Individuals with Neuromuscular Problems***
Selma H. Calmes, MD

10:15 am - 10:30 am **BREAK**

PAVILION I-II-III & EAST FOYER

10:30 am - 11:30 am **SESSION II OPTIONS**

PAVILION SALON A **The Polio Virus and Acute Poliomyelitis***
Burk Jubelt, MD

PAVILION SALON E **Nasal and Face Masks: What's Available**
Alan D. Fiala, PhD; Susan Sortor Léger, RRT
Working with a Home Care Company
Bob Fary, RRT

PAVILION SALON F **Assessing Our Activities to Effectively Manage Our Lives**
Hilary Hallam; Richard Boone

PAVILION SALON B **Footwear and Care for Polio Survivors***
Dennis J. Janisse, C.Ped

Friday, June 9, 2000



- 7:30 am - 1:30 pm **Registration** (OUTSIDE PAVILION SUITES I-II-III)
- 8:30 am - 5:00 pm **Exhibits Open in Pavilion Suites I-II-III**
- 7:45 am – 8:15 am **CONTINENTAL BREAKFAST FOR PTs/OTs**
FORT SAN CARLOS (1ST FLOOR)
- 8:15 am – 4:45 pm **SEMINAR FOR PTs/OTs** (*PT/OT Program follows Main Schedule*)
FORT SAN CARLOS (1ST FLOOR)
- 8:30 am - 9:15 am **CONTINENTAL BREAKFAST**
EAST & WEST FOYERS
- 9:15 am - 10:15 am **SESSION I (PLENARY)**
- PAVILION BALLROOM **Pulmonary Problems: Signs & Symptoms & Screening**
Peter C. Gay, MD (sponsored by ResMed, Corp.)
Cardiac Problems: Signs & Symptoms & Screening
Rupert D. Mayuga, MD
- 10:15 am - 10:30 am **BREAK**
PAVILION I-II-III & EAST FOYER
- 10:30 am - 11:30 am **SESSION II OPTIONS**
- PAVILION SALON A **Managing Our Weight: What We Can Do***
Josephine F. Walker
- PAVILION SALON B **Managing Cardiopulmonary Problems***
Peter C. Gay, MD (sponsored by ResMed, Corp.); Rupert D. Mayuga, MD
- PAVILION SALON C **Court Cases and Their Implications**
David Newburger, JD
- PAVILION SALON D **What About the Muscles?**
Barbara Ivanyi, MD, PhD; Jacquelin Perry, MD; Sophia Chun, MD
- PAVILION SALON E **Finding and Screening Information: Why, When, and How**
Sally Aitken; Cyndi Jones
- PAVILION SALON F **The Sleep-Bladder Connection**
Mary Umlauf, RN, PhD; John McBurney, MD; Eileen Chasens, RN, DSN
- 12:00 noon - 1:00 pm **NETWORKING LUNCHEON**
PAVILION BALLROOM (Ticket required)
- 1:30 pm - 2:45 pm **SESSION III OPTIONS**
- PAVILION SALON E **The Challenge of Polio and AIDS**
Sharon Maxwell Henkel
Gastrointestinal Distress: Listen to Your Gut
Linda L. Bieniek, CEAP

PAVILION SALON C	Involved in Life: A Study of Polio Survivors; Implications of the Mobility, Disabilities, Participation, and Environment Research Project David B. Gray, PhD; Karen Hirsch, PhD; Mary Gould, RN, BA; Heather Vargus, OTS
PAVILION SALON G	Self-Management of Chronic Conditions Peter Jay
12:00 - 12:45 pm PAVILION BALLROOM	LUNCHEON (Ticket required)
12:45 pm - 1:15 pm PAVILION BALLROOM	Celebrating the Tenth Anniversary of the ADA: The Unfinished Revolution Robert J. Provan Lighting of Spirit of the ADA Torch Cyndi Jones; Robert J. Provan; Bill Stothers
1:30 pm - 2:15 pm	SESSION III OPTIONS
PAVILION SALON B	Ventilator Users: Unanswered Questions* Augusta S. Alba, MD; Audrey J. King, MA; E. Anthony Oppenheimer, MD
PAVILION SALON D	An Ideal Post-Polio Clinic: Philosophy and Design Jessie K.M. Easton, MD; Karen Kennedy, MSW, CSW; Wendy Malisani; Jack Martin, PT
PAVILION SALON A	Guide to Developing a Post-Conference Personal Plan of Action* Linda L. Bieniek, CEAP; Linda Wheeler Donahue
2:15 pm - 2:30 pm PAVILION I-II-III & EAST FOYER	BREAK
2:30 pm – 3:15 pm	SESSION IV (PLENARY)
PAVILION BALLROOM	Report from March of Dimes International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care ... the role of the March of Dimes as convener of their conference Michael Finnerty ... a review of the information Frederick M. Maynard, MD
3:30 pm - 4:30 pm	CLOSING SESSION (PLENARY)
PAVILION BALLROOM	Planning for the Future ... the perspective of a ventilator user, polio survivor, and behavioral health professional Linda L. Bieniek, CEAP ... the perspective of a researcher Burk Jubelt, MD ... the perspective of a primary care physician and polio survivor Marny K. Eulberg, MD ... the perspective of a clinician Martin B. Wice, MD ... the perspective of a polio survivor and advocate Joan L. Headley, MS

**Learning About and From Post-Poliomyelitis:
A Seminar for Physical and Occupational Therapists
and Physical and Occupational Therapist Assistants**



*The meeting room for this seminar is Fort San Carlos (first floor).
Details and abstracts for this seminar are found after the
Saturday, June 10, Closing Plenary Session.*

FRIDAY, JUNE 9, 2000

7:45 - 8:15 am Continental Breakfast (*served in Fort San Carlos*)

8:15 - 9:10 am ***Pathophysiology of Acute Poliomyelitis and Post-Polio Syndrome***

FREDERICK M. MAYNARD, MD, Upper Peninsula Rehabilitation Medicine Associates, Marquette, Michigan

OBJECTIVE: Describe the pathophysiology of acute polio; compare/contrast with the pathophysiology of other frequently occurring neuromuscular diseases; describe the pathophysiology of the late effects of polio.

9:15 - 10:15 am ***Pulmonary Problems: Signs and Symptoms and Screening***
(*Plenary session for entire conference, Pavilion Ballroom*)

PETER C. GAY, MD, Division of Pulmonary and Critical Care, Mayo Clinic, Rochester, Minnesota

OBJECTIVE: Describe the signs and symptoms of breathing problems of aging polio survivors; describe appropriate screening techniques; explain interpretation of results.

Cardiac Problems: Signs and Symptoms and Screening
(*Plenary session for entire conference, Pavilion Ballroom*)

RUPERT D. MAYUGA, MD, Assistant Professor of Clinical Medicine (Cardiology), Northwestern University Medical School, Chicago, Illinois

OBJECTIVE: Describe the signs and symptoms of cardiac problems of aging polio survivors; describe appropriate screening techniques; explain interpretation of results.

10:30-11:30 am ***The Impact of the Polio Experience on PT/OT Management***

MARIANNE WEISS, MS, PT, Assistant Professor, Department of Physical Therapy, University of Findlay, Findlay, Ohio

OBJECTIVE: Discuss the sociological, cultural, and psychological experiences of polio survivors (and their significant others) and determine the impact of these factors on participation in and response to PT/OT examinations and interventions.

1:15-2:15 pm ***Guidelines to Implement Examination and Intervention Options***

MARIANNE WEISS, MS, PT

OBJECTIVE: Apply appropriate Preferred Practice Patterns from the *Guide to Physical Therapist Practice* to implement examination and intervention options and to measure outcomes for individuals exhibiting the late effects of polio.

OR

BETH KOWALL, MS, OTR, Post-Polio Resource Group of Southeastern Wisconsin; Occupational Therapy Association Research and Scholarly Activities Committee, Greenfield, Wisconsin

OBJECTIVE: Apply appropriate AOTA Practice Guidelines to implement examination and intervention options and to measure outcomes for individuals exhibiting the late effects of polio.

- 2:15-2:45 pm ***Outcomes Measures: A New Approach***
DAVID GRAY, PhD, Professor, Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri
HOLLY HOLLINGSWORTH, PhD, Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri
OBJECTIVE: Present a new assessment battery that is reliable, valid, and sensitive to individual and environmental factors to measure community participation among individuals with mobility impairments.
- 3:15-4:00 pm ***Coping Styles and Personal Perspectives of Polio Survivors***
FREDERICK M. MAYNARD, MD
SUNNY ROLLER, MA, Research Program Manager, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, Michigan
OBJECTIVE: Incorporate the firsthand experiences related by polio survivors who are coping with aging with a disability into effective planning of PT/OT interventions.
- 4:00-4:45 pm ***Experience from Your Practice***
OBJECTIVE: Describe "best practice" intervention strategies; strategize about marketing services to polio survivors; apply lessons learned from treating polio survivors to the treatment of others who exhibit muscle weakness.

SATURDAY, JUNE 10, 2000

- 7:45-8:15 am Continental Breakfast (*served in Fort San Carlos*)
- 8:15-9:00 am ***Revisiting the Traditional Methods of Gait Analysis***
JACQUELIN PERRY, MD, DSc (HON), Chief, Polio Service, Rancho Los Amigos National Rehabilitation Center, Downey, California
ANN E. HUETER, RPT, Post-Polio Clinic, Saint Anthony's Family Medical Center West, Denver, Colorado
OBJECTIVE: Apply observational gait analysis to the examination and intervention for polio survivors; implement motor learning principles for gait training of polio survivors; appropriately recommend orthotic interventions and/or assistive gait devices for polio survivors.
- 9:00-9:30 am ***Applicable Updated Assistive Technology***
ROBBIE B. LEONARD, MS, PT, Physical Therapy Program, Medical University of South Carolina, Greenville, South Carolina
BETH KOWALL, MS, OTR
OBJECTIVE: Review appropriate new assistive technology applicable to promoting independent living for people who experience the late effects of polio.
- 9:30-10:15 am ***Complementary/Alternative Therapies: How to Decide***
S. LAURANCE JOHNSTON, PhD, Falconwing Biomedical and Disability Research Consulting and Associate Member, Mountain States Paralyzed Veterans of America, Indian Hills, Colorado
OBJECTIVE: Discuss reasons why use of alternative medicine is now routine for many Americans; discuss a variety of alternative/complementary approaches relevant to physical disability.
- 10:30-11:55 am ***Practicing New Skills***
MARIANNE WEISS, MS, PT; BETH KOWALL, MS, OTR; ROBBIE B. LEONARD, MS, PT
OBJECTIVE: Experienced therapists will demonstrate and guide examination skills on volunteer polio survivors.

Presenters

Sally Aitken, Co-editor of *Folio Polio*, Polio Quebec, Westmount, Quebec, Canada

Augusta S. Alba, MD, Coler/Goldwater Memorial Hospital, Roosevelt Island, New York

Darwyn Apple, Violinist, Saint Louis Symphony Orchestra

Neena Bhandari, Journalist, Harrow, England

Linda L. Bieniek, CEAP, LaGrange, Illinois

Richard Boone, Lincolnshire Post-Polio Network, Palmetto, Florida

Lynne Breakstone, Saint Louis, Missouri

Mary Ellen Brown, PT, Ygnacio Valley Physical Therapy, Danville, California

Elaine Burns, The Greater Boston Post-Polio Association, Wellesley, Massachusetts

Selma H. Calmes, MD, Anesthesia, Olive View-UCLA Medical Center, Sylmar, California

Nancy L. Caverly, OTR/L, Bland, Missouri

Eileen Chasens, RN, DSN, University of Alabama School of Nursing, Birmingham, Alabama

Sophia Chun, MD, Polio Service, Rancho Los Amigos National Rehabilitation Center, Downey, California

Norma Collins, AARP (American Association of Retired Persons)

Deborah Cunningham, Memphis Center for Independent Living, Memphis, Tennessee

Linda Wheeler Donahue, Southbury, Connecticut

Jessie K.M. Easton, MD, Sioux Falls, South Dakota

Marny K. Eulberg, MD, Saint Anthony's Family Medical Center West, Denver, Colorado

Bob Fary, RRT, Respiratory Services, Apria Healthcare, Costa Mesa, California

Jeff and Linda Feinstein, Mays Landing, New Jersey

Alan D. Fiala, PhD, Falls Church, Virginia

Bobette Figler, Support Dogs, Inc., Saint Louis, Missouri

Michael Finnerty, Manager of International Programs, March of Dimes Birth Defects Foundation, White Plains, New York

Anne C. Gawne, MD, Post-Polio Clinic, Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia



Peter C. Gay, MD, Mayo Clinic/Rochester, Rochester, Minnesota

Jack Genskow, PhD, CRC, Springfield, Illinois

Mary Gould, RN, BA, Division of Infectious Diseases, Washington University School of Medicine, Saint Louis, Missouri

David B. Gray, PhD, Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri

Hilary Hallam, Lincolnshire Post-Polio Network, Lincolnshire, England

Joan L. Headley, MS, GINI, Saint Louis, Missouri

Sharon Maxwell Henkel, Beckemeyer, Illinois

Karen Hirsch, PhD, Missouri Institute for Mental Health (MIMH), Saint Louis, Missouri

Holly Hollingsworth, PhD, Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri

Todd Holmes, MD, Sister Kenny Institute, Minneapolis, Minnesota

Ann E. Hueter, RPT, Saint Anthony's Family Medical Center West, Denver, Colorado

Barbara Ivanyi, MD, PhD, Rehabilitation Medicine, University of Groningen, Netherlands

Dennis J. Janisse, C.Ped, National Pedorthic Services, Inc., Milwaukee, Wisconsin

Peter Jay, British Polio Fellowship, Spalding, England

S. Laurance Johnston, PhD, Falconwing Biomedical and Disability Research Consulting and Mountain States Paralyzed Veterans of America, Indian Hills, Colorado

Cyndi Jones, The Center for an Accessible Society, San Diego, California

Doris Jones, Post-Polio Support Group, Saint Louis, Missouri

Burk Jubelt, MD, SUNY Health Science Center, Syracuse, New York

Karen Kennedy, MSW, CSW, Post-Polio Clinic, West Park Hospital, Ontario, Canada

Audrey J. King, MA, Don Mills, Ontario, Canada

Beth Kowall, MS, OTR, Greenfield, Wisconsin

Nickie Lancaster, RN, Polio Heroes of Tennessee, Hermitage, Tennessee

Susan Sortor Léger, RRT, ResMed, Paris, France

Robbie B. Leonard, MS, PT, Medical University of South Carolina, Greenville, South Carolina

David A. Livingston, Lorain County Post-Polio Support Group, North Ridgeville, Ohio

Wendy Malisani, Post-Polio Clinic, West Park Hospital, Toronto, Ontario, Canada

Frederick M. Maynard, MD, Upper Peninsula Medical Center, Marquette, Michigan

Jack Martin, PT, Bacharach Rehabilitation Hospital, Pomona, New Jersey

Rupert D. Mayuga, MD, Clinical Medicine, Cardiology, Northwestern University Medical School, Chicago, Illinois

John McBurney, MD, University of Alabama School of Medicine, Sleep-Wake Disorders Center, Birmingham, Alabama

Pima McConnell, PT, ATP, Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia

Lotte Mortensen, Institutionen for Respirationspatienter, Copenhagen, Denmark

Kathleen A. Navarre, PhD, Delta College, University Center, Michigan

David Newburger, JD, Newburger & Vossmeier, Attorneys at Law, Saint Louis, Missouri

Nete Munk Nielsen, MD, BSc, Danish Epidemiology Science Centre, Statens Serum Institute, Copenhagen, Denmark

Dorothea Nudelman, MA, Portola Valley, California

Michael Nudelman, Portola Valley, California

Grethe Nyholm Olsen, RNP, Respiratory Centre East, Copenhagen University Hospital, Copenhagen, Denmark

Edward Anthony Oppenheimer, MD, Pulmonary & Critical Care, Southern California Permanente Medical Group, Los Angeles, California

Paul Ott, RD, Saint Louis, Missouri

Linda Palmer, OTR, Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia

Vera Parkin, Pianist, Saint Louis, Missouri

Paul E. Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia

Ammanath Peethambaran, MS, CO, Orthotics & Prosthetics Center, University of Michigan, Ann Arbor, Michigan

Jacquelin Perry, MD, DSc (Hon), Polio Service, Rancho Los Amigos National Rehabilitation Center, Downey, California

Robert J. Provan, Provan & Associates, PC, Austin, Texas

Sunny Roller, MA, Physical Medicine & Rehabilitation, University of Michigan Health System, Ann Arbor, Michigan

Robert J. Ronald, SJ, Operation De-Handicap, Taipei, Taiwan, ROC

Susana Saavedra, Foundation for Equal Opportunities, Republic of Panama

Yoichi Sakakihara, MD, Pediatrics, The University of Tokyo, Tokyo, Japan

Edmund J. Sass, EdD, College of Saint Benedict, Saint Joseph, Minnesota

Dorothy Woods Smith, RN, PhD, HNC, Lockport, Illinois

Mary St. Clair, MAT, ATR-BC, LCSW, Saint Louis Institute of Art Psychotherapy, Saint Louis, Missouri

Patricia Strong, MA, Whittier, California

Mark K. Taylor, MLS, CPO, Orthotics & Prosthetics Center, University of Michigan, Ann Arbor, Michigan

Joyce Ann Tepley, LMSW/ACP, LPC, Dallas, Texas

Robert H. Thayer, Mississippi Polio Survivors Association, Clinton, Mississippi

Linda Tompkins, National Center for Health, Statistics, Hyattsville, Maryland

Mary Umlauf, RN, PhD, University of Alabama School of Nursing, Birmingham, Alabama

Carol B. Vandenakker, MD, Physical Medicine and Rehabilitation, University of Miami School of Medicine, Miami, Florida

Heather Vargus, OTS, Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri

Josephine F. Walker, Narberth, Pennsylvania

Marianne T. Weiss, MS, PT, University of Findlay, Findlay, Ohio

Martin B. Wice, MD, St. John's Mercy Rehabilitation Center, Saint Louis, Missouri

Daniel J. Wilson, PhD, Muhlenberg College, Allentown, Pennsylvania

Who was Gini? What is GINI?

Gini was the nickname of Virginia Grace Wilson Laurie, the catalyst for the post-polio and independent living conferences that began in 1981.

Gini often claimed that polio was the motif of her life. Named after two sisters who died during a polio epidemic in Saint Louis, Gini was born the following year in 1913. She grew up sensitized to disability issues by her close relationship to her brother Bobby who had been disabled by polio during the same epidemic that took the lives of their older sisters. In the 1950s, Gini lived in Cleveland, Ohio during the polio epidemics and served as a Red Cross volunteer at the respiratory polio ward, the Toomey Respiratory Center.



Gini with her brother Bobby, 1919



Gini at work on the Rehabilitation Gazette

In 1958, Gini inherited editorship of the *Toomey j Gazette*, a small mimeographed newsletter to help polio survivors keep in touch with each other.

Over the years, this newsletter evolved into *Rehabilitation Gazette*, an international journal of independent living by people with disabilities. *Rehabilitation Gazette* connected people with disabilities and provided accurate, practical information, earning Gini the title of "one of the grandmothers of the independent living movement." In 1974, she helped found the American Coalition of Citizens with Disabilities.

Gini recognized the significance of a 1979 letter from a polio survivor describing what is now known as the late effects of polio. In 1981, she instigated the first international conference on post-polio problems.

In 1983, Gini wanted to ensure that the organization would continue without her, and thus Gazette International Networking Institute or "big GINI" was created. GINI is now the umbrella organization over International Polio Network and International Ventilator Users Network.

Gini edited and published the first edition of the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* in 1984. (The expanded and revised edition, the compilation of the research and experience of more than 40 experts, was published in 1999.)

Gini Laurie died in 1989, not long before the Americans with Disabilities Act at last realized her goal of equal rights for people with disabilities. She is remembered as a motivator for everyone, demanding that each individual, with a disability or without, live life to its fullest. She believed in the dignity of each individual and believed, as she often said, that "Peopleness is the only thing that matters." 福



Gini in 1986 after receiving the prestigious St. Louis Award, recognizing her work "as an historian, researcher, and advocate for the right of persons with disabilities to live independently."

The Missouri History Museum (314-746-4599, www.mohistory.org), at the junction of Lindell and DeBaliviere Boulevards in Forest Park in Saint Louis, has honored Gini Laurie within a new display on disability rights, "Seeking St. Louis - Reflections," located on the upper level of the McDonnell Douglas Gallery.

More about GINI ...

Gazette International Networking Institute (GINI) is the umbrella organization over International Polio Network (IPN) and International Ventilator Users Network (IVUN).

GINI's mission statement reads, "Since 1958, GINI's mission is to enhance the lives and independence of polio survivors, ventilator users, and others living with disabilities by promoting networking and advocacy among these individuals, health care professionals, and service providers; publishing information; funding research; and coordinating international conferences."

International Polio Network (IPN) disseminates information and organizes conferences about the late effects of polio, encourages research, and promotes networking among the post-polio community worldwide.

IPN publishes the quarterly *Polio Network News*, edited by Joan L. Headley. IPN also annually publishes the *Post-Polio Directory*, which lists self-identified clinics, health professionals, and support groups.

International Ventilator Users Network (IVUN) connects ventilator users and their families with each other and with health professionals committed to home mechanical ventilation.

IVUN publishes the quarterly *IVUN News*, edited by Judith R. Fischer. IVUN also annually publishes the *IVUN Resource Directory*, which lists health professionals, ventilator users, equipment and mask manufacturers, service and repair sites, and organizations.



The GINI Research Fund was established in 1995 by the Board of Directors of Gazette International Networking Institute (GINI). A generous bequest from Thomas Wallace Rogers provided the impetus for this fund's creation. Thomas Wallace Rogers contracted polio at age 19 and was paralyzed from the neck down. With breathing assistance from a rocking bed, Rogers

pursued an education and worked as a financial planner and investment advisor. His financial contribution acknowledged the importance of GINI's work and challenged GINI to promote research in addition to its exemplary educational endeavors.

The GINI Research Fund supports the work of researchers and clinicians investigating the late effects of poliomyelitis and/or neuromuscular respiratory disease through one of two grants:

The Thomas Wallace Rogers Memorial Respiratory Research Grant to study the cause and treatment of neuromuscular respiratory insufficiency and the effects of long-term mechanical ventilation;

The Post-Poliomyelitis Research Grant to study the cause(s), treatment, and management of the late effects of polio.

The GINI Research Fund will award its first grant in the year 2000.

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors

was revised in 1999. Edited by Frederick M. Maynard, MD, currently in private practice of physiatry in Marquette, Michigan, and Joan L. Headley, MS, polio survivor and Executive Director of GINI, the *Handbook* retains the easy-to-use dictionary format in presenting information appropriate for polio survivors and the health professionals who treat them. The 90 topics, from A to W, are diverse and include: Adaptive Equipment, Anesthesia, Communication, Coughing, Diagnosis, Epidemiology, Evaluation, Independent Living, Orthotics, Pain, Pulmonary Function Tests, Swallowing, Vaccines, Weakness, and Wellness. The content is a compilation of the research and experience of more than 40 experts. The sections are cross-referenced, and the book contains over 200 references.

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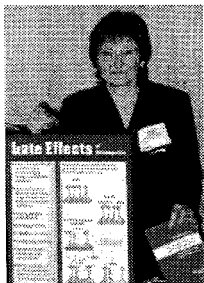
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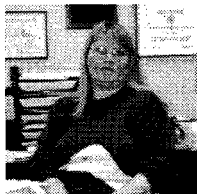


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GINI thanks the presenters for providing the excellent information contained in this book. If you share this information, we respectfully ask that you acknowledge both the presenter and that the information was disseminated at GINI's Eighth International Post-Polio and Independent Living Conference in June 2000. GINI will incorporate the additional information presented at the conference and make the book available through its publications and www.post-polio.org.

GINI honors ...



AUGUSTA S. ALBA, MD



JACQUELIN PERRY, MD, DSc (HON)

We thank you for your loyalty to GINI and its worldwide network. Your commitment in helping the post-polio community has been extraordinary. Your dedication in teaching others so that your work will continue through them is exemplary. It is for all of this that we honor you with the degree of RD - Real Doctor.

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Friday, June 9: 8:30 am - 5:00 pm

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variety of educational materials and resources for patients, as well as families and health professionals working with tracheostomized and ventilator dependent patients.

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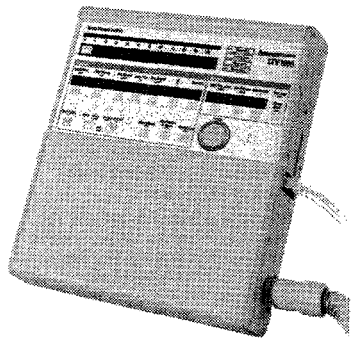
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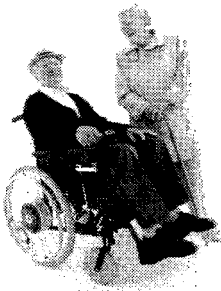


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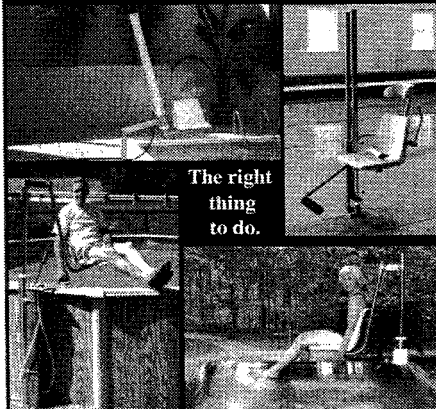
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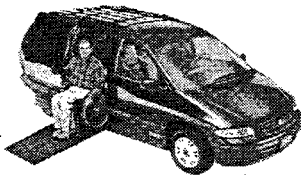
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AN OPEN LETTER TO ALL PEOPLE WITH DISABILITIES

When we first became "involved" with people with disabilities, we must apologetically admit that it was in a mercenary sense. We knew that we had a product which many of them could use and we needed the "business".

Through an interesting series of events, we soon found ourselves with an entry into the *Texas Polio Survivors*. When we made our first sale to that individual, I was excited at the prospects of finally getting out of debt and now "making some money!" That was in 1994, and we are still in debt! But what we found . . . money could not buy!

When we set up our first display at the *Texas Polio Survivors* initial fund-raising golf tournament in 1996, little did we know the journey on which we were about to embark. It did not happen overnight, most things really worth-while don't. But instead of monetary rewards, we began to admire a life-style in these people which has ACTUALLY made me, at times, wish that I was one of them. (Those to whom I have made this statement reply emphatically, "No you don't!"). I could see in them a determination, a persistence and a love of life which "people like that" shouldn't have. I had never (to my recollection) had a friend in a wheelchair or confined to a respirator. Quite frankly, I "felt sorry for them" (or at least I thought I did) and never gave much thought to what their life was really like.

Needless to say, if one has any heart at all, he or she cannot be around such people for long and remain unchanged. For four years now, we have been "involved" with polio survivors and others who experience extreme difficulties doing things to which I never give a second thought! And yes, our mission has changed. We now truly have as our goal, to help as many people as possible to find a better lifestyle through the use of the "magnetic field". We don't understand it, but neither do most practitioners who use it. I can no longer say that I have no friends in wheelchairs. I have found that people with disabilities can teach us so much about caring and sharing and having to depend on others for the things which are impossible to do otherwise. And given the chance, they become very loyal and loving friends!

At one time, I would say, "I am blessed with health." You would likely say the same thing. But let me say that all of you, if you have lived with the same attitude as this "family" of polio survivors here in Texas, have been a blessing to many others whom you have touched in some way. You are exceptional people and you have a very special place in the hereafter. I don't "think" that, I know it!

What we consider now a ministry as much as a business, has allowed us to make "friends" in many states and even foreign countries. Though we are small, and only operate through referrals from satisfied customers or health care professionals, who know the way we function, we make every effort to give back to you a portion of what you have given us. We do provide magnetic therapy products, most of which we manufacture ourselves. We want to thank you (particularly the polio community) for your part in keeping us "in business", but much more importantly, for the inspiration which you have provided when we could have folded up our tent and said, "This is just too hard!"

Today, as volunteers for TPSA, we would give anything to be with you at your millennium meeting in June. However, due to certain health conditions, we are prevented from such. We wish all of you the many blessings, which you so richly deserve and which I am sure you will receive.

Kurt & Mary Nauck
Owners

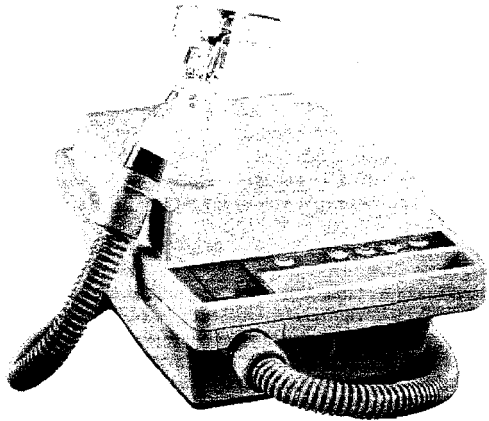
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SESSION I

1:30 pm - 2:45 pm

- PAVILION SALON D **Telling Our Own Stories: Polio Narratives Then and Now**
Daniel J. Wilson, PhD; Edmund J. Sass, EdD; Sally Aitken
- PAVILION SALON F **Ventilator Users: Exploring the Issues – Learning from Each Other**
Deborah Cunningham; Audrey J. King, MA; Doris Jones
- PAVILION SALON C **Managing Chronic Pain: Self-help Techniques**
Dorothy Woods Smith, RN, PhD, HNC
- PAVILION SALON A **What the Numbers Say: Epidemiological Studies***
Nete Munk Nielsen, MD, BSc; Barbara Ivanyi, MD, PhD; Linda Tompkins, MS
- PAVILION SALON E **Strategies for Obtaining the Best Bracing**
Mark K. Taylor, MLS, CPO; Ammanath Peethambaran, MS, CO
- PAVILION SALON G **Post-Polio Syndrome: The Theories**
Paul E. Peach, MD
- PAVILION SALON B **A Multidisciplinary Team: Evaluation and Treatment
of Polio Survivors***
Anne C. Gawne, MD; Pima McConnell, PT, ATP; Linda Palmer, OTR/L
Assessing Our Activities to Effectively Manage Our Lives*
Hilary Hallam

*Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000*

Telling Our Own Stories: Polio Narratives Then and Now

Daniel J. Wilson, Ph.D.
Muhlenberg College

Edmund J. Sass, Ed.D.
College of St. Benedict

Sally Aitken
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TELLING OUR OWN STORIES: POLIO NARRATIVES THEN AND NOW

Daniel J. Wilson, Ph.D.

Polio stories have been told as long as the disease has crippled humans. In twentieth-century America, polio survivors have published their narratives in book-length autobiographies and memoirs and in shorter pieces for the popular press. These narratives provide valuable insights into the experience of having polio. The published polio narratives fall into two broad patterns: narratives published from the 1930s to the 1960s that emphasize the individual's triumph over the disease, and more recent conflicted narratives that put greater emphasis on the struggle to live with a life-long disability. The earlier narratives reflect the more confident mood of mid-century America when individuals expected that hard work would bring success, including a successful recovery and rehabilitation from polio. Many of these early narratives were written within a few years of having polio. The more recent narratives reflect the more complex, often conflicted culture that emerged in the 1960s and 1970s. Written years, sometimes decades, after polio struck, these later narratives recognize that living with a serious disability is often a life-long struggle with physical and psychological pain.

POLIO NARRATIVES: TRIUMPHANT, CONFLICTED, AND EVERYWHERE IN
BETWEEN

Edmund J. Sass, Ed.D.

The book, *Polio's Legacy: An Oral History*, contains 35 polio narratives gathered between 1992 and 1996 and provides many examples of both triumphant and conflicted themes. Though not a hard and fast rule, most of the triumphant narratives tell the stories of those who had polio prior to World War II. The stories of baby-boomers (those born after World War II) are much more likely to be conflicted and often describe the difficulties, both physical and emotional, of adjusting to a secondary disability resulting from polio's late effects. Still, even these conflicted narratives contain many positive elements and generally describe satisfying, albeit complicated lives.

TELLING OUR POLIO STORIES

Sally Aitken

Polio Québec's recently published book, in French, deals with the accounts of those who have experienced polio, either personally or as a family member. They are all living in Québec, a province of Canada which is predominantly French, but the narratives include the broad spectrum of our population, including immigrants who contracted polio in their country of origin. Given the dearth of written information in French, the book also contains a brief history of polio, the vaccine, and of our Association. My presentation will deal only with the insights revealed in compiling *L'Histoire Vecue de la Polio au Québec* (The Oral History of Polio in Québec). Co-author Gilles Fournier was to have come with me, but due to recent surgery is unable to travel.

Ventilator Users: Exploring the Issues – Learning from Each Other

Audrey King, M.A.

Center for Independent Living, Toronto (CILT)
Citizens for Independence in Living and Breathing

During the late 1970's ventilator users around the world, many disabled from the polio epidemics of the 40's and 50's, were feeling isolated and challenged by their aging equipment and circumstances. Many were living active independent lives but felt out of touch, not only with those they knew in the polio days but also with modern technology, resources and opportunities. Few modern health care providers were aware of their existence or aware of the wealth of experience they had to offer.

The *First International Post-Polio and Independent Living Conference* in 1981, brought together ventilator users, manufacturers, vendors and health care professionals in a fabulously rich environment of mutual learning and sharing. Delegates came from all around the world and returned back to their communities with knowledge, ideas and a new sense of purpose. Frog breathing, new smaller ventilators, customized masks and headgear, positive versus negative pressure, one-of-a kind gadgets and devices, attendant service programs, problem solving and travelling with a ventilator were just some of the topics shared.

Answers to personal problems weren't the only outcomes of this first conference. Local and regional post-polio networks and support groups were established in many countries. In Ontario, Canada, the Ontario March of Dimes responded by establishing a provincial polio program. There are now some 22 local groups throughout the province. An Ontario March of Dimes Post-Polio registry was created with 5000 members to date.

Citizens for Independence in Living and Breathing (CILB), a national Toronto based grass roots support group for ventilator users came into being. Education, information, problem solving, connecting to resources and just listening are some of the ways Canadian and international ventilator users are helping each other. Telephone, letters, meetings, e-mail and the Internet are just some of the ways we communicate. CILB (which some have likened to a GINI North) hosts a major conference every few years, publishes a regular newsletter called *Airwaves*, and also acts as a resource and advisor to agencies and government.

Through personal anecdotes and examples one person's journey from isolation to supporting and learning from each other will be shared. Current issues, questions, dilemmas and ideas related to ventilator use will be discussed with other panel participants during the presentation.

CONNECTIONS IN LIFE
by
Doris Jones
Greater St. Louis Post-Polio Support Group

I would like to take this opportunity to welcome you to the St. Louis area, and hope that when you return home, you will have had a rewarding experience and enjoyed your visit.

The year was June 1946, and I had just turned eight years old in April. School was out and I was looking forward to summer vacation. A few days into the last week of June, my legs and body began to get achy and my stomach was uneasy. I was just laying around listening to the radio in the front room. I got up to go to the bathroom, got half way across the room, when my legs buckled under me. I was never able to walk unaided again. Mother helped me the rest of the way to the bathroom, so I could relieve my self. Then she and my aunt took me to a doctor a few blocks away.

They called dad away from work, and I was taken to DePaul hospital and placed in quarantine. They ran all sorts of blood tests, and I vividly remember the spinal tap. That confirmed my diagnosis: "Infantile Paralysis". The paralysis had spread throughout my body, and the doctors were concerned about my ability to breathe. So they transferred me to City Hospital where they had "iron lungs". Upon arrival there I was placed into one and stayed in it during my crisis period. They slowly weaned me from it by opening it up for short periods to see how I managed on my own. Finally, after seven days, they transferred me to a regular hospital bed; but they left the iron lung in my room for a day or so in case I needed to go back into it. They finally had to remove it as they needed it for someone else. I stayed at City Hospital for about four weeks where they began hot baths to soothe my aching muscles. I began to regain some use in my left arm and hand while there. At the end of July they transferred me to Lutheran Hospital where they had a small ward of polio patients and put me under the care of an orthopedist. I began hot packs and stretching. My arms continued to regain more use, but my right "dominate" hand never did return as much as my left. I was fitted with a back brace and leg braces and learned to manipulate a wooden wheelchair to get around and released at the end of October.

Soon my parents heard about a larger ward at County Hospital and they got me into it in 1947 on an outpatient basis first and eventually admitted me for more concentrated therapy, twice daily every day. Here they had a Hubbard Tank for water therapy.

It was here that I was made friends with several other patients, **Shirley Kopecky**, and **Dorothy Daniels**. They both used an iron lung nocturnally and, during the day, were on gurneys. They were both a few years older than I was and became more like big sisters to me during my hospitalization. After about six months, this "Polio Ward" was transferred to St. Anthony's Hospital where there was more space and larger rehabilitation facilities. It was here that we

really bonded. When we were not in therapy or attending our "One Room School" to help us keep up with our studies, Shirley and Dorothy would think up things to do; and I would carry them out. I was able to get in and out of bed by myself. I think we became known as "the mischief makers". I was finally released in 1949 when another polio epidemic hit St. Louis, and occupied beds were needed. The whole ward was sent home, except for a few who were full time in iron lungs. I graduated to a new EJ collapsible wheelchair as well. Despite being released, Shirley and Dorothy and I stayed in touch by telephone. Sadly, Dorothy passed away a few years later. But Shirley and I stayed in touch.

Over the years, my health remained fairly normal, aside from an occasional cold like most kids; but I never required hospitalization because of any respiratory weakness. I continued with physical therapy at home and was tutored at home as well until I graduated from 8th grade.

In 1953, we moved into a brand new home in a North St. Louis County community called Dellwood. In the fall of that year I started high school. The principal arranged for all my classes to be on the first floor. I took a cab to and from school for transportation. There I made even more friends after I got passed the fright of this new venture. During my four years there I became active on the year book staff, and pep club and attended many football and basketball games. I received good grades and was "tapped" for the National Honor Society.

In 1957 I enrolled in St. Louis University and majored in Accounting. The Commerce and Finance Building had an elevator in it so that worked for all my business courses, but I required assistance from other students to navigate steps and distances to my liberal arts courses. The road here was much tougher.

It was while I was in college that flu shots were introduced, and I began getting one every year for added medical protection. During college I did have several good chest colds, but they never got me down. In my Junior year I had more trouble with a pinched nerve in my neck that grounded me during Easter break that year. I graduated in 1961.

Since it was difficult for women to break into the accounting field, I began a small practice in my home and did income tax returns in season. I also began a more trying medical period. I had developed colitis and some other periodic pelvic discomfort. I had lower GI's etc. Nothing specific was discovered. By 1966, the discomfort became more pronounced and was associated with my monthly menses. In 1967, my internist had me try a birth control pills to see if that would help. After 3 days of that a blood clot developed in my left groin. My doctor referred me to a surgeon for treatment. I was hospitalized and treated with blood thinners. I stayed there for 18 days. When it was time to be released, I asked the surgeon about my back brace. He suggested not wearing it for at least six months as it compressed the area where I had the clot.

My problem with pelvic pain still was not resolved and I was referred to an OB-GYN. For the next several years he tried a variety of treatments. By 1970, I was in pain a good bit of the time- taking tranquilizers and sleeping pills just to stay on an even keel. Finally, I asked for surgery - a hysterectomy - so in February 1971 I underwent surgery. It turns out I had

endometriosis and multiple cysts on both ovaries. It was the best decision I could have made at the time. In several months time, I was feeling much better and back to doing things again.

In September of that year I received a telephone call from a lady called Gini Laurie, who said Shirley Kopecky had told her I had taken accounting in college and had given her my number. She was looking for someone to "do" her books. Would I be interested? My "big sister" Shirley wouldn't give my name to just anyone. Gini and "Papa Joe" would be glad to come pick me up and bring me down to their office where I could do their work. I said I would give it a try. I was a little concerned about who would pick me up and where I would be going, and before the appointed day, I did have a conversation with my big sister Shirley. She assured me it would be all right. This was to be another major decision in my life.

In my monthly trip down to the Laurie residence, we had great conversations... mostly, about disabilities and the "movement" that had to evolve. They introduced me to others with disabilities and the equipment they used, i.e. wheelchair lifts and hand controls. This had been a long-time dream. But how to finance all that equipment. Gini's reply- "have you talked with voc rehab?" Well, no, but they did pay for my college education. So one thing led to another. In 1974 I got my first van with a wheelchair lift, wheelchair tiedowns, hand controls. Paul Finkes, a neighbor, volunteered to teach me how to drive. I proudly passed my driving test the first time. This opened up a whole new world for me - travel, - work, visiting and mostly being more "Independent".

I even demonstrated adaptive equipment for a few years. While I was with a company in St. Charles, I heard the tragic news that my dear friend and "big sister" had died. I was sick at heart. She had caught a cold and was having trouble coughing up phlegm; and, on top of that, her iron lung decided to break down. She was taken to a local ER, but they were not sure what to do with her problem. They were not able to give her proper respiratory assistance and she died. This scenario has stuck with me for years.

My health over the years until 1980 had been pretty good. I had started a new job early that year which was very stressful, and developed some food allergies I had never had before. By March, I had to resign as I was unable to put in a full day. In 1981 I began seeing an allergist to help control my allergies. This proved to be helpful. I still had some fatigue that cut down on some of my activities.

Gini Laurie was at work again, she called and asked if I would be interested in a support group. I thought to myself, I don't think I really need that, but for Gini I'll give it a try. It was there that I first met Dr. Oscar Schwartz, M.D., a pulmonologist. In 1985, I became a patient of his. Since I had been in an iron lung some 40 years earlier, I felt to have a base line study done on my pulmonary capabilities, was a good idea. He did ABG's and vital capacity. I was to see him annually for many years. He did have me start using a forced cough bag. I would use it before I went to bed, and it helped to keep some elasticity in my lungs.

Later, Gini Laurie and Judy Fischer, learned of Dr. Martin Wice, Physiatrist, locally at St. John's Medical Center, was developing a "Post-Polio Clinic" there. In 1987 I had him establish

an overall baseline of my muscle function, and have continued to see him at least once a year. He played a vital role in getting me back to wearing a back brace and into a power wheelchair.

Just this past year, I started using a BIPAP S/S ventilator nocturnally. When I saw Dr. Schwartz last April, he had another vital capacity done and ABGs. My CO₂ level was 49%. I was not sleeping well, and tired so much of the time. He said he usually didn't insist on going on a ventilator until a person's CO₂ level reached 50%, but left the decision up to me. I decided not to wait until I had a bigger problem, but to begin to make the adjustment now, on my own terms, rather than HAVE TO later down the road. He didn't wait for me to change my mind either. The next day I had a BIPAP at my bedside. Those first few nights were the worst, as I started with a face mask. I could only tolerate 3-4 hours of use before the pressure on the bridge of my nose began to hurt, as well as under my nose. "Bob," my Respiratory Therapist, brought out an Adam's Circuit with nasal pillows to try. I soon was able to use it all night with just a few minor adjustments. I have managed to avoid a major infection. I do have some heart irregularities I have to deal with from time to time; sinus tachycardia and premature ventricular contractions.

Gini Laurie started several publications as a way to spread the word. The Rehabilitation Gazette, is news about individuals with many different kinds of disabilities. The Post-Polio Newsletter, focuses on just polio issues. IVUN relates news about a variety of pulmonary problems, how people coped, what equipment they used, --a lot of "how I did it" information. Also conferences, such as this, have been most enlightening to me over the years. They have encouraged me to extend my boundaries, not to be afraid to try something new. I have learn from many people, oftentimes in very subtle ways.

I would be remiss if I did not thank the members of Northminster Presbyterian Church, where I am a member, my neighboring community, the local support group, the cadre of medical people that I see, and most especially my mother, who is here with me today, for their support to me over the years. Both Shirley Kopecky and Gini Laurie were firm believers of Christian principles and of being a link in a large network of resources. I try to exercise those ideas today. I have had the opportunity to assist in making my church more accessible. This allowed a number of our members to participate in services, functions and the ongoing mission work that takes place there. The church hired me in 1965 as Financial Secretary and this has allowed me to continue my career in accounting. It has also given me opportunity to grow spiritually and play a role in the community at large.

So , over the years, my contacts with knowledge connections have paid off.

There is much more I could tell if time permitted, but I do appreciate the opportunity to express these thoughts to you today. Thanks to Joan Headley for inviting me to be a part of this panel.. She has been a most valued comrade in the exchange of information on many levels.

Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000

Managing Chronic Pain: Self-help Techniques
Dorothy Woods Smith, RN, Ph.D., HNC
Associate Professor Emerita, University of Southern Maine, Portland, ME

Purpose of Session

People participating in the session will learn some self-help techniques practiced in the Pilot Program for People with Chronic Pain (PPPCP). There will be guided experiences in eliciting the relaxation response, including using breathing, imagery, and a mini-relaxation technique; and group discussion of pacing and pleasurable activities. Group members are invited to discover ways to adapt general techniques to their individual needs.

Outline of Session

Rate pain and distress on scales of 1-10 before practicing self-help techniques
Identify signs of tension and stress, and of the relaxation response.
Practice a breathing exercise to increase awareness of own pattern.
Experience visualization: develop an image to create a "mini"--a quick relaxation strategy that can be used any time, any place.
Participate in guided imagery for relaxation, a systematic process to become aware of, and decrease, tension in specific areas of the body.
Practice "mini"
Identify healthy pleasures and/or pacing strategies.
Practice "mini"
Experience guided imagery designed for deeper relaxation, imaging a safe place unique to each person which can be re-created and accessed at will.
Rate pain and distress on scales of 1-10 before closing.

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Managing Chronic Pain: Self-help Techniques
Dorothy Woods Smith, RN, Ph.D., HNC
Associate Professor Emerita, University of Southern Maine, Portland, ME

Self-help Techniques for Managing Post-Polio Pain: Overview

Good medical management has made it possible for many polio survivors to lead rich and productive lives for many years. However, when post polio syndrome is diagnosed, and after surgical and pharmaceutical treatments have been implemented and assistive devices adopted, many physicians and polio survivors become discouraged when debilitating pain and fatigue persist. What do polio survivors do at this point? And is there anything else physicians can offer to lessen fatigue, relieve pain, diminish distress, and/or improve quality of life?

Pain, of muscles and/or joints, is one of the three most common symptoms of Post-Polio Syndrome (PPS). In addition, fibromyalgia pain occurs in 10 to 20% of people with PPS (Post-Polio Task Force, 1999). All aspects of a person are affected by pain: physical, mental, emotional, social, and spiritual. The 12-week Pilot Program for People with Chronic Pain (PPPCP) was designed to treat the whole person, recognizing that all human beings are more than, and different from the sum of their "parts". The core program was derived from principles and practices based on Dr. Herbert Benson's research on the relaxation response. The PPPCP, which included eliciting the relaxation response, group support, information, guided imagery, and cognitive restructuring, followed Dr. Margaret Caudill's workbook from the Benson-affiliated Chronic Pain Program in Boston. In addition randomly selected participants received Therapeutic Touch (TT) for the first three weeks of the program.

Benefits of the relaxation response include decreased oxygen consumption, accompanied by a slower respiration rate, lower blood pressure, decreased muscle tension, stabilized blood flow to arm and leg muscles, less pain, and less anxiety (Benson, 1992; Caudill et al., 1991). Other beneficial changes include decreased demands on weak and painful muscles, and improved overall health and sense of well-being. The benefits of group support and information include becoming actively involved in one's own care and making better choices. Learning a variety of ways to elicit the relaxation response, including with visualization and guided imagery, provides an independent way to reduce unnecessary muscle tension and increase muscle oxygenation. Cognitive restructuring helps participants with problem-solving, coping, goal setting, and pacing activities to enjoy life more fully. The Therapeutic Touch component was based on studies showing that it promotes relaxation, decreases pain, and accelerates the healing process.

People completing the PPPCP showed significant increases in self-efficacy (managing pain) and in power (awareness, choices, feeling free to act intentionally, and involvement in creating change); they all reported decreases in pain sensation and even greater decreases in emotional distress. Those who also received TT the first three weeks of the program experienced the greatest improvements.

EIGHTH INTERNATIONAL POST-POLIO AND INDEPENDENT LIVING CONFERENCE,
ST. LOUIS, MISSOURI, JUNE 8-10, 2000.

CANCER AND MULTIPLE SCLEROSIS IN A COHORT OF DANISH POLIO PATIENTS.
- A DANISH REGISTER STUDY -

Nete Munk Nielsen (1), Jan Wohlfahrt(1), Mads Melbye (1), Henrik Hjalgrim (1), Søren Rasmussen (2), Carsten B. Pedersen (1), Dorthe Askgaard (3), Kåre Mølbaek (1), Peter Aaby (1).

(1) Department of Epidemiology Research, Danish Epidemiology Science Centre, Statens Serum Institut, Copenhagen, Denmark. (2) Danish Institute of Clinical Epidemiology, Copenhagen Denmark. (3) Department of Infectious Diseases M, Rigshospitalet, Copenhagen, Denmark.

Objectives. To examine the incidence of cancer and multiple sclerosis (MS) among polio patients.

Material and methods. Patients diagnosed with acute poliomyelitis between 1919 to 1954 in the greater capital area of Copenhagen, Denmark, were followed until the middle of 1990 with respect to cancer and MS. Information on vital status, diagnosis of cancer and MS was obtained through linkage with the Danish Civil Registration System, the Danish Cancer Registry and the Danish Multiple Sclerosis Registry. The observed incidence of cancer and MS among the patients was compared with the expected incidence calculated according to national gender, age and period-specific rates of cancer and MS. The ratio of the observed number of cancers and MS, respectively, to the number expected (SIR) served as measure of the relative risk of MS and cancer.

Results. Overall, 6423 polio patients were identified, 5% did not survive the hospital admission. More than 93% of the remaining group of polio patients were followed with respect to cancer and MS. Overall 717 cases of cancer were observed among the polio patients vs. an expected number of 645 (SIR=1.11 (95% confidence interval 1.03-1.20)). The increased risk was restricted to female polio patients, among whom the risk was particularly high for breast cancer (SIR=1.35 (1.12-1.62)) and for skin cancer (SIR 1.66 (1.32-2.07)). However, only female polio patients with a history of paralytic polio had an increased risk of breast cancer (SIR=1.62 (1.24-2.10)). Furthermore 19 cases of MS were found among the polio patients, whereas only 11 cases were expected, (SIR=1.73 (1.04-2.74)). Neither gender nor the acute severity of polio modified the risk of MS.

Conclusions. Women diagnosed with poliomyelitis, in particular paralytic polio, may be at increased risk of breast cancer and skin cancer. Furthermore, however, based on small numbers, polio patients might be at an increased risk of MS.

Introduction:

Based on few case stories poliomyelitis has been hypothesized to be associated with a subsequent risk of tumors of the central nervous system [1] as well as neurological disorders such as cerebrovascular disease, MS, epilepsy, Parkinson's disease and amyotrophic lateral sclerosis [2,3,4,5,6]. Despite the growing medical and scientific interest taken in the health of the polio patients, representing more than 600,000 individuals in USA [7], the full spectrum of long-term consequences of poliomyelitis still remains to be established. This study will focus on the incidence of MS and cancer among a cohort of Danish polio patients.

Methods and material:

The study is based on poliomyelitis records from the main infectious disease hospital in Copenhagen, the Blegdamshospital. To identify the polio cases more than 80,000 consecutive hospital records from the period 1919 to 1954 were reviewed. Information extracted from the records included name, date, place of birth and details concerning the acute severity of the disease (paralytic/non-paralytic).

Since April 1, 1968, all Danish citizens have been given a unique identification number (CRS-number). As none of the polio patients, all being discharged before 1968, had a CRS-number, a linkage procedure was undertaken with the Civil Registration System. Through a match on sex, name, date and place of birth, identity was ensured and the CRS-number was supplied.

To identify cases of cancer among the polio patients, the cohort was linked with the Danish Cancer Registry using the CRS-number as the key, or alternatively names and dates of birth for those patients who died or had emigrated prior to April 1, 1968. All patients in the cohort were followed with respect to the occurrence of cancer from the start of the Danish Cancer Registry (January 1, 1943) [8] or the month following discharge from hospital, whichever came last, until the date of death, emigration or December 31, 1995, whichever came first.

By using the CRS-number as a key we likewise linked the cohort of polio patients with the Danish Multiple Sclerosis Registry, which since 1956 has collected detailed information on all cases of multiple sclerosis or suspected multiple sclerosis diagnosed in Denmark [9]. All polio patients were followed with respect to the occurrence of MS from April 1, 1968, until death, emigration or December 31, 1996, whichever came first.

The ratio between the observed number of cancers and number of MS, respectively, and the number expected if the cohort was at the same risk as the general population, i.e. the standardised incidence ratio (SIR), served as a measure of the relative risk of cancer and MS in the cohort. Expected number of cancers and MS in the cohort was calculated as the sum of the sex-, age- and period specific person-time at risk in the cohort multiplied by the corresponding national sex-, age- and period-specific cancer and MS incidence rates, respectively. By means of Byar's approximation, 95% confidence intervals (95% CI) for the observed SIR were estimated [10].

Results:

Between 1919 to 1954, 6,423 persons were diagnosed with poliomyelitis (40% with paralytic polio) at the Blegdamshospital. Dates of birth could not be established for 36 individuals and another 342 patients did not survive the hospital admission. Of the remaining 6,045 polio patients, 162 were lost to follow-up, 74 emigrated and 157 died before the establishment of the CRS system. The CRS-numbers of the remaining 5,652 patients were identified.

A total of 717 cases of cancer were observed among the 5,883 patients during 249,084 person-years of follow-up, vs. an expected number of 645 (SIR=1.11(1.03-1.20)). Considering the risk of cancer at specific anatomical sites, two sites, i.e. breast cancer (SIR=1.34 (1.11-1.61)) and skin cancer (SIR=1.43 (1.21-1.69)) appeared to explain the overall increased risk of cancer. The number of cancers of the central nervous system did not differ from the expected (SIR=1.09 (0.72-1.60)). Furthermore an overall increased incidence of cancer was observed only for female polio patients (SIR=1.18 (1.07-1.30)), whereas the occurrence of cancer among male polio patients did not differ from the expected (SIR=1.03 (0.92-1.15)). Again the increased cancer risk in women was explained by an increased risk of breast cancer (SIR=1.35 (1.12-1.62)) and skin cancer (SIR=1.66 (1.32-2.07)), the latter being most pronounced for non-melanoma skin cancer (SIR=1.73 (1.33-2.22)). Among men discharged with polio the acute severity of the disease did not have any influence on the cancer risk, however among women, those with a paralytic disease tended to have a higher risk of developing cancer (SIR=1.29 (1.11-1.49)) than those with non-paralytic poliomyelitis (SIR=1.10 (0.96-1.26)). Correspondingly, the relative risk of breast cancer was higher among women with paralytic poliomyelitis (59 cases observed vs. 36 expected, SIR=1.62 (1.24-2.10)) than in non-paralytic female patients (59 vs. 51, SIR=1.15 (0.88-1.49)). The difference was less pronounced with respect to the risk of skin cancer, being increased among both paralytic (SIR=1.91(1.35-2.63)) and non-paralytic female polio patients (SIR=1.49 (1.08-2.02)).

During 149,364 person years of follow-up, nineteen cases of MS were diagnosed after April 1, 1968, among the 5,652 polio patients with a CRS-number. We would have expected 11.0 cases (SIR=1.73 (1.04-2.74)). Among women ten cases of MS were diagnosed compared with 5.7 expected (SIR=1.75 (0.84-3.29)), and among men 9 cases were diagnosed compared with 5.2 cases expected (SIR=1.72 (0.79-3.36)). No difference in incidence was seen between paralytic (SIR=1.74 (0.70-3.74)) and non-paralytic polio patients (SIR=1.73 (0.89-3.08))

Discussion:

Our study found an overall but modest increased incidence of cancer among persons previously diagnosed with poliomyelitis, but in contrast to previous expectations [1] there was no indication of an increased incidence of CNS tumors. The increased risk of cancer was almost exclusively explained by a 35% increased risk of breast cancer and a 66% increased risk of skin cancer, primarily of the non-melanoma type. We speculate that this may result from the special

circumstances, and changed living conditions following poliomyelitis. Paralytic polio patients might have been exposed to an excessive number of diagnostic X-ray, which could lead to an increased risk of carcinomas of the breast [11,12]. Being severely handicapped could lead to a lower parity or postponement of the birth of the first child, contributing to a higher risk of breast cancer [13]. However, carrying out separate analysis adjusting for parity showed that the female polio patients did not differ from the Danish female population with respect to parity or age at first delivery. Less exercise, high socioeconomic status and obesity are others factors which should be taken into consideration [14,15,16,17].

Given the high degree of underreporting of non-melanoma skin cancers to the Danish Cancer Registry [18], it is possible that the observed increased risk of skin cancer primarily results from diagnostical bias. However, bias remains an unlikely explanation for the increased risk of breast cancer in the same population. Thus, a linkage between female polio patients and the register of the Danish Breast Cancer Cooperative Group revealed that size of the breast cancer at time of diagnosis was similar for patients with and without a previous diagnosis of poliomyelitis. If differential misclassification were the case, tumors in polio patients would have been expected to be smaller at diagnosis than in other women.

We observed a 70% increased risk of multiple sclerosis among previous polio patients, which was independent of degree of severity of acute illness and gender. MS and poliomyelitis might share some of the same risk factors, however the literature is conflicting [19,20,21]. It is also theoretically possible that poliovirus might directly contribute to the aetiology of MS or indirectly trigger complicated immune reactions leading to MS. It has been postulated that MS is an auto-immune disease which could be triggered by several viruses [22,23,24]. Whether poliovirus might possess this property is unknown. Finally, despite the high validity and completeness of the Danish Multiple Sclerosis Register [9] the clinical features of MS and the Post-polio syndrom could have been confused.

In conclusion, the present investigation suggests that individuals with a history of poliomyelitis may be at increased risk of MS and that women who suffered from paralytic poliomyelitis have an increased risk of breast cancer. The mechanism underlying the associations is, however, unknown, and further studies are needed.

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**PRESENT HEALTH CONDITIONS AND FUNCTIONAL STATUS OF A
POPULATION BASED COHORT OF THE 1956 POLIOMYELITIS OUTBREAK IN
THE NETHERLANDS**

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BACKGROUND

New neuromuscular complaints among polio survivors are reported with a frequency of 25-85%. However, results are often biased by the selection of the study population. Data on disabilities and handicaps resulting from the occurrence of the new neuromuscular complaints are rare.

AIMS OF THE STUDY

1. to determine the prevalence of the late onset polio sequelae in a representative sample of the survivors from the 1956 polio outbreak in the Netherlands;
2. to investigate the present level of impairments, disabilities and handicaps in this cohort;
3. to find possible risk indicators reflecting the complaints on increasing muscle weakness.

PARTICIPANTS AND DESIGN

During the 1956 polio outbreak in the Netherlands 1784 cases were registered as having paralytic poliomyelitis. Most files had been destroyed over the years. Only lists containing names of cases registered in two southern provinces were available encompassing 564 cases. Of these 564 cases 23 had died due to the polio infection or in the following years. The present addresses of 350 living cases could be traced. They all received a mailed questionnaire. The questionnaire consisted of questions about impairments, disabilities and handicaps at onset of polio, at maximal recovery from polio, during the stable period following polio and at present. The frequency of present neuromuscular complaints was compared with the frequency of these complaints during the stable period in order to determine the prevalence of the late onset polio sequelae.

STATISTICS

Possible risk indicators for complaints of increasing muscle weakness were examined individually using bivariate analysis. The combined predictive value of the risk indicators was analyzed using stepwise multiple logistic regression.

RESULTS

There were 260 respondents (response rate was 74%), 19 denied and 8 could not recall having had paralytic poliomyelitis. The study population comprised the remaining 233 subjects with a mean age of 44.0 years (range 39-77, SD 6.3) and a male/female ratio of 1.0.

TABLE I.

Reported severity and site of muscle weakness in the study population.

Muscle weakness	At onset of polio (N = 223)	At maximal recovery (N = 224)	Stable period (N = 230)
Severity of weakness			
1 extremity	33%	38%	35%
2 extremities	41%	15%	12%
3 extremities	1%	2%	2%
4 extremities	10%	1%	1%
site of weakness			
one or both legs	74%	46%	42%
one or both arms	38%	19%	17%
trunk muscles	28%	15%	16%
facial or swallow muscles	14%	9%	8%
respiratory muscles	9%	5%	5%

During the stable period the reported muscle weakness did not show an increase as compared to muscle weakness at maximal recovery from the polio.

At present 58% of the cases reported an increase in muscle weakness when compared with their muscle strength during the stable period. The most frequent site of the increased muscle weakness were one or both legs and trunk muscles.

Risk factors for increased muscle weakness were the presence of neuromuscular complaints during the stable period and current age.

TABLE II.

Frequency of neuromuscular complaints during the stable period following acute poliomyelitis and at present.

Neuromuscular complaints	Stable period (N=208)	Present (N=233)
Fatigue	21%	44%
Muscle twitches	19%	24%
Muscle cramps	16%	22%
Pain		
- back	18%	38%
- muscles	16%	34%
- joints	12%	33%
- neck	11%	28%

The frequency of all complaints listed was significantly higher at present time as compared to the stable period following polio (range in p values 0.001 to 0.004).

CONCLUSIONS

Nearly 60% of a sample of Dutch survivors of the 1956 polio outbreak experience late onset polio sequelae resulting in an increase of their disabilities and handicaps.

Increasing muscle weakness is not reported during the stable period and is therefore a late onset polio sequela. In contrast, various neuromuscular complaints as fatigue, pain, muscle cramps and muscle twitches are already present during the stable period after recovery from polio and their presence is the strongest risk indicator of the late complaints of increased muscle weakness.

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Eighth International Post-Polio and Independent Living Conference
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**Polio and Post-Polio Syndrome Survivors:
Who Are They and How Are They Doing?**

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Abstract

With the last of the U.S. polio epidemics in the 1950s and the discovery of vaccines to fight the disease, polio survivors, having faced difficult periods of recovery, rehabilitation, and adapting to life with a disability, were once under the belief that the "worst was over" for themselves and for others in fear of contracting the disease. However, for more than twenty years, the "late effects of polio," or "post-polio syndrome" (PPS), has been of concern to survivors and researchers alike. Its symptoms include fatigue, new muscle weakness, pain in joints and muscles, and sometimes difficulty in swallowing or breathing. Typically, these problems appear 15 to 40 years after the onset of the poliovirus, occurring in polio survivors originally thought to have had the paralytic form of the disease. Estimates of the percent of polio survivors now experiencing PPS have been as high as 80 percent. However, since these symptoms are often diagnosed as other illnesses, no one has an accurate estimate of the number of polio survivors currently suffering from PPS.

This presentation will give preliminary estimates of the number and types of problems being experienced by polio survivors identified by the 1994 and 1995 National Health Interview Survey's Disability Supplement. It will also describe survivor's experiences with the initial illness, periods of rehabilitation, and new symptoms that began after establishing stable disability.

POST POLIO SYNDROME WHAT DOES IT MEAN ORTHOTICALLY?

By

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What is post polio syndrome? This becomes a complex question that may have many answers depending on the specifics of a patient's complaints and problems. There was a time that some feared the dreaded disease was coming back and that it would cause additional paralysis in what muscles were left. These issues puzzled patients and physicians alike. Many physicians practicing today have not had the experience of working with the polio population, as many polio patients have been stable for some time. However, after many years of use, muscles and joints seem to be screaming out, "I've had enough, I need relief, I need some rest!" These symptoms consisting of muscle and joint pain come from different parts of the body depending on the affected areas.

First of all, we need to describe exactly what polio is. After entering the body through the gastro-intestinal tract and an incubation period of two weeks, the virus attacks the anterior horn cell of the spinal cord or the brainstem (1). The ventral root, which synapses with a motor nerve, is damaged to the point that it is unable to send messages to the muscle cell through the terminal axon sprouts. This lack of innervation causes muscle weakness or paralysis. If enough damage is done, partial or total paralysis of the lower or upper limbs will result as well as complications and paralysis of the respiratory system. It is believed that some of the terminal axon sprouts are able to branch out to muscle cells,

which have been affected and help in innervation. (2). This will allow function of the muscle cell however, that particular muscle probably will be much weaker than a normal group of cell innervation.

There are five main stages of polio. These consist of a prodromal phase lasting two days, an acute illness lasting approximately two months, a recovery or convalescence period lasting up to two years, a stable disability or stage of chronicity and then a post polio syndrome (3), (4) which includes symptoms of muscle pain, joint pain fatigue accompanied by additional weakness and atrophy of muscle tissue. Usually the stage of stable disability lasts for 20 to 30 years. These chronic disabilities become increasingly challenging for polio patients trying to keep up a normal pace. The exacerbation of symptoms of the polio patient is classified as " Post Polio Syndrome", a condition composing of a "...cluster of symptoms in individuals who had paralytic polio many years earlier" (5).

From a survey conducted in 1987 by the National Commission on Health Statistics, there were 1.63 million polio survivors with 641,000 having some type of paralysis (6). If you divide this by the approximately 1,000 ABC facilities, there are about 600 patients per facility who will need some manner of care. Even if this number were cut in half, there would still be a substantial population for each facility. A recent problem that has arisen from this group is that many of them who require orthotic care have felt reluctant to confide in their orthotist. Many orthotic professionals have told them that they (polio patients) are hard to deal with, they are set in their ways and take a considerable amount

of time to provide care. The orthotic profession must be careful not to prejudge these patients as all difficult type "A" personalities (7). Many of them have expressed offense as they have shared their feeling in the many seminars and support groups which I have had the privilege of presenting. We as professional practitioners, need to take the time to listen and to properly evaluate these patient's conditions. It is imperative that orthotic practitioners become familiar with the polio patient's history. Practitioners need to understand exactly what they are dealing with. Polio survivors are the type of patients that practitioners need to evaluate hands on and to know "first hand" the muscle weakness and range of motion and how the patient is substituting for the weakness to be able to function.

The polio patient is the most important member of this/her rehabilitation team. He/she must be allowed to assist in the design of the orthosis. He/she needs to understand that orthotic practitioners are not sentencing them to 24-hour orthotic wear but are trying to provide a system that will protect and stabilize. Be flexible with these patients. Leave options in the treatment plan. Provide patients with a choice and lead them in the right direction. Let them know that your abilities and expertise can help eliminate unwanted range of motion and allow for a more normal function. By all means, don't lock their joints unless you absolutely have to. If you do, you may find that your carefully designed orthosis will end up in their closet, not because of your design, but because you have taken away from them the simple motions that they use to substitute for muscle weakness and joint deformity.

When assessing a post polio orthotic patient, consider all design options, which are available. Some of these options may be a combination of two or more orthotic designs. For example, you may have a patient that needs additional knee stability due to weakened quadriceps but is unable to tolerate the weight of conventional designs. One idea is to provide a hybrid orthosis consisting of a leaf spring design orthosis with a pre-tibial shell which provides minimum quadricep support and give just enough feedback to prevent the knee from buckling. Younger and stronger patients [40-60] can accept more aggressive designs and seem to have a willingness to try harder in allowing time for adjustment to new designs. They seem to have a better understanding of what the intended outcome is and will work to make it happen if possible. Older polio ambulatory [60-75] are often more complicated due to additional muscle and joint fatigue. They seem to be more apprehensive about change. Orthotic practitioners need to realize that these older patients have experienced much in dealing with past orthotic challenges. These patients need to lead the way in their orthotic care and are the ones who need options to choose from. Elderly ambulators [75 +] usually need lightweight orthoses. They want little change and practitioner listening skills need to be especially keen for this group. You must let these elderly patients know that you care about them and you also must learn to take their criticism with a smile.

What drives many of these patients to their physicians and eventually to orthotic facilities is pain. Polio patients with post polio syndrome will have pain. There is a reason for this pain. Pain is good: it is a tool by which a patient can be protected from further damage if he/she respects it (8). Pain is the , “Personal Awareness of Internal Notification” system.

It is important to identify the source of the pain. Orthotic professionals need to focus on the musculoskeletal issues. If possible, joints need to be protected to prevent further damage while allowing the patient to continue to have mobility. By providing stability and more normal biomechanical function, joint destruction and muscle fatigue and stress can be reduced.

Many new and amazing materials are becoming available to orthotic professionals. This allows for lighter and stronger orthotic designs. New techniques are also available through modern technology by surgeons. Some joint deformities can now be improved dramatically, relieving stress and pain around joints and surrounding tissue. Keep your polio patients informed and don't be afraid of the challenges. Many of you have been trained professionally to handle these types of conditions. Please remember that your area of expertise is greatly needed and polio survivors will be relying55 more on your professional services.

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STRATEGIES FOR OBTAINING BEST BRACING

A SOCIOLOGICAL PERSPECTIVE

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Orthotic management of lower extremity musculoskeletal disorders represents a complex phenomenon. Much research addressing the gait and biomechanics with various KAFO and AFO designs have been conducted. The majority of the users abandon the orthosis primarily due to discomfort and poor ergonomic factors.

Over the years there have been numerous developments in the design of lower extremity orthotic systems. These include KAFOs, AFOs and computerized electrical stimulation for walking. However many of these designs have proven unsuccessful in terms of usage in the community, home, and work place. Certainly factors such as cosmesis, ease of application and removal, ease of maintenance, ergonomic function and well-being may be far more important than biomechanical performance.

The knee-ankle-foot-orthoses that are currently available are effective mechanism to adequately support the lower extremity segment. The conventional designs available are fabricated from metal and leather combination or more recently metal and thermoplastic combination. They are cumbersome, heavy with many straps attached to control various segment deviations. These mechanical devices sometimes induce potential hazards from the physical and

psychological stress of spending long hours wearing them, limiting activities rather than accomplishing important objectives or performance.

A questionnaire result from UMOPC study indicates that patients with lower extremity impairment were able to enhance their ergonomic function in relation to performance, satisfaction and well-being when a user friendly design is applied. The area needed most attention is the patient's feelings related to performance, satisfaction and well-being. Also the design should be easy to use and ergonomically efficient. As the age of polio patients increases, the problems associated with pain and fatigue, loss of muscle strength and ligament laxity of the lower extremity are also expected to increase. The percentage of time wearing an orthosis may increase considerably and this increase in time would make the ergonomic factors more important especially body comfort, satisfaction and performance.

POST-POLIO SYNDROME – THE THEORIES

Paul E. Peach, MD

- I Acute Polio – Degrees of Severity
 - a) subclinical & abortive poliomyelitis
 - b) non-paralytic poliomyelitis
 - c) paralytic poliomyelitis
 - 1. varying degree of paralysis
 - 2. bulbar paralysis
 - respiration impairment
 - swallowing impairment
 - 3. RAS
 - 4. Brain damage?
- II Recovery from Polio
 - a) giant motor units – formed in survivors
 - reinnervation during recovery
 - b) deconditioning – resolving
 - c) muscle hypertrophy
- III Theories of PPS
 - a) mild form of ALS
 - b) chronic viral infection
 - c) immune response (chronic fatigue syndrome)
 - d) “premature” aging of motor units
 - 1) after sixth decade normal loss – effect on polio survivors with already depleted reserve of motor units
 - 2) any evidence of truly “premature” aging?
 - e) motor unit dysfunction
 - 1) constant remodeling
 - 2) collateral sprouts
 - dropping off
 - transmission blocks
 - 3) chronic metabolic overload
 - f) chronic and acute overuse
 - 1) neuromuscular overuse
 - 2) musculoskeletal overuse
 - g) concept of functional reserve
- IV Nonparalytic Polio – is there a risk of PPS?
 - a) definition of acute polio
 - b) When are nonparalytic polio survivors truly “nonparalytic”?
 - are current diagnostic criteria sensitive enough to include all paralytic cases?
 - c) Theories proposed in support of this?

- 1) lack of sensitivity of current diagnostic criteria?
 - 2) other proposed theories
- V Most likely explanation
- a) is there just one? - or are there multifactorial etiologies?
 - b) the need to apply rational and veritable clinical measurements
- VI Clinical outcomes with treatment interventions

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Evaluation and Treatment of Polio Survivors A Multidisciplinary Team Approach

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Proper assessment of the polio survivor presents a dilemma because of the diversity and the nonspecific nature of their complaints. Appropriate treatment is a challenge because of the lack of curative therapeutic interventions. Therefore, comprehensive, coordinated assessment and treatment is required. We meet these needs at the Roosevelt Warm Springs Institute for Rehabilitation by performing a multidisciplinary evaluation for all patients seen in our Post-Polio clinic. This presentation will discuss the role of the each team member, the goals of a multidisciplinary post-polio evaluation, and how we develop a treatment plan to help each patient not only feel better, but also achieve an improved level of function.

A typical evaluation in the RWSIR Post-Polio clinic includes assessments by a nurse, a physician, a physical therapist, an occupational therapist, and frequently an orthotist. When necessary, referrals are made to other health care providers. These include Social workers or Case Managers, Psychologists, Dieticians, or Respiratory Therapists. The nurse initially assesses the patient's health status including medical history, functional status, and then coordinates evaluations and tests.

The physician does a comprehensive history and physical exam with attention to present complaints, polio history, musculoskeletal and neurological examinations. The physician determines the need for diagnostic tests including laboratory tests, X-rays, pulmonary function tests and electrodiagnostic studies (EMG). We usually obtain baseline labs including thyroid tests, a test for anemia, glucose and cholesterol. New weakness is one of the most common complaints for many patients when they come to the clinic for the first time; therefore, we feel the work up for new neurogenic weakness should include an EMG. Data will be presented supporting how this test can detect the presence of other conditions such as carpal tunnel syndrome and rule out other causes of weakness such as a radiculopathy. Pain is the most prevalent complaint seen in our clinic, and there are many possible causes. There are three types of pain seen in post-polio patients: post-polio muscle pain, overuse pain, and biomechanical pain. We have also found that fibromyalgia causes pain in many of our patients. The physician then makes referrals to the team members for further evaluation and treatment. Following these evaluations, the physician meets with the patient on the second day of the evaluation to review the results of the tests and the recommendations of team members.

The physical therapist's role in the evaluation includes a baseline manual muscle test, a joint range of motion, and evaluation of posture, gait and mobility as well as patient education. A baseline manual muscle test is performed of major muscle groups, noting any history of muscle transfers, stabilization or surgical interventions. Range of motion and leg length discrepancy measurements are made. Posture is evaluated in sitting and standing (if appropriate) Gait patterns are evaluated, making modifications as needed with appropriate assistive devices. The physical therapist addresses mobility issues in the Seating and Wheeled Mobility Clinic. Patients are given the opportunity to try manual wheelchairs, power operated vehicles (scooters) and power wheelchairs. Seating systems are also used to provide pelvic and trunk support in order to decrease pain and prevent deformity. And finally, the physical therapist provides patient education. Patient education includes information on appropriate exercise protocols, the importance of utilizing available technology to lessen fatigue and accepting/coping with post-polio syndrome.

The occupational therapist (OT) assesses a person's independence with activities of daily living (i.e. dressing, bathing, cooking, driving and child care) The occupational therapist analyzes the activities a person does every day to determine the amount of energy required and the amount of stress put on each specific muscle group. Different people value different activities; therefore, the total amount of energy required for each person is unique. Treatment can include upper extremity stretching, providing adaptive equipment to compensate for weak or atrophied muscles and providing hand splints to improve hand function or protect weak muscles. The focus of the OT treatment is energy conservation. As the overuse theory suggests, people with PPS only have a small amount of energy with which to power their muscles, therefore it has to be carefully managed, just as a small amount of money has to be budgeted.

The orthotist evaluates the gait and the bracing needs. He makes necessary adjustments and repairs to existing braces and crutches and will determine the needs for those who may be needing braces for the first time or putting a brace back on again after years without one. For those who gave up their braces years ago, wearing a brace again may be a difficult experience. However, many times the brace may be necessary to improve gait, decrease pain or prevent further joint deformity such as knock-knee or back knee. The materials to be used and the type of brace is dependent on the patient's strength, lifestyle, and what he is used to wearing in the past.

In summary, we believe this model serves as a useful evaluation tool for all patients who present first to a Post-polio clinic. Because the polio survivor's needs are so diverse, just one team member cannot meet them. We also believe that by providing services over a two day period the polio survivor is given a more energy efficient evaluation, yet there is adequate time for there questions to be answered and their brace work to be done. By presenting this at the 2000 GINI conference we hope to provide participants with the knowledge of the requirements of an appropriate polio evaluation.

Suggested Reading

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St. Louis, Missouri, June 8 - 10, 2000**

**ASSESSING OUR ACTIVITIES TO EFFECTIVELY MANAGE OUR LIVES
and provide the medical profession
with more information on the changes that are taking place.**

Presented by Founder Hilary Hailam and USA Member Richard Boone
Lincolnshire Post-Polio Network, U.K.

Summary of Talk to be followed by Interactive Session Sharing Ways We Now Do Tasks.

It has been 45 years since the vaccine was first introduced. 'No need to research it anymore, no need for long lectures or new polio specialists'. Very few Medical Professionals working today have actually seen a case of polio. If a health professional sees thin legs, different size feet, and callipers, then polio springs to mind. If we don't have these and say 'We have had polio', we are often asked 'Are you sure you had polio?'

There is a lack of knowledge in the UK of polio in its first instance and its late effects. Until recently most health professionals were not aware that PPS existed. Many inaccuracies are still being reported e.g. that it does not exist, that it does not affect the brain, you can't have problems in areas you were not paralysed. The majority of assessments are single disciplinary one of manual muscle testing (MMT) which grossly overgrade our actual muscle ability in contradiction to the symptoms we are reporting. We need multi-disciplinary PPS clinics staffed by specialists.

We ask that you take the following facts into consideration and then look back on your life.

- a) That at least 90% of all anterior horn cells were in some way affected during the polio infection (1. Bodian 1947)...
- b) but required the death of more than 60% to demonstrate any paralysis (2. Bodian 1949).
- c) That 40% damage found on autopsies had not shown clinically evident weakness. (3. Sharrard 1955). Therefore the diagnosis non paralytic polio comes above 40% and below 60% damage.
- d) This year the criteria for PPS should now be modified from paralytic polio to a history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous systems in earlier life. (4. Hatstead & Silver 2000) which quotes Lincolnshire Post-Polio Library article January 1999 Non Paralytic Polio and PPS (5. Falconer & Bollenbach 1999)
- e) That a polio muscle manually muscle testing at '5 - normal' is only functioning at 53 to 59%, 4 at 40%, 3 at 20%, 2 at 10% and 1 at 1%. (6. Beasley 1981 and 7. Perry 1995)
- f) That one off manual muscle testing in a single discipline assessment does not test repetitive or sustaining power - weakness that we are reporting. (8. June LincPIN 1999)
- g) MMT tests instant strength. Muscle fibres contract, then rest, allowing others to take over. Someone with PPS may have only 40% of his original muscle fibres so in a short while there are no substitutes to take the load off resulting in fatigue of contracting muscles. Explained in Lincolnshire Post-Polio Library article Polio Biology X. (9 Bollenbach 2000)
- h) Decreased muscle strength due to a loss of anterior horn cells is a normal part of the aging process (10 Holman 1986) but there is no significant motor neuron loss before the age of 60 (11 Tomlinson & Irving 1985) yet many postpolio individuals experience serious changes at a much younger age, lessening the credibility of the theory that aging alone can explain the late effects of polio. The youngest patient diagnosed with PPS in Montreal is reported as 14 years of age (12 Cashman 1997)
- i) As we recovered from polio we learned substitution of muscles and we also 'asked' muscles up the chain to help so that we could achieve tasks. Most often we achieved way beyond what was expected initially, totally disguising the actual functioning level of our polio affected muscles. We have not forgotten this but we may not notice that it is happening unless we start to assess how we actually do what we do.

When and if PPS will start will all depend on what damage you had originally, how you recovered, what you have done with your life, and are still doing. We believe that by assessing how you actually do daily tasks now and comparing that with the way you used to do them at best recovery and how that has changed in between will give you information that you can pass on to those examining you. Saving money, time and stress for yourself and Health Professionals. When did you start noticing any change and what can you do to help yourself?

Polio Survivors

1. Fill out assessment sheets for all your daily activities. We need to assess each activity that we do and compare that with how we did this at best recovery. What has changed? When did this start changing and what is the progression. (Basic Example page 3 - and space for you to write down some of yours - use more columns for years in long version.)
2. Provide a visual time line of shaded in bodies with a few notes underneath. (Basic Example page 4 - space for you to do a simple version with only one PPS body, its better with more.)
3. This visual time line needs to be part of a File that you make about yourself in two formats. Long for your own reference with photographs and stories of your polio life and achievements from yourself/family/friends; your symptoms and when they started; and photocopies of your medical reports. Short notes - preferably on one side of one sheet only - that are double spaced to hand to those examining you.

To Health Professionals we ask:-

1. Please can you change your questioning from 'Can you do this activity?' to 'How do you do this activity?' Allowing us permission to tell you how we do it, rather than answer Yes.
2. That when you use one of manual muscle testing of muscles and you find e.g.:-
 - a) strong muscles but we say that arm is weaker that you ask us to do tasks with that arm, e.g. pick up a heavyish item from a table and bring it towards us.
 - b) strong leg muscles but we are reporting functional decline that you see us walking along a corridor not four steps across your office; climbing a flight of stairs rather than the 3/4 steps in a physio gym.
3. That you refer us to a recognised multi-disciplinary PPS clinic.

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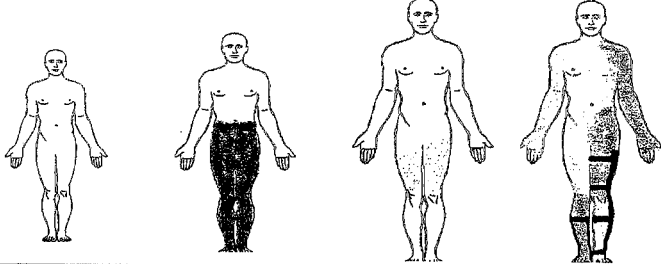
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Lincolnshire Post-Polio Library - <http://www.clt.zynet.co.uk/polio/lincolnshire/library/>
 Newsletters - <http://www.clt.zynet.co.uk/polio/lincolnshire/network.htm#linkpin>
 Lincolnshire Post-Polio Network, 69 Woodville Avenue, Lincoln, LN6 3RD, U.K.
 Tel: +44 (0) 1522 888601. Fax: +44 (0)370 1600840 Email: linpolio@legend.co.uk

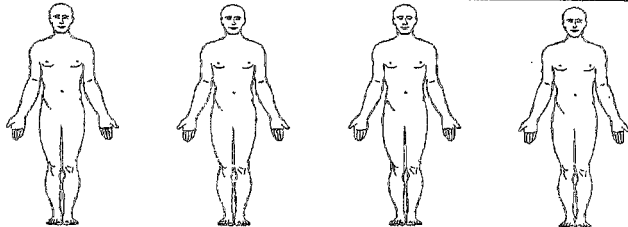
EXAMPLE OF SIMPLE ASSESSMENT FORM - HILARY HALLAM		
ACTIVITY	AT BEST	SINCE NEW SYMPTOMS FOLLOWING FALL IN OCT.1988
STAIRS	Go up two at a time.	'89 Normal '94 One at a time rt. foot. '97 Pull up with right arm as well '99 Go up once a night only. 2000 Live downstairs - do not use stairs unless no other way to get somewhere.
SWIMMING	Lifeguard Distinction Advanced Swimming/Lifesaving Teacher Grade I Examiner Lifeguard Training Officer.	Spring '89 Back to work following Fall Cannot swim as fast, fail all Lifesaving Awards, cannot pull self out of water. Forced to stop Teaching/Lifeguarding.
TYPING	Secretary - touch typist.	'97 Ergonomic Keyboard, '99 now left palm rest - plus type and rest.
WALK	'69 39 Mile Lyke Wake Walk '73 -'87 2 - 10 mile walks	'91 Started using cane on walks. '95 Started using cane in street '96 Manual chair but could not push it '97 Got Electric Scooter. '98 Got Ankle Foot Orthosis '99 Got Intelligent Knee Orthosis.
DRIVE	Advanced Police Driver	'91 Start lifting left leg onto clutch '95 Have to lift leg onto clutch '98 Have to drive automatic motability car.
CARRY BAGS	Could carry 56lb Sack of Potatoes	'89 Cannot hold items in left hand have to clutch to chest or hold arms length. '98 Now cannot carry handbag with left arm.
PICK UP PINT AND DRINK	Normally with one hand	Can pick up pint of fluid, but need two hands to carry it to mouth to drink.
ENTER YOUR OWN ITEMS - BRING THESE AND MORE TO SHARE DURING THE TALK		

SIMPLIFIED VERSION OF VISUAL TIME LINE - HILARY HALLAM			
BEFORE POLIO	POLIO	STABLE FUNCTIONING YEARS	NEW PROBLEMS (shaded) SINCE FALL OCT 1988 MAIN AIDS USED
0 - 5 YEARS 2 MONTHS.	5 YEARS 3 MONTHS	AGE 14 TO 41	OCT 88 (41) - JUNE 2000 (53)



NO KNOWN PROBLEMS	WAIST DOWN PARALYSIS	WEAK TIGHTS, BUT ACHIEVED THE FOLLOWING	'99 LEFT LEG UTX SWING '98 RIGHT LEG AFO
	RECOVERY IN WORDS ONLY	POLICEWOMAN 1969 - 1973	'97 ELECTRIC SCOOTER
	LEARNED TO WALK AGAIN	RLSS LIFEGUARD >1988	'99 ELECTRIC RISE CHAIR
	DROPPED FEET - COULD NOT RUN	ADVANCED SWIMMING TEACHER >1989	'97 ROLL IN SHOWER
	MULT. TENDON TRANSFERS	ORANGE BELT JUDO	'97 ERGONOMIC KEYBOARD
	OPERATIONS ON BOTH FEET AGE 13	CANOE - ICE SKATE DANCE - LONG WALKS	'98 MOBILITY CAR & HOIST

SIMPLE SAMPLE FOR YOU TO FILL IN - FOR BETTER VERSION WE RECOMMEND YOU USE MORE THAN ONE BODY TO SHOW PROGRESSION FROM BODY THREE TO BODY FOUR



EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference
SAINT LOUIS, MISSOURI

Thursday, June 8, 2000

SESSION II

3:15 pm - 4:30 pm

- PAVILION SALON C **Beyond the Blues: Negotiating the Pitfalls of Depression Creatively**
Dorothea Nudelman, MA; Patricia Strong, MA
- PAVILION SALON B **The Sleep-Bladder Connection***
Mary Umlauf, RN, PhD; John McBurney, MD; Eileen Chasens, RN, DSN
- PAVILION SALON D **Influencing Those Who Do Not "Get It" ...**
... Working with the Media
Cyndi Jones
... Advancing Disability Studies
Karen Hirsch, PhD
... Teaching About Disability
Kathleen A. Navarre, PhD
- PAVILION SALON E **Assessment of 277 Post-Polio Clinic Patients**
Wendy Malisani
Nutrition for the Ventilator User
Paul Ott, RD (sponsored by Pulmonetic Systems, Inc.)
- PAVILION SALON A **Strategies for Management of Arms and Shoulders**
Mary Ellen Brown, RPT; Nancy L. Caverly, OTR/L
- PAVILION SALON F **Self-empowerment and the Post-Polio Support Group:
A Conversation for Support Group Leaders**
Jeff and Linda Feinstein
- PAVILION SALON G **Footwear and Care for Polio Survivors**
Dennis J. Janisse, C.Ped

Eighth International Post-Polio and Independent Living
Conference, St. Louis, Missouri, June 8-10, 2000

Beyond the Blues: Negotiating the Pitfalls of Depression Creatively

Presenters: Margaret L. Campbell, National Institute of Disability and Rehabilitation Research;
Dorothea Nudelman, polio survivor, co-author of *Healing the Blues*, retired College English Professor;
Patricia Strong, polio survivor, co- author of post-polio articles in peer-reviewed journals and conference presenter.

Do you often wonder if aging with a chronic disability like post-polio syndrome inevitably results in cyclical episodes of depression? Do you feel alone in your bleak outlook and consider yourself weak or shameful for harboring such feelings, even occasionally? The bad news is that stigma still surrounds depression. The good news is that depression can be healed: people not only survive but can thrive as they age with increasing polio-related disability.

In this session presenters will share both data and personal stories to help participants recognize and understand depression more fully; its prevalence among polio survivors, its many feelings and risk factors, and creative coping strategies. Emphasis will be on specific and realistic ways to promote better mental health and greater life satisfaction in the years that lie ahead.

The three presenters have a thorough understanding of this often neglected but important aspect of health. Margaret Campbell has spent years as the director of research of the Aging with Disability study at the Rehabilitation Research & Training Center at Rancho Los Amigos Medical Center in Downey, California, and currently is director of programs with the National Institute of Disability and Rehabilitation in Washington, D.C. As polio survivors and writers, both Patricia Strong and Dorothea Nudelman have experienced and recovered from major depressions resulting from the losses of post-polio. Their experiences—from deep depression to surviving and then thriving—will be familiar to many and are told to encourage others.

In addition to presenting epidemiological data and personal experiences the presenters will focus on audience participation wherein your own experiences, viewpoints, and questions can create a dialogue between presenters and audience. We want to know, for example, how your experiences with using and accepting new assistive devices have changed your outlook and feelings about life. Has the use of medication or changes in different medications helped when coping isn't enough? Have support groups helped you maintain a sense of hope or feelings of empowerment? We want to hear how you have coped with losses associated with valued activities - such as work or hobbies - and gone on with your life. We want to hear your depression-management ideas. And we want to share our collective wisdom on ways to add life to our years.

Please join us for an organized but informally presented session where all viewpoints are accepted, data is solid, stories are shared, and laughter is encouraged.

Eighth International Post-Polio And Independent Living Conference
St. Louis, Missouri, June 8-10, 2000
Margaret Campbell, Ph.D., Dorothea Nudelman, M.A., & Patricia Strong, M.A.

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Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri June 8 –10, 20000

The Sleep-Bladder Connection
 Mary Umlauf, RN, PhD, John McBurney, MD, Eileen Chasens, RN, DSN
 University of Alabama at Birmingham

Chasens, ER, Umlauf, M., Valappil, T., Singh, KP. (2000). **Nocturnal Problems in Post-Polio Syndrome: Sleep Apnea Symptoms and Nocturia.** *Rehabilitation Nursing.* (accepted for publication).

Abstract

There are 640,000 polio survivors in the United States at risk for both age-related disorders and the effects of post-polio syndrome (PPS). Nocturia, generally accepted as the inevitable consequence of aging, is also a symptom of a potentially lethal condition - obstructive sleep apnea (OSA). Persons with PPS, especially those who suffered bulbar involvement and respiratory impairment during the acute polio episode, are at highest risk for sleep-related breathing disturbances. The purpose of this study was to examine the prevalence and effects of nocturia and sleep related breathing problems in persons with polio and to test The Sleep Disordered Breathing – Nocturia Model in this population. This model describes the cascade of events that result in increased urine production in persons with sleep-related breathing disorders. A 34-item questionnaire was published in the newsletter of a national polio support group. The data from the 584 returned questionnaires showed statistically significant associations between OSA symptoms, nocturia, poor sleep quality, use of hypnotic/stimulant medications, excessive daytime sleepiness, lower urinary tract symptoms, naps, and decreased self-rated health. The study results not only support the model but also document how nocturia and sleep-disordered breathing negatively impact the well being of persons with polio.

Sleep Disturbances and Bladder Symptoms among Post Polio Subjects

	OSA Symptoms	Poor Sleep Quality	Daytime Sleepiness
Post-Polio Only (n =277)			
Poor Sleep Quality	.63 ♦		
Daytime Sleepiness	.40 ♦	.52 ♦	
Sleep Medications	.44 ♦	.29 ♦	.32 ♦
Nocturia	-.07	.20 *	.04
Post-Polio & Hx Breathing Problems (n =156)			
Poor Sleep Quality	.61 ♦		
Daytime Sleepiness	.58 □	.57 ♦	
Sleep Medications	.49**	.31**	.31**
Nocturia	.34 *	.32**	.34 ♦

Pearson's r, * p < .05; ** p < .01, □ p < .001, ♦ p < .0005

Even in the absence of apnea, breathing may fall short of needs during sleep, resulting in retention of carbon dioxide and decreased oxygen levels. These may result from respiratory muscle weakness as may occur with the post-polio syndrome. During REM sleep extra muscles involved during breathing in wakefulness and NREM are normally paralyzed. Respiration is solely dependent on the diaphragm during REM. If the diaphragm is weakened or paralyzed due to polio, hypoventilation may occur.

2. Periodic Limb Movements Syndrome (PLMS). PLMS is manifested by repeated, stereotyped movements of the limbs during sleep. The legs are most commonly affected, but the arms may be involved as well. These repeated movements result in sleep disruption and may result in insomnia or hypersomnia. Risk factors for PLMS include diseases of the brain and spinal cord, such as post-polio syndrome, peripheral neuropathy, spinal diseases such as spinal stenosis or herniated discs or a variety of metabolic problems such as renal insufficiency or iron deficiency. Individuals with PLMS often experience restless legs as well (see #3 below). PLMS is very common, and increases with advancing age. 50% of individuals aged 70 or greater have PLMS.

3. Restless Legs Syndrome (RLS). RLS refers for a disagreeable sensation in the limbs that is accompanied by a compulsion to move the limb in an attempt to temporarily relieve the symptoms. Symptoms worsen at night and may result in severe insomnia. 80% of individuals with RLS also have PLMS once asleep. Conditions that predispose to PLMS also may predispose to RLS.

4. Fibromyalgia Syndrome. Fibromyalgia syndrome refers to diffuse musculoskeletal pains associated with discrete tender spots, called trigger points, in predictable locations in muscles and connective tissues. Sleep in fibromyalgia is disrupted and poorly restful. During NPSG fibromyalgia sufferers are seen to retain remnants of waking EEG patterns during sleep. This is termed *alpha intrusion* for the alpha waves of wakefulness. In severe cases, fibromyalgia patients feel that they do not sleep at all, despite objectively being demonstrated to be asleep. This is termed *sleep state misperception*. Varying degrees of depression often accompany fibromyalgia. Post-polio syndrome predisposes to fibromyalgia due to altered mobility, decreased range of motion, altered function in joints with increased biomechanical stresses and decreased exercise capacity.

Making the Most of Your Sleep

Healthy sleep habits are the cornerstone of a healthy lifestyle. Here are some important suggestions for maintaining healthy sleep.

- Maintain a regular sleep schedule. After a bad night, avoid "sleeping in" to make up for lost sleep.
- Limit napping
- Avoid caffeine and alcohol. Caffeine causes sleep disruption even if you are not experiencing insomnia. Alcohol increases wake time in the early morning and may dramatically worsen sleep disordered breathing.
- Make the sleeping environment comfortable both physically and emotionally. Avoid using the bedroom for other functions such as a home office. Keep the room dark, quiet and cool.
- Check your worries at the door. If necessary, set aside "worry time" at some other time and in another place.

Diagnosing Sleep Disorders

The most important step in diagnosing a sleep disorder is that recognition that there is a problem. Most individuals with primary sleep disorders have never seen a sleep medicine specialist or had any evaluation! Some primary sleep disorders such as PLMS/RLS or fibromyalgia can often be diagnosed by a careful history and physical. Others, such as OSA, require specialized testing such as nocturnal polysomnography (NPSG) for diagnosis. Often a NPSG reveals multiple primary sleep disorders in the same patient. This is termed *comorbidity*, and is seen in up to 30% of patients who undergo NPSG at our center. Examples include OSA and CSA, OSA and PLMS, PLMS, RLS and fibromyalgia all coexisting in the same patient.

Treating Sleep Disorders

Most sleep disorders can be diagnosed and effectively treated. Sleep disordered breathing usually responds well to continuous positive airway pressure (CPAP). Types of positive airway pressure include nasal CPAP, and bilevel positive airway pressure (BIPAP). Each has an important role in managing this problem depending on whether the problem is OSA, CSA or hypoventilation. Supplemental oxygen may be added in some instances. PLMS and RLS usually respond well to medications such as l-dopa/carbidopa (Sinemet), dopa agonists such as pramipexole (Mirapex), clonazepam (Klonopin) and gabapentin (Neurontin). Often iron supplementation may improve symptoms as well. The treatment of fibromyalgia includes low dose tricyclic antidepressants, physical therapy and exercise.

Normal Sleep and Sleep Disorders

John W. McBurney, M.D.
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Sleep accounts for approximately one-third of our lives, but the impact that sleep and sleep disorders have on our health is often under appreciated. In addition, many, if not most, chronic medical conditions have demonstrable effects on sleep, and may predispose to sleep disorders. The purpose of this discussion is to examine the ways in which post-polio syndrome may affect sleep, and important sleep disorders that are common in post-polio syndrome.

Normal Sleep

Sleep is a reflection of active brain processes. It is divided into rapid eye movement (REM- when most dreaming occurs) and non-rapid eye movement (NREM) portions. NREM is further subdivided into 4 stages (I-IV). Stages III and IV are collectively referred to as slow wave sleep. NREM sleep is felt to result in rest and recuperation. REM sleep is thought to be involved in the restitution of brain functions active in wakefulness – sort of like defragmenting the hard drive on a computer. Across the night sleep normally evolves in a predictable sequence. This is referred to as *sleep architecture*. A key feature of sleep architecture is that REM is normally entered only after 90-120 minutes of NREM. NREM slow wave sleep is seen mainly during the first half of the night and REM increases in the second half. Sleep architecture changes as we age. Newborn babies spend 2/3 of each 24 -hour period asleep and half of that time is spent in REM. The 24-hour sleep-wake cycle is established by age 6. Adolescents have increased sleep needs and have large amounts of slow wave sleep. Middle age adults spend about 90 minutes each night in stage REM, and about 45 minutes in slow wave sleep. By retirement age, the amount of slow wave sleep is decreased to nearly none, although REM continues to occupy 20% of sleep time. Increasing sleep fragmentation and increased awake time is noted with advancing age. Sleep onset often occurs at an earlier time in the evening with corresponding earlier awakening. Daytime napping becomes more common in advanced age.

Sleep and Medical Conditions

Since sleep is a reflection of active processes within the central nervous system it is not surprising that is affected by conditions that affect the nervous system or other organ systems monitored by the nervous system. Sleep disorders typically cause either *insomnia*, in which sleep amount is not adequate to meet needs, or *hypersomnia*, in which daytime function is compromised by unwelcome sleepiness. Insomnia is the most common medical complaint. Insomnia can result from emotional or behavioral problems, effects of substances such as caffeine or alcohol, side-effects of prescription drugs, effects of physical illnesses, or primary sleep disorders. Post-polio syndrome may predispose individuals to insomnia or hypersomnia in any of these ways.

Primary Sleep Disorders in Post-Polio Syndrome

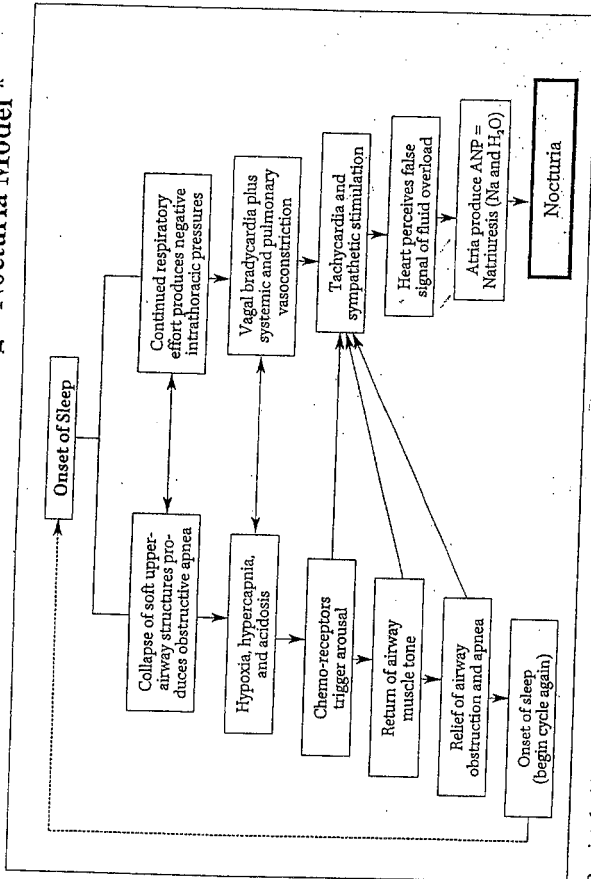
1. Sleep Disordered Breathing: Obstructive Sleep Apnea (OSA), Central Sleep Apnea (CSA) and Hypoventilation. Post polio may cause breathing problems during sleep including OSA, CSA and Hypoventilation. During sleep important changes occur in the physiology of breathing. These include an increase in the resistance to airflow in the upper airway, reduced responsiveness to blood carbon dioxide level, and, during REM sleep, reduced ventilatory effort. Because post-polio syndrome may affect control of the muscles of the upper airway, reflex responses to the level of oxygen and carbon dioxide in the blood, and weakness of muscles of respiration, these normal phenomena may be exaggerated. OSA results when the upper airway collapses and causes repeated interruptions in airflow (apneas). Apneas are terminated by arousal from sleep, which may occur scores, even hundreds of times per night resulting in sleep disruption. This may result in either hypersomnia or insomnia. OSA is a risk factor for hypertension (high blood pressure), myocardial infarction (heart attack), congestive heart failure (CHF) and stroke. Individuals with OSA are also at a 7 times increased risk of motor vehicle accidents. OSA is suggested by a history of loud snoring, observed interruptions in breathing and daytime sleepiness.

OSA is very common, affecting 9% of women and 24% of men, and most cases remain undiagnosed. CSA occurs when the brain reflexes for triggering breathing during sleep are defective. This can occur due to with brain diseases (such as some examples of post-polio syndrome) or cardiovascular diseases, and may co-exist with other breathing problems during sleep, such as OSA or hypoventilation. Many individuals with CSA have difficulty initially falling asleep because of frequent central apneas with arousal at the transition from wakefulness to sleep (transitional central apneas).

Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri June 8-10, 20000

The Sleep-Bladder Connection
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The Sleep Disordered Breathing - Nocturia Model *



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Eight International Post-Polio and Independent Living Conference, St.
Louis, Missouri, June 8-10, 2000

Influencing Those Who Do Not Get It:
Advancing Disability Studies

Karen Hirsch, Ph.D.
Missouri Institute of Mental Health

Disability Studies as a new scholarly field is currently gaining attention within the world of academics. This paper will raise and briefly answer the five basic questions: What? Why? Who? How? Where?

What is Disability Studies? It is the examination, analysis, and interpretation of the human experience informed by the perspectives of people with disabilities. It is by nature cross-disciplinary, covering a wide range of intellectual bases: law, medicine, psychology, sociology, anthropology, history, literature, religion, philosophy, and the arts. Scholarship does not become a part of Disability Studies merely by covering a topic related to health, impairment, and the provision of services to people with disabilities. Disability history, for example, is not the same as medical history, or the history of institutions.

Why do we need Disability Studies? We need Disability Studies in order to change the way people think about and understand the world. As the women's movement grew, we needed to develop Women's Studies programs in order to add the perspective of women to the way people thought and wrote about history, art, literature, etc. By now, we take for granted that gender is an important factor in a person's understanding of the world. Likewise, we need to question why thinking and theorizing is still automatically rooted in an able-bodied perspective; we need to examine how the perspective of people with disabilities can add complexity and meaning to theoretical constructs, policy development, and probably most human intellectual and practical endeavors.

Who can do Disability Studies? While anyone can learn to question and reject the privileged position of the able-bodied perspective on the world, Disability Studies cannot be developed without the leadership and grass-roots participation of people with disabilities. Thus, everyone can do

it, but people without disabilities must recognize their need to learn from disabled scholars and to step out of the way when a lived disability perspective bring changes to understanding, knowledge, and interpretations of the human experience.

How do you do Disability Studies? As a person with a disability, you can participate in the exciting development of Disability Studies in many ways. We do not, for example, have much reliable data about countless disability related questions. Increasingly, people with disabilities are being asked to participate in research projects by answering questions and giving opinions. Our willingness to participate in such research is likely to enhance the development of Disability Studies—if the research is relevant to our lives and we also, as a group, participate in determining both the research questions and the interpretations of the findings. As a non-disabled person you can participate in the development of Disability Studies if you accept the limitations of your intellectual authority within the process.

Where do you find out about Disability Studies? If you have Internet access, the best place to find out about Disability Studies is on the Web page of the Society for Disability Studies: www.uic.edu/orgs/sds/. If you do not have Internet access, you could start by contacting your local Independent Living Center. The Society for Disability Studies holds annual meetings where scholars from a variety of disciplines and from all over the world give presentations about their research, perform Disability Art, show disability related films, and discuss every conceivable disability topic. The meeting this year is in Chicago, on June 29—July 2nd.

**INFLUENCING THOSE WHO DO NOT "GET IT"
... TEACHING ABOUT DISABILITY**

Kathleen A. Navarre, PhD
Psychology Department, Delta College, Michigan

TIMING IS EVERYTHING

I have taught psychology at Delta College for over 15 years and still find that many new students are uncomfortable at first with a teacher in an Amigo power chair. I think some of the discomfort comes from experiencing a disabled person in, what seems to them, a non-traditional role. Part of what I try to accomplish in a 15-week semester, is to help the students see the individual, not the disability. Most students, by the time they get to college, have been exposed to disability stereotypes such as "Jerry's Kids" and now have to adjust to one of "Jerry's Kids" (at this point many people with disabilities are seen as having MD simply because of all of the media exposure) as a person with intelligence, authority, and control of their classroom. This can be a jarring experience for them and presents them with the need to view the "handicapped" professor in a new light.

It has been my experience that referring to my disability too soon can make an awkward situation (awkward for the student, that is) worse. I have found that casually integrating the fact of my not walking due to polio as part of an example of the physiology chapter a very effective way to "break the ice." Also, comparing Christopher Reeves' spinal cord injury to the physical damage of the poliovirus takes the focus off of me and makes for a safer questions-and-answer period. I find students very uncomfortable if I am too open too soon in the semester. They need to know me as a person first and then we are able to talk about disability issues. Also, a discussion of Salk vs. Sabin creates a relevant level for the young mothers and fathers in the class.

I find a noticeable ease in the class once the "mystery" of the Professor in the Amigo has been solved.

I will also share with the conference members attending this session my student's reaction to the film "A Paralyzing Fear." I was able to obtain a preview film of this PBS documentary from the producers and showed it to approximately 100 students having them fill out a standard evaluation form I use for my telecourse class. Some interesting comments will be shared.

POST-POLIO CLINIC, WEST PARK HOSPITAL, TORONTO, CANADA

A DESCRIPTIVE STUDY

ASSESSMENT OF 277 POST-POLIO CLINIC CLIENTS

Lead Investigator: Dr. Peter Parker, M.D., F.R.C.P.(C)

Co-investigator: Wendy Malisani, Post-Polio Clinic Co-ordinator

Presented by: Wendy Malisani

The primary goal of this study was to gain a better understanding of the medical and socio-demographic characteristics of the individuals attending the Post-Polio Clinic of West Park Hospital. We identified clients who have a confirmed history of poliomyelitis, presenting with the Late Effects of Polio. The individuals fall within three main diagnostic subgroups: Post Polio Syndrome, Post Poliomyelitis Progressive Atrophy, and orthopaedic complications due to previous poliomyelitis. Two hundred and seven clients, out of the two hundred and seventy seven, who attended the clinic during a one-year period, met the criteria.

Frequencies and means will be reported and cross-tabulations will compare the medical and demographic characteristics of the identified client base. This study will provide the foundation for an evidenced-based approach to treatment and diagnosis. This knowledge may lead to interventions and management strategies that are more effective, thereby potentially lessening the health care costs incurred while ensuring the best quality of service provision. Finally, reporting on an in-depth examination of this population will help identify what we do and do not know, thereby establishing groundwork and guidelines for future research.

STRATEGIES FOR MANAGEMENT OF ARMS & SHOULDERS

Mary Ellen Brown, RPT and Nancy L. Caverly, OTR/L

POSTURE & ALIGNMENT

1. Keep your arms in good alignment. This allows improved function, minimizes stress and pain. To have your arms in proper alignment requires good postural alignment of the entire spine and good stabilization of the shoulder girdle muscles. In other words, SIT UP STRAIGHT with chest up and shoulders back and down!
2. To have good posture and a stable position of the spine requires functional trunk strength and/or custom seating to support the back while in a seated position and possibly a custom brace for upright positions instead of just standing.
3. Learn RELAXATION techniques for neck, shoulders, arms, wrists and hands to avoid fatigue from tension and to prevent unnecessary muscle overuse from muscle stress. Explore a variety of relaxation techniques, for the resting body, to find one suitable for you. These may include meditation, listening to music, creative visualization, and/or taking a class on stress management. Deep relaxed breathing is essential. Note: relates to LIFESTYLE, also.
4. Do a daily stretching routine to maintain good mobility of joints and muscles. If you cannot do these exercises yourself, have someone do them with you.

FINE MOTOR/ HAND TASKS

1. Make sure your hands are comfortably warm to facilitate improved function and relaxation. Sometimes gloves with the fingertips cut off are helpful.
2. Become more ambidextrous, alternating use of right hand and then left. Don't make the same muscles do everything.
3. Make sure your glasses are adjusted to avoid strain on your neck and shoulders. Remember your postural alignment will shift to enable you to see.
4. When turning pages of a book, use a rubber eraser on a pencil to decrease use of fingertips, or use a mouth wand to eliminate upper extremity (arms, shoulders) demands altogether.
5. Adapt writing implements and other tools so that your hand is supported and comfortable rather than held in a tight pinched grip or awkward position.
6. When picking up light objects with your hands, mold your hand, using the strength of the palm muscles rather than pinching with the thumb and fingertips.
7. Prevent pressure on the thumb side of your fingers. Using hands incorrectly pushes the fingers away from the thumb into a deforming position. For example, hold purses and bags on the forearm instead of with the fingers.
8. Use scissors to open packaged foods, letters, tightly sealed packages. This reduces hand strain.

9. For drinking, try using a straw with the cup, can or bottle resting on a tabletop to avoid a sustained grasp.

10. Check the ADL section of catalogs such as Sammons Preston or Smith Nephew for self help devices for kitchen, bathroom and other needs. There are wonderfully helpful things to make life easier from one-handed potato peelers to book racks to portable toilet seats to graters on suction cups, etc., etc., etc. Regular stores may have can openers, jar grabbers, etc.; also, JC Penney and Sears have catalogs for "Special Needs".

LIFESTYLE / STRESS MANAGEMENT

1. During rest breaks in mid-morning and mid-afternoon, make sure your arms are resting, too. Holding a book to read while relaxing the body doesn't rest the arms.
2. DELEGATE chores that are too demanding such as vacuuming, mopping, scrubbing, chopping, stirring, gripping. "If you have four things to do today, pace yourself to do one in the morning, one in the afternoon, one in the evening, and delegate the fourth. That's one of the reasons we have friends and family."
3. Do deep breathing exercise frequently for relaxation and good oxygen supply to the tissues. Use respiratory assistance if necessary.
4. Eat a healthy well balanced diet low in animal fat and high in vitamins and minerals from fruits, vegetables and grains. Add extra high quality protein for neuromuscular maintenance.
5. Make sure you get plenty of sleep regularly to allow your body to repair itself from any effects of soft tissue micro trauma.

MOBILITY

1. Avoid stairs! Banisters may help legs (lower extremities) but they only strain upper extremities. Use elevators or escalators, if your balance is good enough.
2. Sit in chairs that have sturdy armrests and that are firm. Avoid soft couches as you will really strain your arms getting up and down. One exception to the couch rule -- if you are on the floor, maneuver yourself to the nearest couch, put your arms up on the couch, and then roll yourself onto the couch. This is usually easier than trying to rise from the floor.
3. Avoid falls!! No matter what you might hurt, your upper extremities will pay the price. If you hurt a leg, your arms will be stressed using crutches. If you hurt an arm, you will become more dependent. Some falls are impossible to avoid, but many could be prevented by using the proper bracing, treating medical problems that cause dizziness or balance difficulties. When getting new glasses or trying new medications, be very careful as perceptions and orientation to space may change. Also avoid falls by keeping your environment safe by eliminating clutter, staying off slippery floor surfaces, getting rid of all throw rugs. Stay inside on rainy or snowy days. If you have to go out in inclement weather, always carry a small towel to wipe off the bottom of crutch or cane tips when you go inside.

ENERGY CONSERVATION FOR SHOULDERS

1. When using upper extremities for any activity, take a break at the first sign of fatigue. Do not wait for pain. Take frequent stretch and rest breaks -- at least every 15 minutes with any activity.

2. When lifting anything heavy, use both hands and have object close to your body to decrease stress on shoulders.
3. When reading a book, support the arms with pillows or with well-positioned armrests. Prop the book on a slanted reading rack or similar prop on a stand.
4. Use a headset for telephoning to keep neck straight and eliminate need for using arms and hands. Get comfortable in a recliner chair or lying down and enjoy your chat!
5. Alternatives for heavy purses or bags are fanny packs, backpacks, large jacket pockets. Leave your purse in your vehicle when shopping, carrying cash, checkbook or plastic in your pocket.
6. Large pockets, belt loops are good places to relax arms when standing; rest arm on a fanny pack at your waist or place arms on top of your head for a few minutes. Pillows are essential for arm support when sitting or lying down. Arms are very heavy, so get rid of their weight by supporting them on whatever is available.
7. Avoid unnecessary carrying by putting duplicate supplies in several areas, such as towels, sheets, cleaning supplies in each room where they will be needed.
8. Eliminate ironing from your life by buying permanent press clothing and hanging garments on hangers when still partially damp from the dryer. If clothes must be ironed, rotate iron on and off of the garment without picking it up each time.
9. Use reachers for picking up light objects off floor or other places. Remember the length of the reacher increases the lever arm, so it puts more stress on the shoulder when lifting. Do not try to lift heavy objects.
10. If your legs are getting a little weaker and it is getting harder to get up and down, don't strain your arms to get into an upright position. Use pillows in chairs to raise the height of the chair a little or get a chair with a hinge mechanism to lift you part way up out of the chair.
11. Raised toilet seats make getting up and down easier; now there are even adapters to lift up the height of the toilet itself.
12. Using a regular toilet in some restrooms is a real challenge, so always wait for the handicapped accessible stall. The toilets are higher and there is more space for maneuvering your body, using grab bars. These stalls are for "walkers" as well as wheelchair users. Note: Alert the facility to any problems with accessibility in the restroom.
13. Get a bathtub seat than can be lowered and raised hydraulically into the tub. Don't try to use arms alone to get in and out of the tub if your legs can't help very much. That is too scary and too much stress on your arms and shoulders! Use a sturdy seat in the shower so you can relax and enjoy the water.

CHOOSING ASSISTIVE DEVICES (ASSISTIVE TECHNOLOGY)

If you are beginning to need assistive devices for walking, think about this very carefully. The use of canes, crutches, walkers and manual wheelchairs will be putting more demands on your upper extremities that already have a full time job.

1. If the need for a cane begins to arise because you need extra security with balance, get a cane with an anatomically correct handle. You can get a right-handed or left-handed cane, also, depending on which side you need support. Collapsible canes are available for those

special occasions when you are feeling a little insecure. A cane with a seat allows you to sit when necessary.

2. A better choice, if you are beginning to feel weaker, would be very lightweight forearm crutches. (One supplier is Walk Easy 1-800-441-2904.) These will be less demanding on the upper extremities than trying to take weight off the legs with a cane that is not secure. If you are having increased hip weakness, you definitely need to obtain forearm crutches, as no brace will help the hips. When standing at rest with forearm crutches, rest forearms on cuffs, to relieve stress on hands.
3. Be sure you use any lower extremity bracing that may increase your stability and security, as this will decrease the need to depend so much on crutches and canes which stress the joints and muscles in the arms. This will decrease the chance of falling.
4. Walkers are a good choice for assisting weak legs with your arms. They are usually more stable and you can carry other things in baskets or bags that hang on the walker. Also available are wheeled walkers (4 wheels) with a seat, tray and shelf space that are useful in your home, the mall or craft fairs.
5. For longer distance mobility, you may need wheels! If your arms are really strong, a manual wheelchair may be an option, but again, great demands are placed on your upper extremities. The shoulders, elbows, wrists, and hands are working hard to propel all of you -- plus the wheelchair. If this choice works for you, the wheelchair needs to be very lightweight and the width of the chair needs to be narrow enough to allow your arms to be as close to your body as possible, for better mechanical advantage in propelling the chair. Keep a friend close by to push, in case you get tired.
6. To make life a little easier and decrease the demands on the upper extremities, adding a motor to your wheels makes good sense. There are attachments that can be added to manual wheelchairs to convert them into motorized chairs for short distances. There are many brands of motorized scooters available; choose one according to your need. The scooters put demands on your upper extremities in that you need to be able to steer them but this, in most cases, would be easier than propelling the chair. You need to have fairly good trunk control to stay balanced in the chair/seat.
7. If your upper extremities, trunk and lower extremities are all feeling weaker and fatigued, a motorized wheelchair is certainly the least demanding physically on the upper extremities of any mobility device. Custom seating can be developed to support spine and upper body in a more stable position allowing the upper extremities to be more functional with less fatigue. Sometimes a tendinitis can develop in the thumb and fingers from operating the controls of a motorized wheelchair, so the upper extremities always have some demand unless you get into advanced computer technology.

TECHNOLOGY CHALLENGES

If you have joined the folks in the fast lane and are using a computer, the demands on your upper extremities have just multiplied many times, and could be the subject of a two-day course! The "normal" population in our country is suffering at epidemic proportions from repetitive strain injury (RSI) from many hours at the computer. Over 62% of all workplace injuries are now for upper extremity repetitive strain injuries related to computer work. So, if the "normal" population is having this much trouble with their arms, we, the polio population, need to take our time at the computer very seriously. Because mobility is a problem and the computer can do so much for us, DON'T SACRIFICE YOUR ARMS in the process.

1. Get an expert in ergonomics (an occupational therapist, physical therapist or others) to set up your workstation.
2. Make sure your chair supports your spine in neutral, so that your shoulder girdle and upper extremities are in good alignment. Use well positioned armrests to support the weight of your arms. Your feet should be supported, using a footstool if necessary. If you are a wheelchair user, have your workstation designed around your chair.
3. Take a 5-minute stretch break at least every 15 minutes with micro breaks more often. Limit the overall time you spend at the computer to 4 separate hours per day, depending on your strength/weakness.
4. Consult your ergonomic specialist frequently with any problem that gives you pain or causes fatigue.

A REMINDER

If you develop any pain, increased weakness, excessive fatigue in the upper extremities, and reasonable amounts of rest do not decrease the symptoms, get a medical evaluation and begin treatment as soon as possible. Many upper extremity problems can be eliminated with proper management, and the sooner the symptoms are addressed, the less risk you face of permanent decrease of upper extremity function. If your doctor does not suggest treatment such as physical therapy and occupational therapy, **INSIST ON IT**. "Normal" people rarely hesitate to seek medical assistance when pain or weakness occurs in their arms and shoulders. Neither should you, who has much more to lose -- your independence.

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Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri
June 8-10, 2000

***Self-empowerment and the Post-Polio Support Group:
A conversation for support group leaders***

***Presenters: Jeff and Linda Feinstein
Atlantic County Post-Polio Support Group
Mays Landing, NJ***

Conducting a support group workshop invites definition—how do Linda and I define "support group"? Having established the Atlantic County Post-Polio Support Group seven years ago (we now number 185 members), and profoundly considering this much-banded term, we reach definite consensus—self-empowerment defines, drives, realizes, and idealizes support groups.

The workshop, ***Self-empowerment and the Post-Polio Support Group: A conversation for support group leaders***, actively involves attendees, fostering immediate opportunities to self-empower, knowing, comprehending, analyzing, applying, evaluating, and synthesizing our successful support group techniques. We intend to include the following staple components:

1. Forming a group;
2. Facilitating positively;
3. Recruiting members (media);
4. Deciding meeting times and finding meeting places;
5. Determining appropriate meeting content;
6. Keeping members interested;

**Self-empowerment and the Post-Polio Support Group:
A conversation for support group leaders**

7. Locating and enlisting guest speaker
8. Composing newsletters;
9. Educating members, members' families, and health-care professionals;
10. Accessing the Internet;
11. Involving the community;
12. Fundraising;
13. Do our members choose "to self-empower," choose to accept responsibility for the group's success and their individual wellness?

This quite ambitious workshop offers attendees opportunities to use freewriting, small group collaboration, whole group discussion, role-play, and other participatory venues to learn, enjoy, and experientially mirror an active, self-empowering support group meeting.

Eighth International Post-Polio and Independent Living Conference
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PEDORTHIC MANAGEMENT OF POST-POLIO SYNDROME
Shoes and Shoe Modifications

Dennis J. Janisse, C.Ped., Board Certified Pedorthist
Clinical Assistant Professor, Dept. of Physical Medicine and Rehabilitation
Medical College of Wisconsin, Milwaukee, Wisconsin

Conditions that may need to be treated

1. Pes cavus foot
2. Varus heel
3. Forefoot valgus
4. Inverted forefoot
5. Metatarsalgia
6. Mis-mated feet
7. Leg length discrepancies

Treatment objectives

1. Accommodate toe deformities
2. Relieve pressure (metatarsals, lateral border)
3. Control flexible conditions
4. Accommodate rigid conditions
5. Provide shock absorption
6. Balance weight bearing
7. Improve gait
8. Proper shoe fit

Modalities to accomplish objectives

1. Shoes
2. Custom-made shoes
3. Shoe modifications
4. Foot orthoses

In-depth shoe

INCLUDES

1. Strong counter
2. Adequate toe box
3. Shock absorbing sole
4. Removable insole
5. Wide range of sizes

PROVIDES

1. Shock absorption
2. Control of varus heel
3. Cushioning of metatarsals
4. Accommodation of toe deformities
5. Accommodation of custom foot orthoses
6. Mis-mated sizes / proper shoe fit

Shoe modifications

SOLE AND/OR HEEL EXTENSION

1. Accommodate leg / foot length
2. Balance weight bearing
3. Improve gait

LATERAL SOLE AND HEEL FLARE

1. Control varus heel
2. Control supination
3. Stabilize foot

LATERAL HEEL WEDGE – INTERNAL OR EXTERNAL

1. Control varus heel
2. Control supination

ROCKER SOLE WITH APEX PROXIMAL TO METATARSAL HEADS

1. Relieve metatarsal heads
2. Provide shock absorption
3. Replace lost or painful motion

CUSHION HEEL

1. Absorb shock at heel strike

FIBERGLASS LATERAL COUNTER

1. Control supination
2. Control varus heel
3. Provide support

FOOT ORTHOSES

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Redistribute weight

FLEXIBLE ORTHOSES WITH METATARSAL RELIEF AND P.Q.
VISCOELASTIC POLYMER FOR METATARSALS

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Extra relief for metatarsal heads

FLEXIBLE ORTHOSES WITH METATARSAL PADS AND P.Q. RELIEF FOR
5TH METATARSAL SHAFT AND 5TH METATARSAL HEAD

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Relieve pressure on lateral border of the foot and metatarsal heads

LATERAL FOREFOOT POST

1. Help control varus heel
2. Compensate for forefoot valgus
3. Relieve pressure on lateral border

HEEL EXTENSION

1. Accommodate equinus deformity
2. Balance weight bearing
3. Improve gait

Summary

- BIOMECHANICAL KNOWLEDGE IS NECESSARY WHEN PRESCRIBING. ONE OR COMBINATION OF ALL MODALITIES MAY BE NEEDED.
 1. Shoes
 2. Foot orthoses
 3. Shoe modifications
 4. Custom-made shoes
- RIGID AND FLEXIBLE CONDITIONS ARE TREATED DIFFERENTLY. ENCOURAGE COMPLIANCE WITH PEDORTHIST.
 1. Complete prescription
 2. Return visits as needed
- MODIFICATIONS MUST BE DONE CAUTIOUSLY AND MONITORED WITH FOLLOW-UP VISITS.
- CONDITIONS/PROBLEMS CAN CHANGE, SO PEDORTHIC PRESCRIPTION MUST BE CHECKED PERIODICALLY.

Thank you.

NATIONAL PEDORTHIC SERVICES

Milwaukee, Wisconsin
Madison, Wisconsin
Downers Grove, Illinois
Muncie, Indiana
Indianapolis, Indiana
Rochester, New York
St. Louis, Missouri

EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference
SAINT LOUIS, MISSOURI

Thursday, June 8, 2000

TWILIGHT SESSION

6:30 pm - 8:00 pm

- PAVILION SALON A **Writing Your Story: Getting Started**
Daniel J. Wilson, PhD; Edmund J. Sass, EdD; Sally Aitken
- PAVILION SALON G **Drawing Connections: Exploring Yourself Through Art**
Mary St. Clair, MAT, ATR-BC, LCSW
- PAVILION SALON B **Ronald's Rules for Winning**
Robert J. Ronald, SJ
- PAVILION SALON D **A Musician's Lesson: Listening and Learning from Our Bodies**
Darwyn Apple, Violinist, Saint Louis Symphony Orchestra
Vera Parkin, Pianist
- PAVILION SALON F **Expressing Intimacy & Sexuality**
Linda L. Bieniek, CEAP
- PAVILION SALON C **Rejuvenating Partnerships: A Discussion for Survivors, Spouses,
and Significant Others**
Dorothea and Michael Nudelman; Jack Genskow, PhD, CRC;
Joyce Ann Tepley, LMSW/ACP, LPC
- PAVILION SALON E **More Than A Best Friend**
Bobette Figler, Support Dogs, Inc., Saint Louis, MO

DESSERT BAR

8:00 pm

Pavilion Suites I-II-III and East Foyer

*Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000*

Writing Your Own Story: Getting Started

Daniel J. Wilson, Ph.D.
Muhlenberg College

Edmund J. Sass, Ed.D.
College of Saint Benedict

Sally Aitken
Polio Québec

This interactive workshop is designed to provide participants with suggestions and guidance in writing or recording their own polio narratives, as well as the narratives of other polio survivors. The workshop will provide advice on how to prepare to write your own story and where to find historical documentation to refresh and support your memory. It will also provide recommendations for publishing or recording your completed narratives. Model narratives will be discussed as examples to be followed. Participants will be provided with appropriate handouts to facilitate discussion in the workshop and to encourage the writing of a personal narrative. The workshop will also involve some small-group work to develop ideas and strategies.

Topics to be covered include:

- Why write a polio narrative.
- Where to find historical documentation to support your narrative.
- Whether to record a narrative or to write it.
- Whether to publish the narrative, and if so, where.

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri June 8-10, 2000

**DRAWING CONNECTIONS:
EXPLORING YOURSELF THROUGH ART**

Mary St. Clair, MAT, ATR-BC, LCSW
Saint Louis, Missouri

This session will explore the energy and enjoyment that can come from spontaneously and safely using art materials to express one's self. This is not about artistic performance. Rather, research continues to demonstrate the value of the right brain – how expressing one's intuition can enhance one's health, decision-making, and relationships. Mary St. Clair will guide individuals through a process of discovering how to experience the pleasure of drawing connections – with one's hand, mouth, or however one can. Come join in the fun.

*Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000*

**Ronald's Rules for the Millenium:
Challenging Choices for Winning While You Lose**
By Robert J. Ronald, S.J. Veterans General Hospital-Taipei
Operation De-Handicap-Taipei

Winning and losing are really just a matter of attitude. This is why it is possible to win when everything goes wrong. Even winners suffer at the mercy of things out of their control, also weep, also get angry, also lose their way, also fail, but winners don't lose, because they stay in control. Winning is not measured by how much you achieve nor by how much you regain of our old activities, but by how much you manage to keep alive your will to make every day satisfying and productive in whatever way you can.

Avoiding polio and post-polio is luck. Beating it is not luck. It is hard work, but mental rather than physical. Winning is realistic. It doesn't try to pretend things are good, when there're bad. But it finds a way to snatch good out of the bad. Even when everything you try fails, winning finds something to be glad about.

"Two men looked through prison bars. One saw mud, the other stars." Winners see both. Losers don't see where they are going because they don't look up or they trip on the rocks because they don't look down. Losers stop if they don't see light at the end of the tunnel. Winners light up the tunnel.

Some people have the knack of being unhappy even when they have everything, others the knack of being happy even when they have nothing. If you're unhappy, then it's time to change knacks. These rules are my knacks for knocking out the gremlins that post-polio brings. They are ways of facing decline gracefully and turning circumstances you can't control into situations you can live with.

About fifty years ago a Jesuit priest wrote a book called "I'll Die Laughing" about the funny things that were always happening to him and his friends. They weren't all pleasant things, but experiencing them with humor made life not only bearable but fun. Blessed is the person who can make post-polio fun. We can all die laughing if we can find a way to live laughing, or at least smiling, well, at least thumbs up, not weeping, finding something to enjoy, looking at the bright side, enjoying the little things that fill our days. That's what Ronald's Rules are all about.

A good summary of these rules would be:

Maintain the three “A”s: stay ALERT, keep ACTIVE, feel ALIVE.

Avoid the three “O”s: OVERDO, OVERWEIGHT, OVERREST

Employ the three “P”s: PLAN ahead, set PRIORITIES, PACE yourself.

Act with the three “E”s: EMBELLISH every day with meaningful events,
EMBRACE every engagement with ENTHUSIASM,
ENJOY the EXECUTION of every effort.

Rely on the three “F”s: have FAITH in your God, FRIENDS at your side,
FACE the facts, and FOLLOW your heart.

No rule is going to make you happy, only you can do that by the way you handle your problems. These prescriptions won't keep post-polio away or cure it when it comes, but they can make life with it more bearable and rewarding.

Can you enjoy life with post-polio?

Yes, if you try to make the most of each day with whatever you have each day.

Yes, if you have a strong will to live the best you can.

Yes, if you can accept whatever happens to you.

Yes, if you stay open to the world with continuing concern for others.

Yes, if you believe in our own worth regardless of what others think.

Yes, if you can find satisfaction in the little things you still can do.

In the world of post-polio, winning is

staying on course toward your goals.

finding new ones.

not succumbing to discouragement.

not being deterred by difficulties.

not turned back by obstacles.

not stopped by failure.

keeping your spirits up while adjusting down.

You may be just a shadow of your former self, but you are not a shadow. You are always the whole that casts the shadow. No matter how much you've lost, you still have 100% of what's left. Use it wisely to preserve it. But use it with a smile. Relish whatever experiences you have. That is winning.

Winning opens the door when post-polio knocks, gives it the guestroom, but doesn't let it take over the house. Losing pretends it's not at home when post-polio knocks and ignores it when it breaks into the house.

Winning used to be discarding what we no longer needed. Now winning means adding what we need so we won't be discarded.

Winning is walking when you can't run and rolling when you can't walk.

Winning is keeping upbeat when things are downbeat.

Winning is to looking forward when you falling backward.

Winning is finding something to do when you have nothing to do.

Winning is holding your head high when you can no longer hold up your head.

Winning is accepting what you can't avoid and making something of it.

Winning is having something to aim at when you're blown off course.

Winning is staying in touch while the world recedes.

Winning is having someone to slow down with you.

Winning is wiping your eyes after a good cry and putting your glasses back on.

Winning is taking your eggs out of one basket and carrying them one at a time.

Winning turns on a light when darkness comes. Losing lets the spirit dim when the body fades.

Winning is keeping all the rules when you play the game of life, even if you're losing. Losing is trying to win by breaking the rules.

Winning is finding a way to enjoy whatever you can do today. Losing spoils today with its regrets for the past and fears for the future.

Winning is enjoying the last bite as much as the first.

Winners know the bottom is coming and plan the next rise while still going down.

Winners aren't afraid of breaking down, because they have other options waiting.

Winners take a break before they fall asleep. Losers fall asleep before the break.

Winners are not ashamed to ask for help they need. Losers pretend they need nothing.

Winners graciously accept help they need. Losers take it with a sour face.

Winners refuse with courtesy help they don't need, but accept it with courtesy when refusing would cause embarrassment or offense. Losers reject with anger what is offered with kindness.

Winners don't take their feelings out on God, on themselves, or on anyone else. They turn their anger, grief and regret into energy for leaving their troubles behind. Losers make everything and everybody miserable because they feel miserable.

Winners know how to replace the sadness for what they lost with gratitude for having had it. Losers see only what they lost.

Winners don't just cry over spilt milk. They wipe up the mess and get something to replace it.

Winners are happy that the dollar they spend brings something they didn't have before. Losers are sad, because they have a dollar less.

Winners win because they stay engaged in battle. Losers quit fighting.

Winners embrace each day for its opportunities. Losers reject today's opportunities because they aren't as good as yesterday's.

Winners put into little things the same enthusiasm they had for big things.

Winners are open with wonder and excitement to new experiences, even those that come with decline.

Winners enjoy the ride down even when they know there is no way back up.

Winners enjoy the game of life without being afraid to lose. Losers are afraid to play because they might lose.

Winners live as well as they can, even when they're dying. Losers give up, because they are going to die.

Winning is losing with dignity without quitting. Winning without joy, without sharing, without honor, or without hope is really losing.

Don't face post-polio alone. Winning is having someone to guide you and someone with whom to share your triumphs and your failures.

Winning is hiking with companions who know the trail. Losing is setting out into the unknown without a map.

Winning is having a shoulder to cry on attached to an arm that can reach out and help you on your way. Losing is being caught in the dark without a light and no one to hear your cry for help.

Winning keeps you cool when things heat up and warm when things turn cold.

Winning shines in the dark, glows in a person's face, radiates peace even in defeat, brings calm to calamity.

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri June 8-10, 2000

**A MUSICIAN'S LESSON:
LISTENING AND LEARNING FROM OUR BODIES**

Darwyn Apple

Violinist, Saint Louis Symphony Orchestra

Accompanied by
Vera Parkin, Pianist

For more than two decades, one of Saint Louis' leading music makers hardly needs any introduction. Since his debut with the Detroit Symphony Orchestra at an early age, Darwyn has performed as a solo artist extensively throughout the continental United States and in both Europe and South America. In 1993, he performed by special invitation during the presidential inauguration week in Washington, DC. The former Fulbright scholar has a long history as an educator, clinician, speaker, role model, and arts advocate within this community.

Mr. Apple's program, a potpourri of classical favorites for the violin, will feature works from the Baroque period through the 20th century. The composers will include Vivaldi, Chopin, Mendelssohn, Bartok, and Still. His presentation, interspersed with anecdotal comments about the music, is guaranteed to have something for everyone.

Following the "mini concert" there will be a question-and-answer session during which Mr. Apple will share ideas about how musicians maintain health throughout a lengthy performance career.

Supported by a grant from the
Saint Louis Symphony Orchestra Community Partnership Program Agreement

EXPRESSING INTIMACY & SEXUALITY

Embracing Life, Being Loving to Yourself & Loving a Partner

Linda L. Bieniek, CEAP

INTIMACY: Innermost experience of a very personal or private nature; connection with one's deepest character. Mutual sense of acceptance, commitment, tenderness and trust marked by a special close relationship developed through long association.

1. Intimacy with Oneself: Know, Accept and Value Yourself

People, with or without disabilities, need to be intimate with themselves before they can be intimate with another. (Renshaw) Each person has a "True Self" (Whitfield) and "Inner Life" or self (Schwartz) comprised of values, beliefs, feelings, thoughts, needs, desires, choices, decisions, sensations, intuitions, and experiences--conscious and unconscious. One's values, beliefs, and feelings about intimacy and sexuality are examples of one's inner life that a person can choose to disclose to another person or keep private. Being intimate with oneself involves self-awareness, understanding (e.g., the reasons for your feelings, attitudes, behaviors), self-acceptance, and an appreciation of one's valuable traits as well as one's limitations. Most importantly, a person needs to approach oneself compassionately. For compassion, an empathetic acceptance, provides a foundation for intimacy.

2. Developing Healthy Intimacy with Another Person

Schwartz contends that an "I" needs to be present before there can be a "we". Even when individuals become a couple, they need to maintain their individuality and distinct personalities. Masters and Johnson's Relational Therapy assists individuals in resolving intimacy and sexuality problems. Often, this involves: 1) developing self-awareness; 2) recognizing the causes of difficulties; 3) changing the negative effects of past experiences on one's ability to develop and maintain satisfying relationships (e.g., childhood traumas, hurtful experiences such as divorce); and 4) building the understanding, skills, and boundaries of a healthy relationship.

The **PRAISES Model of "Healthy Steps to Intimacy" (Glaser)** outlined below encourages individuals to share various aspects of one's life with another person, preferably in sequential order. In this gradual process, an acquaintance evolves into a friend and eventually grows into an intimate partner. Mason advises sharing at least 4-5 levels of experiences before engaging in sexual intimacy.

1. **Physical:** share physical space and surroundings; be physically present to each other
2. **Recreational:** share common interests or activities together
3. **Aesthetic:** share experiences of enjoying beauty, the arts, Nature together
4. **Intellectual:** share thoughts, ideas, opinions
5. **Spiritual:** share values, priorities, life goals, spiritual experiences
6. **Emotional:** share feelings, reactions, affectionate expressions
7. **Sexual:** share physical sensations, fantasies, touching, intimacy, sexual expressions.

3. Essential Ingredients of Healthy Intimacy

The following list differentiates the characteristics of an unhealthy relationship from *healthy approaches (stated in italics)* to developing an intimate relationship. When a person recognizes that one's own experiences relate to "unhealthy" patterns, this insight offers the possibility of negotiating the terms of a current relationship or seeking a relationship that enhances one's self-esteem and enriches one's life. Rather than judging one's past relationship difficulties, a valuable approach is to spend energy identifying what one needs to experience healthy intimacy. A skilled, ethical therapist specializing in relationship issues can assist a person in developing the understanding and abilities to learn how to protect one's vulnerabilities, fulfill one's needs, and enjoy opening one's heart in an intimate relationship.

Unhealthy Characteristics in Relationships vs. *Healthy Approaches to Intimacy* *Adapted from Masters & Johnson Relational Therapy Program*

INTENTIONS:

- ❑ Obsession with finding "someone to love" vs. *Development of self as first priority*
- ❑ Need for immediate gratification vs. *Desire for long-term commitment develops step-by-step*
- ❑ Expectation that one partner will fix or rescue the other vs. *Each partner practices self-responsibility, interdependence*

EQUALITY:

- ❑ Pressuring partner for sex or commitment vs. *Freedom of choice*
- ❑ Imbalance of power vs. *Balance & mutuality in the relationship*
- ❑ Power plays for control vs. *Compromise, negotiation or taking turns at leading*

COMMUNICATION:

- ❑ No talk rule, if the relationship is not working out or there are tensions or conflicts vs. *Sharing wants, feelings & appreciation of what your partner means to you*
- ❑ Manipulation vs. *Directness*

TRUST:

- ❑ Lack of trust vs. *Appropriate trust based on evidence of your partner's dependability to behave according to his/her fundamental nature*
- ❑ Fearful reactions expressed through passionate impulses to prove one's worth & prevent the loss of a partner vs. *Sex grows out of friendship & caring*
- ❑ Cycle of pain & despair vs. *Cycle of comfort & contentment*

INDIVIDUALITY:

- ❑ Fusion (being obsessed by each other's problems or feelings) vs. *Loving detachment (healthy concern about partner's well-being while letting go of fixing problems)*
- ❑ Attempts to change partner to meet one's own needs vs. *Accepting & appreciating each other for who each one is*

PROBLEM-SOLVING:

- Blaming self or partner for problems vs. *Problem solving together*
- Relationship based on delusion & avoidance of the unpleasant vs. *Relationship deals with all aspects of reality honestly, openly, directly, sensitively, & appropriately (HODSA)*

SEXUAL WISDOM FROM MASTERS & JOHNSON

- ❖ A stiff penis does not make a solid relationship nor does a wet vagina.
 - ❖ Absence of sensation does not mean absence of feelings.
 - ❖ Inability to move does not mean inability to please.
 - ❖ Inability to perform does not mean inability to enjoy.
- ❖ Loss of genitals does not mean loss of sexuality. (Anderson & Cole, 1975)

SEXUALITY: Expression of internal energy: one's libido and personality—attitudes, ideas, feelings, intentions, values and enthusiasm for life. Communicated through interactions with others, personal hygiene and attire, speech, expressions of affection, and self-image. Features of femaleness or maleness expressed in physical, emotional, intellectual and social aspects of one's life. (Ducharme)

4. Sexuality: Making Healthy Decisions & Choices

The following questions can enlighten a person about the potential benefits and risks related to choices about one's sexual activities. Understanding one's patterns provides a way to gain clarity about what one needs to experience safe, fulfilling, and loving sexuality.

1. **VALUES:** Does your sexual behavior reflect and respect your values? Does your partner's?
2. **SAFETY:** Are your sexual activities safe for your health & well-being? Do you feel safe with your partner? What are the emotional impacts of having sex with this person?
3. **RESPECT:** Are the sexual choices you make respectful to both you and your partner?
4. **INTIMACY:** Are the sexual expressions you give and receive playful, nurturing, or comforting? Will they increase understanding, trust & closeness between you and your partner?
5. **HONESTY:** Do each of you honestly share intimate feelings for each other's personality? Or are your sexual behaviors primarily ways of gaining attention, validation or gratification?
6. **FREEDOM:** Are you both free to choose what you will do?
7. **COMMUNICATION:** Are you each able to express your feelings, desires and limits in constructive, respectful ways?

Renshaw asserts that an active and fulfilling sex life does not have to include intercourse. The inability to have intercourse does not mean the loss of ability to have an orgasm or the loss of the ability to love. A disability does not prevent a person from discovering new ways to express sexual feelings or from giving and receiving sexual pleasure.

5. Sexuality & Disability--Increasing Sexual Pleasure

Adapted from Kitzinger, Renshaw

- Discover new areas of sensory stimulation. When touch receptors are weak in one area of the body, explore touching other parts of the body; find one's most sensitive, stimulating parts.
- Make sex exciting and fulfilling through fantasies, poetry, novels and other romantic and erotic literature, films, and sexually stimulating words. Express romance, tenderness & gratitude.
- Use color, patterns, texture and accessories (art) to invite intimacy & stimulate the senses.

- Arouse emotions & evoke sensual feelings with music. Find words & rhythms that stimulate senses & create a mood of openness, relaxation, excitement & enjoyment.
- Take breaks to rest on your ventilator or clean your catheter. Incorporate humor or pleasurable music; express tenderness & gratitude to generate openness & acceptance.
- Give & receive messages of sexual longing & love by stroking with one's lips, tongue, cheeks, & little finger, any part that is mobile & not stiff or in pain.
- Prepare for lovemaking by incorporating undressing, bathing or showering (e.g., in candlelight with music playing) & positioning as part of the lovemaking experience.
- Obtain vibrators & playful sexual aids & toys to enhance giving & receiving pleasure.
- Use aids to create comfort & ease: Cushions & pillows in different shapes & sizes to help with positioning; a bean bag in a semi-upright position for firm support; a heated waterbed for flexibility with arthritic pain; oils or gels to increase lubrication, a vibrator to compensate for weakness.
- Create a space free of dust & respiratory irritants. *Adjust the temperature in the room to a comfortable setting or open windows to provide adequate air.* Use an electric air filter, humidifier or other products to enhance the air quality. Choose lighting to enhance the mood.
- Use an upright kneeling position, if possible, to take pressure off an ostomy bag; cover the bag or any other distracting part with some erotic fabric to enhance comfort & arouse the senses.
- Avoid alcohol. It is a depressant: suppresses the respiratory system, making breathing difficult; impedes sexual responses, dulls a sense of touch & arousal, & numbs emotional feelings. No fun!
- Practice positioning. What makes it easiest to breathe? Lying on one's side on two pillows? What helps to move (e.g., certain fabrics)? Receive touching? Consult professionals & others for useful suggestions. Use the spoon position (woman lies parallel to the man with his chest facing her back and he enters her vagina from the rear with her guidance) to take pressure off the chest wall or rib cage. Lying with legs crossed over a partner's can be erotic. Lessen pressure on painful joints by using the L-shape position (lie facing each other with your trunks at right angles and legs intertwined). The top position is helpful for a person with breathing difficulties if the person has flexibility.
- Plan ahead: Arrange sexual activities when each partner is most energetic. Make a date. Get enough rest; take a nap on a ventilator beforehand. Turn off the telephone & other distractions.
- Explore oral stimulation: Use one's tongue to stimulate tender spots on the hand, cheek, armpit or knee. Take rests to breathe. Less can be more when love is expressed tenderly & sensually.
- Consult physicians about what are safe sexual activities. Find out one's limits & ways to express affection, if cardiac or respiratory problems create fear of oversteering on one's system.
- Approach yourself compassionately. Relationships can cause a variety of reactions. Develop the courage to obtain the support & resources that will increase your capacity to experience life fully.

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Eighth International Post-Polio & Independent Living Conference
Saint Louis, Missouri June 8-10, 2000

Rejuvenating Partnerships: A Discussion for Survivors, Spouses, and Significant Others

Dorothea and Michael Nudelman, Polio Survivor and Husband

Jack Genskow, PhD., CRC; University of Illinois at Springfield

Joyce Ann Tepley, LMSW/ACP, LPC, Private Practice

This session is designed to be interactive, with full audience participation and sharing. The presenters will primarily share their personal experience, and will encourage the audience to do the same. The emphasis will be on sharing what works, but will also try to identify problem areas and ways to deal with them. Come to this session prepared to participate. The presenters do not see themselves as experts.

A Quick Look at Support Dogs, Inc. And Its Programs

What's Involved Producing a Service Dog

- Cost - \$27,000
- Training time averages two years to two-and-a-half years
- What type of dog – Golden Retriever, Labrador Retriever, or cross of the two breeds
- Trained to: Open Doors
 - Pull Wheelchairs
 - Carry Bags
 - Retrieve small and/or distant objects
 - Help with dressing
 - Rise to counters
 - Assist with transfers to and from wheelchairs, beds, etc. (stand and brace)

Path of a dog on its way to becoming a Service Dog

- Obtain dogs from Support Dogs' breeding program
- Placed in Puppy Raising home at seven-weeks of age
- Stays in home for approximately a year and a half
- Comes to "Canine College" at approximately 18 months of age
- Attends college for approximately four to nine months, learning advanced skills listed above
- Placed with a client during Team Training

Team Training

- Support Dogs, Inc. serves individuals from all around the country
- Individuals come to St. Louis for a month-long training program
- Average cost of Team Training - \$3300 per person

Types of Service Dogs

- Street Certified – qualified to accompany their person in public, performing those functions listed above
- Home Certified – same capabilities as street certified, but limited to home service
- Facility Based Therapy – Lives with a therapist at a facility, providing therapy to the residents of that facility
- Home Based Therapy – Placed in the home as a companion to someone to provide emotional support
- Pediatric Partner – dog which is placed with a child, providing emotional support, as well as basic retrieval and support skills

TOUCH (Therapy of Unique Canine Helpers) Program

- Visit over 60 facilities a year
- Over 200 active teams visit hospitals, nursing homes, rehabilitation units, and other healthcare facilities
- Teams must be certified through Support Dogs, Inc., completing an 10-week training course
- Use all types and sizes of dogs
- It costs Support Dogs, Inc. \$1400 to provide training and support to each TOUCH Team annually

Education

- Participated in 146 presentations, fairs, booths, and seminars in 1999
- Reached approximately 30,000 people in the St. Louis and Southern Illinois Community
- Educate on all service animals, SDI programs, and proper canine handling
- Educational Volunteers (core of 13) contributed 1127 hours educating the community in 1999

Sources of Funding

- 9% United Way of Greater St. Louis
- 91% private and corporate donations. Support Dogs, Inc. receives no federal or state assistance

EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference
SAINT LOUIS, MISSOURI

Friday, June 9, 2000

SESSION I (Plenary)

9:15 am - 10:15 am

PAVILION BALLROOM

Pulmonary Problems: Signs & Symptoms & Screening

Peter C. Gay, MD (sponsored by ResMed, Corp.)

Cardiac Problems: Signs & Symptoms & Screening

Rupert D. Mayuga, MD

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri
June 8-10, 2000

Pulmonary Problems:
Signs, symptoms, and screening &
Managing Pulmonary Problems

Peter C. Gay, MD, Associate Professor
Consultant in Pulmonary, Critical Care and Sleep Medicine
Mayo Graduate School of Medicine
Rochester, MN

INTRODUCTION

One could easily imagine why the polio epidemics from the early to mid-part of the 20th century had similar impact on the practice of pulmonary medicine as even the best-known infectious lung disease, tuberculosis. The modern day intensive care units are now primarily staffed by pulmonologists largely due to the huge need from breathing problems created by these two infectious diseases. Since acute polio infection has vanished from the developed world, we presently recognize pulmonary problems from polio as a late complication of residual muscle weakness and/or skeletal deformities such as kyphoscoliosis. During the following review, the initial discussion will note common patient complaints occurring at rest, with increased activity, and during sleep. Secondly, there are physical signs and clinical tests that help predict or further define these symptoms that should be explained. Lastly, the appropriate treatment methods can be identified and placed into perspective.

SIGNS & SYMPTOMS

Up to 6% of polio patients studied in one series required full-time ventilator support but larger percentages present to pulmonary physicians.¹ The most common respiratory symptom reported by polio patients is shortness of breath and may come from a variety of causes.² It is difficult to classify the subtypes of patients because the most profound abnormalities occur in those with severe kyphoscoliosis who invariably have muscle weakness as well. Shortness of breath during activities of daily living is most related to ventilation at polio onset, contracting polio after age 10, or having polio for over 35 years.³ Patients tend to adapt a breathing pattern of more shallow rapid breathing that tends to relieve the shortness of breath.⁴ Physicians will often further assess this by observing whether the patients worsen when lying flat - so-called 'supine dyspnea.' When the diaphragm muscle is severely affected and weak, this can be appreciated

further by observing for supine abdominal paradox where the abdomen will inappropriately collapse inward as the chest expands during inspiration. In those with severe chest wall muscle wasting and intact diaphragms, there may be an exaggerated outward motion of the diaphragm and the chest wall shows a 'paradoxical' collapse during inhalation.

Patients may also have sleep related breathing disorders, regardless of whether or not they report disturbances to their sleep. Daytime hypersomnolence is commonly reported, but morning headache, and nocturnal awakenings are also present.⁵ Patients who gain weight tend to have exercise intolerance, but this also predisposes them to more classic obstructive sleep apnea that is *could be suspected* when loud snoring is present.

CLINICAL TESTING

Traditional pulmonary function testing includes spirometry that assesses expired flows and volumes after a maximal effort. Polio patients classically exhibit restrictive physiology with reduction in lung volumes and a proportionate decrease in flows. Measurements of respiratory muscle strength, identified with maximal inspiratory and expiratory pressures (PiMax, PeMax), may also be reduced.³ Patients from a cohort study of those reporting a history of polio on average, have only a mild reduction in pulmonary function tests but those who specifically reported either respiratory muscle involvement at onset of polio or later developed kyphoscoliosis, have more profound abnormalities including elevated carbon dioxide levels on arterial blood gases, which portends a poorer prognosis.^{1,6,7} Cardiorespiratory exercise testing is useful in helping to separate out activity limitations from heart or lung impairment versus the often severe deconditioning that also occurs in these patients.⁸

Overnight oximetry and formal sleep studies (polysomnography or PSG) are used to prove whether polio patients have central hypoventilation, classic obstructive sleep apnea, or a mixed disorder.⁵ Patients with kyphoscoliosis with ill-defined symptoms should be considered for screening overnight oximetry. Those complaining of sleep disordered breathing symptoms as noted above, especially in the presence of moderate restrictive lung disease or daytime hypercapnia, should undergo a PSG study which can reveal profound nocturnal hypoxemia particularly during REM sleep.^{5,6}

TREATMENT

The mainstay of treatment for daytime shortness of breath is reconditioning with pulmonary rehabilitation. These programs usually include other helpful techniques such as cough assistance. The same data that suggests increased activity and possibly reduced hospitalizations for COPD patients seems to apply to restrictive lung disease patients.⁹

Oxygen therapy is generally contraindicated for patients with post-polio problems but ventilatory assistance with non-invasive techniques, primarily nasal nocturnal ventilation has

dramatic effects especially in patients with kyphoscoliosis.^{10,11,12} Corrective surgery to reduce spinal curvature can improve pulmonary performance.¹³ Careful attention to the cause of ventilatory insufficiency now offers patients marked increases in quality of life.

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CARDIOVASCULAR ISSUES AND THE POST-POLIO SYNDROME

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Cardiovascular disease (CVD) is the leading cause of death in both men and women in the United States. One of every 2.4 deaths is attributable to it. In addition, it results in substantial morbidity, accounting for more than 6 million hospital discharges per year in this country.

The actual incidence of CVD in individuals suffering from post-polio syndrome (PPS) is not known. However, there is reason to suspect that individuals with PPS might be at increased risk. Certain features of PPS such as generalized fatigue, generalized and specific muscle weakness, joint and/or muscle pain may result in physical inactivity - deconditioning, obesity, and dyslipidemia. Respiratory difficulties may result in hypoxemia. Any of these can predispose those with PPS to increased cardiovascular risk. Furthermore, most individuals with PPS are now at an age group where CVD such as heart attack, stroke, and heart failure become increasingly more likely. Common symptoms and signs of CVD include exertional chest discomfort, exertional and non-exertional shortness of breath, sudden shortness of breath and/or chest discomfort after lying down, swelling of the ankles and legs, heart enlargement, palpitation, loss of consciousness, and easy fatigability. It is evident that there are symptoms of CVD that overlap with common symptoms of PPS. This could present a problem since individuals suffering from PPS may not recognize cardiovascular symptoms by thinking that these may just be a progression or altered manifestation of PPS symptoms. The resulting delay in diagnosis can be costly. It is important to emphasize that CVD is often a "silent" disease without significant symptoms until its life-threatening or catastrophic sequelae appear suddenly. All too often, the first manifestation of CVD is sudden death, stroke, or a heart attack. The need to identify individuals at increased risk early enough to alter its catastrophic course cannot be overemphasized.

Available information on heart disease and PPS in the scientific literature is regrettably limited. Some interesting studies, however, may be of practical importance to PPS patients. One such study evaluated the cardiovascular autonomic function of subjects with antecedent poliomyelitis (Borg et al) and concluded that there was no significant dysfunction of autonomic nerves despite the presence of progressive muscle atrophy. This finding becomes important when one considers that many current methods for assessing cardiovascular function and fitness include evaluation of parameters such as heart rate, blood pressure, heart rate variability, valsalva response etc., all of which require an intact autonomic system. The study results suggest that individuals with PPS in general can use any of a number of standardized tests for cardiovascular risk assessment such as the exercise stress test without a decrease in test sensitivity, provided

that due consideration of the presence of muscular dysfunction is made. For example, an arm ergometer may be used instead of a treadmill as the method of providing the exercise in PPS individuals with lower extremity weakness. There are also non-exercise types of cardiovascular stress testing such as pharmacologic, vasodilator perfusion stress tests (dipyridamole or adenosine stress tests) used in conjunction with nuclear imaging, or a dobutamine - echo stress test. These are the preferred tests for those who cannot perform significant exercise.

Apart from cardiac stress testing, there are also an increasing number of ways to evaluate cardiovascular risk. Evaluation for coronary risk factors is of major importance to everyone with or without a history of PPS. Risk factors include cigarette smoking, hypertension, elevated LDL cholesterol (the "bad" cholesterol), low HDL cholesterol (the "good" cholesterol), diabetes, male gender (and post menopausal women), family history of premature coronary heart disease, the presence of peripheral arterial occlusive disease, and last but not least, obesity and physical inactivity. The presence of multiple risk factors results in more than just additive risk. Newer tests with possible utility in further defining increased risk for future cardiovascular events (i.e. heart attack, stroke) are currently under consideration. These include carotid artery duplex scanning, electron beam CT, ultrasound-based endothelial function studies, ankle/brachial blood pressure ratios, MRI techniques and testing for hs CRP - a possible marker of increased risk for coronary atherosclerotic plaque instability. Although there appear to be no large scale studies evaluating whether individuals suffering from PPS are at increased risk for CVD, it is probably safe to assume that there may be increased risk in certain individuals who have the traditional risk factors mentioned earlier. A study of 64 post-polio patients (Agre JC et al) found that 66% of the men and 25% of the women had hyperlipidemia with men also having low HDL cholesterol. These findings underscore the need to actively screen for dyslipidemia and/or hypercholesterolemia. In addition, deconditioning and obesity was found by Agre et al to be strongly associated with the presence of dyslipidemia. Therefore, it is important to address these issues in individuals with PPS.

In individuals with identified PPS symptoms consistent with cardiovascular deconditioning, there has been some hesitation in prescribing an exercise program to improve conditioning because of fears that traditional exercise regimens may lead to further loss of muscle from overuse. The prospect of safely and effectively training PPS subjects was evaluated by a number of investigators (Kriz JL et al, Jones DR et al, Owen RR et al). All investigators found that a carefully designed exercise program that avoided excessive muscle fatigue was able to provide positive results. Jones DR et al and Owen RR et al used lower extremity exercise. Kriz JL et al showed that PPS subjects can use upper extremity exercise (using an arm crank ergometer) for 20 minutes three times a week to achieve a significant improvement in cardiovascular conditioning (19% improvement in VO₂ max in the study). A very gradual training period of 16 weeks was used to allow all PPS subjects to reach a consistent exercise level and to avoid muscle damage from overuse. The results of these studies support the need to develop safe, effective, and easily accessible exercise programs for PPS individuals. This has the advantage of allowing the benefits of cardiovascular conditioning without the potential risk of further muscle damage.

Recommendations:

1. Determine if you have any of the common signs and/or symptoms of cardiovascular disease.

CVD signs: Enlarged heart, swelling of the ankles or legs, unusual/excess weight gain, wounds that do not heal well.

CVD symptoms: Chest discomfort (pain, pressure, squeezing, heaviness, etc.) especially if brought on by exertion and relieved by rest, shortness of breath with minimal exertion or upon lying down, palpitation or irregular heart beats, severe dizziness or loss of consciousness, sudden weakness or paralysis of one part of the body, sudden slurring of speech or loss of vision, frequent nocturnal urination, unusual and progressive fatigue, leg pain/discomfort with walking.

Consult your health care professional as soon as possible if you have any of the above signs and/or symptoms.

Signs and symptoms of a heart attack or impending heart attack: Continuous chest and or throat discomfort/pressure/pain/heaviness lasting more than 15 minutes even with rest and even after sublingual nitroglycerin. This may be associated with shortness of breath, sweating, dizziness, and palpitations. Discomfort may radiate to the left arm or jaw. **What to do:** Immediately proceed to the nearest Emergency Room or call the paramedics (911). If you have no severe allergies to aspirin, chew one tablet of regular 325mg. aspirin. This can help immediately by preventing or delaying further accumulation of blood clot in the arteries of the heart. In the Emergency Room you can be given powerful clot dissolving medications or if the facilities are available, emergency coronary angioplasty (a means of re-opening a blocked artery using a small balloon at the tip of a catheter) can be performed. These procedures can prevent an impending heart attack or reduce the size of a heart attack that has already started, thus reducing significantly the risk of dying as well as the risk of future complications. **Remember:** This is only effective if the blocked coronary artery causing the heart attack can be opened within the first few (preferably less than 3) hours of the onset of chest discomfort. So do not delay in getting to the ER!

2. Make certain that blood pressure, cholesterol/lipid profile, fasting blood sugar (FBS), body weight and an ECG are included in your annual physical examination. A chest X-ray would also be useful periodically to determine heart size and the status of the lungs. More frequent testing as well as additional specific tests (stress tests, echocardiograms, coronary angiograms, etc.) may be recommended as needed.

3. Avoid physical deconditioning and becoming overweight. Consult your health care professional for appropriate recommendations. In general, exercise has to be started very gradually and at a lower level and individually tailored to each individuals

physical status and needs. Care should be taken not to over exercise. Nutritional counseling is a useful resource.

References:

1. American Heart Association. 1999 Heart and Stroke Statistical Update. Dallas, Tx: American Heart Association; 1998.
2. Smith Jr. SC, Greenland P, Grundy SM. *AHA Conference Proceedings: Beyond Secondary Prevention: Identifying the High-Risk Patient for Primary Prevention*. Circulation, January 4/ 11, 2000
3. Borg K, Sachs C, Kaijser L. Autonomic cardiovascular responses in antecedent poliomyelitis. *Acta Neurol Scand*. 1988;77:402-408.
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EIGHTH INTERNATIONAL
Post-Polio AND
**Independent
Living**
Conference
SAINT LOUIS, MISSOURI

Friday, June 9, 2000

SESSION II

10:30 am - 11:30 am

- PAVILION SALON A **Managing Our Weight: What We Can Do***
Josephine F. Walker
- PAVILION SALON B **Managing Cardiopulmonary Problems***
Peter C. Gay, MD (sponsored by ResMed, Corp.); Rupert D. Mayuga, MD
- PAVILION SALON G **Court Cases and Their Implications**
David Newburger, JD
- PAVILION SALON D **What About the Muscles?**
Barbara Ivanyi, MD, PhD; Jacquelin Perry, MD; Sophia Chun, MD
- PAVILION SALON E **Finding and Screening Information: Why, When, and How**
Sally Aitken; Cyndi Jones
- PAVILION SALON F **The Sleep-Bladder Connection**
Mary Umlauf, RN, PhD; John McBurney, MD; Eileen Chasens, RN, DSN

Managing Our Weight: What We Can Do

Josephine F. Walker, Presenter

BACKGROUND

The Dilemma of Early Retirement

Discovering "PPS activity"

Weight Management: A Polio Perspective

The Polio/Food Connection

A Personal Food History

Family portraits adjust our expectations

History clarifies eating habits and their sources

Exposes food myths

Links food behaviors to polio experience

A Personal Mobility Story

Transcending "I can't exercise; therefore I gain weight."

Reveals environmental constraints on activity

Provides an energy expenditure evaluation, over time

Mobility questions worth asking

WHAT WORKS FOR ME

Eat Intentionally (Nutritional Awareness)

Dietitians/Nutritionists are our friends

Meal management begins with questions

Polio nutrition

A long range view: two problems

Enhance Activity (Environmental Awareness)

Sleep

Rest

Energy Conservation

Environmental engineering: "designed to do"

Have Incentives (Motivational Awareness)

Social events, reunions - memories are motivation for moving
Rewards
Pain control

Have a Witness/Helper

Counselors -- hang up your hang ups
Support groups
A friend and super ego

Nourish mind and spirit, as well as body

Spiritual eating
Reading and reflection
Full life, not stomach

USE POLIO COMPETENCIES

1. Planning

2. Patience

3. Coping

4. And, in Charge

5. Compensation

6. Crutches

7. Connection

8. Compassion

9. Commitment

Reference: Stein K, Lee RG: *Chronic Illness and Shame*, in Lee RG and Wheeler G, Eds.
The Voice of Shame, Jossey-Boss Publishers, SF, 1996

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri
June 8-10, 2000

Pulmonary Problems:
Signs, symptoms, and screening &
Managing Pulmonary Problems

Peter C. Gay, MD, Associate Professor
Consultant in Pulmonary, Critical Care and Sleep Medicine
Mayo Graduate School of Medicine
Rochester, MN

INTRODUCTION

One could easily imagine why the polio epidemics from the early to mid-part of the 20th century had similar impact on the practice of pulmonary medicine as even the best-known infectious lung disease, tuberculosis. The modern day intensive care units are now primarily staffed by pulmonologists largely due to the huge need from breathing problems created by these two infectious diseases. Since acute polio infection has vanished from the developed world, we presently recognize pulmonary problems from polio as a late complication of residual muscle weakness and/or skeletal deformities such as kyphoscoliosis. During the following review, the initial discussion will note common patient complaints occurring at rest, with increased activity, and during sleep. Secondly, there are physical signs and clinical tests that help predict or further define these symptoms that should be explained. Lastly, the appropriate treatment methods can be identified and placed into perspective.

SIGNS & SYMPTOMS

Up to 6% of polio patients studied in one series required full-time ventilator support but larger percentages present to pulmonary physicians.¹ The most common respiratory symptom reported by polio patients is shortness of breath and may come from a variety of causes.² It is difficult to classify the subtypes of patients because the most profound abnormalities occur in those with severe kyphoscoliosis who invariably have muscle weakness as well. Shortness of breath during activities of daily living is most related to ventilation at polio onset, contracting polio after age 10, or having polio for over 35 years.³ Patients tend to adapt a breathing pattern of more shallow rapid breathing that tends to relieve the shortness of breath.⁴ Physicians will often further assess this by observing whether the patients worsen when lying flat - so-called 'supine dyspnea.' When the diaphragm muscle is severely affected and weak, this can be appreciated

further by observing for supine abdominal paradox where the abdomen will inappropriately collapse inward as the chest expands during inspiration. In those with severe chest wall muscle wasting and intact diaphragms, *there may be an exaggerated outward motion of the diaphragm and the chest wall shows a 'paradoxical' collapse during inhalation.*

Patients may also have sleep related breathing disorders, regardless of whether or not they report disturbances to their sleep. Daytime hypersomnolence is commonly reported, but morning headache, and nocturnal awakenings are also present.⁵ Patients who gain weight tend to have exercise intolerance, but this also predisposes them to more classic obstructive sleep apnea that is could be suspected when loud snoring is present.

CLINICAL TESTING

Traditional pulmonary function testing includes spirometry that assesses expired flows and volumes after a maximal effort. Polio patients classically exhibit restrictive physiology with reduction in lung volumes and a proportionate decrease in flows. Measurements of respiratory muscle strength, identified with maximal inspiratory and expiratory pressures (PiMax, PeMax), may also be reduced.⁹ Patients from a cohort study of those reporting a history of polio on average, have only a mild reduction in pulmonary function tests but those who specifically reported either respiratory muscle involvement at onset of polio or later developed kyphoscoliosis, have more profound abnormalities including elevated carbon dioxide levels on arterial blood gases, which portends a poorer prognosis.^{1,6,7} Cardiorespiratory exercise testing is useful in helping to separate out activity limitations from heart or lung impairment versus the often severe deconditioning that also occurs in these patients.⁸

Overnight oximetry and formal sleep studies (polysomnography or PSG) are used to prove whether polio patients have central hypoventilation, classic obstructive sleep apnea, or a mixed disorder.⁵ Patients with kyphoscoliosis with ill-defined symptoms should be considered for screening overnight oximetry. Those complaining of sleep disordered breathing symptoms as noted above, especially in the presence of moderate restrictive lung disease or daytime hypercapnia, should undergo a PSG study which can reveal profound nocturnal hypoxemia particularly during REM sleep.^{5,6}

TREATMENT

The mainstay of treatment for daytime shortness of breath is reconditioning with pulmonary rehabilitation. These programs usually include other helpful techniques such as cough assistance. The same data that suggests increased activity and possibly reduced hospitalizations for COPD patients seems to apply to restrictive lung disease patients.⁹

Oxygen therapy is generally contraindicated for patients with post-polio problems but ventilatory assistance with non-invasive techniques, primarily nasal nocturnal ventilation has

dramatic effects especially in patients with kyphoscoliosis.^{10,11,12} Corrective surgery to reduce spinal curvature can improve pulmonary performance.¹³ Careful attention to the cause of ventilatory insufficiency now offers patients marked increases in quality of life.

¹ Windebank AJ, Litchy WJ, Daube JR, Kurland LT, Codd MB, Iverson R. Late effects of paralytic poliomyelitis in Olmsted County, Minnesota. *Neurology*. 41(4):501-7, 1991.

² Knobil K, Becker FS, Harper P, Graf LB, Wolf GT, Martinez, F. Dyspnea in a patient years after severe poliomyelitis. The role of cardiorespiratory exercise testing. *Chest*. 105(3): 777-81, 1994.

³ Dean E, Ross J, Courtenay L, Madill KJ. Pulmonary function in individuals with a history of poliomyelitis. *Chest*. 100(1): 118-23, 1991.

⁴ Scano G, Gigliotti F, Duranti R, Gorini M, Fanelli A, Marconi G. Control of breathing in patients with neuromuscular disease. *Monaldi Arch Chest Dis*. 48(1): 87-91, 1993.

⁵ Hsu A, Staats B. "Postpolio" sequelae and sleep-related disordered breathing. *Mayo Clin Proc*. 73: 216-24, 1998.

⁶ Dolmage TE, Avendano Ma, Goldstein RS. Respiratory function during wakefulness and sleep among survivors of respiratory and non-respiratory poliomyelitis. *Eur Respir J*. 5(7): 864-70, 1992.

⁷ Midgren B. Lung function and clinical outcome in post-polio patients: A prospective cohort study during 11 years. *Eur Respir J*. 10(1): 146-9, 1997.

⁸ Stanghelle JK, Festag L, Aksnes AK. Pulmonary function and symptom-limited exercise stress testing in subjects with late sequelae of poliomyelitis. *Scand J Rehab Med*. 25(3): 125-9, 1993.

⁹ Bach J. New therapeutic techniques and strategies in pulmonary rehabilitation. *Yonsei Med J*. 34(3): 201-11, 1993.

¹⁰ Gay PC, Edmonds LC. Severe hypercapnia after low-flow oxygen therapy in patients with neuromuscular disease and diaphragmatic dysfunction [see comments]. *Mayo Clin Proc*. 70(4):327-30, 1995.

¹¹ Gay PC, Patel AM, Viggiano RW, Hubmayr RD. Nocturnal nasal ventilation for treatment of patients with hypercapnic respiratory failure. *Mayo Clin Proc*. 66(7):695-703, 1991.

¹² Leger P. Nasal intermittent positive pressure ventilation. Long-term follow-up in patients with severe respiratory insufficiency. *Chest*. 105(1): 100-5, 1995.

¹³ Baydur A, Swank SM, Stiles CM, Sassoon, CS. Respiratory mechanics in anesthetized young patients with kyphoscoliosis. Immediate and delayed effects of corrective spinal surgery. *Chest*. 97(5): 1157-64, 1990.

CARDIOVASCULAR ISSUES AND THE POST-POLIO SYNDROME

Rupert D. Mayuga, MD

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Cardiovascular disease (CVD) is the leading cause of death in both men and women in the United States. One of every 2.4 deaths is attributable to it. In addition, it results in substantial morbidity, accounting for more than 6 million hospital discharges per year in this country.

The actual incidence of CVD in individuals suffering from post-polio syndrome (PPS) is not known. However, there is reason to suspect that individuals with PPS might be at increased risk. Certain features of PPS such as generalized fatigue, generalized and specific muscle weakness, joint and/or muscle pain may result in physical inactivity - deconditioning, obesity, and dyslipidemia. Respiratory difficulties may result in hypoxemia. Any of these can predispose those with PPS to increased cardiovascular risk. Furthermore, most individuals with PPS are now at an age group where CVD such as heart attack, stroke, and heart failure become increasingly more likely. Common symptoms and signs of CVD include exertional chest discomfort, exertional and non-exertional shortness of breath, sudden shortness of breath and/or chest discomfort after lying down, swelling of the ankles and legs, heart enlargement, palpitation, loss of consciousness, and easy fatigability. It is evident that there are symptoms of CVD that overlap with common symptoms of PPS. This could present a problem since individuals suffering from PPS may not recognize cardiovascular symptoms by thinking that these may just be a progression or altered manifestation of PPS symptoms. The resulting delay in diagnosis can be costly. It is important to emphasize that CVD is often a "silent" disease without significant symptoms until its life-threatening or catastrophic sequelae appear suddenly. All too often, the first manifestation of CVD is sudden death, stroke, or a heart attack. The need to identify individuals at increased risk early enough to alter its catastrophic course cannot be overemphasized.

Available information on heart disease and PPS in the scientific literature is regrettably limited. Some interesting studies, however, may be of practical importance to PPS patients. One such study evaluated the cardiovascular autonomic function of subjects with antecedent poliomyelitis (Borg et al) and concluded that there was no significant dysfunction of autonomic nerves despite the presence of progressive muscle atrophy. This finding becomes important when one considers that many current methods for assessing cardiovascular function and fitness include evaluation of parameters such as heart rate, blood pressure, heart rate variability, valsalva response etc., all of which require an intact autonomic system. The study results suggest that individuals with PPS in general can use any of a number of standardized tests for cardiovascular risk assessment such as the exercise stress test without a decrease in test sensitivity, provided

that due consideration of the presence of muscular dysfunction is made. For example, an arm ergometer may be used instead of a treadmill as the method of providing the exercise in PPS individuals with lower extremity weakness. There are also non-exercise types of cardiovascular stress testing such as pharmacologic, vasodilator perfusion stress tests (dipyridamole or adenosine stress tests) used in conjunction with nuclear imaging, or a dobutamine - echo stress test. These are the preferred tests for those who cannot perform significant exercise.

Apart from cardiac stress testing, there are also an increasing number of ways to evaluate cardiovascular risk. Evaluation for coronary risk factors is of major importance to everyone with or without a history of PPS. Risk factors include cigarette smoking, hypertension, elevated LDL cholesterol (the "bad" cholesterol), low HDL cholesterol (the "good" cholesterol), diabetes, male gender (and post menopausal women), family history of premature coronary heart disease, the presence of peripheral arterial occlusive disease, and last but not least, obesity and physical inactivity. The presence of multiple risk factors results in more than just additive risk. Newer tests with possible utility in further defining increased risk for future cardiovascular events (i.e. heart attack, stroke) are currently under consideration. These include carotid artery duplex scanning, electron beam CT, ultrasound-based endothelial function studies, ankle/brachial blood pressure ratios, MRI techniques and testing for hs CRP - a possible marker of increased risk for coronary atherosclerotic plaque instability. Although there appear to be no large scale studies evaluating whether individuals suffering from PPS are at increased risk for CVD, it is probably safe to assume that there may be increased risk in certain individuals who have the traditional risk factors mentioned earlier. A study of 64 post-polio patients (Agre JC et al) found that 66% of the men and 25% of the women had hyperlipidemia with men also having low HDL cholesterol. These findings underscore the need to actively screen for dyslipidemia and/or hypercholesterolemia. In addition, deconditioning and obesity was found by Agre et al to be strongly associated with the presence of dyslipidemia. Therefore, it is important to address these issues in individuals with PPS.

In individuals with identified PPS symptoms consistent with cardiovascular deconditioning, there has been some hesitation in prescribing an exercise program to improve conditioning because of fears that traditional exercise regimens may lead to further loss of muscle from overuse. The prospect of safely and effectively training PPS subjects was evaluated by a number of investigators (Kriz JL et al, Jones DR et al, Owen RR et al). All investigators found that a carefully designed exercise program that avoided excessive muscle fatigue was able to provide positive results. Jones DR et al and Owen RR et al used lower extremity exercise. Kriz JL et al showed that PPS subjects *can use upper extremity exercise* (using an arm crank ergometer) for 20 minutes three times a week to achieve a significant improvement in cardiovascular conditioning (19% improvement in VO₂ max in the study). A very gradual training period of 16 weeks was used to allow all PPS subjects to reach a consistent exercise level and to avoid muscle damage from overuse. The results of these studies support the need to develop safe, effective, and easily accessible exercise programs for PPS individuals. This has the advantage of allowing the benefits of cardiovascular conditioning without the potential risk of further muscle damage.

Recommendations:

1. Determine if you have any of the common signs and/or symptoms of cardiovascular disease.

CVD signs: Enlarged heart, swelling of the ankles or legs, unusual/excess weight gain, wounds that do not heal well.

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3. Avoid physical deconditioning and becoming overweight. Consult your health care professional for appropriate recommendations. In general, exercise has to be started very gradually and at a lower level and individually tailored to each individuals

physical status and needs. Care should be taken not to over exercise. Nutritional counseling is a useful resource.

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6. Jones DR, Speier JL, Canine JK, Owen RR, Stull GA. Cardiorespiratory responses to aerobic training by patients with post- poliomyelitis sequelae. *JAMA* 1989;261:3255-8.

Court Cases and Their Implications

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The following is a brief summary of all the cases decided by the Supreme Court of the United States in the last 10 years related to disabilities rights. The summary was prepared and published by West Publishing Co. in connection with publishing these cases, and edited by the presenter to eliminate some legalistic jargon and for minor clarifications.

1. *Olmstead v. L. C. ex rel. Zimring*, 527 U.S. 581 (1999)

Patients with relatively mild retardation and psychiatric disabilities brought suit against state, challenging their confinement in segregated environment. The Supreme Court, Justice Ginsburg, held that, under Title II of the ADA: (1) patients were qualified for community-based treatment thereby entitling them to community placement, but (2) state could take into account the available resources in determining whether patients were entitled to immediate community placement.

Justice Stevens filed opinion concurring in part and concurring in the judgment. Justice Kennedy filed opinion concurring in the judgment in which Justice Breyer joined in part.

Justice Thomas filed dissenting opinion in which Chief Justice Rehnquist and Justice Scalia joined.

2. *Albertsons, Inc. v. Kirkingburg*, 527 U.S. 555 (1999)

Former employee, who was fired from his job as a truck driver after he failed to meet the Department of Transportation's basic vision standards and was not rehired even though he had obtained a waiver of the DOT standards, brought action against former employer under the ADA. The Supreme Court, Justice Souter, held that: (1) individuals with monocular vision are not per se "disabled" within meaning of the ADA but, rather, must prove their disability on a case-by-case basis by offering evidence that the extent of the limitation on a major life activity in terms of their own experience is substantial, and (2) former employer could use its compliance with applicable DOT safety regulations to justify its visual-acuity job qualification standard, despite existence of experimental program by which DOT standard could be waived in an individual case.

Justice Thomas filed a concurring opinion.

Justice Stevens' and Justice Breyer's partial concurrences were noted.

3. *Murphy v. United Parcel Service, Inc.*, 527 U.S. 516 (1999)

Employee, whose mechanics position required him to drive commercial vehicles, sued employer under Title I of the ADA when he was fired upon discovery that his blood pressure exceeded Department of Transportation (DOT) health certification requirements for drivers of commercial vehicles. The Supreme Court, Justice O'Connor, held that: (1) determination whether employee's impairment "substantially limits" one or more major life activities is made with reference to the mitigating measures he employs; (2) employee's high blood pressure did not substantially limit his major life activities when he was medicated for his position and thus he was not disabled under ADA; and (3) employee was not "regarded as" substantially limited in major life activity of working by reason of his dismissal for inability to obtain DOT certification as he remained generally employable in mechanics positions that did not require driving commercial vehicle.

Justice Stevens filed dissenting opinion, in which Justice Breyer joined.

4. *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999).

Severely myopic job applicants brought disability discrimination action against airline, under ADA, challenging airline's minimum vision requirement for global pilots. The Supreme Court, Justice O'Connor, held that: (1) corrective and mitigating measures should be considered in determining whether individual is disabled under ADA; (2) applicants were not disabled under ADA; and (3) applicants failed to state claim that airline regarded them as disabled in violation of ADA.

Justice Ginsburg filed concurring opinion.

Justice Stevens filed dissenting opinion, in which Justice Breyer joined.

Justice Breyer filed dissenting opinion.

5. *Cleveland v. Policy Management Systems Corporation*, 526 U.S. 795 (1999)

Employee sued former employer for wrongful termination under ADA. On writ of certiorari, the Supreme Court, Justice Breyer, held that: (1) claims for Social Security Disability Insurance (SSDI) benefits and for ADA damages did not inherently conflict, and (2) employee was entitled to an opportunity to explain discrepancy between her statement in pursuing SSDI benefits that she was totally disabled and her ADA claim that she could perform essential functions of her job.

Unanimous.

6. *Cedar Rapids Community School District v. Garret F.*, 526 U.S. 66 (1999)

School district brought action challenging administrative determination that district was required to provide continuous nursing services to quadriplegic student under Individuals with Disabilities Education Act (IDEA). The Supreme Court, Justice Stevens, held that continuous nursing service was "related service" that district was required to provide under IDEA .

Justice Thomas filed dissenting opinion in which Justice Kennedy joined.

7. *Wright v. Universal Maritime Service Corporation*, 525 U.S. 70 (1998)

Longshoreman filed suit alleging that stevedore companies discriminated against him in violation of the ADA when they refused to employ him following his settlement of a claim for permanent disability benefits for job-related injuries. The trial court dismissed the case on grounds that the plaintiff failed to pursue an arbitration agreement provided for in the collective bargaining agreement. The Court of Appeals affirmed. The Supreme Court said the arbitration agreement was only general and therefore did not apply to claims for an ADA violation.

Unanimous.

8. *Pennsylvania Department of Corrections v. Yeskey*, 524 U.S. 206 (1998)

State prison inmate, who was denied admission to prison boot camp program due to history of hypertension, sued Pennsylvania Department of Corrections and several officials under the ADA. The Supreme Court, Justice Scalia, held that Title II of the ADA, prohibiting "public entity" from discriminating against "qualified individual with a disability" on account of that individual's disability, applied to inmates in state prisons.

Unanimous.

9. *Bragdon v. Abbott*, 524 U.S. 624 (1998)

Patient infected with HIV brought action under the ADA against dentist who refused to treat her in his office. The Supreme Court, Justice Kennedy, held that: (1) HIV infection is a "disability" under the ADA, even when the infection has not yet progressed to the so-called symptomatic phase, as a physical impairment which substantially limits the major life activity of reproduction, and (2) with regard to "direct threat" provision of the ADA, the existence, or nonexistence of a significant health risk from treatment or accommodation of a disabled person must be determined from standpoint of the person who refused the treatment or accommodation, but the risk assessment must be based on medical or other

objective evidence, and not simply on that person's good-faith belief that a significant risk existed.

Justice Stevens filed concurring opinion in which Justice Breyer, joined.

Justice Ginsburg filed concurring opinion.

Chief Justice Rehnquist filed opinion concurring in the judgment in part and dissenting in part, in which Justices Scalia and Thomas joined, and in Part II of which Justice O'Connor joined.

Justice O'Connor filed opinion concurring in the judgment in part and dissenting in part.

10. *Lane v. Pena*, 518 U.S. 187 (1996)

Merchant Marine Academy cadet, whose enrollment was terminated on ground that his recently diagnosed diabetes mellitus rendered him ineligible to be commissioned for service in the Navy/Merchant Marine Reserve Program or as a Naval Reserve Officer, brought suit alleging that his separation from the Academy violated the Rehabilitation Act. The Supreme Court, Justice O'Connor, held that: (1) Congress has not waived federal government's sovereign immunity against awards of monetary damages for violations of section of Rehabilitation Act prohibiting discrimination on basis of disability "under any program or activity conducted by any Executive agency"; (2) cadet, who prevailed on claim that his separation from the Academy violated section of the Rehabilitation Act, was not entitled to an award of compensatory damages on ground that Department of Transportation, which administers Academy through the Maritime Administration, is a "federal provider" within the meaning of the Act, and thus is liable for such award regardless of sovereign immunity; and (3) "equalization" provision of the Rehabilitation Act Amendments of 1986 does not reveal congressional intent to equalize remedies available against all defendants for Rehabilitation Act violations, such that federal agencies, like private entities, are subject to monetary damages for such violations.

Justice Stevens filed dissenting opinion in which Justice Breyer joined.

11. *City of Edmonds v. Oxford House, Inc.*, 514 U.S. 725 (1995).

City filed declaratory judgment action, seeking ruling that single-family residential zoning provision limiting maximum number of unrelated occupants of single-family residence did not violate Fair Housing Act's (FHA) prohibition against handicapped discrimination. Government filed action alleging city's failure to make reasonable accommodation for group home of more than five unrelated recovering alcoholics and drug addicts violated FHA.. The Court of Appeals held FHA's absolute exemption from maximum occupancy limits inapplicable. The Supreme Court, Justice Ginsburg, held that, zoning provision governing area zoned for single-family dwelling units, which defined family as persons related by

genetics, adoption of marriage or group of five or fewer unrelated persons, described who could compose a family unit, not the maximum number of occupants that dwelling unit could house, and thus did not fall within FHA's absolute exemption for total occupancy limits.

Justice Thomas dissented with whom Justices Scalia and Kennedy joined.

12. *Florence County School District Four v. Carter*, 510 U.S. 7 (1993)

Parents sought reimbursement for costs of private placement of their learning disabled child. The Supreme Court, Justice O'Connor, held that: (1) IDEA's definition of free appropriate public education cannot be read as applying to parental placement; (2) reimbursement is not barred because private school chosen by the parents did not meet IDEA's definition of free appropriate public education; (3) reimbursement is not barred because private school is not on state's approved list of private schools; and (4) court may consider relevant factors in fashioning discretionary equitable relief, and total reimbursement is not appropriate if court determines that cost of private education was unreasonable.

Unanimous.

13. *Heller v. Doe*, 509 U.S. 312 (1993)

Class of involuntarily committed mentally retarded individuals brought suit challenging constitutionality of Kentucky's involuntary commitment procedures. The United States Supreme Court, Justice Kennedy, held substantively that: (1) statutory scheme requiring higher standard of proof for involuntary commitment of mentally ill, as opposed to mentally retarded, persons had rational basis such that it did not violate equal protection; (2) rational basis also justified Kentucky's provision of party status for relatives and legal guardians in involuntary commitment proceedings involving the mentally retarded, but not the mentally ill; and (3) granting party status to legal guardians and close relatives of mentally retarded persons facing involuntary commitment did not violate due process.

Justice O'Connor filed opinion concurring in judgment in part and dissenting in part.

Justice Blackmun filed dissenting opinion.

Justice Souter filed dissenting opinion, in which Justice Blackmun and Justice Stevens joined and in which Justice O'Connor joined in part.

COMPUTED TOMOGRAPHIC STUDY OF THE SKELETAL MUSCULATURE IN 45 POSTPOLIO PATIENTS

Barbara Ivanyi MD, PhD
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BACKGROUND

The use of computed tomography (CT) of the skeletal musculature in patients with neuromuscular diseases enables us to map the areas affected by disease. Although CT scanning is not diagnostic in itself, in some neuromuscular diseases more or less distinctive patterns can be recognised.

CT scan studies on postpolio patients are scarce and CT scan patterns in postpolio patients are not well documented. No attempts have been made to investigate possible CT scan differences between postpolio syndrome (PPS) patients and stable postpolio patients.

AIMS OF THE STUDY

1. to describe muscle CT scan pattern in postpolio patients;
2. to look for differences in CT features between PPS patients and stable postpolio patients;
3. to make correlations between CT scan data and muscle strength measurements.

PARTICIPANTS AND DESIGN

Muscle computed tomography and muscle strength assessment of the pelvic girdle and leg muscles were performed in 32 postpolio patients experiencing new muscle weakness, and in 13 postpolio patients with stable neuromuscular condition.

Muscle CT scans were performed including 24 muscles at the lumbar region, pelvic girdle thighs and lower limbs. Muscle strength was assessed by manual muscle testing (MMT) based on Medical Research Council rating.

RESULTS

The most frequent CT scan abnormality consisted of atrophy and decreased attenuation of selective muscle groups. The CT scan abnormalities were asymmetrically distributed and most pronounced in the lower legs without preferential involvement of a particular muscle.

Muscles of the postpolio patients experiencing new muscle weakness showed significantly more CT scan abnormalities as compared to the stable postpolio patients. No other CT scan features discriminative of symptomatic postpolio patients were found.

When comparing muscle strength with radiological findings 33.8% of the muscles with normal strength on MMT were shown to have CT scan abnormalities while 8.3% of the paralytic muscles had a normal CT scan appearance.

CONCLUSIONS

Muscle CT scan evaluation does not contribute to a distinction between PPS and a stable neuromuscular condition in the individual postpolio patient. However, this investigative tool proves to be of value in the assessment of the neuromuscular status by obtaining information about the skeletal muscles in addition to manual muscle testing.

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WHAT ABOUT THE MUSCLES?

Jacquelin Perry, MD (JP)
Sophia Chun, MD (SC)

- I. Post-Polio Muscles: Different muscles are differently affected by polio (SC)
 1. Stable re-innervated muscles
 2. Unstable muscles
 3. Normal muscles

- II. Exercise Experience (SC)
 - a. Most studies done on grade 4-5 strength muscles
 - b. Most show at least moderate gain in resistance
 - c. Short term effects seldom show injury—no structural or biochemical changes.

- III. Muscle Chemistry & Physiology (SC)
 - A. Chemistry
 1. Citrates Synthase decreased:
 - a. consistent with heavy resistance training in healthy subjects
 2. Oxidative enzyme changes:
 - a. indicative of reduced adaptation to endurance activity
 - B. Physiological tests
 1. MR spectroscopy: Large variation in polio patients

- IV. How does Creatinine fit into the picture? (SC)
 - A. Review of Creatinine theory
 - B. Review of general Creatinine literature
 - C. How does the literature relate to PP?
 - D. Results of the survey
 - E. What issues need to be studied
 - a. Safety
 - b. Efficacy in strength, endurance, fatigue symptoms
 - c. How to dose and safety of chronic long term use.

- V. Post-Polio Muscles (JP)
 - A. Muscle fiber hypertrophy
 - 1. 8 year follow-up of mixed PPS and PP subjects
 - a) greater in men, 2X age matched controls
 - b) involved both type I and type II:
 - c) subjects with the greatest hypertrophy had the greatest strength loss
 - d) Fiber size did not correlate with strength
 - B. Motor units enlarged (11 times) (JP)
 - C. Imaging studies / EMG studies (JP)
 - 1. MRI: shows fat replacement
 - 2. EMG: Ant. Tib overuse, higher rate of firing/ duration
- III. Conclusion (JP)
 - A. Muscle hypertrophy is a spontaneous adaptation to over demand
 - B. Chronic overuse causes motor unit loss (small angulated fibers)
 - C. Exercise cautiously
 - D. Avoid Fatigue

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri June 8-10, 2000

**FINDING AND SCREENING INFORMATION:
WHY, WHEN, AND HOW**

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My experience in finding and screening information comes from having been jointly responsible as a volunteer for compiling a bilingual polio newsletter and for gathering material for a book about the story of polio from a Québec perspective, in French. When I first took responsibility for the newsletter over 12 years ago, the process was very democratic and included consultation, committee meetings, and occasional questionnaires, to ensure the material we printed was wanted. We have since become, regretfully, more energy efficient. E-mail, faxes and telephones have taken over.

Although the information and stories we print try to reflect our mission as an organization, this is sometimes compromised by what is available, by time constraints, or in Québec, by language and expediency.

**Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri June 8 -10, 20000**

The Sleep-Bladder Connection
Mary Umlauf, RN, PhD, John McBurney, MD, Eileen Chasens, RN, DSN
University of Alabama at Birmingham

Chasens, ER, Umlauf, M., Valappil, T., Singh, KP. (2000). **Nocturnal Problems in Post-Polio Syndrome: Sleep Apnea Symptoms and Nocturia.** *Rehabilitation Nursing.* (accepted for publication).

Abstract

There are 640,000 polio survivors in the United States at risk for both age-related disorders and the effects of post-polio syndrome (PPS). Nocturia, generally accepted as the inevitable consequence of aging, is also a symptom of a potentially lethal condition - obstructive sleep apnea (OSA). Persons with PPS, especially those who suffered bulbar involvement and respiratory impairment during the acute polio episode, are at highest risk for sleep-related breathing disturbances. The purpose of this study was to examine the prevalence and effects of nocturia and sleep related breathing problems in persons with polio and to test The Sleep Disordered Breathing – Nocturia Model in this population. This model describes the cascade of events that result in increased urine production in persons with sleep-related breathing disorders. A 34-item questionnaire was published in the newsletter of a national polio support group. The data from the 584 returned questionnaires showed statistically significant associations between OSA symptoms, nocturia, poor sleep quality, use of hypnotic/stimulant medications, excessive daytime sleepiness, lower urinary tract symptoms, naps, and decreased self-rated health. The study results not only support the model but also document how nocturia and sleep-disordered breathing negatively impact the well being of persons with polio.

Sleep Disturbances and Bladder Symptoms among Post Polio Subjects

	OSA Symptoms	Poor Sleep Quality	Daytime Sleepiness
Post-Polio Only (n =277)			
Poor Sleep Quality	.63 ♦		
Daytime Sleepiness	.40 ♦	.52 ♦	
Sleep Medications	.44 ♦	.29 ♦	.32 ♦
Nocturia	-.07	.20 *	.04
Post-Polio & Hx Breathing Problems (n =156)			
Poor Sleep Quality	.61 ♦		
Daytime Sleepiness	.58 □	.57 ♦	
Sleep Medications	.49**	.31**	.31**
Nocturia	.34 *	.32**	.34 ♦

Pearson's r, * p < .05; ** p < .01, □ p < .001, ♦ p < .0005

Even in the absence of apnea, breathing may fall short of needs during sleep, resulting in retention of carbon dioxide and decreased oxygen levels. These may result from respiratory muscle weakness as may occur with the post-polio syndrome. During REM sleep extra muscles involved during breathing in wakefulness and NREM are normally paralyzed. Respiration is solely dependent on the diaphragm during REM. If the diaphragm is weakened or paralyzed due to polio, hypoventilation may occur.

2. **Periodic Limb Movements Syndrome (PLMS).** PLMS is manifested by repeated, stereotyped movements of the limbs during sleep. The legs are most commonly affected, but the arms may be involved as well. These repeated movements result in sleep disruption and may result in insomnia or hypersomnia. Risk factors for PLMS include diseases of the brain and spinal cord, such as post-polio syndrome, peripheral neuropathy, spinal diseases such as spinal stenosis or herniated discs or a variety of metabolic problems such as renal insufficiency or iron deficiency. Individuals with PLMS often experience restless legs as well (see #3 below). PLMS is very common, and increases with advancing age. 50% of individuals aged 70 or greater have PLMS.

3. **Restless Legs Syndrome (RLS).** RLS refers to a disagreeable sensation in the limbs that is accompanied by a compulsion to move the limb in an attempt to temporarily relieve the symptoms. Symptoms worsen at night and may result in severe insomnia. 80% of individuals with RLS also have PLMS once asleep. Conditions that predispose to PLMS also may predispose to RLS.

4. **Fibromyalgia Syndrome.** Fibromyalgia syndrome refers to diffuse musculoskeletal pains associated with discrete tender spots, called trigger points, in predictable locations in muscles and connective tissues. Sleep in fibromyalgia is disrupted and poorly restful. During NPSG fibromyalgia sufferers are seen to retain remnants of waking EEG patterns during sleep. This is termed *alpha intrusion* for the alpha waves of wakefulness. In severe cases, fibromyalgia patients feel that they do not sleep at all, despite objectively being demonstrated to be asleep. This is termed *sleep state misperception*. Varying degrees of depression often accompany fibromyalgia. Post-polio syndrome predisposes to fibromyalgia due to altered mobility, decreased range of motion, altered function in joints with increased biomechanical stresses and decreased exercise capacity.

Making the Most of Your Sleep

Healthy sleep habits are the cornerstone of a healthy lifestyle. Here are some important suggestions for maintaining healthy sleep.

- Maintain a regular sleep schedule. After a bad night, avoid "sleeping in" to make up for lost sleep.
- Limit napping
- Avoid caffeine and alcohol. Caffeine causes sleep disruption even if you are not experiencing insomnia. Alcohol increases wake time in the early morning and may dramatically worsen sleep disordered breathing .
- Make the sleeping environment comfortable both physically and emotionally. Avoid using the bedroom for other functions such as a home office. Keep the room dark, quiet and cool.
- Check your worries at the door. If necessary, set aside "worry time" at some other time and in another place.

Diagnosing Sleep Disorders

The most important step in diagnosing a sleep disorder is that recognition that there is a problem. Most individuals with primary sleep disorders have never seen a sleep medicine specialist or had any evaluation! Some primary sleep disorders such as PLMS/RLS or fibromyalgia can often be diagnosed by a careful history and physical. Others, such as OSA, require specialized testing such as nocturnal polysomnography (NPSG) for diagnosis. Often a NPSG reveals multiple primary sleep disorders in the same patient. This is termed *comorbidity*, and is seen in up to 30% of patients who undergo NPSG at our center. Examples include OSA and CSA, OSA and PLMS, PLMS, RLS and fibromyalgia all coexisting in the same patient.

Treating Sleep Disorders

Most sleep disorders can be diagnosed and effectively treated. Sleep disordered breathing usually responds well to continuous positive airway pressure (CPAP). Types of positive airway pressure include nasal CPAP, and bilevel positive airway pressure (BIPAP). Each has an important role in managing this problem depending on whether the problem is OSA, CSA or hypoventilation. Supplemental oxygen may be added in some instances. PLMS and RLS usually respond well to medications such as l-dopa/carbidopa (Sinemet), dopa agonists such as pramipexole (Mirapex), clonazepam (Klonopin) and gabapentin (Neurontin). Often iron supplementation may improve symptoms as well. The treatment of fibromyalgia includes low dose tricyclic antidepressants, physical therapy and exercise.

Normal Sleep and Sleep Disorders

John W. McBurney, M.D.
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Sleep-Wake Disorders Center

Sleep accounts for approximately one-third of our lives, but the impact that sleep and sleep disorders have on our health is often under appreciated. In addition, many, if not most, chronic medical conditions have demonstrable effects on sleep, and may predispose to sleep disorders. The purpose of this discussion is to examine the ways in which post-polio syndrome may affect sleep, and important sleep disorders that are common in post-polio syndrome.

Normal Sleep

Sleep is a reflection of active brain processes. It is divided into rapid eye movement (REM- when most dreaming occurs) and non-rapid eye movement (NREM) portions. NREM is further subdivided into 4 stages (I-IV). Stages III and IV are collectively referred to as slow wave sleep. NREM sleep is felt to result in rest and recuperation. REM sleep is thought to be involved in the restitution of brain functions active in wakefulness – sort of like defragmenting the hard drive on a computer. Across the night sleep normally evolves in a predictable sequence. This is referred to as *sleep architecture*. A key feature of sleep architecture is that REM is normally entered only after 90-120 minutes of NREM. NREM slow wave sleep is seen mainly during the first half of the night and REM increases in the second half. Sleep architecture changes as we age. Newborn babies spend 2/3 of each 24-hour period asleep and half of that time is spent in REM. The 24-hour sleep-wake cycle is established by age 6. Adolescents have increased sleep needs and have large amounts of slow wave sleep. Middle age adults spend about 90 minutes each night in stage REM, and about 45 minutes in slow wave sleep. By retirement age, the amount of slow wave sleep is decreased to nearly none, although REM continues to occupy 20% of sleep time. Increasing sleep fragmentation and increased awake time is noted with advancing age. Sleep onset often occurs at an earlier time in the evening with corresponding earlier awakening. Daytime napping becomes more common in advanced age.

Sleep and Medical Conditions

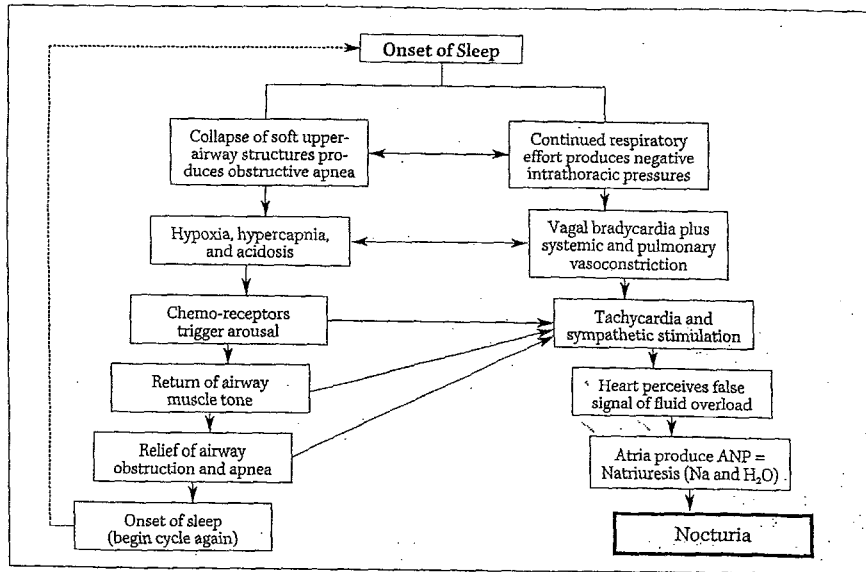
Since sleep is a reflection of active processes within the central nervous system is not surprising that is affected by conditions that affect the nervous system or other organ systems monitored by the nervous system. Sleep disorders typically cause either *insomnia*, in which sleep amount is not adequate to meet needs, or *hypersomnia*, in which daytime function is compromised by unwelcome sleepiness. Insomnia is the most common medical complaint. Insomnia can result from emotional or behavioral problems, effects of substances such as caffeine or alcohol, side-effects of prescription drugs, effects of physical illnesses, or primary sleep disorders. Post-polio syndrome may predispose individuals to insomnia or hypersomnia in any of these ways.

Primary Sleep Disorders in Post-Polio Syndrome

1. Sleep Disordered Breathing: Obstructive Sleep Apnea (OSA), Central Sleep Apnea (CSA) and Hypoventilation. Post polio may cause breathing problems during sleep including OSA, CSA and Hypoventilation. During sleep important changes occur in the physiology of breathing. These include an increase in the resistance to airflow in the upper airway, reduced responsiveness to blood carbon dioxide level, and, during REM sleep, reduced ventilatory effort. Because post-polio syndrome may affect control of the muscles of the upper airway, reflex responses to the level of oxygen and carbon dioxide in the blood, and weakness of muscles of respiration, these normal phenomena may be exaggerated. OSA results when the upper airway collapses and causes repeated interruptions in airflow (apneas). Apneas are terminated by arousal from sleep, which may occur scores, even hundreds of times per night resulting in sleep disruption. This may result in either hypersomnia or insomnia. OSA is a risk factor for hypertension (high blood pressure), myocardial infarction (heart attack), congestive heart failure (CHF) and stroke. Individuals with OSA are also at a 7 times increased risk of motor vehicle accidents. OSA is suggested by a history of loud snoring, observed interruptions in breathing and daytime sleepiness.

OSA is very common, affecting 9% of women and 24% of men, and most cases remain undiagnosed. CSA occurs when the brain reflexes for triggering breathing during sleep are defective. This can occur due to with brain diseases (such as some examples of post-polio syndrome) or cardiovascular diseases, and may co-exist with other breathing problems during sleep, such as OSA or hypoventilation. Many individuals with CSA have difficulty initially falling asleep because of frequent central apneas with arousal at the transition from wakefulness to sleep (transitional central apneas).

The Sleep Disordered Breathing – Nocturia Model *



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EIGHTH INTERNATIONAL
Post-Polio AND
Independent Living
Conference
SAINT LOUIS, MISSOURI

Friday, June 9, 2000

SESSION III

1:30 pm - 2:45 pm

PAVILION SALON E

The Challenge of Polio and AIDS

Sharon Maxwell Henkel

Gastrointestinal Distress: Listen to Your Gut

Linda L. Bieniek, CEAP

PAVILION SALON F

Breathing Devices: What's Available

Augusta S. Alba, MD; Alan D. Fiala, PhD

PAVILION SALON B

Influencing Policy* ...

... Aging Issues

Norma Collins

... MiCASSA (Personal Assistance Legislation)

Deborah Cunningham

PAVILION SALON D

Managing Chronic Pain: Findings of a Pilot Program

Dorothy Woods Smith, RN, PhD, HNC

Benefits of Hot Pool Therapy

Nickie Lancaster, RN

PAVILION SALON A

Spinal Problems and Solutions (Part I)*

Carol B. Vandenakker, MD

Eighth International Post-Polio and Independent Living Conference

St. Louis, Missouri

June 8-10, 2000

POLIO and AIDS

Sharon Maxwell Henkel
Community Constituency Group Member
AIDS Clinical Trials Group

Are older adults at risk for HIV infection? Unfortunately the answer is yes. Over 11% of new AIDS cases in the United States occur in people over the age of 50. In the last few years, new AIDS cases rose faster in the middle age and older adult than in people under age 40. While many of these AIDS cases are the result of HIV infection at a younger age, many are due to becoming infected after age 50.

Here are some startling statistics from the Center for Disease Control:

- Total reported HIV Infections yearly: 40,000+
- Total Cases of AIDS as of 1998: 688,200
- Total Deaths caused by AIDS: 401,028
- Every 5 minutes one person between the ages of 10 to 24 years old contracts HIV.
- Twenty percent of all new infections in the United States in 1998 occurred in women.
- It is estimated that there are over 200,000 HIV+ infected people who DO NOT know they are carrying the disease.
- Between 1991 and 1996 heterosexual transmission of HIV increased 106% in women over age 50.

As the post-polio population continues to age, the risk of contracting HIV increases. Spouses are lost to many factors and people go back into the dating world, unaware of the dangers of unprotected sex or sharing needles. It is difficult at times, to determine rates of HIV infection among older adults, as very few persons over the age of 50 at risk for HIV get tested. Many older adults are first diagnosed with HIV at a late stage of infection – when they seek treatment for an HIV-related illness. Unfortunately HIV can sometimes mimic other conditions: hot flashes in women, dry skin, yeast infections, fatigue and muscle wasting, tingling in the feet and hands, inability to sleep, lung and breathing difficulties – many symptoms which could be misdiagnosed for post-polio or other problems. Many symptoms of HIV and infections may coincide with other diseases associated with aging and thus be overlooked.

Older persons with AIDS get sick and die sooner than younger persons. This is due to late diagnosis of the disease as well as co-infection with other diseases that may speed the progression of AIDS. Also, new drugs for HIV treatment may interact with the medications the older individual is taking to treat pre-existing chronic conditions.

Tips for Educating Persons Over Age 50 About HIV/AIDS

From NAHOF: National Association of HIV Over Fifty

FACTS

- About 11% of new and existing AIDS cases occur in people over age 50.
- Numbers of cases are expected to increase, as people of all ages survive longer due to triple-combination drug therapy and other treatment advances.
- Between 1991 and 1996, AIDS cases in the over-50 population rose more than twice as fast as those among younger adults.
- Older individuals with HIV infection or AIDS usually are invisible, isolated and ignored.
- Despite myths and stereotypes, many seniors **are** sexually active, and, some are drug users; therefore, their behaviors **can** put them at risk for HIV infection.
- Health care and service providers---and older adults, themselves---do not realize that seniors are at the same risk as other age populations; professionals often are reluctant to discuss or question matters of sexuality with aging patients/clients.
- Rates of HIV infection (not AIDS) in seniors are especially difficult to determine because older people are not routinely tested.
- HIV/AIDS educational campaigns and programs are not targeted at/to older individuals (has a wrinkled face ever appeared on a prevention poster?).
- Seniors are unlikely to consistently use condoms during sex because of a generation mindset and unfamiliarity with HIV/STD prevention methods.

SPECIAL CONSIDERATIONS

- Older people with HIV/AIDS face a double stigma: ageism and infection with a sexually-or-IV-drug transmitted disease.
- Because of the stigma, it can be difficult for seniors---women, in particular---to disclose their HIV status to family, friends and their community.
- For older women, there are special considerations: after menopause, condom use for birth control becomes unimportant, and normal aging changes such as a decrease in vaginal lubrication and thinning vaginal walls can put them at higher risk during unprotected sexual intercourse.
- As HIV symptoms often are similar to those associated with aging or other conditions- (fatigue, weight loss, dementia, skin rashes, swollen lymph nodes); misdiagnosis is frequent in older people who are, in fact, infected.
- Because the aging process lowers energy levels and results in restrictions in social routines, which can cause emotional/psychological problems, the older adult additionally, infected with HIV may feel another "loss" and endure more severe depression.
- Seniors often are less likely to find support and comfort among family and friends, and because they are traditionally not comfortable in support groups, they may be less inclined to join them, citing lack of shared experiences concerning different issues.
- Due to the general lack of awareness of HIV/AIDS in older adults, this segment of the population, for the most part, has been omitted from research, clinical drug trials, educational prevention programs and intervention efforts.

THERE'S ALWAYS ROOM FOR HOPE

By Sharon Maxwell Henkel

It's amazing how your mind can remember traumatic events. I still see myself sitting on the edge of my bed, standing up to walk across the room - and falling. Standing up again and falling again. I was three years old, it was 1951 and a polio epidemic had spread across the city in which we lived. I had contracted polio.

Update to the early 90's - I'm sitting in a clinic and the doctor comes in and says, "I'm afraid it's not good news - you are HIV positive, in fact you have AIDS."

Your mind goes into a whirl - this can't be. I'm married, with children - the doctor says you've had HIV for a long time. My husband was just diagnosed with AIDS two weeks earlier. My first reactions were "great - first polio and now AIDS!" The next month was a blur of realizing what had just occurred. I really was disabled! I really could die - and maybe soon.

I wanted all of you to understand my background before I went any further. It is one thing to deal with a disability like polio - it is another to deal with an AIDS diagnosis. And yet they are not so different. I remember when I told my parents that I was HIV+. I said to my mother, "remember what it was like when polio was spreading across the nation - quarantined homes, people not wanting their children to play with your children - endless doctor visits - the possibility of an early death." "Well, I am HIV positive, have AIDS and it's about the same as it was with polio."

I think that once you've said it - the possibility of an early death - things change. You realize that there may be hope. This is how I felt the day I received my positive diagnosis. There's hope - I made it through polio, and I can get through this - with a little help!

The help came from many sources. I never realized how my life was being set up for dealing with an AIDS diagnosis because of polio. My parents raised me to go ahead and 'be a kid'. True I wore a long leg brace on my left leg but it never stopped me. Broke the polio leg twice while in the brace - usually hanging from ropes or monkey bars. My parents 'held their breath' and let me grow up as a child - with a disability, but a child first. In fact, I knew I limped but I was stunned to see it on a video when I was 35 years old. I never saw myself as disabled. I was just a girl with a brace.

I went on to college and graduated with a degree in fine art and went to work. Through my contacts with clients I discovered a network of polio survivors in our area. What a wonderful happening! To find others with whom I could share experiences, ask questions; learn about doctors, hospitals, braces, and medicines. All the things that this 40-year old now needed to know. I was beginning to experience a small amount of fatigue - but aren't most post-polios, type A personalities? Well I was, and the fatigue could very well have been just overwork. At least that is what I convinced myself it was.

There was a very reliable polio doctor in St. Louis and I began the extensive testing for post-polio syndrome (PPS). Diagnosis: the beginnings of PPS. Treatment: begin to slow down, rest, and take naps.

The diagnosis was taken lightly. Afterall, I was still in relatively little pain, and had little fatigue. This all changed when I attended the International Polio Conference in St. Louis in 1985. As I walked in to the huge conference room there were hundreds of men and women with polio - on stretchers, beds, wheelchairs, using oxygen, and breathing apparatus. Here I was "walking" and there are all the others - I broke down and cried - partially for myself in the future and partially for all these wonderful people at this conference.

At that moment I dedicated my life to taking control of my health. I was determined to slow down the late effects of polio. It's from this point that my life took a turn that would help me with deal with AIDS.

I researched the fatigue issue. Found out that I was eligible for a three-wheel scooter because I still worked and wanted to continue to do so. The Department of Rehabilitation funded the scooter and the lift for my car. I remember the first time I used the 3-wheeler in public. I went to a grocery store and took my husband and children with me - afterall, I didn't want people staring at me as if I were disabled! After a few trips

and several more excursions in public, the scooter became very handy. I used it to go to the zoo - to holiday shopping at the malls (I have two baskets for all my goodies) - and to vacation getaways. My fatigue level diminished considerably. I felt I was again in control of my life. I had taken the steps to ensuring a longer life.

Next came the health issues - Because of the harmful effects raw sugar, caffeine and alcohol have on my system, I decided to limit them and then give them up entirely. It took a few months because I love that morning coffee "hit, and the Pepsi in the afternoon. At the time I began to read Bill Moyer's book "Healing and the Mind." There was so much in the book that made sense to me - I immediately began to set some of his ideas into motion.

The local health food store became my greatest friend. I researched what vitamins were good for PPS survivors - decided on a regime of some herbs and some vitamins. The book mentioned meditation and several of my friends were involved with this therapy for pain control. I began a 10-minute meditation session each morning along with an exercise program of sitting exercises.

This got me through many years and eased the problems associated with polio. In fact, I was able to do the same things I had always done - just smarter! Hope had shown me the way to survive polio.

Now enter the AIDS diagnosis... I remember thinking that this is not fair. I been there, done this disability thing before. I had moved on. I didn't need AIDS at this time in my life. It took several months of asking myself "what now?", what else can I do - before I realized that I had already done it. Gotten over it - moved on. I did it with polio and I could do it with AIDS. Don't get me wrong, I believe that HIV is a very serious condition, not to be taken lightly. However, today it is becoming a manageable disease - not necessarily an end to life. I realized that again there was reason for hope.

The doctors gave me a plan of attack. I needed to rest when I was tired, take proper precautions with food, vegetables, water and meat/poultry products, take a multi-vitamin daily. Sound familiar to you post-polio survivors - It was the same plan I was already involved in. The only exception was that I now took the 3-drug mixture (cocktail) that just came upon the market.

I can't say that this double disability is easy - it's not. You wonder who you can share your HIV status with, who will not come around the house anymore if they knew, who won't let their children be around you or your family. But you do learn who your caring friends are - they're the ones who support you, send you clippings from the newspaper on the latest research, and check in on you to see if you are OK. Again, there's hope!

And you join a support group for HIV persons. I was amazed at the number of married couples and single people who were in the group. Each person had his own story and each person was there to help. It was the same as the post-polio support groups I had attended earlier. Each person learned about new medications, doctors, hospitals, infections and nutrition. The similarity was amazing. The polio had taught me how to deal with AIDS.

I'm happy to report that as of today, I'm in very good health. My counts are rising and the amount of virus in my blood has fallen. All thanks to the 3-drug cocktail and the lifestyle changes. But there is hope today for me because I have taken control of my life. I work when I need to, rest when I need to, eat much healthier foods and continue with the stress-reduction meditation. The strength that this lifestyle gives me is astonishing. I awake each morning with a renewed realization that I have another day to LIVE.

THERE IS ROOM FOR HOPE

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GASTROINTESTINAL DISTRESS--LISTEN TO YOUR GUT

Linda L. Bieniek, CEAP

Symptoms are the body's way of telling us that we are experiencing some imbalance in the body.

Gastrointestinal (GI) distress can cause discomfort and disturb everyday functioning for individuals with and without disabilities. For individuals with neuromuscular conditions, GI problems can be debilitating. When the digestive tract spasms and the abdomen becomes bloated, **pressure on the diaphragm** can impair a person's breathing and even result in **acute respiratory distress**.

GI symptoms need attention because they indicate some **imbalance in the body's functioning**. Minimizing or discounting one's distress could result in overlooking symptoms of conditions as serious as colon or ovarian cancer. Individuals need to be aggressive about investigating the causes of their GI distress and factors that may irritate one's condition.

Physicians and professionals specializing in **Integrated Medicine** have become especially attuned to the variety of factors that can cause GI problems. Progressive laboratory studies can identify **bacteria, parasites, and flora imbalances that impair the digestive system, metabolism, and the immune system**. Pathogens can enter one's GI system from foods and exposure to globalization. Flora imbalances can result from the side effects of medications. When irritants make their way into a person's system, they can disrupt the digestive tract.

Good health depends on the **adequate digestion and assimilation of nutrients**. Without proper digestion, even the most nutritious diet offers limited value. **Every cell in the body has some basic requirements for efficient functioning**. Without an adequate supply and the proper balance of nutrients cell function is compromised and eventually pathology and disease develop. Using antacids, laxatives, or antidiarrheals can compound the imbalance. The GI system also has the **challenge of eliminating toxins from the body**. Dysfunction in nutrient absorption or preventing toxins from entering the bloodstream can lead to illness.

TESTING FOR GASTROINTESTINAL PROBLEMS

(Adapted from J. Bicknell, MS, CNS)

Physicians traditionally use standard blood tests to identify **pathology and disease**. Frequently the test results return as "normal" even when a person continues to experience GI problems. These imbalances may not have progressed to the point of manifesting in pathology or disease, and this may be the reason that the blood test results appeared "normal".

Evaluating a standard blood test from the **viewpoint of health**, rather than disease identification, allows imbalances, stresses, and weaknesses in the body to be discovered and corrected before they develop into pathology. When the imbalances are identified, recommendations for specific nutritional supplements, dietary changes, and lifestyle changes can be developed. Treatment recommendations can correct the imbalances and improve cell function, which in turn, supports overall healing and health.

CAUSES OF GASTROINTESTINAL DISTRESS

The possible causes of GI distress can vary with each individual and include:

- Bacterial, viral, or parasitic infection.
- Adverse reactions to foods (such as wheat or dairy products).
- Highly sensitive smooth muscle tissue.
- Inflammation in the lining of the intestine, also known as "leaky gut".

- Intestinal candidiasis.
- Disturbed bacterial microflora resulting from antibiotic or antacid usage.
- Stress reactions, especially associated with anxiety and post-traumatic stress.

TOOLS FOR EVALUATING GI DISTRESS

Specific blood tests provide valuable information regarding the **possibility of pathogens**, i.e., **parasites, bacteria and fungi in the GI tract**. Left untreated, pathogens have a negative impact on digestion and absorption of nutrients, which eventually leads to the development of other health problems.

Great Smokies Diagnostic Laboratories offer a Comprehensive Digestive Stool Analysis (CDSA) that evaluates the **health of the digestive tract**. This test helps pinpoint imbalances and explains the causes of current symptoms by evaluating markers for digestive and absorptive ability and intestinal ecology. Intestinal flora is important for healthy intestinal functioning and taking antibiotics can destroy good bacterial flora. (Individuals who take frequent dosages of antibiotics for respiratory infections may be especially prone to this disorder.) Dysbiosis, **a state of disordered microbial ecology**, can contribute to vitamin B12 deficiency, steatorrhea, irritable bowel syndrome, inflammatory bowel disease and systemic disorders such as autoimmune arthropathies, food allergies, colon and breast cancer, various skin conditions, and **chronic fatigue**. In addition to measuring levels of the beneficial bacteria and the presence of possible bacterial or fungal pathogens, the CDSA test analyzes sensitivities to effective antimicrobial treatments. These include pharmaceutical and natural substances.

Proper immune function in the gut is critical. Low levels of **secretory IgA** can result in easier colonization by pathogens and translocation of toxins across the gut wall resulting in "leaky gut" syndrome. Tests such as the CDSA can provide information on secretory IgA levels for improving the health of the gastrointestinal system, and subsequently, one's overall health.

IRRITABLE BOWEL SYNDROME (IBS)

Often, when physicians and gastroenterologists do not find evidence of a problem on x-rays, blood tests, and examinations of the digestive tract with an endoscope, they diagnose the symptoms as **Irritable Bowel Syndrome (IBS)**. Since IBS is a diagnosis of exclusion, a thorough assessment of one's medical history and symptomatology is important before diagnosing IBS.

OTHER EXCLUSIONS: Conditions that Need to Be Excluded Before IBS is Diagnosed

Since IBS is a diagnosis of exclusion, the following conditions that involve symptoms similar to IBS, need to be excluded:

- Infectious diarrhea such as amebiasis and giardiasis
- Inflammatory bowel disease
- Lactose intolerance
- Laxative abuse
- Malabsorption diseases such as pancreatic insufficiency and celiac disease
- Metabolic disorders such as adrenal insufficiency, diabetes, and hyperthyroidism
- Mechanical causes such as fecal impaction
- Diverticular disease
- Cancer (e.g., colon or ovarian cancer may display gastrointestinal problems)

SYMPTOMS OF IRRITABLE BOWEL SYNDROME (IBS)

Normally, food is propelled through the digestive tract by rhythmic contractions of the intestinal muscles-- a process called peristalsis. In IBS, the muscles go into spasm, and the contractions become uncoordinated. This disturbance can cause the intestine's contents to move too fast or too slow, leading to abdominal pain and either diarrhea or constipation. IBS differs from colitis in that there is no inflammation of the bowel. Despite its name, Irritable Bowel Syndrome develops in the colon. The following symptoms can be intermittent or continuous for an extended period:

- Diarrhea, constipation, or alternating bouts of each (usually for several months).
- Abdominal cramping or pain often relieved by a bowel movement or passage of gas/flatulence.
- Mucus in the stool.
- Gas, bloating and swelling of the abdominal area.
- Nausea, vomiting or dry heaving.
- Pain in the pelvis, rectum or anus.
- Bowel incontinence.
- Heartburn or indigestion.
- Lump in the throat or trouble swallowing.
- Stool passage ranges from straining to feeling an urgent need to get to the bathroom or not feeling fully emptied.

MANAGING GASTROINTESTINAL DISTRESS & IBS—WHAT CAN HELP

(Adapted, in part, from M. Castleman)

1. **Educate Yourself.** Read about and investigate testing and treatment options. Become an informed consumer. Take responsibility for your health. Find out what has helped others, yet be careful not to self-diagnose the causes of your symptoms. Consult credible, ethical health professionals. Be careful of any approach that makes absolute promises. Verify the validity of information.
2. **Increase Fiber;** Fruits, vegetables, whole grains and beans are essential to stimulate digestion and important when IBS is present. Gradually add fiber to a diet. Bran can aggravate diarrhea.
3. **Reduce Irritants to the System.** *Fats, sugars, alcohol, caffeine and carbonated beverages* can trigger IBS attacks. In a Mayo Clinic study, a high-fat meal caused colon spasms in IBS sufferers.
4. **Eliminate Foods Your System Does Not Tolerate.** Food sensitivities and allergies can cause GI problems. The most common are *dairy products and grains*. Allergy testing can provide useful information for chronic symptoms because several sensitivities may be compounding a problem.
5. **Practice Assertiveness.** Suppressing feelings can cause a variety of physiological reactions. Find ways to constructively express yourself. Study assertiveness training.
6. **Resolve Emotional Triggers.** Identify issues and feelings that cause stress to one's GI tract. People experiencing depression, chronic anxiety, and Post-Traumatic Stress Disorder often report GI difficulties. Trauma resolution therapies including Art and Movement Therapy and Emotional Freedom Release Techniques can reduce physiological reactions that stem from past experiences.
7. **Incorporate Relaxation Techniques.** Anxiety about having an IBS attack can aggravate symptoms. Learning stress management techniques, biofeedback, and especially hypnotherapy can reduce IBS occurrences. A British study found that hypnotherapy helped two-thirds of IBS sufferers.

8. **Exercise Appropriately.** Stretching and breathing releases muscle tension, helps manage stress, and can improve the functioning of the digestive tract.
9. **Explore Herbal Medicines.** Peppermint can calm an overactive GI tract according to Taiwanese research that found enteric-coated peppermint-oil capsules resulted in fewer spasms.
10. **Add Friendly Flora.** A lack of health-promoting bacteria in your colon could affect its functioning. Taking *Lactobacillus acidophilus* can help repair the digestive tract with healthy bacteria.
11. **Increase Circulation through Acupuncture.** Various forms of acupuncture can help calm the spasms, stimulate digestion, and release energy blocks stemming from adhesions.
12. **Investigate Homeopathy.** Since homeopathic formulas are medicinal, it is important to have them prescribed by a certified health professional that understands their potential benefits and interactions.
13. **Stimulate your System through Massage and Various Forms of Bodywork.** Individuals can benefit from bodywork that releases muscle tension and stimulates the digestive system.

NEUROMUSCULAR AND RESPIRATORY CONDITIONS

Individuals who are accustomed to enduring pain and discomfort may either minimize their GI distress or delay taking action to avoid dealing with yet another condition and set of medical procedures. Stool testing and a colonoscopy can create an ordeal for a person with limited mobility or weak limbs.

Muscle weakness related to neuromuscular conditions may affect the muscles that support digestion. Digestion begins in the mouth and polio survivors have experienced swallowing problems that have been studied and documented. In addition since fatigue, muscle weakness and pain are symptoms of the late effects of polio, an impaired immune system stemming from gastrointestinal problems can also exacerbate similar symptoms. For this reason it appears important to address and alleviate GI problems and their subsequent impact on the absorption of nutrients and the immune system.

A recent article in the *American Journal of Gastroenterology* documents the effectiveness of an Integrated Medicine approach in alleviating Irritable Bowel symptoms. Research is needed to determine whether resolving GI distress improves immune functioning and increases energy, stamina, and muscle strength in consumers with neuromuscular conditions.

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8th International Post Polio and Independent Living Conference
Friday June 9, 2000
1:30 - 2:45 p.m.

SESSION III OPTIONS

BREATHING DEVICES WHAT'S AVAILABLE

Speaker: Augusta S. Alba, M.D.

8th International Post Polio Independent Living Center
Friday, June 9, 2000
Augusta S. Alba, M.D.
1:30 - 2:45 p.m.

SESSION III OPTIONS

BREATHING DEVICES: WHAT'S AVAILABLE

Airway Ventilators:

LP-20 Mallinckrodt:

Best used in a subacute setting where alarms are necessary. There is no way to disable or modify the alarms, which may not be needed during noninvasive ventilation.

Achieva Mallinckrodt:

Weight 32 lbs.

Type: Positive pressure volume ventilator; the pump is a piston

The Achieva and Achieva X provide assist/control with or without pressure control, SIMV with or without CPAP.

In addition, the Achieva PS and Achieva Psx provide SIMV with or without pressure support, spontaneous (pressure support) with or without CPAP.

The Achieva X and Achieva Psx have an internal O₂ blender and internal modem for accessing stored data.

Internal battery: 4 hours of operation.

External battery: 20 hours of operation.

V.I.P. Bird Gold for infant/pediatric ventilation

InExsufflator (Cough machine)

Acceptance has been slowly increasing, especially in hospital settings where the standard of practice has been the use of a tracheostomy and tracheal suctioning.

In adults 35-40 cm H₂O pressure both on inspiration and expiration are generally acceptable.

Wherever there are multiple caregivers or "floaters" the use of the InExsufflator with the timing device is preferable.

Pulmonetics:

Unit weighs 12 lbs., can be stored in a computer carrying case for traveling.

Popular with pediatric ventilator users of small size, and portability.

Louder than a volume ventilator because there is a turbine in the unit, but is less noisy than Maxivent.

Machine uses 12 volts, can operate on a cigarette lighter.

Gel batteries available, one lasting 3 hrs. the other 9 hrs.

- LTV-900: volume control, CPAP, IMV, pressure support
- LTV-950: Above features plus pressure control
- LTV-1000:02 blender.

Oxygen Delivery:

Trend toward smaller, lighter and quieter units continues.

Helios, by Mallinckrodt, liquid O₂, portable, 3 ½ lbs. At 2 LPM lasts 8 hrs.

Newer concentrators, Chad Therapeutics and Invacare, can be used to fill small O₂ tanks.

Methods being developed to further conserve O₂ for the individual who needs O₂.

Humidification in Noninvasive Ventilation

Study published 3/2000¹ involved the use of nasal continuous positive airway pressure (CPAP) for obstructive sleep apnea, but the results are applicable to nasal intermittent positive pressure ventilation (IPPV).

Increased airflow through the nose especially when there are mouth leaks (***which further increases airflow if the set pressure is to be maintained***) causes nasal/oral dryness, nasal congestion, rhinorrhea, sneezing, epistaxis. Those at greater risk include the elderly, persons with chronic nasal disease, and persons who have had prior surgery to the nasal and oropharynx for obstructive sleep apnea.

- If the person using CPAP has allergic rhinitis as well, warm humidified air attenuates the response to inhaled antigens, while cold dry air increases osmolality of nasal secretions, thereby, triggering the release of inflammatory mediators that induce more symptoms.
- The flow of blood in the nasal mucosa in the presence of unhumidified CPAP was increased 65% when there were mouth leaks.
- Nasal resistance increased over 300%.

The time spent mouth breathing was less than the average of $\frac{1}{3}$ of the night when a heated humidifier was used.

These side effects can be eliminated by the use of heated humidification. Nasal corticosteroids and chinstrap to help prevent mouth leaks can also be tried.

The various types of humidifiers are the heated humidifier (HH), hygroscopic heat and moisture exchanger (HHME), heat and moisture exchanger(HME), active hygroscopic heat and moisture exchanger (combined with a heat and water source -AHME)

Body Ventilators

Pneumobelts:

Made by Respironics.

- The **Maxivent and the Companion 2500** have been used to power the pneumobelt. The Maxivent has not been manufactured for more than ten years. The units still available are being kept in repair by local skilled respiratory mechanics. The Companion 25000 has a 2-way valve which allows rapid deflation of the belt, with the air being dumped into the machine. When an external valve is added to other airway ventilators, the 1500-2000 cc of air in the bladder is dumped on each cycle outside the machine when the bladder deflates. This produces a loud expulsive noise that is socially unacceptable. The pneumobelt is a good means of ventilation for the individual in a wheelchair, and when the user has a breath-controlled motorized chair, it is almost indispensable for noninvasive ventilation.
- The **Pulmonetics LTV-950** has been used with the pneumobelt. Flow is 10 LPM.. The wave profile is adjusted to 8-9. It appears to produce the same wave form in the pneumobelt bladder as the Maxivent.

High-frequency Chest Wall Oscillation (HFCWO):

HFCWO: is an effective means of raising secretions. Can be provided via the ABI Vest Airway Clearance System ²

1. Brown, L.K. MD. *Back to Basics: If It's Dry, Wet It. The Case for Humidification of Nasal Continuous Positive Airway Pressure Air.* *Chest* 117(3):617-619, March, 2000.
2. Ndkwu, I. M. MD, et al. *Comparison of High Frequency Chest Wall Oscillation (HFCWO) and Manual Chest Physiotherapy (MCPT) in long-term acute care hospital (LTAC) ventilator-dependent patients.* *Chest* 116 (4):311S. Oct., 1999.

Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri
June 8 - 10, 2000

AARP and Advocacy
Norma J. Collins, Advocacy Representative
AARP Missouri State Office
700 W. 47th Street Suite 110
Kansas City, MO 64112
816-360-2201

AARP and Advocacy will address the organizational structure and primary goals of advocacy for members at the local, state, regional, and national levels.

- AARP at the Grassroots
 - Organization
 - AARP/VOTE
 - State VOTE Programs
 - State Legislative Committees
- Organization
 - AARP is non-partisan
 - Volunteer and member issue advocacy
- AARP/VOTE
 - What is VOTE
 - Projects working in pilot states
- 50 State Programs
- Five Primary Goals
 - Educate
 - Inform
 - Advocate
 - Help
 - Empower
- AARP at the State Level
 - State Legislative Committees
 - Representation at the Capitol

- Mobilizing the Grassroots

- Issues at the congressional level
 - Rapid Response System
 - Visits to legislators
 - Surveys

- AARP's Impact

- Focus on Issues
 - Mobilization
 - Public Forums/Candidate Forums
 - Public Education

S. 1935 MiCASSA: A Vision for Attendant Services and Supports for the New Millennium

Deborah Cunningham
Executive Director
Memphis Center for Independent Living

Ever wonder why it's so hard to get attendant services all over this country? Why, even though we would obviously prefer to live in our own homes, over 2 million of us are locked up in nursing homes and other institutions? The long term care system in America has a terrible bias toward institutional services with over 80% of the long term care funds going for these services, so that only 20% are left to pay for ALL the community based programs. Every state that gets Medicaid dollars must have a nursing home program, while community based services are optional!



Introducing MiCASSA!

What is the answer? November 16th Democratic Senator Tom Harkin, with Republican Senator Arlen Specter introduced S. 1935, the Medicaid Community Attendant

Services and Supports Act, MiCASSA. MiCASSA gives people real choice in long-term services. MiCASSA would allow individuals eligible for Nursing Facility Services or Intermediate Care Facility Services for the Mentally Retarded (ICF-MR) the choice to use these dollars for "Community Attendant

Services and Supports." **THE MONEY FOLLOWS THE INDIVIDUAL!**

The Memphis Center for Independent Living
163 Angelus St.
Memphis, TN 38104
(901) 726-6404 [v/tty]
www.mcil.org

National ADAPT - Stephanie Thomas
1339 Lamar SQ Dr. #101
Austin, TX 78704
(512) 442-0252
www.adapt.org

Specifically what does this bill do? MiCASSA...

1. Provides community attendant services and supports which range from assisting with activities like: eating, toileting, grooming, dressing, bathing, transferring, meal planning and preparation, managing finances, shopping, household chores, phoning, participating in the community, and health-related functions like taking pills, bowel and bladder care, ventilator care, tube feeding, etc.

2. Includes hands-on assistance, supervision, help to learn, and also keep and enhance skills to accomplish such activities.

3. Requires services be provided in THE MOST INTEGRATED SETTING appropriate to the needs of the individual.

4. Provides Community Attendant Services and Supports that are based on an assessment of functional need; provided in home or community settings like - school, work, recreation or religious facility; selected, managed and controlled by the consumer of the services; supplemented with backup and emergency attendant services. Furnished according to a service plan agreed to by the consumer; and include voluntary training on selecting, managing and dismissing attendants.

5. Allows consumers to choose among various service delivery models including vouchers, direct cash payments, fiscal agents and agency providers, all of which are required to be consumer controlled.

6. For consumers who are not able to direct their own care independently, MiCASSA allows for "individual's representative" to be authorized by the consumer to assist. A representative might be a friend, family member, guardian, or advocate.

7. Allows health-related functions or tasks to be assigned to, delegated to, or performed by unlicensed personal attendants, according to state laws.

8. Covers individuals' transition costs from a nursing facility or ICF-MR to a home setting, for example: rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.



9. Serves individuals with incomes above the current institutional income limitation - if a state chooses to waive this limitation to enhance the potential for employment.

10. Provides for quality assurance programs that promote consumer control and satisfaction.

11. Allows states to limit the aggregate amount spent on long-term care in a year to that amount the state would have spent on institutional services for such eligible individuals in the year.

12. Provides maintenance of effort requirement so that states cannot diminish more enriched programs already being provided.

MiCASSA also provides grants for Real Choice Systems Change Initiatives to help the states transition from current institutionally dominated service systems to ones more focused on community services and supports.

Why We Need MiCASSA NOW!

- The demographics of our nation are changing - population is aging, more people with disabilities are living and needing assistance with daily living tasks.
- Although people with disabilities overwhelmingly prefer home and community services and supports over institutional services, the current long-term care system favors costly institutional programs and profit seeking corporations.
- Currently, in America, non-institutional long-term care services are fragmented between many different funding sources and administering agencies and eligibility tends to be based on age or medical diagnosis rather than functional need.
- The over 30-year-old system we have now **does not work**.
- **MiCASSA** gives people a real choice of how to live their lives.

What does passing such a bill involve?

MiCASSA has almost 400 organizations signed up as supporting the bill. If you or your group has not signed on yet, now is

the time. Powerful lobby groups like the nursing home PAC the American Health Care Association, and pro-institution groups like Voice of the Retarded are actively working to kill MiCASSA. It will take all our combined efforts to create the changes that are so badly needed.

MiCASSA Talking Points

1) Our long term service system must change. Created over thirty years ago it is funded mainly by Medicare and Medicaid dollars. These medical dollars were not to have met the long-term care needs of people. We must think out of the box to new system that empowers people and allows REAL choices.

- The money should follow the individual not the facility or provider.
- A national long-term service policy should not favor any one setting over the other. It should be neutral and let the users choose where services should be delivered. Current system is not neutral.
- Over 80% of our Medicaid dollars (\$41 billion) spent on long term care is spent on institutional services, leaving only 10% (%10.5 billion) for all community services.
- Current system is expensive and ways to meet the needs of people in the most cost-effective way must be explored.
- Community services on average have been shown to be less expensive than institutional services and better liked by individuals.

2) Demographics of our country are changing

- a) Aging process
- b) Children being born with disabilities
- c) Young adults - Medical technology keeping people alive who would have died previously.

3) Families must have REAL choice.

People with disabilities both old and young, even those with severe mental or physical disabilities want services in the most integrated setting possible.

4) People with disabilities and their families want REAL choice which means:

- a) Equitable funding opportunities.
- b) No programmatic or rule disincentives to community services.
- c) Options for services delivery to include agency, vouchers and fiscal intermediaries. Empower people with disabilities and families.

5) Family values, keep families together.

- a) communities taking care of their own.
- b) children belong in families.
- c) Mom and Dad together with their grandkids.

6) A functional system based on need instead of medical diagnosis could end FRAGMENTATION of service delivery system.

7) Keeping people in the community allows the possibility for individuals with disabilities to train for work so they can become TAXPAYERS instead of TAX USERS.

8) Overwhelmingly people prefer community services to stay in their own home. Federal government needs to work in partnership with the states to create flexible delivery systems that gives people with disabilities REAL choice.

9) Change can cause fear of the unknown. There are some long time providers of services and families who believe REAL choice would threaten what they have. We cannot continue the system as it is today. It is expensive, fragmented, over medicalized and not liked by almost everyone.

International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000
Managing Chronic Pain: Findings of a Pilot Program
Dorothy Woods Smith, RN, Ph.D., HNC, Associate Professor Emerita
University of Southern Maine, Portland, ME

Chronic non-malignant pain is widely experienced by people with post-polio syndrome (PPS) (Post-polio Task Force, 1999). The process, which is biological, emotional, psychological social, and spiritual, is associated with an increase in physical stress and emotional distress (Arnstein, 1998). The 12-week Pilot Program for People with Chronic Pain (PPPCP) provided a variety of non-pharmacological options for people who had pain persisting three months or more despite medical treatments, and who had a physician referral or approval. The PPPCP included the relaxation response, group support, information, guided imagery, and cognitive restructuring. In addition randomly selected participants received Therapeutic Touch (TT) for the first three weeks of the program.

There is support in the literature for the effectiveness of all components of the PPPCP in addressing chronic pain. Caudill (1991), then Director of the Behavioral Medicine Pain Program in Boston, reported outcomes of decreased severity of pain, increased activity, decreased anxiety, decreased depression, and decreased anger for people completing that program. Follow-up two years after completing the program indicated ongoing effects, with the 50 participants making 36% less visits to their health care facilities than before the program (Benson, 1996; Caudill, 1991). A 1996 National Institute of Health special communication, "Integration of Behavioral and Relaxation Approaches into the Treatment of Chronic Pain and Insomnia," stated that "relaxation techniques generally alter sympathetic activity which can be measured by decreases in oxygen consumption" (observed as lowered respiratory rate, pulse, and blood pressure). The report further noted that "cognitive-behavioral therapy appears to effect an individual's subjective experience of pain by decreasing symptoms of depression and anxiety" (Finger, 1997, pp. 129-130).

The PPPCP was unique in adding Therapeutic Touch (TT), a complementary therapy practiced primarily in nursing for the past 25 years. TT is a process based on the idea that "the human being is a complex system of energy" in which "physical, emotional, mental and intuitive energies interact continuously" (Wager, 1996, p. 2). TT, which typically takes 10 to 20 minutes, takes place with the patient fully clothed, seated or lying down in a comfortable position. In the process of TT, one person (often a nurse) , helps balance and support the patient's energy (also called chi or prana) by moving their hands a few inches above the person's body. Research studies support TT as a means of promoting self-healing, eliciting the relaxation response, reducing pain, decreasing anxiety, and accelerating the healing process (Mulloney & Wells-Federman, 1996). TT was included in the PPPCP with the anticipation that barriers to learning, such as the expectation of continued pain, and the anxiety and discomfort that make attending class difficult, would be reduced by starting the program with TT treatments.

Eighth International Post-Polio and Independent Living Conference
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Dorothy Woods Smith, RN, Ph.D., HNC, Associate Professor Emerita
University of Southern Maine, Portland, ME

Randomly selected participants received three weekly TT treatments prior to the nine-week group pain management program. During each of these visits, participants were also introduced to ways to independently elicit the relaxation response. The other 5 participants received the same training in eliciting the relaxation response as the others during the first three weeks. For the following nine sessions, clients participated in a group program modeled after, but not affiliated with, the clinical programs of the Division of Behavioral Medicine of the New England Deaconess Hospital established by Herbert Benson, M.D. and associates. The topical outline and participant exercises were derived from the Behavioral Medicine Pain Program, and the book, Managing Pain Before It Manages You, by Margaret A. Caudill, M.D., Ph.D. During the two hour group sessions, participants took part in deep relaxation exercises; heard presentations about physiological and psychological dimensions of pain and the interconnectedness of mind-body-spirit; learned and practiced new techniques and behaviors to manage pain, decrease stress, and promote wellness; took part in cognitive restructuring exercises to change perceptions about pain; and shared their experiences with the group. During the week, each participant practiced the relaxation response, and kept a daily diary, also doing weekly readings and workbook exercises.

The two clinical providers for the 12-week program were registered nurses with extensive experience using non-pharmacological techniques, including TT, with people with pain. The program was reviewed by the Clinical Research Review Committee of the University of Southern Maine, and by physicians and nurses with expertise in chronic pain.

Of the three men and nine women enrolled in the PPPCP, seven were randomly placed in the experimental group which received TT. Participants ranged in age from 31 to 56, with education from grade 12 to graduate degrees. Primary sources of pain were head and face (1), neck (4), upper limbs (1), lower limbs (3), and lower back (3). The duration of pain prior to entering the program ranged from 13 months to 22 years (mean 7.5 years), with beginning levels of pain intensity ranging from 2.2 to 10. Although recruitment included the Post-Polio Support Group of Maine, no polio survivors took part in the program.

It was hypothesized that after completing the program, participants would experience less pain sensation, emotional distress, and pain-related disability; and greater power and self-efficacy; and that participants who received TT would experience more rapid or profound changes than those who did not. Measurement instruments completed before and after the program included 10-point Visual Analog Scales for Pain Sensation and Pain Distress, Power as Knowing Participation in Change Test (Barrett, 1987), Chronic Pain Self-Efficacy Scale (Anderson et al., 1995), and Pain Disability Index (Pollard, 1984). Reliability for the measurement instruments, using Cronbach's alpha tests, ranged from .89 to .97.

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Statistical analysis was done using SPSS to compare pre and post-PPPCP means. Completers (participants who completed the program, $n = 8$) were compared with non-completers ($n = 4$). The completers showed statistically significant increases in power ($t = 3.8, p > .01$), and in self-efficacy ($t = 3.6, p > .01$). The decrease in pain disability approached significance ($t = 2.1, p = .07$). There were no significant changes among the non-completers on these variables. Completers showed decreases in pain sensation (-18%, to 4.5) and pain distress (-33% to 3.9), while the four non-completers showed an increase in pain sensation (+6% to 7) and the same pain distress (6.1). These changes, while meaningful, were not statistically significant.

Data was also analyzed comparing those in the experimental group who received Therapeutic Touch ($n = 7$) with those in the control group who received the program without TT ($n = 5$). The experimental group showed statistically significant increases in power ($t = 4.2, p > .01$), and in self-efficacy ($t = 4.0, p > .01$). The decrease in pain disability approached significance ($t = 2.2, p = .07$). The control group did not have significant changes in these variables. Changes in pain sensation and pain distress in the experimental group were respectively reduced by 16% (to 4.8) and 30% (to 4.2), compared with the control group whose reductions were 2% (to 6.1) and 10% (to 5.2). These findings suggest that having TT for the first three weeks of the program was associated with completing the program, and with achieving greater changes than completing the program without TT.

Participants completing the program described changes in their behaviors and attitudes, expressing overall optimism about being able to effect changes in their pain. Several people experienced dramatic reductions in pain, after being disabled with pain for many years. All marveled at the power of being with a group of people who knew firsthand the experience of pain, a hidden and often misunderstood disability.

The pilot program numbers are small, but do indicate trends that support extending this multi-faceted, non-pharmacological program for people with chronic pain to a larger population, and including Therapeutic Touch at the beginning of the program. People with post-polio pain should be excellent candidates for such a program.

Chronic non-malignant pain typically defies management by medical means alone. Helping people discover ways to respond to pain that diminishes rather than intensifies symptoms and distress is both gratifying and cost-effective. Cluster studies replicating the program and measurements are strongly recommended, so that this and similar programs will become available to those who want to actively participate in managing their own chronic pain.

Project funding included awards from the American Holistic Nurses Association, Nurse Healers Professional Associates, and the University of Southern Maine College of Nursing. Research co-investigator is Paul Arnstein, R.N.; Ph.D., Co-Director of the Beth-Israel-Deaconess Behavioral Medicine Pain Program in Boston.

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BENEFITS OF WARM WATER POOL THERAPY
TO INDIVIDUALS WITH POST-POLIO SYNDROME

Nickie Lancaster, R.N., Polio Heroes of TN, Easter Seals of TN, Coordinator

PURPOSE AND GOALS: To promote pool therapy for well-being and pain relief in individuals with the Late Effects of Polio and to encourage community efforts to build suitable pools in many locations.

PRESENTATION BODY:

Sister Elizabeth Kenney, an Australian Midwife, knew in the 1920's that hot moist heat was the most effective pain relief for acute polio patients. It enabled muscles to remain pliable and decreased contractures. Her methods became the acceptable treatment for polio, worldwide, for decades. Franklin Roosevelt discovered the warm springs of Georgia as the best treatment for him psychologically and physically after his acute polio which left him with leg paralysis the rest of his life. Sister Kenney and F.D.R. were not wrong. Their theories were as true yesterday as today. Hot moist heat is still one of the safest and best pain relief for those with the late effects of Polio. Dry heat does not give the same results.

Pool therapy is "exercise" most polio survivors can tolerate and are familiar with.

Guidelines for consideration:

1. You do not need to know how to swim.
2. A physician or therapist needs to evaluate range of motion, muscle strength and endurance prior to beginning a program.
3. Water should be 90 to 95 degrees (most indoor pools are 82 degrees, these regulations are usually set by your local health department which may not be familiar with warm water therapy). 86-90 degree water can work for some individuals. If using an outdoor pool, late afternoon instead of morning is best. Water is warmest between 2-5pm. Water should never be warmer than body temperature.
4. Pool room atmosphere and locker rooms should be heated to prevent vascular collapse and chilling.
5. Water should be at least chest high, preferably shoulder/neck high. In water up to your neck you loose 80% of your body weight, lessening stress and body weight on joints, muscles and bones.
6. Persons with lower extremity paralysis, braces or walking limitations can be assisted into the pool by transfer platforms (new to pools) or hydraulic lift chairs that lower one into the water and out again.
7. Non-swimmers should not depend on floatation devices and those with atrophied or "hollow" limbs may require ankle weights to keep legs down in the water. Vests, "noodles", bars and other aquatic therapy aids assist in balance.
8. Stretching and range of motion flexibility are key "exercises". Start at the neck and work down the body. Only gentle movements in the water that are non-resistive.

9. Resting between repetitions is important. No more than 5 slow repetitions per movement to start is recommended. Smooth and slow, not jerky or hard. Rest between sets of routines.
10. If one can only enjoy being in the water, the relaxation and stimulation of the circulatory system is extremely beneficial. Warm water increases the metabolic rate, heart rate, circulation, and respiratory rate. (Dead blood in your feet returns to your head.) As a result, one tends to think better and feel sharper on pool days.
11. Initial pool visit should be no more than 20 minutes, building to 45 to 60 minutes, but no more than that. Hot water can be fatiguing in itself if used too long at one time. Two to three times per week is recommended.
12. Walking backwards and sideways in the pool helps balance and coordination, as well as circulation. These muscles are used very little on dry land and can often be strengthened for stability.
13. Gentle jets in some pools also help massage backs, hips or even fingers.
14. The psychological and social benefits are as important as the physiological. Meeting new people with all types of limitations and interests and those with other disabilities such as strokes or replacement of hips or knees can be mutually beneficial. Recovery from fractures is much quicker with pool therapy, also from any orthopedic surgery.

Negatives or contra-indications for pool therapy:

1. Uncontrolled high blood pressure or severe cardiac conditions.
2. Open or draining wounds or skin irritations.
3. Lack of bladder or bowel control.
4. Fever or headache.
5. Recent immunizations within 2 weeks. (Most immunizations are for virus born illnesses and pool chemicals do not affect viruses.) No un-potty trained children should be allowed in the pool.
6. Skin rashes after pool therapy has begun. (One must shower or wash thoroughly after getting out of the pool to remove all pool chemicals from the skin as some of the chemicals trigger a rash in some individuals if not washed off.)

Most pools will allow you an inspection and trial period. The cost is usually very small compared to other treatments and a lot more fun. Most therapy pool facilities have memberships so that other family members can use other parts of the facility if they do not want to join in the pool.

The availability of adequate pools is a gradual and persistent effort. Arthritis patients, those with orthopedic problems and surgeries, stroke patients and many others besides polio survivors can benefit from warm water pools with hydraulic lifts. Forming a group to influence hospital and free standing rehab facilities to build such pools benefits the whole community. "Build it and they will come." We have an aging population that can keep active with pool therapy. Mary Agnes was a Polio victim at age 5 and had not been able to move her legs for 50 years, always wearing long leg braces, until she was lowered in to water. Russ had his hip fused 60 years ago and was recovering from a recent stroke. He barely walks on dry land and wears

an AFO, but in water, he walks for an hour unassisted 4 times a week. Lou Lou wears a brace on both knees and a back brace, but walks and swims for an hour 2 times a week. Jack has been confined to a wheel chair most of his life, but floats on his back and totally relaxes in the water. (And drives many miles to get to the pool.) One man, who was 102, still swam everyday in the warm water pool at his retirement center. Ten years ago, a small Adventist Hospital in Madison, TN (in Nashville) had the foresight to build two pools, one a full lap warm water pool (usually 84-88 degrees), and the other a hot therapy pool (94-96 degrees). The polio group was the first to use and encourage the use of the pools. Word of mouth spread the benefits of this facility. Now, nearly 300 people per day use this comprehensive therapy center, which expanded to other fitness programs for all types of rehabilitation and disabilities. Last year Easter Seals of Tennessee built a similar facility on the opposite side of Nashville, thanks to a generous local business man's efforts.

Sister Kenney and F.D.R. knew that polio and hot moist heat go together. Many neuromuscular aches and pains can be alleviated with warm water pool therapy. Sometimes it may even be called "Holy Water" for the way it heals the body and mind. All you have to remember is Dr. Jacqueline Perry's rule of exercise: "If there is no pain or fatigue, continue. If there is pain or fatigue, cut it $\frac{1}{2}$ in two. If the pain or fatigue continues, stop!" This also applies to water.

Additional sources:

Robbie Leonard, MS, PT, Medical Univ. of S. Carolina, Greenville, SC
(formerly of Warm Springs Roosevelt Rehabilitation Ctr.)

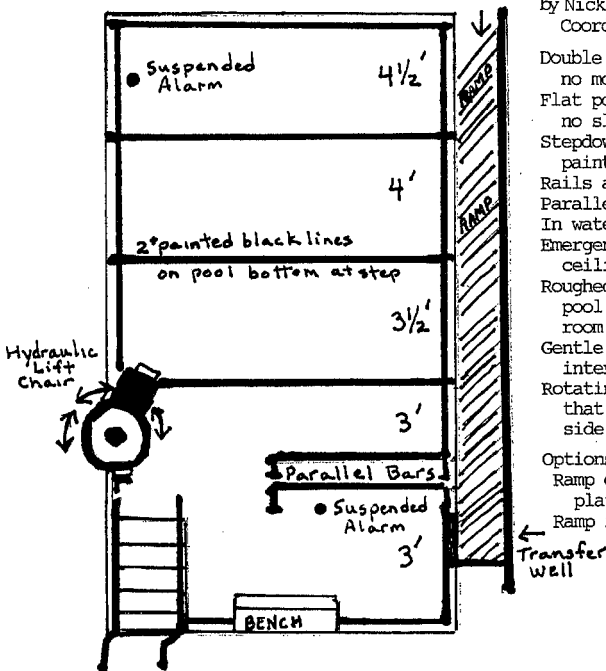
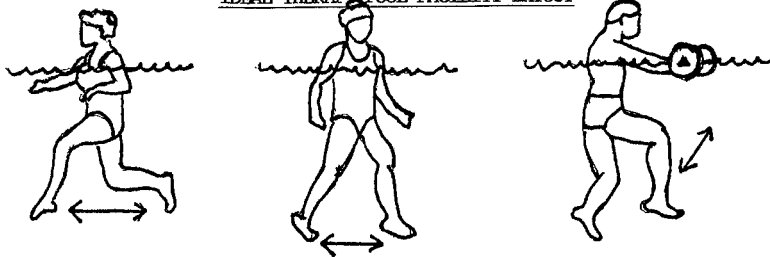
Roosevelt Warm Springs Polio Pool Therapy Video featuring
Robbie Leonard, MS, PT.

Keith Puttman, MS, Pool Therapy Director, TN Christian Medical Ctr.,
Madison, TN

(All of these sources have extensive experience with warm water therapy and Polio patients.)

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IDEAL THERAPY POOL FACILITY LAYOUT



by Nickie Lancaster, RN,
Coordinator, Polio Heroes of TN

Double railed, wide steps with no more than 4" stepdown. Flat pool surface in lanes, no slant to bottom of pool. Stepdowns marked by black lines painted on pool bottom. Rails all around pool edge. Parallel bars in water. In water bench in 3' level. Emergency alarm suspended from ceiling over each end of pool. Roughed pool floor and non-slip pool deck (including locker room floor). Gentle jets around pool at intervals. Rotating hydraulic lift chair that can operate from pool side and water levels.

Options:

- Ramp outside of pool to transfer platform.
- Ramp in to water for use of ambulatory walker or wc patients. (Difficult for wc patients when exiting pool as weight of water and uphill climb is a strain.)

Room atmosphere in pool room and locker rooms should be warm. Showers should be wc accessible and extra wide to accommodate bench or chair (removable) and hand controls. At least 3-4 showers in each locker room. All toilet stalls should also be handicap accessible.

4' and 4 1/2' levels in pool are the most used lanes.

*Illustrations
by Nickie Lancaster*

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Eighth International Post-Polio and Independent Living Conference,
St. Louis, Missouri
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SPINAL PROBLEMS AND SOLUTIONS

Carol Vandenakker, MD
University of Miami Post-Polio Clinic
Department of Orthopaedics and Rehabilitation
University of Miami School of Medicine

I. Introduction

The spine and supporting muscles are responsible for support and movement of the trunk. The spine protects the spinal cord and serves to support and stabilize the head, arms, and legs. Problems in the spine or the supporting muscles affect the entire body. Polio survivors may experience spinal problems related to paralysis such as scoliosis and osteoporosis. They also experience problems related to aging. Symptoms of several of these spine problems may be confused with post-polio syndrome.

II. Spinal Anatomy

The spine is composed of:

33 vertebrae- 7 cervical, 12 thoracic, 5 lumbar, 5 fused to form the sacrum and 4 form the coccyx

Intervertebral discs- outer fibrous tissue/fibrocartilage attached to the vertebral bodies with a soft nucleus pulposus that act as shock absorbers

Ligaments- collagen and elastic tissue that support the spine

Facet joints- joints between the vertebrae that permit movement

Spinal cord and nerve roots (31 pairs) –

The spinal cord consists of descending tracts carrying messages from the brain through motor nerves to muscles and ascending tracts carrying sensory feedback to the brain.

There are 31 pairs of spinal nerves (8 cervical, 12 thoracic, 5 lumbar, 5 sacral, and 1 coccygeal) that exit the spine.

Muscles- support and move the spine and trunk

III. Spine problems related to paralytic polio.

In individuals affected by paralytic polio, the virus crosses the blood brain barrier and infects the anterior horn cells in the spinal cord. Spinal cord involvement in acute polio results in paralysis of arms, legs, trunk and sometimes the diaphragm. Muscles stabilizing the spine are affected depending on which spinal nerves are involved.

Bone metabolism is also affected by paralysis. Acutely, calcium is lost from bone rapidly, peaking at 5 weeks, and continuing for 5-6 months. Immobilization causes further bone resorption. Mobilization can reverse the resultant osteopenia depending on the extent of motor recovery.

A. Osteoporosis

As a polio survivor ages with paralysis, limitations in weight bearing activities as well as the usual age-related causes of osteoporosis further impact bone density. Bone is an active tissue, constantly remodelling. It is when resorption of bone occurs at a faster rate than new bone formation that bone density is lost. Bone density peaks before age thirty and then decreases. Factors contributing to bone loss include inadequate calcium intake, vitamin D deficiency, disuse, certain drugs- including cigarettes and alcohol, and hormone changes, either menopausal or disease related. Once bone density falls below a certain level it is classified as osteoporosis. If the trunk is significantly affected by polio, osteoporosis can be expected. As a polio survivor ages and bone density decreases, risk of vertebral fractures increases.

C. Scoliosis

Studies have determined that the risk of a poliomyelitis survivor developing scoliosis is approximately 30 per cent. Spinal deformity results from trunk involvement with asymmetric intercostal, abdominal, and paraspinal muscle paralysis. Pelvic obliquity secondary to asymmetric muscle paralysis of the pelvic girdle is also a causative factor. The prognosis for worsening of the deformity is correlated to degree of weakness and age at curve onset. The spinal deformities in polio are generally long "C" shaped curves with associated pelvic obliquity. Other curve patterns are seen involving the lumbar or thoracic spine an isolated manner. As with other neuromuscular scoliosis, bracing has not been shown to alter the natural history of the curve. Bracing may be useful in young children with flexible curves but delaying surgical fusion in progressive curves is not recommended because of risk of dramatic increase during the adolescent growth spurt.

It was originally believed that when skeletal maturity is reached, scoliotic curves stabilize. The phenomenon of curve progression after skeletal maturity is now clearly established. The increased deformity may be a result of asymmetrical disk degeneration, vertebral compression, or lateral slippage of the vertebrae known as spondylolisthesis. The spine may become increasingly unbalanced or develop areas of stenosis, causing pressure on nerves. Cardiorespiratory function may be impacted with loss of lung capacity and increased pressure on the right side of the heart.

Pain is often associated with progression of scoliosis. The pain may be caused by muscle spasm, disc degeneration, facet arthrosis or a combination of these factors. Secondary central or foraminal stenosis can cause nerve pain. People with problems related to scoliosis may report loss of balance and increased frequency of falls, leg pain or weakness, and back pain. These symptoms may lead to increase in fatigue, loss of mobility and further weakness, making differentiation from post-polio syndrome difficult.

V. Spinal problems related to aging

Degenerative changes occur in the spine with aging. The degeneration usually starts with degeneration in the disks resulting in bulging of the annulus or disk herniation. Osteophytes then form from the bone, ligaments thicken, and facet joints sublux or become hypertrophied.

Spinal stenosis, which may occur in association with scoliosis or in a "normal" spine is defined as decreased dimension of the spinal canal and/or neural foramen. This decreased space may cause compression of nerves or blood vessels. The stenosis may be local, segmental or generalized. It may result from bone or soft tissue and may be congenital, acquired or a combination. The most common cause of stenosis is degenerative change in the spine.

The presenting symptoms of stenosis are vague back and/or leg pain and dysesthesias. Symptoms are increased by standing and walking and initially relieved by sitting or lying down. Symptoms worsen and become more disabling as the stenosis progresses.

Neuroforaminal stenosis causes pain when nerve roots are impinged upon. The pain may be associated with weakness or numbness in the distribution of the nerve root which exits the narrowed foramen.

V. Evaluation of spinal problems

Evaluation of the spine starts with a detailed medical history related to the symptoms experienced- duration, intensity, location and character. Aggravating and alleviating factors should be identified. History of injury or other health problems must be assessed.

Physical exam includes a thorough musculoskeletal and neurological exam. Any spinal deformities should be noted. Complete assessment of strength and sensation should be performed. Gait evaluation, posture and onset of symptoms in certain positions or with specific maneuvers are evaluated.

Diagnostic studies are useful to confirm or eliminate a diagnosis. Commonly X-rays, CT scan or MRI, and possibly bone scan or EMG are ordered.

VI. Solutions

Treatment for osteoporosis is available but prevention is considered the best approach. For a polio survivor with osteoporosis in areas of the body affected by paralysis, it is not known if the usual osteoporosis treatment is effective. Osteoporosis prevention and treatment focuses on proper nutrition and exercise. Approved medications for osteoporosis are estrogen, calcitonin, alendronate and raloxifene. Estrogen, raloxifene and alendronate are also approved for prevention.

Treatment for degenerative spine problems, progressive scoliosis, and spinal stenosis ranges from conservative to surgical. Conservative treatment may include nonsteroidal anti-inflammatory drugs, analgesics, and physical therapy. Corticosteroid injections are also used to reduce nerve inflammation and treat acute pain. If conservative treatment fails, surgical intervention may be indicated depending on the degree of symptoms, secondary disability, risk factors, and patient preference.

INFORMATION ON SPINAL PROBLEMS AND RELATED ISSUES

National Institutes of Health
Osteoporosis and Related Bone Diseases – National Resource Center
1232 22nd Street, NW, Washington DC 20037-1292
Tel (202) 223-0344 or (800) 624-BONE
Fax (202) 293-2356
TTY (202) 466-4315
Email orbdnrc@nof.org

Information on Spinal Stenosis
American Academy of Orthopaedic Surgeons
6300 North River Road
Rosemont, IL 60018-4262
Tel (847) 823-7186 or (800) 346-2267
Fax (847) 823-8125
Email webhelp@aaos.org
World Wide Web address <http://www.aaos.org/>

National Institute of Arthritis and Musculoskeletal and Skin Diseases
Information Clearing House
National Institute of Health
1 AMS Circle
Bethesda, MD 20892-3675
Tel (301) 495-4484
Fax (301) 718-6366
TTY (301) 565-2966
Automated faxback system (301) 881-2731
World Wide Web address: <http://nih.gov/niams/>

The Spine – Third Edition Volume 1
W.B. Saunders Company
The Curtis Center
Independence Square West
Philadelphia, PA 19106

Rehabilitation of the Spine
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EIGHTH INTERNATIONAL

Post-Polio
AND
**Independent
Living
Conference**

SAINT LOUIS, MISSOURI

Friday, June 9, 2000

SESSION IV

3:15 pm - 4:30 pm

- PAVILION SALON G **Wheelchairs and Scooters: Making the Transition**
Linda Wheeler Donahue
Funding through Medicare
Robert H. Thayer
Selecting the Appropriate Mobility Device
Robbie B. Leonard, MS, PT
- PAVILION SALON A **A Tracheostomy: What, Why, When***
Edward Anthony Oppenheimer, MD
- PAVILION SALON F **Advocacy ...**
... **It's Personal**
Audrey J. King, MA
... **It's Cultural**
Neena Bhandari
... **It Makes A Difference**
Susana Saavedra
- PAVILION SALON E **Strategies for Obtaining the Best Bracing**
Mark K. Taylor, MLS, CPO; Ammanath Peethambaran, MS, CO
- PAVILION SALON B **Finding, Nurturing, and Utilizing Local Resources***
Elaine Burns
Revitalizing the Support Group Membership*
David A. Livingston
- PAVILION SALON D **Complementary/Alternative Therapies: How to Choose**
S. Laurance Johnston, PhD

Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000

**TRANSITIONING TO A WHEELCHAIR:
AN EXPLORATION OF OUR
FUNDAMENTAL FEARS**

Linda Wheeler Donahue
Professor Emeritus of Humanities

Does your polio experience sound something like this?

- ◆ polio onset in childhood
- ◆ long hospitalization
- ◆ emerged using braces and crutches
- ◆ gradually eliminated these aids
- ◆ had corrective surgeries around age 10
- ◆ spent 3 or so decades walking unaided
- ◆ post-polio syndrome set in
- ◆ began using a cane for support
- ◆ began using forearm crutches
- ◆ began using grocery store electric carts
- ◆ began declining activities that heavily involved walking

Are you unable to do some of the activities you once enjoyed due to increased weakness, pain, profound fatigue, and lack of endurance? Did you once adore attending pops concerts in the park? Now you decline to go because the walking on that uneven grass would be far too difficult for you. You stay home.

Did you once savor the thrill of cruising the mall with your daughter-in-law? Now you decline to go because that much weight-bearing and walking would be far too exhausting and painful. You stay home.

Did you once thrill to walking the boardwalk at the beach absorbing the sights and sounds of the ocean ambiance? Now you decline

because the length of that long, winding boardwalk is too much for you to manage without pain and fatigue. You stay home.

You and your physiatrist recognize that the time has come when you should begin to use a wheelchair for most of your mobility needs. But the thought of appearing in public in a wheelchair fills you with dread. Your emotions run high with terror and distaste. You realize on an objective rational level that using a wheelchair would be very liberating. But that rational base is far overpowered, indeed almost buried, by the negative emotional layer, which shouts in your ear, "No. No! No wheelchair for me!"

In my presentation, we will examine some of the underlying psychological rationale for this resistance.

- ◆ The wheelchair makes it virtually impossible to be a "passer," that is, to pretend you are able-bodied.
- ◆ Indeed, it is the wheelchair itself, which is used as the universal symbol of disability.
- ◆ Society places an inordinately high value on walking.
- ◆ As a child, you were given heavy praise for your attempts to walk unaided.
- ◆ Much of your self-esteem is wrapped up in the fact that you are still able to walk.

These are some of the tugs in this Approach/Avoidance wrestling match. But we must not stop here; we have only just scratched the surface. When we probe deeper we find submerged layers of even greater significance. We know that our resistance to using a wheelchair is intimately connected to our view of ourselves as Disabled. This realization confronts a deep-rooted prejudice in the society that it must be better to be ambulatory than to be in a chair. For example, there could hardly be a greater medical triumph than getting someone "up out of a chair." Consider the hidden negatives in our language: "wheelchair bound," "confined to a wheelchair."

Almost universally people who are not totally wheelchair dependent, make far too little use of the wheelchair, if they are willing to use it at all. Likewise people who are gait impaired but not crutch dependent, make far too little use of crutches, if they are willing to use them at all. "I'm not THAT disabled. I don't need it/them," are considered

self-evident sufficient reasons to forgo the enhanced function, ease, safety, and health benefits they could have from selective use of adaptive aids.

When a polio survivor chooses to use a wheelchair, he/she faces practical, emotional, interpersonal, and social/professional issues which can be deeply troubling and anxiety producing. How my heart pounded with dread and self-consciousness the first semester I rolled into the faculty opening-day seminar on wheels. That wheelchair gets the credit for "outing" me. I now had to admit to the world that I was, indeed, A Person With A Disability. But ever since that day . . . oh, the liberation that has been mine!

It is an important healing step to act on the belief that is OK to be YOU. Know that the consumerist driven, stereotypical images of "attractive" are oppressive falsehoods rather than the truth. Consider this thought: It is stunningly appealing to exhibit self-acceptance. People are not used to seeing this in someone who is disabled. When you see others' positive responses and you realize these responses are to YOU, as you are, you will be freed. You will receive positive reaction to the real you, not *despite* your disability, nor because they are unaware of your disability, but to YOU. You will shed a burden you may have carried around since adolescence.

Societal attitudes about people with disabilities are vastly different in the Nineties than they were in the Fifties. Are you still suffering from antiquated tapes playing incessantly on your emotional internal tape recorder? It's time to erase those old tapes. How? You can trade in your negative thought patterns for new high-powered positive thought patterns. You can liberate yourself and claim your space in the mainstream of society.

You were paralyzed by polio; don't be paralyzed by society!

Visualize yourself sitting proudly, head held high, in your sleek Quickie manual chair or perhaps in your speedy, sporty, power chair. Visualize yourself maneuvering gracefully over the grass at the pops concert in the park. How lovely the grounds look when you are no longer fearful of the placement of each footstep. How sweet the evening air as the melodic musical sounds touch your heart.

Visualize yourself on your mobility scooter at the shopping mall with your favorite daughter-in-law, scooping up bargains. You can shop till you drop and still have some energy left over to go out to dinner at the end of your day.

Visualize yourself traveling the length of the boardwalk at the ocean. Your senses overflow with the ambiance of the seashore. Since you have no pain or fatigue, you are much more free to hear the seagulls scream, to smell the salty sea breeze, and to celebrate the sheer joy of this experience.

I know that this is a difficult decision. Generally speaking I think we are in a climate everywhere in the world where the mobility impaired person has to swim upstream against self-imposed inner resistance, as well as resistance from family and society. If we are to make optimal advantage of wheelchair mobility, when it is not strictly speaking absolutely necessary, we need a lot more people willing to swim upstream, proudly and confidently, to change that climate.

Won't you join me in the swim?

Linda Wheeler Donahue

**EIGHTH INTERNATIONAL POST-POLIO AND
INDEPENDENT LIVING CONFERENCE, ST LOUIS,
MISSOURI, June 8 – 10, 2000**

Funding a Scooter with Medicare and Tricare (Champus)

Robert H Thayer, Mississippi Polio Survivors Association, Inc

Disclaimer: I am not a lawyer. This is a report of my personal successful experiences in filing claims with Medicare and Tricare (Champus) and is presented for your information. It took me two years to successfully complete the Appeals.

I. ROUND ONE - THE "HOOPS" ONE MUST JUMP THROUGH

- A. Original Filing** – This will be done by your physician and supplier. You will receive an approved claim or a denial notice from Medicare. In all probability the claim will be denied the first time.
- B. Appeal When Denied** – Have your Doctor write a second letter with more supportive evidence. You may need to show the Doctor some of the specific Medicare Guidelines, Policies and Specific Wording required. I am convinced **this a word game** and if a claim is worded correctly, it will be approved. You can **also** respond to this notice yourself. If denied the second time, appeal. You will be referred to a Medicare Hearing Officer.
- C. Medicare Hearing – 3 Choices Offered By Hearing Officer (A Lay Person)**
 - 1. Personal Hearing – This is a Personal Interview.
 - 2. Phone Interview – I choose this and it was difficult to get my point across.
 - 3. Correspondence – The doctor and you can send in additional information.

My personal view is this Hearing is just another exercise, but drive home your point. Include supportive medical literature in your letter or hearing.

- D. Hearing And Interview With Administrative Law Judge.** You can do this yourself without an attorney, **BUT BE PREPARED.** You will be thoroughly questioned about not having legal representation. **If you don't feel comfortable with this by all means get an attorney.**

PREPARING YOURSELF FOR THE APPEAL

I. FIRST STEP - UNDERSTANDING MEDICARE

- A. One must understand what Medicare requires. Request a copy of the Regulations From Medicare (HCFA), Policies, and Procedures. Expect some "Run-Around" from this.** Legally they have to give it to you. Watch out, they might try to sell you the whole Medicare Law for several hundred dollars. You don't need this.
- B. REMEMBER MEDICARE POLICIES ARE NOT CAST IN STONE. REGULATIONS ARE CAST IN STONE.**
- C. Medicare Caseworkers are trained on guidelines, policies, and procedures. It appears they only make favorable decisions when their guidelines and policies are met without question. Caseworkers are not capable of making exceptions or value judgements. Save the exceptions for the Judge. The CLAIMANT must learn their "Lingo" and submit a claim in proper language and form. You Must Play This Word Game.**

II. PHYSICIAN REQUIREMENTS:

- A. Must be a Specialist in Physical Medicine, Orthopedics, Neurology, or Rheumatology.**

III. BENEFIT DETERMINATION Must Be Based On The Following.

- A.** The patient CANNOT use a Manual Wheelchair.
B. The physician has determined this particular type of Assistive Device, a scooter, best meets the patient's medical needs.
C. Claims **Must Be Sufficiently Documented** to confirm that the proper evaluation of the patient's medical and physical condition has been made ascertaining that the patient requires such a vehicle and is capable of operating it.

IV. MEDICARE COVERAGE

- A.** Medicare is only **Supplemental Insurance**. It is **NOT** comprehensive.
B. HCFA translates (INTERPRETS) laws into **POLICIES and PROCEDURES**.
C. Questions? Call Medicare 1-800-213-5452.

V. MEDICARE PAYMENT

- A.** Sales Tax and Shipping are **NOT** Covered.
B. Pays **30%** of the **Approved Amount**, which in reality is **37% to 40%** of the total cost of the scooter and lift.
C. Medicare Will Not Tell You The Approved Amount.

PREPARING YOUR CASE

I. NECESSARY ENCLOSURES WITH YOUR LETTER OF APPEAL

- A.** Copy of the Original Claim.
B. Doctor's Prescription for the Scooter and Lift.
C. Doctor's Letter of Medical Necessity and Patient Evaluation.
D. Supporting Medical Literature. Medicare may trash it.
Put it in your letter anyway. It may help your case.

II. OVERCOMING MEDICARE OBSTACLES

- A.** Medicare will state that you cannot have a scooter because you can walk or you must use a manual wheelchair. Medicare views a scooter as **Medically Unnecessary And Considers It A Transportation Device. You Must Prove The Medical Necessity Which Must Demonstrate That You Cannot Use Your Arms To Propel A Manual Wheelchair. Your Doctor Must Put This In Writing Or The Judge Will Deny The Claim. The Judge Can Ask For Such A Statement If He Feels Gracious To You And Grants You Time To Get It. It Is Best Not To Count On A Judge's Goodness Or Generosity.**
- B.** Have your physician submit a letter stating: **The Polio Virus invades the entire body causing problems with all of your muscles and For You To Use Your Arms To Propel A Manual Wheelchair Will Cause Further Damage. Preventing Further Damage To The Remaining Muscles By Using A Scooter Is A Basic Tenant for Using Assistive Devices. Preventing Muscle Damage Is What The Doctor Expects To Accomplish. THIS IS A KEY POINT. Other Conditions That Prevent Use Of Arms With a Manual Wheelchair are Lack of Strength, Stamina, Endurance, Energy, And Pain.**

III. USE SUPPORTING MEDICAL LITERATURE

- A. **Polio Late Effects**, Infectious Diseases, Reprinted from 1985 Medical & Health Annual Encyclopedia Britannica Inc. (cr).
- B. **Current Issues In Neurological Rehabilitation**, Chapter 17, Laura K Smith (Part I), Johnny Bonk & Anne MacRae (Part II).
- C. **Pain in Post Polio Syndrome**, Anne C Gawne, MD, Spain Rehabilitation Center, Univ. of Alabama Birmingham, Polio Network News, Winter 1997.
- D. **Fatigue in Post Polio Syndrome**, Archives of Physical Medicine Rehabilitation, Vol. 72 Feb 91.
- E. **Energy Conservation, Occupational Therapy & The Treatment of Post Polio Syndrome**, Dept of Occupational Therapy, Kaiser-Permanente Medical Center, Downey CA. Orthopedics November 1991 Vol. 14 No 11.
- F. **General Guidelines for Physical Activity & Exercise**, TIRR (Texas Institute for Rehabilitation & Research)

GOING BEFORE THE HEARING OFFICER OR JUDGE

I. BASIC GUIDELINES

- A. Dress in a Business or Professional Manner.
- B. Conduct yourself with **Good Manners and Polite Behavior**.
- C. **Keep Your Cool and DO NOT Argue or Contradict**.
- D. Go to the trial early at by least one-half hour and preferably one hour to review your records. This gives you extra time to review your presentation. At this review, I learned Medicare had trashed all of my Third Party Medical Evidence. My letters were there but my additional supportive information had been removed.
- E. Take two copies of all supporting evidence with you. This will permit you to give evidence to the Judge. Keep one copy for yourself. Be sure to **Hi-Lite all references to the medical necessity of a scooter for Post Polio Patients**.

II. OTHER SUGGESTIONS

- A. Keep a copy of all letters sent and received.
- B. Send all Correspondence **Certified With Return Receipt**.
- C. Staple the Mail Receipt to your copy of the correspondence

III. ROUND TWO - APPEALING

- A. Medical Hearing Officer will probably strictly adhere to the Policies and not make a medical judgement. Go prepared anyway. It may help and it won't hurt your case.
- B. Have the physician write another supporting letter with more documentation.
- C. **At This Point It Is A Judgement Call As To Whether To Press Extra Hard For Your Case Or Save It For The Judge**.
- D. Appeal to the Administrative Law Judge if claim is denied.

Tricare (Champus) uses physicians for the "Hearing Officer". I did not have to appear before a Hearing Officer with Tricare. Supporting Medical Literature was successful in getting my claim approved. This approval was a GREAT piece of New Evidence for the Medicare Judge and I am sure it helped him to make a favorable decision for me with My Medicare Claim for a Scooter. The Judge agreed that Medicare and Tricare have similar Policies and approved my claim.

IV. ROUND THREE - The Judge (Administrative Law Judge)

- A. Take Your Records & Medical Literature With You, Two Copies. Be Prepared To Give The Judge New Supportive Medical Evidence. (The Info You Have Been Saving For The Final Round).**
- B. Go to Court at least one-half hour early to review your file. One hour is preferable. You Will Probably Find Your Supportive Medical Evidence Missing.**
- C. Read & Know The Key Points In These Medical Reprints. Hi-Lite Every Reference Made For the Necessity of Using A Scooter So The Judge Can Flip Thru, See and Believe.**
- D. Dress Appropriately, Observe Good Behavior, and Don't Argue.**
- E. Get An Attorney If You Do Not Feel Comfortable By Yourself.**

My Case Number: Is: 000-47-1810 March 20, 1998, Social Security Office Of Hearing Appeals, 100 West Capitol Street, McCoy Federal Building Suite 1014, Jackson, MS 39269. Telephone 601 - 965 - 4650.

Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri
June 8-10, 2000

Selecting the Appropriate Mobility Device
Robbie B. Leonard, M.S., P.T.
Medical University of South Carolina

Steps To Assure Success in Choosing a Mobility Device

1. Perform an honest self assessment
 - a. Weakness
 - b. Fatigue
 - c. Pain
 - d. Functional limitations

2. Perform an environmental assessment (home and work)
 - a. Entrances
 - b. Door widths
 - c. Turning radius
 - d. Transportation
 - e. Outdoor environment
 - f. Community environment

3. Find the right professionals
 - a. Physician
 - b. Therapist
 - c. Assistive technology provider

Eighth International Post-Polio and Independent Living Conference

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4. Be evaluated
 - a. Seating and mobility evaluation
 - b. Test drive the recommended device
 - c. Pick the right accessories
 - 1) Correct drive type
 - 2) Tires/casters
 - 3) Batteries
 - 4) Seating
 - 5) Controls
5. Be your own advocate for funding

A Tracheostomy: What, Why, When

Edward Anthony Oppenheimer, MD

Indications for Tracheostomy:

- Failure of noninvasive ventilation (NIV)
- Hemodynamic instability
- Secretions – if tracheostomy is needed to clear airways secretions
- Long term endotracheal tube (ET) – need to convert to tracheostomy
- Facial trauma
- Upper airway obstruction

A few historical notes:

- 1960s convert from ET to tracheostomy needed earlier due to stiff high pressure cuffs
- 1970s softer ET tubes and low-pressure cuffs
- 1990 risk/benefit of converting ET tube to tracheostomy
- less than 1% mortality
- less than 6% complications

Appropriate timing for tracheostomy and related issues:

- To avoid inadvertent extubation – tracheostomy less likely than ET tube
- Possibly tracheostomy is more comfortable
- Avoids risk of sinusitis associated with ET tube (particularly nasal ET)
- Tracheostomy allows better suctioning
- May facilitate more rapid weaning

Possible problems:

- Communication
- Eating and swallowing
- Infection is more common
- Respiratory care more complicated
- Mobility and independence more complicated

Choice of various NIV options versus Tracheostomy

- Physiological / medical aspects (see above)
 - e.g.: failure of noninvasive ventilation (NIV); secretions; upper airway obstruction, etc....
 - Skills of patient / family
 - Desires of patient
 - Availability of equipment and support
 - Biases and skill of clinician
-

	NIV:	Tracheostomy:
Speech	usually normal	Inflated cuff → no speech – unless using a “talking trach” Deflated cuff → speech is possible ± fenestrated tube Cuffless tube with Passy Muir-valve → speech
Taste / Smell Humidification + filtering	normal	by-passed if tracheostomy is cuffed tracheostomy without cuff allows part of in-coming air to flow above tracheostomy (closing glottus increases flow to lungs) talking during inspiration – but with P-M valve talking is spread thru inspiration and expiration
Eating	swallowing preserved	Swallowing may be impaired – cuff will make this worse P-M valve improves this Decreases mobility of trachea
Infection**	no incision to become infected lack of lower airway access	Local infections and granulation / inflammatory reactions Direct access to lower airways increases infections
Upper airway obstruction	may be a problem	Tracheostomy avoids this problem
Resp Care	Needed less (minimal)	Increased amount needed Suctioning needed
If 24-hour use	May require multiple types of ventilators and interfaces	Single type of ventilator is usual
Mobility	Battery operated is not standard Portable O2 may be needed	Battery operated is standard Portable suction needed Portable O2 may be needed
Face	Interface involves face	Face is free

How to decrease risk of infection with tracheostomy:

- Avoid H2 blockers (e.g.: tagamet)
- Clean suctioning
- Closed suction system
- Use nebulizers only if necessary – MDI with adapter may be safer
- Use humidifier only if necessary – HME (artificial nose) may be safer
- Dry everything

Note: One third of all long-term users of MV are on life-support approx. 24 hours per day

24 hour use of NIV can be done but Tracheostomy-PPV may be better because:

Safer

- Equipment has better alarms
- Equipment has built-in battery
- Interface is more secure

More comfortable

But.... tracheostomy is more invasive compared to NIV

Presence of other lung diseases may effect choice:

Such as: Vocal cord or upper airway problem; or COPD, bronchiectasis, etc.

Safety:

- Ventilation: Tracheostomy-PPV better than NIV – providing breaths & volume
- Disconnects: Tracheostomy safer

Notes:

Advocacy...It's Personal

Audrey King, M.A.

Center for Independent Living, Toronto (CILT)

Citizens for Independence in Living and Breathing (CILB)

It's a terrible thing to feel alone in the world, unable to advocate for yourself and having no one who really understands enough to advocate on your behalf. It's a tremendous feeling when you one day realize you're not alone, you do have a voice, people will listen and positive changes can happen, not only for yourself but for others in similar circumstances.

The journey from helplessness to personal enablement can be a long one, evolving through roles of dependence and partnership with those who control the resources you need, then progressing on to relationships in which you often become the resource on whom others rely.

Effective advocacy involves research, education and knowledge. It involves networking, confidence, patience, a belief in yourself and in the validity of your issues. Advocacy requires persistence and an understanding of institutional systems as well as human nature. The best advocates learn to support, acknowledge and appreciate others, using tact and diplomacy as they build alliances – even with those believed to be your enemies. A willingness to share, to lead and teach others is essential.

Advocacy at all levels enables people with disabilities to become able to fully exist and participate meaningfully within society. Even young children can learn.

Through a variety of personal and career examples spanning several decades the growth and importance of advocacy skills will be demonstrated.

ADVOCACY — IT'S CULTURAL

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In India, one of the last reservoirs of the poliovirus in the world, life of a child with polio is still a struggle against odds.

In the 1950s and 1960s, a large number of children were affected by polio due to lack of awareness and non-availability of the polio vaccine. As most of these children were from the poor strata of society, they were deprived of education, had no control over employment, no access to proper medical care and no money to buy aids like the callipers.

The role of family and community in a developing world plays a major role contrary to the individualistic, high-tech life-style in the West. Living in extended families where three to four generations live under one roof, the streak of independence is seen as rebellion to the laid norms of society. From small everyday errands to ultimately standing up on one's feet and earning a living is discouraged since childhood in a polio patient. As there are enough people/siblings around to help, small tasks like fetching your own glass of water is also discouraged. "You can't do it. Don't do it otherwise you will fall and break bones creating more problems for us" are refrains heard commonly by polio survivors. Unlike the West, a child with polio in India gets sympathy and pity, but not respect and dignity.

While the immediate family tries to help the patient in every possible way, an individual with polio is often ostracised by community and ridiculed by fellow beings. A father sometimes walks 10 km carrying his son to school on his shoulders, but once at school the other pupils are most inconsiderate, teasing and driving the child to a point where he doesn't want to attend school.

Over the years, the World Health Organisation and UNICEF-led Polio Plus programmes gained momentum and vaccines reached the remotest of villages. Advertisements on television and radio enthused people to walk long distances to get their child vaccinated. While a lot is being done to eradicate polio, little has been done for the polio survivors. Post-polio syndrome is a concept alien to even the best of doctors. Disabled access to public transport, places of entertainment and shops doesn't exist. As in all such places mobility is restricted, a polio person spends a lifetime inside the four walls of a home. This further makes independent living an impossibility.

Access to health care is unevenly distributed. There are so many polio-affected children in India, who never received any medical intervention. In my own case, where my grandfather was a doctor and I was immediately rushed to a leading government hospital, it took two weeks for the doctors to diagnose my case as polio. Lack of proper medical care in the initial stages resulted in development of deformities and complications in these children, who continued to crawl or walk awkwardly. In many cases where medical care was available, the parents didn't take the child to the doctor as the ailment was seen as someone bearing the punishment for past sins. Instead, they preferred to take them to faith healers and quacks, who vouched to cure.

While the government has a national health scheme and provides callipers and physiotherapy in most cities and large towns, in the villages these facilities are absent. Again, the number of patients needing orthotics and prosthetics is so high that the hospitals and rehabilitation centres are unable to cope. Manufacturers like ALIMCO, one of the chief suppliers of appliances in India, have priced each kit so high that a substantial section of the population cannot afford it. In cases where callipers are provided, the material used in the aids is so uncomfortable during the extreme climatic conditions that a child automatically discards it and prefers being carried by others or just dragging one on the bottoms.

Concepts of caring, peer support, empowerment of the individual are gaining ground. Some independent institutions like the Mahaveer Viklang Sansthan is helping in rehabilitation by providing free aids, wheelchairs or sewing machines to make a living. Otherwise there is little political or legislative protection for the disabled in the country. There are a small percentage of reservations for the disabled in Government jobs and travel concessions in rail and bus fares. But awareness about such benefits is so limited that those who need it don't know about it.

In this world of fierce competition where the survival of the fittest is more than ever a reality, much needs to be done for polio survivors in the developing world where poverty, extreme climatic conditions and illiteracy are a major hindrance in enabling the disabled.

The presentation includes individual case studies of how despite the odds, some of the polio survivors have learnt to live and not merely exist. For every ailment under the sun, if there is a remedy, try to find it; if there is none, never mind it!

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri, June 8-10, 2000

GREAT EXPECTATIONS AND A WONDERFUL EXPERIENCE

Susana R. Saavedra
Foundation for Equal Opportunities (F.E.O.)

At the Seventh International Post-Polio and Independent Living Conference we mentioned that polio survivors in the Republic of Panama had virtually no information available concerning medical treatment, technical advice, or group support. This situation has much improved.

When we began, the task seemed extremely difficult. First, we attempted to create awareness about the problem among the leaders in the higher levels of government, especially officials in the Ministry of Health and the Social Security Entity; which we accomplished with a positive initial response and finally gaining nearly full support toward our activity.

In addition, we approached the private sector with such success that eventually it became deeply involved in every aspect of our First Conference. A significant number of the people whom we contacted had first-hand experience with the post-polio syndrome, through the medical history of close relatives and friends. As an example, when we dealt with the Sales Manager of American Airlines in Panama City, Irene de Vengoechea, offering her publicity spots on television, radio, and printed media, in exchange for non-revenue tickets that would be used by the main and keynote speakers, she replied that her "brother had suffered a great deal because of polio and that she knew how hard an effort this was for us." She not only offered the tickets, but volunteered to help and work for us. We had a similar response when we went to the five local commercial tv channels, the printers, the radio stations, the educational TV channel, the Miramar Intercontinental Hotel, and the Lions Club. All of them agreed to sponsor us.

Considering that this was the first time the post-polio syndrome topic was treated on a scientific basis, we felt the need to present a strong agenda so as to interest the medical and technical community to participate contacted the Faculty of Medicine of the University of Panama, from them we required and obtained the necessary approval to extend academic credits to the participants. We met Dr. Frederick Maynard as a result of our first visit to the Seventh International Post-Polio and Independent Living Conference, where he learned of our plans and offered his professional assistance and participation in our project.

The Faculty of Medicine of our Main University was so impressed by Dr. Maynard's background that it backed up our request almost immediately, through their recognition of the program of our two-day conference scheduled for January 28th and 29th, 1998, granting sixteen academic credits to those participants who completed the whole journey. Unfortunately, on December 8th, we learned that the other main speaker who would have been in charge of some of the topics as Dr. Maynard's assistant, would be unable to make it.

At such short notice, we had to ask several medical professionals closely related to us that had never dealt with the topic, to become substitute speakers. Initially they were skeptical about the idea of broaching a topic they did not handle at all, and standing beside Dr. Maynard whose prestige is well known. Finally, they accepted to develop one topic each, which required a great deal of preparation on their part. They were: Alfredo Du Bois, Silia de Alegria, Arrigo Guardia (who is a polio survivor), Jeannette de Quintero, Marta Roa, Walter Kravcio, and Neritza de Grimaldo. By the end of the Conference, they became the first members of F.E.O.'s Medical Advisory Board.

Several teaching meetings were also organized, where a great deal of information was distributed, supplied by Joan Headley, GINI's Executive Director, who gave us full support in every possible way, and made the necessary arrangements to provide us with a supply of the CD Rom "A New Challenge for the Survivors of Polio," a highly educational material that was distributed to each of the participants, polio survivors and members of the medical community.

On the other hand, our friend Sheila Maxwell, Executive Director for Easter Seal Society of Oregon, provided us with a very significant contribution – three booklets about important information concerning the post-polio syndrome, focused to the medical community, physical therapists, and polio survivors, which the Medical Advisory Board of Easter Seal Society of Oregon authorized F.E.O. to translate into Spanish and to distribute them at our Conference.

A month before the deadline for the meeting, we started broadcasting it nationwide, for the first time in Panama, and distributing posters advertising both about the possibility of experiencing post-polio syndrome and the date of the Conference, to take place by the end of January 1998. Additionally, two weeks before the event, already fifty (50) attendees were confirmed: four orthotists, two psychiatrists, four orthopedic physicians, five physical therapists, fourteen research scientists, ten polio survivors, three medical students, eight physiatrists, and general public.

Everything was almost ready after four months of real hard work, just waiting for the arrival of Dr. Maynard and his wife, Cathy. We felt tired, anxious, and almost at the end of our endurance; but everything was forgotten when, at the airport, we heard someone calling Liliana's name and there they were ... Dr. Maynard and his wife, Cathy, with huge smiles after a whole day of travel. All of our troubles almost disappeared and we felt much better when they told us that the first post-polio conference held in the United States had been attended by one hundred participants. Panama's population is only two-and-one-half million. This proves that the Panamanian response to our effort was not as meager as we first thought. During the next few days, Dr. Maynard was introduced to both the medical staff and to other members of the Foundation and held several meetings with them.

Polio survivors, as well as relatives and friends, approached us --interested in obtaining as much information as possible about therapy and treatments related to this syndrome, feeling much better when they realized that their misgivings, apprehensions, and anxieties were not mere imaginations, but had medical explanation. Thus, they were extremely grateful both to Dr. Maynard for his willingness to share his knowledge and experiences, as well as for his concern to create awareness abroad; and to F.E.O. for the initiative to organize the first Post-Polio Conference in Panama Rep. Of Panama.

The two-day Conference was held at the National Social Security Agency's Auditorium, were widely announced; participation was good and everything went smoothly and on schedule.

F.E.O.'s headquarters for this event and that of their honored guests were located at the Miramar Intercontinental Hotel, where the closing dinner was held. For this event, the following special personalities were invited: Monseigneur Romula Emiliani, c.m.f., the Minister of Health Dr. Aida Moreno de Rivera, the Dean of the Faculty of Medicine Dr. Carlos Brandaris, our Sponsors – American Airlines, Miramar Intercontinental Hotel, Riba Smith Supermarkets, Panama's Lions Club, Cybersoft, R.P.C. Television F.F. Television, Channel 11 Educational TV, Channel 2 TV, and Telemetro Channel 13; F.E.O.'s Board of Directors, F.E.O.'s Medical Advisory Board, and also polio survivors, relatives and friends. The Minister of Health, on behalf of the medical community in Panama, bestowed upon Dr. Maynard a plaque of appreciation and gratitude for his invaluable teachings. F.E.O.'s President Liliana Bieberach also gave him another plaque for his dedication to this cause, and appointed Dr. Maynard as an honorary member of its Medical Advisory Board.

On the other hand, F.E.O. rewarded the commendable efforts of each and everyone of those who anonymously contributed, donating their art and

creativity, by issuing them certificates of recognition. The audience was impressed by F.E.O.'s accomplishments in so short a time, and by its efforts in obtaining and distributing the information that was sorely needed in Panama to update treatment as well as prevention of this Syndrome.

We must give full credit to our sponsors, who helped us all the way and contributed in making this an experience we will not easily forget. On the other hand, we want to praise the participants who maintained a level of professionalism to the point that twenty-four (24) received academic credits for their efforts. These professionals work either in the public sector or the private sector, and will ensure that our polio survivors will have the option of medical treatment in both of them nationwide.

I will quote now words from a speech given by Gini Laurie during her visit to Munich, Germany in 1988, which embody the ideal we wish to emulate: "In attitude of mutual respect: the medical community, polio survivors, non-governmental organizations and the government will be able to achieve an active dialogue between them, with their counterparts around the world, and with the polio international network. The international work on polio will reach farther, and even farther than the successful immunization of all the children of the world, there will be an immense amount of persons who will need the experience we can share, each country will develop an alternative to our system which will suit their local conditions."

Closing this presentation, I would like to express our gratitude to everyone in charge of promoting Gini Laurie's ideals, which have just become a reality in our country, and for making it possible for us to participate in this great networking.

POST POLIO SYNDROME WHAT DOES IT MEAN ORTHOTICALLY?

By

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What is post polio syndrome? This becomes a complex question that may have many answers depending on the specifics of a patient's complaints and problems. There was a time that some feared the dreaded disease was coming back and that it would cause additional paralysis in what muscles were left. These issues puzzled patients and physicians alike. Many physicians practicing today have not had the experience of working with the polio population, as many polio patients have been stable for some time. However, after many years of use, muscles and joints seem to be screaming out, "I've had enough, I need relief, I need some rest!" These symptoms consisting of muscle and joint pain come from different parts of the body depending on the affected areas.

First of all, we need to describe exactly what polio is. After entering the body through the gastro-intestinal tract and an incubation period of two weeks, the virus attacks the anterior horn cell of the spinal cord or the brainstem (1). The ventral root, which synapses with a motor nerve, is damaged to the point that it is unable to send messages to the muscle cell through the terminal axon sprouts. This lack of innervation causes muscle weakness or paralysis. If enough damage is done, partial or total paralysis of the lower or upper limbs will result as well as complications and paralysis of the respiratory system. It is believed that some of the terminal axon sprouts are able to branch out to muscle cells,

which have been affected and help in innervation. (2). This will allow function of the muscle cell however, that particular muscle probably will be much weaker than a normal group of cell innervation.

There are five main stages of polio. These consist of a prodromal phase lasting two days, an acute illness lasting approximately two months, a recovery or convalescence period lasting up to two years, a stable disability or stage of chronicity and then a post polio syndrome (3), (4) which includes symptoms of muscle pain, joint pain fatigue accompanied by additional weakness and atrophy of muscle tissue. Usually the stage of stable disability lasts for 20 to 30 years. These chronic disabilities become increasingly challenging for polio patients trying to keep up a normal pace. The exacerbation of symptoms of the polio patient is classified as “ Post Polio Syndrome”, a condition composing of a “...cluster of symptoms in individuals who had paralytic polio many years earlier” (5).

From a survey conducted in 1987 by the National Commission on Health Statistics, there were 1.63 million polio survivors with 641,000 having some type of paralysis (6). If you divide this by the approximately 1,000 ABC facilities, there are about 600 patients per facility who will need some manner of care. Even if this number were cut in half, there would still be a substantial population for each facility. A recent problem that has arisen from this group is that many of them who require orthotic care have felt reluctant to confide in their orthotist. Many orthotic professionals have told them that they (polio patients) are hard to deal with, they are set in their ways and take a considerable amount

of time to provide care. The orthotic profession must be careful not to prejudge these patients as all difficult type "A" personalities (7). Many of them have expressed offense as they have shared their feeling in the many seminars and support groups which I have had the privilege of presenting. We as professional practitioners, need to take the time to listen and to properly evaluate these patient's conditions. It is imperative that orthotic practitioners become familiar with the polio patient's history. Practitioners need to understand exactly what they are dealing with. Polio survivors are the type of patients that practitioners need to evaluate hands on and to know "first hand" the muscle weakness and range of motion and how the patient is substituting for the weakness to be able to function.

The polio patient is the most important member of this/her rehabilitation team. He/she must be allowed to assist in the design of the orthosis. He/she needs to understand that orthotic practitioners are not sentencing them to 24-hour orthotic wear but are trying to provide a system that will protect and stabilize. Be flexible with these patients. Leave options in the treatment plan. Provide patients with a choice and lead them in the right direction. Let them know that your abilities and expertise can help eliminate unwanted range of motion and allow for a more normal function. By all means, don't lock their joints unless you absolutely have to. If you do, you may find that your carefully designed orthosis will end up in their closet, not because of your design, but because you have taken away from them the simple motions that they use to substitute for muscle weakness and joint deformity.

When assessing a post polio orthotic patient, consider all design options, which are available. Some of these options may be a combination of two or more orthotic designs. For example, you may have a patient that needs additional knee stability due to weakened quadriceps but is unable to tolerate the weight of conventional designs. One idea is to provide a hybrid orthosis consisting of a leaf spring design orthosis with a pre-tibial shell which provides minimum quadricep support and give just enough feedback to prevent the knee from buckling. Younger and stronger patients [40-60] can accept more aggressive designs and seem to have a willingness to try harder in allowing time for adjustment to new designs. They seem to have a better understanding of what the intended outcome is and will work to make it happen if possible. Older polio ambulatory [60-75] are often more complicated due to additional muscle and joint fatigue. They seem to be more apprehensive about change. Orthotic practitioners need to realize that these older patients have experienced much in dealing with past orthotic challenges. These patients need to lead the way in their orthotic care and are the ones who need options to choose from. Elderly ambulators [75 +] usually need lightweight orthoses. They want little change and practitioner listening skills need to be especially keen for this group. You must let these elderly patients know that you care about them and you also must learn to take their criticism with a smile.

What drives many of these patients to their physicians and eventually to orthotic facilities is pain. Polio patients with post polio syndrome will have pain. There is a reason for this pain. Pain is good: it is a tool by which a patient can be protected from further damage if he/she respects it (8). Pain is the , “Personal Awareness of Internal Notification” system.

It is important to identify the source of the pain. Orthotic professionals need to focus on the musculoskeletal issues. If possible, joints need to be protected to prevent further damage while allowing the patient to continue to have mobility. By providing stability and more normal biomechanical function, joint destruction and muscle fatigue and stress can be reduced.

Many new and amazing materials are becoming available to orthotic professionals. This allows for lighter and stronger orthotic designs. New techniques are also available through modern technology by surgeons. Some joint deformities can now be improved dramatically, relieving stress and pain around joints and surrounding tissue. Keep your polio patients informed and don't be afraid of the challenges. Many of you have been trained professionally to handle these types of conditions. Please remember that your area of expertise is greatly needed and polio survivors will be relying⁵⁵ more on your professional services.

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5. *IBID*, 7
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*Eighth International Post-Polio and Independent Living Conference,
St Louis, Missouri, June 8-10, 2000*

STRATEGIES FOR OBTAINING BEST BRACING

A SOCIOLOGICAL PERSPECTIVE

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Orthotic management of lower extremity musculoskeletal disorders represents a complex phenomenon. Much research addressing the gait and biomechanics with various KAFO and AFO designs have been conducted. The majority of the users abandon the orthosis primarily due to discomfort and poor ergonomic factors.

Over the years there have been numerous developments in the design of lower extremity orthotic systems. These include KAFOs, AFOs and computerized electrical stimulation for walking. However many of these designs have proven unsuccessful in terms of usage in the community, home, and work place. Certainly factors such as cosmesis, ease of application and removal, ease of maintenance, ergonomic function and well-being may be far more important than biomechanical performance.

The knee-ankle-foot-orthoses that are currently available are effective mechanism to adequately support the lower extremity segment. The conventional designs available are fabricated from metal and leather combination or more recently metal and thermoplastic combination. They are cumbersome, heavy with many straps attached to control various segment deviations. These mechanical devices sometimes induce potential hazards from the physical and

psychological stress of spending long hours wearing them, limiting activities rather than accomplishing important objectives or performance.

A questionnaire result from UMOPC study indicates that patients with lower extremity impairment were able to enhance their ergonomic function in relation to performance, satisfaction and well-being when a user friendly design is applied. The area needed most attention is the patient's feelings related to performance, satisfaction and well-being. Also the design should be easy to use and ergonomically efficient. As the age of polio patients increases, the problems associated with pain and fatigue, loss of muscle strength and ligament laxity of the lower extremity are also expected to increase. The percentage of time wearing an orthosis may increase considerably and this increase in time would make the ergonomic factors more important especially body comfort, satisfaction and performance.

Finding, Nurturing and Utilizing Local Resources

Elaine Burns, President, Greater Boston Post-Polio Association

The Greater Boston Post-Polio Association, a non-profit organization founded in 1986, is a resource and support organization for individuals who had polio and are now experiencing post-polio syndrome. From our earliest days, a major aspect of our mission has been finding or creating useful resources and making these available to our members. The following items are examples of our efforts.

Support Group

- Reprints of useful literature are obtained from reprint services, the world-wide web and newsletters. Reprint permissions should always be obtained for copyrighted items.
- Books about PPS, are made available for purchase at meetings or by mail.
- A quarterly newsletter is published, featuring medical articles, news of group and subgroup activities, member-written articles, and question-and-answer columns.
- Member-to-member coping tips (Exhibit A) are distributed at meetings and serialized in the quarterly newsletter.
- Meetings are organized presenting speakers and opportunities for informal networking.
- A share list is maintained to supply contact information to facilitate networking between members.
- Meetings are videotaped so that members unable to attend meetings can view presentations. An audio-video library of these and purchased tapes is maintained.
- Newsletters are exchanged with other support groups around the world.

Health Care Providers

- PPS Information packets containing medically-oriented information are provided to health care professionals.
- A resource list, a directory of health-care professionals who have a knowledge of post-polio syndrome is compiled from information submitted by members. Categories include various medical subspecialties, orthotics, alternative medicine, physical therapy and psychological resources.
- Registration fees have been subsidized to permit area physical therapists to attend PPS conferences intended for the health care sector.
- We developed a model for an ideal post-polio clinic and were instrumental in its implementation in a major area hospital.
- Therapy groups – social workers have been educated and encouraged to create short-term therapy groups dealing with the issues of post-polio syndrome. These were publicized and promoted by the support group.

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Health Care Providers (cont'd)

- A mailing lists of health care professionals is maintained so that they can receive educational mailings and newsletters from the support group.
- In-services to educate health care providers about PPS will be sponsored by the support group. These presentations will be made by a person with a medical background and having a high level of knowledge about PPS.
- Health care professionals are encouraged to write newsletter columns inviting and responding to readers' questions.

Other

- A web page will be created to provide information about group activities, and available resources. Such a page will also be a repository of articles and reference material and will contain links to other PPS-oriented sites.
- A vendor list has been compiled and is maintained, listing suppliers of adaptive equipment. This list is based on recommendations by support group members who have used the vendors. Categories include hand controls, van conversions, bath/shower equipment, home modifications, etc.
- A list of available literature is maintained. This list should be continually updated to include the latest literature on post-polio syndrome.
- A voicemail line staffed by volunteers allows individuals to leave messages and obtain answers to questions, locate resources or request literature at any time. This line also provides a channel for member suggestions and feedback.

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Exhibit A – An example of member-to-member tips.

Techniques for Managing Post-Polio Syndrome
by Fredson T. Bowers, Jr., Secretary, GBPPA

Given the fact that relatively limited research is taking place, is there anything that we can do to help ourselves? As a matter of fact, there is. Some very good medical advice is available, and the rest of it is mostly good old-fashioned common sense. The following techniques are offered for your consideration:

1. Good nutrition - a balanced diet is important for everyone, but especially those who have less physical strength and energy because of post-polio syndrome (PPS).
2. Energy conservation - pace your activities so as not to become overtired. Get more rest, if necessary.
3. Retire early, if financially possible. It could be one of the best moves you have ever made.
4. Make lifestyle changes as necessary in order to improve the quality of life. Use your ingenuity to find different ways of doing things.
5. Moderate exercise is important (listen to your body). Exercise enough to prevent disuse atrophy, but not enough to produce overuse damage. No heavy weight lifting. If you feel tired after exercising, you are doing too much. Check with your physical before undertaking an exercise program.
6. Stretching exercises are important to relieve muscle imbalances, but since muscles and tendons protect joints, overstretching can cause damage. Again, check with your physician.
7. Long range planning - try to anticipate your future needs. Planning ahead also helps you to accept additional lifestyle changes when they become necessary.
8. There are a large number of assistive devices available. Don't be too proud to use them or to accept the assistance of others, if required. The GBPPA vendor list is available to provide you with resources.
9. Make sure that your physician and your physical therapist are familiar with PPS since inappropriate treatment can be detrimental to your welfare. There are knowledgeable healthcare professionals at post-polio clinics.
10. Pain management is a relatively new field, but there are some helpful techniques available which can be fairly effective.
11. Join a post-polio support group and attend its meetings.
12. Maintain a positive attitude. If you can do something about a problem do it! If you can't, try not to worry about it. Worrying takes energy and you can't afford to waste your energy.

Not all of these techniques are needed by everybody, of course. Take what applies to you and give them a chance to help you. You may be surprised and you certainly will be pleased at how well they can assist you.

Revitalizing Support Group Membership

by Dave Livingston, Ohio Polio Network, N. Ridgeville, Ohio

1. Placing fliers in doctor's offices, clinics, and offices of professionals who treat polio survivors.
2. Direct mailings to all who have attended an annual state polio conference.
3. Have a local ½ day seminar that is publicized in the local papers.
4. Try to host a seminar for OT/PT's from nearby colleges/universities.
5. Try having a ½ day Saturday seminar/ meeting inviting only 1 or 2 health care professionals in the area.
6. When we have our annual polio conferences, we advertise on the local cable stations. Have the local newspaper do a story on a polio survivor.
7. In your polio support group meetings:
 - a. Meet once a month or every other month.
 - b. Have several 'share and care' sessions.
 - c. Try and encourage family members to come; share what works for them. Try to provide answers they need to cope with life.
 - d. Try to provide the latest info on PPS. In my case I do the OPN newsletter and offer newsletter exchanges with 17 other support groups, plus what I find on the Internet.
 - e. Let the membership know that you are there for them; that they are not alone in time of need.
 - f. We network with GINI and the other 14 support groups in Ohio.
 - g. We list our support group in the local newspaper; they have a monthly listing of all the various support groups in the area.

List of Resources in Ohio:

1. Polio Organizations: GINI Polio Directory – lists clinics, health professionals, contacts); has library; puts out newsletter.
2. Polio Newsletters: GINI Supp. Group Guidelines and Resource Manual lists at least 50 different newsletters.
3. Internet : has many web sites; see handout
4. Local newspapers: ex. the Cleveland Plain Dealer, the Chronicle Telegram
5. Ohio Bureau of Vocational Rehabilitation
6. Ohio Rehabilitation Services Commission
7. Independent Living Centers: S.I.L (Services for Indep. Living) Cuyahoga Co. and L.E.A.P./ C.I.L. (Linking Employment, Abilities & Potential) Lorain County
8. Ohio Legal Rights Services
9. Ohio Dept. of Health: state health laws and legislation
10. There are many polio support group/state libraries: GINI; Atlanta; Michigan; etc.
11. There are many Advocacy Groups: ex. Disability rights; ADA group
12. Health care professionals: GINI has a list of polio clinics, M.D., PM&R, P.T. etc.

Topic: *Revitalizing the Support Group Membership*

by: Dave Livingston, Ohio Polio Network, N. Ridgeville, Ohio

PPS Internet Sites:

- | | |
|---|---|
| 1. Polic Epic Support Group | http://www.azstarnet.com/~polio/ |
| 2. Tom Dempsey's Lincolnshire site | http://www.zynet.co.uk/ott/polio/lincolnshire/ |
| 3. Drs. Bruno and Frick's Harvest Center | http://members.aol.com/harvestctr/pps/polio.html |
| 4. The Atlantic Co. P-P Supp. Group, N.J. | http://www.community.nj.com/cc/poliosupport |
| 5. the Polio Information Center Online | http://129.59.173.136/PICO/Intro.html |
| 6. Grace Young's Web page | http://www.geocities.com/hotsprings/4713 |
| 7. GINI's web page | http://www.post-polio.org |
| 8. Polio Survivors Friends | http://www.geocities.com/hotsprings/3012/ |
| 9. Post Polio Info page | http://home.earthlink.net/~polioinfo/ |
| 10. Atlanta Post-Polio Assn. | http://petit.phy-astr.gsu.edu/gus/appa/appa.html |
| 11. Polio Heros of Tenn. | E http://www.community.nj.com/cc/poliosupport |
| 12. Medical articles on PPS | http://execpc.com/~epwoll/medindx.html |
| 13. Tom Walter's web page | E-mail tornical@aol.com |
| 14. Polio Echo, AZ | http://aztec.asu.edu/polioecho/ |
| 15. R. Spear's Rollin' Rat web page | http://www.azstarnet.com/~rspear/ |
| 16. Free Medline search service | http://www.nlm.nih.gov/databases/freemed1.html |
| 17. Sparky's web page | http://www.prys.net/mailform/supportgroups.html |
| 18. The Story of Polio, PBS | http://www.pbs.org/storyofpolio/polio/index.html |
| 19. Moss Rehab Resource Net | http://tdt.net/~w1066/ |
| 20. Ontario Canada March of Dimes | http://www.omod.org/poliont.html |
| 21. Polio Connections web page | http://village.ios.com!/w1066/ |
| 22. Polio Outreach of Spokane | http://www.triax.com/PolioNet/POS.htm |
| 23. The PeopleNet Disability DateNet | http://chelsea.ios.com/~mauro |
| 24. The Post Polio Resource Group of S.E. Wisc. | http://www.geocities.com/HotSprings/4760/ |
| 25. St. John's Univ. | E-Mail polio@maelstrom.stjohns.edu |
| 26. A Christian Polio Chat | http://www.gcnhome.com/scripts/chatsupport.idc? |
| 27. Dr. F.T. H'Doubler's web site | http://www.getonthe.net/hdoubler |
| 28. Medscape service | http://www.medscape.com/ |
| 29. Roosevelt Rehab Institute web page | http://www.rooseveltrehab.org |
| 30. A disability travel site | http://www.gimponthego.com |
| 31. The Mayo Clinic web page | http://www.mayohealth.org |
| 32. Celtic Wings web page | http://home.earthlink.net/~celticwings/ |
| 33. Post Polio Newsletter, Australia | http://www.post-polionetwork.org.au/news/ppn39.html |
| 34. Polio Survivors' Page | http://www.iag.net/~bgold/polio.html |

**Eighth International Post-Polio and Independent Living Conference
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The Role of Alternative Medicine – Double-Blind or Double Standard

S. Laurance Johnston, Ph.D.

Consultant & Associate Member, Mountain States Paralyzed Veterans of America

Goal: The goal of this presentation is to attempt to further integrate alternative health-care perspectives to better the health of individuals with disabilities. It is not to advocate alternative or complementary medicine over conventional medicine.

Although this presentation focuses on alternative medicine, it is important to acknowledge the extraordinary contribution that allopathic (i.e., conventional) medicine has made to the health-care of individuals with disabilities over the last 50 years. Nevertheless, allopathic medicine has limitations in perspectives. For example, although there are few factors as important to chronic health as nutrition, only 24% of medical schools require a course in nutrition. This presentation will discuss the trends in alternative medicine, reasons for its popularity, the shift in world view concerning its use, and various specific therapies.

Definitions: Alternative medicine is vaguely defined. It represents a broad range of therapies that have been outside the purview of conventional medicine, including many non-Western and indigenous healing traditions. Health-care consumers define alternative medicine as “medical therapies that I paid for out of my own pocket, and did not feel comfortable discussing with my physician.” Physicians define it as quackery, because it was not taught as a part of a conventional medical school curriculum.

Trends in Alternative Medicine: In recent years, there has been incredible growth in the use of alternative treatments. *JAMA* has reported that 4 in 10 adults now use alternative therapies. Between 1990 and 1997, visits to alternative practitioners jumped 47%. Over that period, Americans visited alternative providers 629 million times compared to 386 million visits to primary care physicians. An estimated 90% of patients using alternative medical care are self-referred.

Although much of the criticism of alternative medicine comes from physicians, many desire additional training in alternative therapies. For example, in a recent survey, 49% of primary care, AMA physicians want training in homeopathy. 64% of U.S. medical schools now offer *some* courses on alternative medicine. Although the content of these courses is unclear, it is reasonable to assume that their inclusion is creating acceptance and respect for alternative medicine. Clearly, alternative medicine has become a key component of the nation’s health care. There is a health-care train leaving the station.

Reasons for Increased Popularity: The population as a whole, including individuals with disabilities, is desiring health care with a more holistic perspective than that currently offered by conventional medicine. Allopathic medicine is technology,

externally oriented. It tends to focus on fixing the symptoms, often ignoring the underlying causes from a mind, body and spirit perspective. Under the pretense of scientific objectivity and reductionism, allopathic medicine detaches itself from the patient's uniqueness. It operates by isolating and fixing the dysfunctional item in the absence of the big picture. In contrast many alternative traditions have more of a looking-inward, holistic perspective. Because most illnesses have *mind, body and spirit* contributions, truly effective treatments should consider all three.

Former Director of NIH's Office of Alternative Medicine, Dr Wayne Jonas summarizes some of the reasons for the surge in popularity of alternative medicine. These include "a rise in prevalence of chronic disease, an increase in public access to worldwide health information, reduced tolerance for paternalism, an increased sense of entitlement to a quality of life, declining faith that scientific breakthroughs will have relevance for the personal treatment of disease, and an increased interest in spiritualism." He also notes that there is growing concern about the adverse effects and escalating costs of conventional care.

Adverse Effects: Many people are turning to what they consider more "naturalistic" alternative therapies as the adverse effects of conventional, allopathic medicine are increasingly being documented. For example, *JAMA* has reported that 106,000 people died from adverse drug reactions in hospitals in 1994, making it the fourth to sixth leading cause of death in this country. In another example, almost two million individuals who enter hospitals in this country acquire infections that they did not have when they went there. Of these, 80,000 die. Finally, at the end of last year the prestigious Institute of Medicine concluded that medical errors result in 44,000 to 98,000 deaths each year. These statistics are especially relevant to individuals with disabilities who are often over medicated and prone to life-threatening infections. Statistics like this warrant a serious consideration of alternatives.

Medicine as the Prevailing Philosophy: Allopathic medicine is based on a "materialism" philosophy, represented by Newtonian physics. With this philosophy "physical matter is the only or fundamental reality, and that all beings and processes and phenomena are manifestations or results of matter." (see D. Eskinazi, *JAMA*, 11/11/98). Consistent with this philosophy, the body represents more or less the sum of its anatomical parts. Because consciousness plays no role in such a system, spirituality has been considered irrelevant to health. However, materialism and, as a result, its product allopathic medicine is a form of religion: "As it has not been demonstrated that physical matter is the only reality, materialism, therefore is akin to a religion, i.e., a system of beliefs held to with ardor and faith. Western allopathic medicine, therefore... reflects the dominant philosophical belief system of the society in which it developed."

Conventional Medicine's Lack of Testing: While it is true that many alternative therapies have not been well tested, the prevailing assumption that allopathic medicine represents scientifically well-tested procedures is inaccurate. For example, the Congressional Office of Technology Assessment concluded that only 10-20 % of conventional medicine techniques has been scientifically proven. Interestingly, Congress

has defined quackery as any unproved therapy (1984). Although this definition targeted alternative therapies, given the limited amount of conventional medicine that has a scientific basis, only one conclusion can be made: if alternative medicine is deemed quackery under this definition so must most of conventional medicine.

This double standard was evident in a recent New England Journal of Medicine editorial. After the authors slammed the use of the anecdotal evidence to support alternative medicine, they then proceed to draw broad conclusions about the risks of alternative medicine using 12 disparate case studies. Finally, a NIH Consensus Conference concluded: "While it is often thought that there is substantial research evidence to support conventional medical practices, this is frequently not the case...the data in support of acupuncture are as strong as those for many accepted western medical therapies."

Reasons that Have Kept Alternative Therapies on the Fringe in the Past: The current state of health care in this nation has been determined as much by politics, market-driven factors, and professional chauvinism as objective science. This approach has deprived all Americans, including individuals with disabilities, effective medical treatments. For a variety of reasons, it has been difficult for most alternative therapies to transition into mainstream treatments:

Economic: First, realistically, given the daunting economics that society demands for proving the safety and efficacy of any new treatment, few will make the transition regardless of merit. It can take almost \$100 million and over 11 years to get a new drug approved. The size of the market associated with most disabilities generally does not justify that expenditure and effort. Only therapeutics with a reasonably large market and deep-pocket financial sponsors (i.e., drug companies) have a chance. Furthermore, since many generic alternative modalities cannot be patented, economic incentives are lacking.

Over three billion prescriptions are filled each year in this country. Are these prescriptions being filled only on the basis of need? If so, why has drug advertising marketing increased in the past decade from \$12 billion to over \$13 billion now?

Furthermore, although the NIH has a program evaluating alternative modalities, it represents less than 0.5 % of the NIH budget. Given that alternative providers are visited 63% more than primary care physicians, it is a huge budgetary discrepancy, reflecting that NIH may have marginal relevance to much of the nation's health care.

Resistance by Organized Medicine: Most alternative treatments have had a history of suppression by the allopathic medical establishment. Example after example can be quoted. For example, the AMA pressured the FDA to ban acupuncture needles unless used in a research protocol. Even after most states had authorized its use, this ban lasted until 1996. Control issues remain to this day. For example, a prestigious NIH Consensus Conference recently concluded that although acupuncture now has many acceptable applications, the patient should first see a M.D. This ignores a differential in training in which physicians can practice acupuncture after 200 hours of training while non-M.D.'s must train over three years in an accredited school of oriental medicine.

In another example, founded largely to fight homeopathy, the AMA allied with the pharmaceutical industry (homeopathic remedies could not be patented), did everything in its power to squash homeopathy. Dogmatic opposition to homeopathy often continues to this day in spite of a growing base of evidence supporting its use.

Limited Scientific Perspectives: Third, alternative medicine often involves paradigm-expanding perspectives not well appreciated by western-trained scientists. Western scientists reject many alternative therapies because it offends preconceived notions about human functioning or because of inappropriate methods of assessment.

For example, for years, scientists dismissed homeopathy because it could not be understood by the biochemical processes that were used to explain most physiological phenomena. It required quantum physics, chaos and complexity theory. Similarly, although the explanation for acupuncture involving life-force ch'i was beyond the understanding of western science, it is now being explained by concepts involving subtle electromagnetic energy.

An Integrated Future for Health Care? There is not one system of medicine that is good and one system that is bad. To varying degrees, most have something positive to offer. Ideally, 21st century medicine will integrate the high technology, scientific reductionism perspectives of allopathic medicine and the naturalistic, holistic perspectives of alternative medicine. They should be complimentary not exclusive. For example, high-tech allopathic medicine should emphasize the diagnosis and treatment of problems in specific anatomical and physiological structures. It will be especially useful in emergency care and the care of people in the advanced stages of illness. Because more naturalistic alternative medicines will augment an individual's immune response, stimulating inherent healing potential, they will be especially effective in treating chronic illness.

Specific Alternative Medicine Therapies: This presentation will highlight aspects of the following alternative medicine therapies published in *Paraplegia News*:

- Acupuncture (*Paraplegia News*, September, 1998)
- Qigong (*Paraplegia News*, January & February, 2000)
- Homeopathy (*Paraplegia News*, January 1999)
- Ayurvedic Medicine (*Paraplegia News*, November & December, 1999)
- Craniosacral Therapy (*Paraplegia News*, November 1998)
- Magnetic Therapy (*Paraplegia News*, March & April 2000)
- Chronologically Controlled Development Therapy (*Paraplegia News*, July 1998)
- Dolphin-Assisted Therapy (*Paraplegia News*, July 1999)
- Human Energy Fields (*Paraplegia News*, March, May & June, 1999)
- Aromatherapy (*Paraplegia News*, to be published July & August, 2000)

EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference
SAINT LOUIS, MISSOURI

Friday, June 9, 2000

7:30 pm - 8:30 pm
PAVILION BALLROOM

Presentation by The Dis-Ability Project

THAT UPPITY THEATRE COMPANY

Sponsored by AT&T

Artistic Director: Joan Lipkin

Community Outreach Coordinator: Edith Ritterband

The Dis-Ability Project Ensemble:

Katie Rodriguez-Banister

Alison Chancellor

Thea deLuna

Stuart Falk

Colleen Gilmore

Suzanne Gundlach

Sally Haywood

Ana Jennings

Nick Kalfas

Andrew Lackey

Marcia LaCour-Little

Hillary Melechen

Rich Scharf

Linda Small

Jim Tuscher

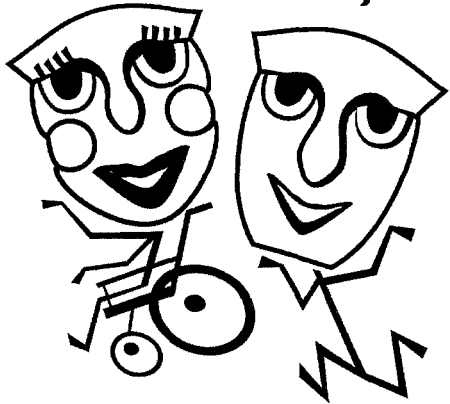
Guest artists this session include Karen Werner and F. Reed Brown

Additional assistance provided by Fran Cohen

that **UPPITY** *presents* theatre company

The Disability Project is an ensemble that engages in conversation, writing, sound, movement and theatrical exercises to develop performance material around the culture of disability. With both disabled and non-disabled participants, from 17-60 years of age, the Project endeavors to empower individuals, honor their stories, imaginations, foster community and enhance public awareness about disability.

The **Dis-Ability** Project



Recent and upcoming presentations include:

- Recreational Council of Greater St. Louis Annual Meeting
- Washington University School of Medicine Program in Occupational Therapy
- Mid-America Theatre Conference
- International Post-Polio Symposium
- Christ Church Cathedral
- Access to Participation Awards Dinner
- St. Louis Community College at Forest Park

Some of the challenges facing our participants have included spinal cord injury, Spina Bifida, Muscular Dystrophy, Multiple Sclerosis, Cerebral Palsy, AIDS, alcoholism, asthma, cancer, Polio, stroke, amputation and depression.

Deeply committed to the greater St. Louis area, we regularly offer open presentations for the public. And we are delighted to do short performances and lectures/demonstrations for various groups and to consult about developing similar projects in other communities.

If interested in learning more about That Uppity Theatre Company or The DisAbility Project, please email Uppityco@aol.com, or call That Uppity Theatre Company's 24-hour hotline at (314) 995-4600.

You can also write to us c/o Joan Lipkin, Artistic Director, That Uppity Theatre Company,
4466 West Pine Blvd., Suite 13C, St. Louis, MO, 63108, USA

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EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference
SAINT LOUIS, MISSOURI

Saturday, June 10, 2000

SESSION I

9:15 am - 10:15 am

- PAVILION SALON G **Spinal Problems and Solutions: Surgical Options (Part II)**
Lynne Breakstone; Carol B. Vandenakker, MD
- PAVILION SALON F **Activities of the Parents' Association of Children
with Ventilators in Japan**
Yoichi Sakakihara, MD
Options for Ventilator Users in Denmark
Lotte Mortensen; Grethe Nyholm Olsen, RNP
- PAVILION SALON A **Health Care Advocacy Strategies***
Robert J. Provan; Patricia Strong, MA
- PAVILION SALON E **Why Do Some People Thrive?**
Joyce Ann Tepley, LMSW/ACP, LPC
Succeeding in a Wellness Program
Sunny Roller, MA
- PAVILION SALON C **Maximizing the Efficient Functioning of the
Musculoskeletal System**
Todd Holmes, MD
- PAVILION SALON B **Anesthesia Concerns for Individuals with
Neuromuscular Problems***
Selma H. Calmes, MD

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri, June 8-10, 2000

SPINAL PROBLEMS AND SOLUTIONS: SURGICAL OPTIONS (Part II)

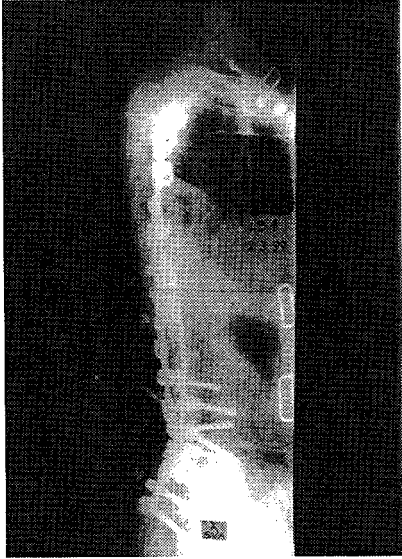
Lynne Breakstone



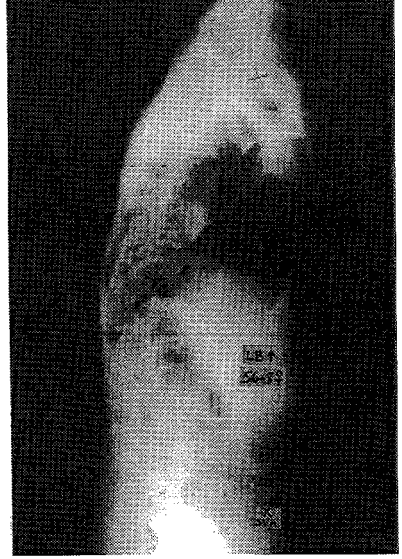
AFTER



BEFORE



AFTER



BEFORE

Eighth International Post-Polio and Independent Living Conference,
St. Louis, Missouri
June 8-10, 2000

SPINAL PROBLEMS AND SOLUTIONS

Carol Vandenakker, MD
University of Miami Post-Polio Clinic
Department of Orthopaedics and Rehabilitation
University of Miami School of Medicine

I. Introduction

The spine and supporting muscles are responsible for support and movement of the trunk. The spine protects the spinal cord and serves to support and stabilize the head, arms, and legs. Problems in the spine or the supporting muscles affect the entire body. Polio survivors may experience spinal problems related to paralysis such as scoliosis and osteoporosis. They also experience problems related to aging. Symptoms of several of these spine problems may be confused with post-polio syndrome.

II. Spinal Anatomy

The spine is composed of:

33 vertebrae- 7 cervical, 12 thoracic, 5 lumbar, 5 fused to form the sacrum and 4 form the coccyx

Intervertebral discs- outer fibrous tissue/fibrocartilage attached to the vertebral bodies with a soft nucleus pulposus that act as shock absorbers

Ligaments- collagen and elastic tissue that support the spine

Facet joints- joints between the vertebrae that permit movement

Spinal cord and nerve roots (31 pairs) –

The spinal cord consists of descending tracts carrying messages from the brain through motor nerves to muscles and ascending tracts carrying sensory feedback to the brain.

There are 31 pairs of spinal nerves (8 cervical, 12 thoracic, 5 lumbar, 5 sacral, and 1 coccygeal) that exit the spine.

Muscles- support and move the spine and trunk

III. Spine problems related to paralytic polio.

In individuals affected by paralytic polio, the virus crosses the blood brain barrier and infects the anterior horn cells in the spinal cord. Spinal cord involvement in acute polio results in paralysis of arms, legs, trunk and sometimes the diaphragm. Muscles stabilizing the spine are affected depending on which spinal nerves are involved.

Bone metabolism is also affected by paralysis. Acutely, calcium is lost from bone rapidly, peaking at 5 weeks, and continuing for 5-6 months. Immobilization causes further bone resorption. Mobilization can reverse the resultant osteopenia depending on the extent of motor recovery.

A. Osteoporosis

As a polio survivor ages with paralysis, limitations in weight bearing activities as well as the usual age-related causes of osteoporosis further impact bone density. Bone is an active tissue, constantly remodelling. It is when resorption of bone occurs at a faster rate than new bone formation that bone density is lost. Bone density peaks before age thirty and then decreases. Factors contributing to bone loss include inadequate calcium intake, vitamin D deficiency, disuse, certain drugs- including cigarettes and alcohol, and hormone changes, either menopausal or disease related. Once bone density falls below a certain level it is classified as osteoporosis. If the trunk is significantly affected by polio, osteoporosis can be expected. As a polio survivor ages and bone density decreases, risk of vertebral fractures increases.

C. Scoliosis

Studies have determined that the risk of a poliomyelitis survivor developing scoliosis is approximately 30 per cent. Spinal deformity results from trunk involvement with asymmetric intercostal, abdominal, and paraspinal muscle paralysis. Pelvic obliquity secondary to asymmetric muscle paralysis of the pelvic girdle is also a causative factor. The prognosis for worsening of the deformity is correlated to degree of weakness and age at curve onset. The spinal deformities in polio are generally long "C" shaped curves with associated pelvic obliquity. Other curve patterns are seen involving the lumbar or thoracic spine an isolated manner. As with other neuromuscular scoliosis, bracing has not been shown to alter the natural history of the curve. Bracing may be useful in young children with flexible curves but delaying surgical fusion in progressive curves is not recommended because of risk of dramatic increase during the adolescent growth spurt.

It was originally believed that when skeletal maturity is reached, scoliotic curves stabilize. The phenomenon of curve progression after skeletal maturity is now clearly established. The increased deformity may be a result of asymmetrical disk degeneration, vertebral compression, or lateral slippage of the vertebrae known as spondylolisthesis. The spine may become increasingly unbalanced or develop areas of stenosis, causing pressure on nerves. Cardiorespiratory function may be impacted with loss of lung capacity and increased pressure on the right side of the heart.

Pain is often associated with progression of scoliosis. The pain may be caused by muscle spasm, disc degeneration, facet arthrosis or a combination of these factors. Secondary central or foraminal stenosis can cause nerve pain. People with problems related to scoliosis may report loss of balance and increased frequency of falls, leg pain or weakness, and back pain. These symptoms may lead to increase in fatigue, loss of mobility and further weakness, making differentiation from post-polio syndrome difficult.

V. Spinal problems related to aging

Degenerative changes occur in the spine with aging. The degeneration usually starts with degeneration in the disks resulting in bulging of the annulus or disk herniation. Osteophytes then form from the bone, ligaments thicken, and facet joints sublux or become hypertrophied.

Spinal stenosis, which may occur in association with scoliosis or in a "normal" spine is defined as decreased dimension of the spinal canal and/or neural foramen. This decreased space may cause compression of nerves or blood vessels. The stenosis may be local, segmental or generalized. It may result from bone or soft tissue and may be congenital, acquired or a combination. The most common cause of stenosis is degenerative change in the spine.

The presenting symptoms of stenosis are vague back and/or leg pain and dysesthesias. Symptoms are increased by standing and walking and initially relieved by sitting or lying down. Symptoms worsen and become more disabling as the stenosis progresses.

Neuroforaminal stenosis causes pain when nerve roots are impinged upon. The pain may be associated with weakness or numbness in the distribution of the nerve root which exits the narrowed foramen.

V. Evaluation of spinal problems

Evaluation of the spine starts with a detailed medical history related to the symptoms experienced- duration, intensity, location and character. Aggravating and alleviating factors should be identified. History of injury or other health problems must be assessed.

Physical exam includes a thorough musculoskeletal and neurological exam. Any spinal deformities should be noted. Complete assessment of strength and sensation should be performed. Gait evaluation, posture and onset of symptoms in certain positions or with specific maneuvers are evaluated.

Diagnostic studies are useful to confirm or eliminate a diagnosis. Commonly X-rays, CT scan or MRI, and possibly bone scan or EMG are ordered.

VI. Solutions

Treatment for osteoporosis is available but prevention is considered the best approach. For a polio survivor with osteoporosis in areas of the body affected by paralysis, it is not known if the usual osteoporosis treatment is effective. Osteoporosis prevention and treatment focuses on proper nutrition and exercise. Approved medications for osteoporosis are estrogen, calcitonin, alendronate and raloxifene. Estrogen, raloxifene and alendronate are also approved for prevention.

Treatment for degenerative spine problems, progressive scoliosis, and spinal stenosis ranges from conservative to surgical. Conservative treatment may include nonsteroidal anti-inflammatory drugs, analgesics, and physical therapy. Corticosteroid injections are also used to reduce nerve inflammation and treat acute pain. If conservative treatment fails, surgical intervention may be indicated depending on the degree of symptoms, secondary disability, risk factors, and patient preference.

INFORMATION ON SPINAL PROBLEMS AND RELATED ISSUES

National Institutes of Health
Osteoporosis and Related Bone Diseases – National Resource Center
1232 22nd Street, NW, Washington DC 20037-1292
Tel (202) 223-0344 or (800) 624-BONE
Fax (202) 293-2356
TTY (202) 466-4315
Email orbdnrc@nof.org

Information on Spinal Stenosis
American Academy of Orthopaedic Surgeons
6300 North River Road
Rosemont, IL 60018-4262
Tel (847) 823-7186 or (800) 346-2267
Fax (847) 823-8125
Email webhelp@aaos.org
World Wide Web address <http://www.aaos.org/>

National Institute of Arthritis and Musculoskeletal and Skin Diseases
Information Clearing House
National Institute of Health
1 AMS Circle
Bethesda, MD 20892-3675
Tel (301) 495-4484
Fax (301) 718-6366
TTY (301) 565-2966
Automated faxback system (301) 881-2731
World Wide Web address: <http://nih.gov/niams/>

The Spine – Third Edition Volume 1
W.B. Saunders Company
The Curtis Center
Independence Square West
Philadelphia, PA 19106

Rehabilitation of the Spine
Science and Practice
Mosby-Year Book, Inc.
11830 Westline Industrial Drive
St. Louis, MO 63416

Introducing the activities of the Parents' Association of Children with Ventilator in Japan

**Yoichi Sakakihara, M.D.
Department of Pediatrics
Faculty of Medicine
The University of Tokyo**

Baku-Baku (onomatopoeia of bagging sound) Association (BBK) was founded in 1989 by the parents' group of children with long-term ventilator support in a hospital (Yodogawa Christians' Hospital) in Osaka, Japan. The aim of the association was to improve the quality of lives of children with ventilator support in the hospital. In those days, going out of the hospital with ventilator support was regarded as almost suicidal among medical professionals. Home ventilator care, which is a common medical practice now, was quite rare at that time. In 1990, BBK became a nation wide association, and current number of active members (children and their families) is 267(families) with 130 support members. The activities of the BBK include publication of bulletin ("Baku-Baku") and manuals for home ventilator-care, running internet home-page (<http://www.nsknet.or.jp/~mmasato>), holding annual meetings (national and regional) and sponsoring symposia on the life of children with ventilator care.

With the advocacy of BBK, going out of hospital with ventilator has become a common practice in Japan. Some of the members of BBK have even climbed snowy mountains and enjoyed sleighing. The number of children with home ventilator care has sharply increased in these years partly because the national insurance has covered cost for ventilator care at home. However the cost for professional care-giver has not been covered. It is one of the major challenge for BBK. BBK is also actively involved in a campaign to facilitate the provision of "medical care" at school. Securing the chances for education for children with ventilator support is another goal of the activities of BBK.

Most children with ventilator support are greatly deprived of motor activities. Development and improvement of special equipment designed to expand their quality of living are also carried out with the support of BBK. Some of the most severely affected children such as those with Werdnig-Hoffmann disease, are able to express their will by the subtle movements of eyeballs and play computer games and compose music.

Although the present situation surrounding children with ventilator support is not satisfactory, BBK is dedicated to the improvement of the quality of life of children with ventilator.

Along with the activities of BBK, I would like to introduce the current situation of children with long term ventilator care in Japan.

**A SURVEY OF 4 POLIO SURVIVORS CARED FOR AT A
DANISH INSTITUTION FOR VENTILATOR USERS (IRP)**

Lotte Mortensen, Matron
Institutionen for Respirationspatienter
Copenhagen, Denmark

The 1952 polio epidemics in Copenhagen left 26 ventilator-dependent patients. The majority could be transferred to their homes within the next few years, but about 10 patients could not be discharged due to family or social reasons. To house and care for those patients, IRP was established. It is an independent carehome situated in a social share-house run by the Copenhagen Municipality.

The patients in the Institution make up the following groups:

- Permanent residents.
- Night residents (they are living together with their families during the daytime).
- Residents living in own flats in the share-house, who are controlled and cared for by the Institution when needed.
- Temporary residents after discharge from hospital (for ventilator weaning, rehabilitation, or organization of proper homeware).
- Temporary stay to relief for family or caretakers.

The capacity of the Institution is 15 beds; 7 are used for night residents only.

A 24-hour duty is carried through by specially trained nurses and nurse-helpers. IRP has close cooperation with Danish Respiratory Center East as the patients are transferred to the center in case of complication. The medical consultant of IRP is also the medical head of the center.

From the very start, the Institution only received polio patients, but is now open to all kinds of ventilator users. For the time being, 8 of the residents have a polio/post-polio diagnosis.

A survey of 4 polio survivors, ventilator users since 1952:

Age in 1952-53:

A - 3 months; B - 2 years; C - 4 years; D - 6 years.

They all were almost totally paralyzed. They had a trach immediately and were ventilated. During the hospitalization, they all learned frogbreathing.

In 1960, they were discharged from the hospital to their families or IRP, all still ventilator-dependent.

While growing up, their needs were taken care of by family, Institution, or personal assistants. They all passed primary school. Two of them went to high school and university. One graduated in Scandinavian Literature; the other in Law.

From 1960-2000, they hardly had any admissions to the hospital. Smaller health problems were taken care of by the physician from the Institution.

Today, all have independent living in apartments attached to the Institution. One of them lives on his own with helpers 24 hours/day. The others are night residents in the Institution and have personal assistants 12-16 hours during daytime.

They are still 24-hour ventilator-dependent and need assistance for all practical doings.

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Home Care Ventilation in Denmark

Grethe Nyholm, Headnurse, Respiratory Centre East, Rigshospitalet,
Copenhagen, Denmark

In Denmark, home mechanical ventilation has been centralized in two respiratory centers. Each center serves a population of approximately 2.6 million people. The polio epidemics in Copenhagen in 1952 left 28 ventilator-dependent patients and some of them are still alive having the same ventilator.

Assignments of the centers:

- Treatment
- Guidelines
- Advisory functions

Concerning:

- Evaluation and control of respiratory insufficiency
- Follow-up and control of treatment
- Information to patient and their relatives
- Instruction, formal training, and supervision of patient, patient's relatives, and personal helpers
- Assistance to acute situations in cooperation with G.P. and local hospital
- Cooperation with governmental and local social authorities
- Follow the development of HMV-treatment

Today, the Respiratory Centre East serves more than 200 patients being home ventilator users. Thirty of them had polio.

In the home ventilation programme, the public helper system is essential. Generally, handicapped individuals in Denmark can have personal helpers to compensate for the loss of their functions.

According to Danish legislation the public service offers the following:

- Paid helpers 24 hours/day
- Free ventilators and equipment, and free service of equipment
- Special adapted modern flats are available
- Ventilator users may purchase a motor vehicle modified according to needs on favorable terms and without the very high Danish tax
- Additional wages for the helpers who go on holiday with the patient.

The personal helpers are preferably recruited among non-professional young people through advertising in the local newspapers. This public helper system makes it possible for ventilator users to establish an independent household, just as other people.

Through questionnaires we know that the quality of life among our patients is high. Studies have mainly focused on the prevalence of HMV and on the outcome of this treatment. In Denmark, six HMV users, the two Respiratory centers, the Danish Association for Muscular Dystrophy have made a study: "Equipment for HMV evaluated by the users." A total of 259 HMV users of either an invasive or a non-invasive respiratory assist device received a questionnaire comprising 29 questions. The main results from this HMV user initiated survey was an overall impression of a relatively high level of satisfaction with most of the available equipment.

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Health Care Advocacy Strategies

Robert Provan, J.D. & Patricia Strong, M.A.

Surveying the Landscape
Stats & stories

A Personal Question: So, who are the good guys?

A Personal Question #2: So, I didn't get one of the good guys, now what?
Nine steps necessary for "fighting the good fight".

Building the Dike Higher: Strategies For Systems Advocacy
Stories from personal experience and suggestions for the process

The Names in the Game
Definitions you'll need to know

Allies and Resources
Websites & phone numbers

Throw the Book At Them!
A brief bibliography

The Fellowship of Heroes
Quotes

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WHY DO SOME PEOPLE THRIVE?

Joyce Ann Tepley, LMSW/ACP, LPC

We are proud of ourselves for being polio survivors, but we do more than just survive. We *thrive*. What makes us *thrivers*, and do we have anything in common with each other? Those are the questions I set out to answer in a research project during a recent Creating Healthier Communities fellowship.

I interviewed twenty people, so far, who had various long-term physical disabilities. These were people from diverse racial and socio-economic backgrounds. I will discuss my preliminary findings about which traits and influences they felt helped them to *thrive*.

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Succeeding In A Wellness Program

Sunny Roller, M.A.

University of Michigan Health System—Ann Arbor, Michigan

*Part of a holistic wellness program can include
stress management exercises.*

*Even five minutes of exercise can make a difference in how you feel!
Adapting to your personal comfort and ability levels,
you are invited to try one of these...**

Progressive Muscle Relaxation Exercise

Do each exercise twice.

1. Clinch your right hand into a fist. Hold it tight. Relax.
Clinch your left hand into a fist. Tight. Hold it. Relax.
2. Lift and flex both arms at once as tight as you can. Relax.
Compare with the tension before. Let your arms go and sink into the
chair or carpet or bed.
3. Raise your eyebrows as far as you can. Relax.
4. Close your eyes tight. Squint them together. Hold them shut tight. Relax.
5. Clinch your jaw, bite hard to feel the tension (do not hurt your teeth).
Relax. When you are relaxed your lips might be slightly apart.
6. Press your tongue against the roof of your mouth. Press it hard. Relax.

7. Press your lips outward in an “O” shape and let them return to normal.
 8. Press your head back and observe the tension in the neck. Relax. Roll your head to the right and roll it to the left. Bring it back to the center.
 9. Press your chin against your chest. Feel the strain in your throat and back of your neck. Relax.
 10. Shrug your shoulders and relax. Let your shoulders drop back.
 11. Breathe in and fill up your lungs. Hold your breath. Exhale slowly and relax. Take another deep breath.
 12. Tighten your stomach muscles—hold it—relax. Put your hand on your stomach and hold your stomach muscles in and relax.
 13. Tighten your buttocks and thighs by pressing your heels against the floor. Hold it. Hold it. Relax.
 14. Arch your back and tense your lower back. Relax.
 15. Curl your toes downward and under, tensing your calves. Hold it. Relax.
 16. Bend your toes toward your face putting tension in your shins. Relax. Relax your feet, ankles, shins, calves, knees, thighs, buttocks, stomach, lower back, chest, shoulders, arms, hands, neck and face. Take a deep breath. Relax.
-

The Breathing Tree

Stand or sit erect. Feet apart, body balanced over hips. Arms at sides, palms forward.

Inhale arms slowly up. Stretch up, up

Exhale arms to starting position

Inhale arms to starting position

Inhale arms slowly up. Stretch up, up

Exhale arms out at shoulder level. Turn head to look at fingertips

Exhale twisting from the waist toward the direction you are looking

Inhale forward. Turn head to look at other fingertips

Exhale twisting from the waist toward the direction you are looking

Inhale head forward and arms down to starting position.

OPTIONAL:

Squeeze buttocks together. Inhale arms up. Tilt back

Relax buttocks. Soften knees. Exhale forward from the waist with extended arms

Inhale slowly up. Return arms to starting position. Relax.

* These exercises were used in the *Wellness for Women with Polio Program*, a pilot wellness workshop at the University of Michigan.



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Maximizing the Efficient Functioning of the Musculoskeletal System

Todd Holmes, MD

- I. Introduction
- I. Efficiency and abnormal function
 - A. Crutches
 - B. Canes
 - C. Wheelchairs
- I. Osteopathic Postural Model
 - A. Asymmetry
 - B. Range of Motion
 - C. Tissue Texture Abnormality
- I. Respiratory Model
 - A. Rib Cage Movement
 - B. Diaphragm Movement
 - C. Spinal Movement
- I. Normal Anatomy vs Abnormal Anatomy
 - A. Skeletal Abnormalities
 - B. Neuromuscular conditions
 - C. Respiratory conditions
- I. Bio-Psycho-Social Model
- I. Alternative/Complementary Approaches
- I. Maximizing Efficiency
- I. Conclusion

Abstract

The osteopathic model strives to improve the efficiency of each patient treated. When chronic conditions such as polio are present, the principles of treatment remain the same, but special efforts must be made to accommodate the changed anatomy and physiology. The structural model tests the elements of asymmetry, range of motion and tissue texture change. These are evaluated in the skeletal system, but also in the rib cage and diaphragm. Other factors in the bio-psycho-social model are examined. Alternative and complementary approaches may also be of benefit. These approaches are combined with the standard medical treatment to maximize the efficiency of the musculoskeletal system.

Todd Holmes MD, Assistant Clinical Professor of Physical Medicine and Rehabilitation, Michigan State University College of Osteopathic Medicine, East Lansing, Michigan; staff physician at Sister Kenny Institute, Minneapolis, Minnesota

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Anesthesia Concerns for the Polio Survivor

Selma Harrison Calmes, Md, Chair, Department Of Anesthesiology,
Olive View -- UCLA Medical Center, Sylmar, California

There are three types of anesthesia: general, regional, and monitored anesthesia care (MAC). *General anesthesia* is used primarily for major operations, and the patient is completely asleep. Gas and injected drugs, including muscle relaxants, are usually administered, and a breathing tube is usually placed. With *regional anesthesia*, only part of the body is numb. It is common to give some sedation also, so patients do not remember being awake. Spinal anesthesia and epidural anesthesia are common types of regional anesthesia and anesthetize the lower part of the body only. Regional anesthesia is useful when surgery is limited. It is also commonly used for prostate surgery. This anesthesia uses only a few drugs and is not as complicated as general anesthesia. MAC means that the surgeon injects local anesthesia at the site of surgery while an anesthesiologist gives sedation intravenously and ensures patient safety and comfort during the surgery. Cataract surgery is generally performed with MAC.

Although we know anesthesia today is extremely safe, no one has studied how well post-polio patients do during anesthesia. Patient safety during anesthesia depends on the anesthesiologist knowing the patient's history and selecting an appropriate anesthesia plan, taking into account all of the patient's disorders, as well as the planned surgery. It is vital that polio survivors speak with the anesthesiologist ahead of time and during the pre-surgery interview inform the anesthesiologist of their special conditions such as ventilator use, sleep apnea, body positioning problems, etc. Once the anesthesiologist has the necessary information, a suitable, safe anesthetic can be chosen. With this communication, polio survivors should not fear anesthesia and surgery, but obviously it helps if the anesthesiologist has had experience with polio survivors.

Problems may occur in post-polio patients during anesthesia. Sleep apnea may be worse immediately after surgery. Those individuals who do not have normal stomach emptying may be at risk for vomiting as anesthesia begins. Low blood pressure may occur with normal doses of common anesthesia medications. Changes in all patients' lungs occur during general anesthesia, and lung function is worse in everyone for about 48 hours after surgery. How much trouble polio survivors may face depends on their pulmonary function before the surgery, and they may have an increased need for ventilation post-operatively.

The most likely anesthesia risks for polio survivors occur with general anesthesia. Because they have lost motor nerves, polio survivors are very sensitive to muscle relaxants, and in essence, they may overdose on what may be a usual dose for others. Another significant risk is worsening ventilation after surgery for those with respiratory muscle involvement. This is temporary and is due to changes in the lung with anesthesia.

Measuring response to muscle relaxants is usually done routinely with a nerve stimulator which allows the anesthesiologist to check each person's response to muscle relaxants. With cautious use of muscle relaxant drugs, usually at half the normal dose, and careful monitoring, polio survivors should have no problems. The only study of post-polio patients undergoing anesthesia with the older muscle relaxants found that polio survivors were twice as sensitive to muscle relaxants as the general population. The recommendation was to cut the dose in half. Clinically, I think that recommendation is appropriate. If a patient also had vomiting preoperatively and had abnormal electrolytes (salts in the blood), even less than half the usual dose might be needed. Low electrolytes, common after vomiting and diarrhea, make muscle relaxants last longer.

With muscle relaxant drugs, all muscles are paralyzed but to varying degrees. The sensitivity of various muscles depends on muscle size and some other factors we do not entirely understand. In general, the eye muscles are very sensitive to muscle relaxants while breathing muscles are very inssensitive to muscle relaxants -- they are the last to be paralyzed when muscle relaxants are administered.

The paralyzing action of all muscle relaxant drugs eventually ends. The drugs are either redistributed away from the nerves, and thus diluted, excreted by the kidneys, or broken down by blood or liver enzymes. If paralysis is prolonged, the anesthesiologist would use a ventilator to breathe for the patient until the patient could breathe on his/her own, perhaps for as long as an hour, or more. Use of a ventilator is fairly common after major surgery and is not considered a serious complication.

Curare was the first available muscle relaxant drug. It comes from natural plants and has many possible side effects, such as flushing of the skin and lowering of blood pressure. When it was first introduced, we also did not have any medicine to reverse its effects. From the time curare was introduced in the late 1950s, drug companies were always actively trying to synthesize better muscle relaxants. They have been successful in the last few years. As a plant preparation from the Amazon, curare is also difficult to obtain now. It is not commonly used today, because there are so many better synthetic muscle relaxant drugs.

Common muscle relaxant drugs are vecuronium, pancuronium, mivacurium, rocuronium, atracurium, cis-atracurium, and succinylcholine. There are theoretical reasons to prefer mivacurium, atracurium, and cisatracurium over the other drugs. The action of these drugs ends by an enzymatic breakdown and is not dependent of redistribution of the drug away from the nerves. There is no information on these drugs with post-polio patients, but theoretically, there would be less chance for overdose. If overdose did occur, the effects would not last as long.

Short-acting muscle relaxants often used in anesthesia are rocuronium and succinylcholine. They cause muscles to contract first, before paralysis occurs, and are often used at the start of general anesthesia to help place a breathing tube. [A new airway device, the laryngeal mask airway (LMA), helps support an adequate airway instead of a breathing tube, and muscle relaxants are not required to place it. However, patients can aspirate stomach contents into the lungs with the LMA. In my experience, many post-polio patients are at risk for aspiration because they often have gastroesophageal reflux or a hiatal hernia, and the LMA would not be safe for them. A breathing tube prevents aspiration which can be a serious and even fatal complication.] Succinylcholine and rocuronium can cause severe muscle pain in polio survivors especially if the survivors will be up and about soon after surgery and should be avoided if possible.

Because of the hazards of general anesthesia in post-polio patients, it is useful to consider regional or MAC instead, if the operation can be done with those anesthetics. There is much less assault on the body and far fewer drugs are used. An epidural anesthetic probably has less risk for aggravating any pre-existing nerve damage in polio survivors and would be a good alternative to a spinal or general anesthetic. Polio survivors, as with the general population, should be in the best shape possible for elective surgery. They should not have a cold or bronchitis. If they still smoke, they should stop smoking as soon as they know about the surgery. They should control their weight and eat a high-protein diet after surgery to help their muscles stay in the best condition possible.

If you are about to undergo surgery, you must inform the anesthesiologist about your post-polio problems, possible sensitivity to muscle relaxants, and the need to monitor your response to them. If you are having elective surgery and have not had a chance to speak with the anesthesiologist beforehand, surgery should be postponed until this critical conversation occurs. Many anesthesiologists now have clinics or offices where they see patients several days before surgery. If the surgery is an emergency and you are physically able to communicate with the anesthesiologist, please do so before the surgery, or have a family member who is knowledgeable about your special conditions speak for you. If you are not satisfied with the response of the anesthesiologist, ask for another. With attention to all these details, you can have surgery safely and remain in the best possible health.

EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference
SAINT LOUIS, MISSOURI

Saturday, June 10, 2000

SESSION II

10:30 am - 11:30 am

- PAVILION SALON A **The Polio Virus and Acute Poliomyelitis***
Burk Jubelt, MD
- PAVILION SALON E **Nasal and Face Masks: What's Available**
Alan D. Fiala, PhD; Susan Sortor Léger, RRT
Working with a Home Care Company
Bob Fary, RRT
- PAVILION SALON F **Assessing Our Activities to Effectively Manage Our Lives**
Hilary Hallam; Richard Boone
- PAVILION SALON B **Footwear and Care for Polio Survivors***
Dennis J. Janisse, C.Ped
- PAVILION SALON C **Involved in Life: A Study of Polio Survivors;
Implications of the Mobility, Disabilities, Participation,
and Environment Research Project**
David B. Gray, PhD; Karen Hirsch, PhD; Mary Gould, RN, BA;
Heather Vargus, OTS
- PAVILION SALON G **Self-Management of Chronic Conditions**
Peter Jay

THE POLIO VIRUS AND ACUTE POLIOMYELITIS

Burk Jubelt, M.D.

History and Epidemiology

In the first half of the this century, epidemics of poliomyelitis (polio) ravaged developed countries. In the epidemic of 1952, over 20,000 Americans developed paralytic polio. With the introduction of the Salk inactivated polio vaccine (IPV) in 1954 and the Sabin live oral polio vaccine (OPV) in 1961, the number of paralytic cases decreased to a handful per year.

Poliomyelitis was reported sporadically from as early as 1600 to 1300 BC. However, epidemic poliomyelitis is a modern disease related to improved sanitation and human hygiene of the Western world. The first epidemics occurred in Europe in the mid-1800s and in North America in the 1890s. Prior to the occurrence of epidemic poliomyelitis in the late nineteenth and early twentieth centuries, paralytic polio was a disease of infancy (true "infantile" paralytic) that occurred as a rare complication of an endemic infection (constantly present in the community). This endemic epidemiologic pattern of disease still occurs in crowded, underdeveloped areas of the world, primarily in the tropics. In the temperate zones and developed areas of the world, there was less opportunity for infection in infancy as sanitary conditions improved. Thus, initial exposure to the virus occurred more frequently in later childhood and adult life when individuals are more likely to develop paralysis and death from the infection. Therefore these changes resulted in a shift from endemic to epidemic disease. Epidemics occurred in the summer and fall when crowding and poor sanitation facilitated hand-to-mouth, fecal-hand-oral dissemination, especially among younger children. In the late 1800s it was recognized that infection and destruction of motor nerve cells in the spinal cord (anterior horn cells) was the cause of the paralysis of poliomyelitis. In the early 1900s it was recognized that asymptomatic infection and transmission occurred via the gastrointestinal tract, and poliomyelitis was due to a virus as the disease could be transferred to monkeys by intracerebral inoculation.

Pathogenesis (the development of the disease)

Poliovirus and most enteroviruses are spread horizontally in the community by preschool children. Introduction of virus into an individual occurs from hand to mouth after fecal-hand-oral transmission. Poliovirus replicates in both the oropharynx (throat) and the gastrointestinal (GI) tract. In 90 to 95 percent of individuals infected with poliovirus (PV), the infection is inapparent (subclinical). Within 1-2 days new virus can be detected in throat and stool. Virus also may spread to the lymphocytes and blood stream from where it enters the central nervous system (CNS). In only about 5 to 10% of cases does virus reach the blood stream, and in only 1-2% does virus reach the CNS and only about half of this number (0.5-1%) develop paralysis. As noted above, the main brunt of infection occurs in the spinal cord anterior horn motor nerve cells. The brain stem (bulbar polio) and brain are less frequently involved.

The Virus

Poliovirus is a member of the picornavirus family. The term "picornavirus" is derived from "pico" meaning small and "RNA" indicating the genetic material of this virus family. Poliovirus is a member of the enterovirus subfamily of the picornavirus family.

Enteroviruses are 22 to 30 nm in diameter and icosahedral shaped. They lack a lipid envelope and thus are resistant to lipid solvents, and they are stable at room temperature and acid pH of 3.0 to 5.0. A single, infectious strand of RNA is enclosed in the capsid (protein shell), which is composed of sixty copies of each of four structural virus proteins. Viral replication occurs in the cytoplasm of infected cells. Enterovirus infections are highly cytotoxic, causing inhibition of cell protein synthesis and usually cell lysis (cell falling apart) through which the virus is released.

Human enteroviruses include the polioviruses (3 types); coxsackieviruses (23 group A and 6 group B types); echoviruses (31 types); and the newer enteroviruses (5 types). The coxsackieviruses were isolated in 1948 in and named after Coxsackie, New York. The echoviruses were isolated in the early 1950s. The newer enteroviruses were not isolated until the 1970s and 1980s. These other enteroviruses (coxsackie, ECHO, etc.) usually cause meningitis.

Until the coxsackie and echoviruses were isolated around 1950 it was thought that there were many cases of non-paralytic polio (only meningitis). However, the viruses circulate in the summer just like poliovirus, and were probably the cause of a majority of the cases of "non-paralytic polio."

Clinical Manifestations

Paralytic poliomyelitis can be of bulbar, spinal, or bulbospinal types. Spinal paralytic poliomyelitis is the most common type. It affects the legs more frequently than the arms, and paralysis is usually asymmetric, flaccid, patchy, and more proximal than distal. As paralysis progresses, reflexes are lost. Over several days, the other extremities may become paralyzed, and bulbar involvement may occur. Extension of paralysis is unlikely to occur 5 to 6 days after the onset of the initial paralysis. Atrophy develops over several weeks.

Bulbar or brainstem polio occurs in 10 to 15% of paralytic cases. It can involve any of the cranial nerves. Affected adults usually have bulbospinal poliomyelitis, whereas children are more likely to have isolated bulbar involvement. The most frequently involved cranial nerves are 7, 9 and 10, resulting in face weakness and difficulty with swallowing and voice. Brain stem involvement can also result in respiratory problems requiring ventilation, cardiovascular dysfunction and an altered level of consciousness (confusion to coma).

Prognosis

With good supportive care, especially for respiratory insufficiency, death from paralytic polio only occurs in 7 to 8% of patients. Death is usually the result of bulbar involvement with respiratory and cardiovascular problems. Patients who survive an acute attack of paralytic polio usually have significant recovery of motor function, although permanent and severe residual paralysis of one or two extremities is not uncommon. Motor improvement usually starts within weeks after onset. About 50% recovery occurs in 3 months, and 75% in 6 months. Minimal further improvement occurs slowly over the next several years.

How and Why Does Post-Polio Syndrome (PPS) Develop Latter

The most accepted criteria for diagnosing PPS are 1. Prior episode of poliomyelitis with residual motor neuron loss (can be confirmed by typical history, neurologic examination or electromyography), 2. After recovery, a period (usually 15 years or more) of neurologic and functional stability, 3. Gradual or rarely abrupt onset of new weakness or abnormal muscle fatigue, muscle atrophy or generalized fatigue, and 4. Exclusion of other conditions that could cause similar manifestations. As you all know, the most common manifestations of PPS are fatigue, pain and weakness. The average time of onset is 35 years after the acute polio.

There are three major theories as to the cause. The first is favored by the majority.

1. *Premature Exhaustion of New Sprouts Developing after Acute Poliomyelitis and of Their Motor Nerve Cells due to Excessive Metabolic Stress*

Enlarged motor units that develop via sprouting after the acute polio are more likely to become unstable later in life than are normal motor units. A motor unit is the motor nerve cell and the muscle fibers it supplies. With increasing time from the acute polio, neuromuscular transmission becomes more unstable. Several studies have shown that transmission delays and blocking occurred more frequently in symptomatic muscles. Muscle biopsy studies have revealed that 30 to 40 years after the acute poliomyelitis, there is disintegration of the new terminal sprouts that developed after the acute infection. It has been frequently hypothesized that the increased metabolic demand of an increased motor unit territory (too many muscle fibers for one motor nerve cell) results in premature exhaustion and death of the nerve cell (motor neuron). Even though there are no definitive studies examining the cell back to prove this, electrophysiologic and muscle biopsy data appear to be supportive. The overuse of muscles resulting in excessive muscular fatigue may also contribute to the excessive metabolic demand on motor neurons, and premature exhaustion might also be enhanced by the prior poliovirus infection of motor neurons with residual damage.

2. *Chronic Persistent Poliovirus Infection*

Poliovirus and other picornaviruses can persist in the CNS of animals and cause delayed or chronic disease. Poliovirus and other enteroviruses can also persist in the CNS in immunodeficient children. Studies in tissue culture have found that poliovirus mutants can persist without killing the host cell. Support for the persistent poliovirus hypothesis was enhanced by the findings of Sharief et al., who demonstrated poliovirus antibodies in the CSF of PPS patients. My collaborators and I have been unable to find poliovirus antibodies in the CSF of PPS patients, similar to the findings of three other studies.

3. *An Immune-Mediated Disease*

The strongest support for an inflammatory or immune-mediated mechanism for PPS stems from the study of Pezeshkpour and Dalakas in which inflammation in the spinal cords of seven post-polio patients was found. All changes were more prominent in the three patients with PPS. Two subsequent studies have also found inflammation in the spinal cords of PPS patients.

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Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri
June 8-10, 2000

**NASAL AND FACE MASKS:
WHAT'S AVAILABLE**

**Alan Fiala, PhD
Susan Sortor Léger, RRT**

View the latest in mask interfaces. Hear about the advantages and disadvantages of each from a respiratory therapist specializing in noninvasive ventilation and practical comments from a ventilator user who uses mask ventilation during the night.

WORKING WITH A HOME HEALTHCARE COMPANY

Robert S. Fary, RRT
Corporate Director of Respiratory Services

Homecare companies provide ...

- Oxygen
- Mobility
- Infusion
- Respiratory
- Incontinence
- Monitoring
- Wound care
- DME

Step 1: Get Prescribed

- Referred by Physician or Payor
- Physician/Case Manager Orders Equipment
- Setup in Hospital/Home

Step 2: Get Acquainted

- Equipment
- Clinicians and Technicians
- Customer Service and Billing

Step 3: Get Comfortable

- Equipment
- Clinicians
- Customer Service
- Family & Friends

Step 4: Get Help!

- 24-hour Service
- Home Visit Schedule
- Equipment Problems
- Change in Condition

Step 5: Get Going

- ADL's
- Air/Ship Travel
- Theater/Symphony

Cultivate and Maintain Relationships

- Clinicians
- Customer Service
- Technicians

**Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8 - 10, 2000**

**ASSESSING OUR ACTIVITIES TO EFFECTIVELY MANAGE OUR LIVES
and provide the medical profession**

with more information on the changes that are taking place.

Presented by Founder Hilary Hallam and USA Member Richard Boone
Lincolnshire Post-Polio Network, U.K.

Summary of Talk to be followed by interactive Session Sharing Ways We Now Do Tasks.

It has been 45 years since the vaccine was first introduced. 'No need to research it anymore, no need for long lectures or new polio specialists'. Very few Medical Professionals working today have actually seen a case of polio. If a health professional sees thin legs, different size feet, and callipers, then polio springs to mind. If we don't have these and say 'We have had polio', we are often asked 'Are you sure you had polio?'

There is a lack of knowledge in the UK of polio in its first instance and its late effects. Until recently most health professionals were not aware that PPS existed. Many inaccuracies are still being reported e.g. that it does not exist, that it does not affect the brain, you can't have problems in areas you were not paralysed. The majority of assessments are single disciplinary one off manual muscle testing (MMT) which grossly overgrade our actual muscle ability in contradiction to the symptoms we are reporting. We need multi-disciplinary PPS clinics staffed by specialists.

We ask that you take the following facts into consideration and then look back on your life.

- a) That at least 90% of all anterior horn cells were in some way affected during the polio infection (1. Bodian 1947)...
- b) but required the death of more than 60% to demonstrate any paralysis (2. Bodian 1949).
- c) That 40% damage found on autopsy had not shown clinically evident weakness. (3. Sharrard 1955). Therefore the diagnosis non paralytic polio comes above 40% and below 60% damage.
- d) This year the criteria for PPS should now be modified from paralytic polio to a history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous systems in earlier life. (4. Halstead & Silver 2000) which quotes Lincolnshire Post-Polio Library article January 1999 Non Paralytic Polio and PPS (5. Falconer & Bollenbach 1999)
- e) That a polio muscle manually muscle testing at '5 - normal' is only functioning at 53 to 59%, 4 at 40%, 3 at 20%, 2 at 10% and 1 at 1%. (6. Beasley 1981 and 7. Perry 1995)
- f) That one off manual muscle testing in a single discipline assessment does not test repetitive or sustaining power - weakness that we are reporting. (8. June LincPIN 1999)
- g) MMT tests instant strength. Muscle fibres contract, then rest, allowing others to take over. Someone with PPS may have only 40% of his original muscle fibres so in a short while there are no substitutes to take the load off resulting in fatigue of contracting muscles. Explained in Lincolnshire Post-Polio Library article Polio Biology X. (9 Bollenbach 2000)
- h) Decreased muscle strength due to a loss of anterior horn cells is a normal part of the aging process (10 Holman 1986) but there is no significant motor neuron loss before the age of 60 (11 Tomlinson & Irving 1985) yet many postpolio individuals experience serious changes at a much younger age, lessening the credibility of the theory that aging alone can explain the late effects of polio. The youngest patient diagnosed with PPS in Montreal is reported as 14 years of age (12 Cashman 1997)
- i) As we recovered from polio we learned substitution of muscles and we also 'asked' muscles up the chain to help so that we could achieve tasks. Most often we achieved way beyond what was expected initially, totally disguising the actual functioning level of our polio affected muscles. We have not forgotten this but we may not notice that it is happening unless we start to assess how we actually do what we do.

When and if PPS will start will all depend on what damage you had originally, how you recovered, what you have done with your life, and are still doing. We believe that by assessing how you actually do daily tasks now and comparing that with the way you used to do them at best recovery and how that has changed in between will give you information that you can pass on to those examining you. Saving money, time and stress for yourself and Health Professionals. When did you start noticing any change and what can you do to help yourself?

Polio Survivors


- 1 Fill out assessment sheets for all your daily activities. We need to assess each activity that we do and compare that with how we did this at best recovery. What has changed? When did this start changing and what is the progression. (Basic Example page 3 - and space for you to write down some of yours - use more columns for years in long version.)
- 2 Provide a visual time line of shaded in bodies with a few notes underneath. (Basic Example page 4 - space for you to do a simple version with only one PPS body, its better with more.)
- 3 This visual time line needs to be part of a File that you make about yourself in two formats. Long for your own reference with photographs and stories of your polio life and achievements from yourself/family/friends; your symptoms and when they started; and photocopies of your medical reports. Short notes - preferably on one side of one sheet only - that are double spaced to hand to those examining you.

To Health Professionals we ask:-

1. Please can you change your questioning from 'Can you do this activity?' to 'How do you do this activity?' Allowing us permission to tell you how we do it, rather than answer Yes.
2. That when you use one off manual muscle testing of muscles and you find e.g.:-
 - a) strong muscles but we say that arm is weaker that you ask us to do tasks with that arm, e.g. pick up a heavyish item from a table and bring it towards us.
 - b) strong leg muscles but we are reporting functional decline that you see us walking along a corridor not four steps across your office; climbing a flight of stairs rather than the 3/4 steps in a physio gym.
3. That you refer us to a recognised multi-disciplinary PPS clinic.

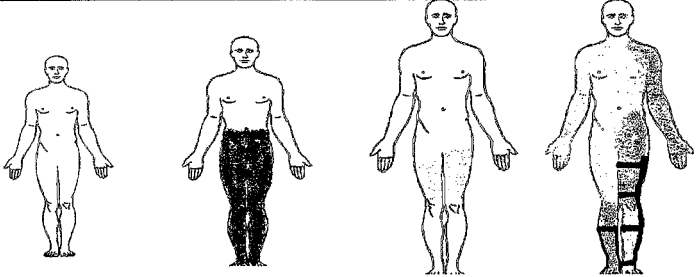
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- <http://www.ot.zynet.co.uk/polio/lincolnshire/network.html#linkpin>
Lincolnshire Post-Polio Network, 69 Woodvale Avenue, Lincoln, LN6 3RD, U.K.
Tel:- +44 (0) 1522 888601. Fax:- +44 (0)870 1600840 Email:- linpolio@legend.co.uk

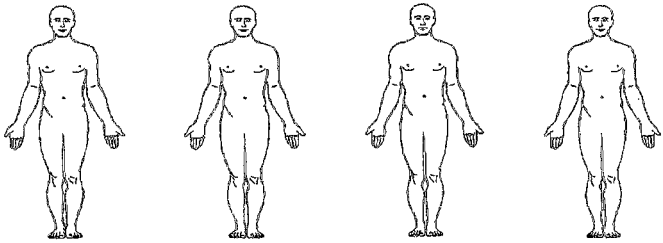
EXAMPLE OF SIMPLE ASSESSMENT FORM - HILARY HALLAM		
ACTIVITY	AT BEST	SINCE NEW SYMPTOMS FOLLOWING FALL IN OCT.1988
STAIRS	Go up two at a time.	'89 Normal '94 One at a time rt. foot. '97 Pull up with right arm as well '99 Go up once a night only. 2000 Live downstairs - do not use stairs unless no other way to get somewhere.
SWIMMING	Lifeguard Distinction Advanced Swimming/Lifesaving Teacher Grade I Examiner Lifeguard Training Officer.	Spring '89 Back to work following Fall Cannot swim as fast, fail all Lifesaving Awards, cannot pull self out of water. Forced to stop Teaching/Lifeguarding.
TYPING	Secretary - touch typist.	'97 Ergonomic Keyboard, '99 now left palm rest - plus type and rest.
WALK	'69 39 Mile Lyke Wake Walk '73 -'87 2 - 10 mile walks	'91 Started using cane on walks. '95 Started using cane in street '96 Manual chair but could not push it '97 Got Electric Scooter. '98 Got Ankle Foot Orthosis '99 Got Intelligent Knee Orthosis.
DRIVE	Advanced Police Driver	'91 Start lifting left leg onto clutch '95 Have to lift leg onto clutch '98 Have to drive automatic motability car.
CARRY BAGS	Could carry 56lb Sack of Potatoes	'89 Cannot hold items in left hand have to clutch to chest or hold arms length. '98 Now cannot carry handbag with left arm.
PICK UP PINT AND DRINK	Normally with one hand	Can pick up pint of fluid, but need two hands to carry it to mouth to drink.
ENTER YOUR OWN ITEMS - BRING THESE AND MORE TO SHARE DURING THE TALK		

SIMPLIFIED VERSION OF VISUAL TIME LINE - HILARY HALLAM			
BEFORE POLIO	POLIO	STABLE FUNCTIONING YEARS	NEW PROBLEMS (shaded) SINCE FALL OCT 1988 MAIN AIDS USED
0 - 5 YEARS 2 MONTHS.	5 YEARS 3 MONTHS	AGE 14 TO 41	OCT 88 (41) - JUNE 2000 (53)



NO KNOWN PROBLEMS	WAIST DOWN PARALYSIS	WEAK THIGHS, BUT ACHIEVED THE FOLLOWING	'99 LEFT LEG UTK SWING '98 RIGHT LEG AFO
	RECOVERY IN WORDS ONLY	POLICEWOMAN 1969 - 1973	'97 ELECTRIC SCOOTER
	LEARNED TO WALK AGAIN	RLSS LIFE GUARD >1988	'99 ELECTRIC RISE CHAIR
	DROPPED FEET - COULD NOT RUN	ADVANCED SWIMMING TEACHER >1989	'97 ROLL IN SHOWER
	MULT. TENDON TRANSFERS	ORANGE BELT JUDO	'97 ERGONOMIC KEYBOARD
	OPERATIONS ON BOTH FEET AGE 13	CANOE - ICE SKATE DANCE - LONG WALKS	'98 MOBILITY CAR & HOIST

SIMPLE SAMPLE FOR YOU TO FILL IN - FOR BETTER VERSION WE RECOMMEND YOU USE MORE THAN ONE BODY TO SHOW PROGRESSION FROM BODY THREE TO BODY FOUR



Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri
June 8-10, 2000

PEDORTHIC MANAGEMENT OF POST-POLIO SYNDROME
Shoes and Shoe Modifications

Dennis J. Janisse, C.Ped., Board Certified Pedorthist
Clinical Assistant Professor, Dept. of Physical Medicine and Rehabilitation
Medical College of Wisconsin, Milwaukee, Wisconsin

Conditions that may need to be treated

1. Pes cavus foot
2. Varus heel
3. Forefoot valgus
4. Inverted forefoot
5. Metatarsalgia
6. Mis-mated feet
7. Leg length discrepancies

Treatment objectives

1. Accommodate toe deformities
2. Relieve pressure (metatarsals, lateral border)
3. Control flexible conditions
4. Accommodate rigid conditions
5. Provide shock absorption
6. Balance weight bearing
7. Improve gait
8. Proper shoe fit

Modalities to accomplish objectives

1. Shoes
2. Custom-made shoes
3. Shoe modifications
4. Foot orthoses

In-depth shoe

INCLUDES

1. Strong counter
2. Adequate toe box
3. Shock absorbing sole
- 4., Removable insole
5. Wide range of sizes

PROVIDES

1. Shock absorption
2. Control of varus heel
3. Cushioning of metatarsals
4. Accommodation of toe deformities
5. Accommodation of custom foot orthoses
6. Mis-mated sizes / proper shoe fit

Shoe modifications

SOLE AND/OR HEEL EXTENSION

1. Accommodate leg / foot length
2. Balance weight bearing
3. Improve gait

LATERAL SOLE AND HEEL FLARE

1. Control varus heel
2. Control supination
3. Stabilize foot

LATERAL HEEL WEDGE – INTERNAL OR EXTERNAL

1. Control varus heel
2. Control supination

ROCKER SOLE WITH APEX PROXIMAL TO METATARSAL HEADS

1. Relieve metatarsal heads
2. Provide shock absorption
3. Replace lost or painful motion

CUSHION HEEL

1. Absorb shock at heel strike

FIBERGLASS LATERAL COUNTER

1. Control supination
2. Control varus heel
3. Provide support

FOOT ORTHOSES

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Redistribute weight

FLEXIBLE ORTHOSES WITH METATARSAL RELIEF AND P.Q. VISCOELASTIC POLYMER FOR METATARSALS

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Extra relief for metatarsal heads

FLEXIBLE ORTHOSES WITH METATARSAL PADS AND P.Q. RELIEF FOR 5TH METATARSAL SHAFT AND 5TH METATARSAL HEAD

1. Cushion foot
2. Relieve metatarsals
3. Control varus heel
4. Relieve pressure on lateral border of the foot and metatarsal heads

LATERAL FOREFOOT POST

1. Help control varus heel
2. Compensate for forefoot valgus
3. Relieve pressure on lateral border

HEEL EXTENSION

1. Accommodate equinus deformity
2. Balance weight bearing
3. Improve gait

Summary

- BIOMECHANICAL KNOWLEDGE IS NECESSARY WHEN PRESCRIBING. ONE OR COMBINATION OF ALL MODALITIES MAY BE NEEDED.
 1. Shoes
 2. Foot orthoses
 3. Shoe modifications
 4. Custom-made shoes
- RIGID AND FLEXIBLE CONDITIONS ARE TREATED DIFFERENTLY. ENCOURAGE COMPLIANCE WITH PEDORTHIST.
 1. Complete prescription
 2. Return visits as needed
- MODIFICATIONS MUST BE DONE CAUTIOUSLY AND MONITORED WITH FOLLOW-UP VISITS.
- CONDITIONS/PROBLEMS CAN CHANGE, SO PEDORTHIC PRESCRIPTION MUST BE CHECKED PERIODICALLY.

Thank you.

NATIONAL PEDORTHIC SERVICES

Milwaukee, Wisconsin
Madison, Wisconsin
Downers Grove, Illinois
Muncie, Indiana
Indianapolis, Indiana
Rochester, New York
St. Louis, Missouri

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri
June 8-10, 2000

Involved in Life: A Study of Polio Survivors

Implications of the Mobility, Disabilities, Participation,
and Environment Research Project

Principal Investigator:

David Gray, Washington University Program in Occupational Therapy

Co-Principal Investigator:

Karen Hirsch, Missouri Institute of Mental Health

Research Project Director:

Mary Gould, Nurse Coordinator, Division of Infectious Diseases,
Washington University School of Medicine

Heather Vargus, OTS, Washington University Program in Occupational Therapy

1) Overview of the Project:

What are we studying?

- ❖ Participation: How much are polio survivors involved in daily life activities?
- ❖ Facilitators: What are the helpful features of the environment?
- ❖ Barriers: Which environmental features make life difficult?

2) What tools are we using?

- ❖ Participation Survey—Mobility (PARTS/M)
- ❖ Facilitators And Barriers Survey—Mobility (FABS/M)

3) What are we finding? See attached abstract.

- ❖ Importance: What is and is not important to polio survivors?
- ❖ Satisfaction: What gives us the most satisfaction?
- ❖ Choice: How much choice do we have in how, when, and where we do things?

4) What are the implications of this research for polio survivors?

- ❖ We are documenting why we call ourselves “survivors.”
- ❖ We are studying the impact of home visits from polio peers.
- ❖ We are finding out what we do of ordinary life activities and what we do that is different.
- ❖ We are sharing with other polio survivors our ideas for how to cope with changes in our physical selves.
- ❖ We are developing ideas for how to change our homes and our activities to make life easier for polio survivors.

What is the value of research, such as this study?

- ❖ We are using our experiences to help develop tools that will be useful for people with all kinds of mobility impairments in the future.
- ❖ We are participating in developing ideas that professionals, such as Occupational Therapists, need to learn about so they can better serve disabled people.
- ❖ We are demonstrating to researchers the value of including people with disabilities in research about disability issues:

Nothing About Us Without Us!

Funded by the Center for Disease Control and Prevention

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri
June 8-10, 2000

Involved in Life: A Study of Polio Survivors

Implications of the Polio Survivors Study from the Mobility, Disabilities, Participation and Environment Research Project

David B. Gray, Ph.D., Heather Vargus, OTS, Kerri Morgan, OTR, and Denise Curl, B.A.

The results of this study regarding physical symptoms experienced by polio survivors are consistent with the inclusion criteria for the diagnosis of post-polio syndrome. Pain, fatigue, and physical impairment, were reported by participants in this study as limitations to participation in various activities. While previous research has studied the pain and fatigue symptoms experienced by individuals with post-polio syndrome, the results of this study indicate that the presence of a physical impairment has the greatest affect on an individual's participation in life activities.

This new information reinforces the importance of the compensatory approach in the treatment of polio survivors. In addition to the compensatory treatments currently used for symptoms of pain and fatigue it is important for medical personnel to incorporate environmental adaptations for many polio survivors experiencing limitations due to a physical impairment.

The results of this study also identify potential areas for intervention when working with a polio survivor. According to the focus group participants, moving activities may be an area in which further therapeutic intervention is appropriate due to the differences between importance and satisfaction scores.

When occupational therapists work with individuals they must remember the experience is a dynamic one. As the client's symptoms, attitudes, and environments change, so must the role of the therapist.

Through the use of an assessment such as the PARTS/M therapists may gain a comprehensive understanding of an individual's perception of their performance in

various activities: how important the activity is to them, how much choice they feel they have when participating, and how satisfied they are with their participation. If there is a great discrepancy between the importance of a particular activity and the satisfaction or choice an individual feels they have – it would be a potential area for occupational therapy to address.

The PARTS/M and FABS/M can also help identify potential reasons for not participating which may also need to be addressed by the therapist. These issues may be personal factors (such as illness, pain, fatigue, a physical impairment) or those in the external environment (the attitudes of others, inaccessibility of the environment, etc).

The knowledge provided by these two surveys facilitates a therapist's ability to develop a comprehensive client-centered therapy program. They can tailor the program to meet all activity areas in which the individual participates. The scales provided for each activity relating the client's perceived importance, satisfaction, and amount of choice provided helps determine the need for OT intervention in that given activity.

**Eighth International Post-Polio and Independent Living Conference,
St. Louis, Missouri, June 8-10, 2000**

**Self-Management of Chronic Conditions
Peter Jay, The British Polio Fellowship**

In July 1999, the British Government launched a White Paper, entitled *Saving Lives: Our Healthier Nation*; its five year action plan to tackle poor health.

The Paper outlines proposals to develop a programme to assist people living with long-term conditions to become better self-managers. Specifically, the Government has established a Task Force under the auspices of the Chief Medical Officer to:

- * design an expert patients pilot programme
- * look at the role those affected can have to help themselves better manage their condition
- * set out the relationship between expert patients programmes and the support people require from the National Health Service (NHS)
- * provide advice on what needs to be done to make services for people with long term conditions a central part of the NHS

The launch of this Paper towards the end of the first year of the *Lill Project* is not only a ringing endorsement of self-management, but provided an opportunity to use the *Lill Project* as a conduit to promote the views of people living with long-term conditions to the Government's Task Force.

What is the Lill Project? Lill stands for Living with Long-Term Illness

Lill is a three year action research project supported amongst others by the Department of Health, The Kings Fund and GlaxoWellcome. Its aims are to develop existing knowledge of self-management programmes in the UK, and increase the number of self-management programmes, among organisations working with people living with long term illness.

One of the most defining and powerful characteristics of the project is the fact that the courses are lay led, delivered by lay people all living with long-term conditions. In May 1999 14 volunteers, including myself, were trained to deliver Kate Lorig's Chronic Diseases Self Management Programme. Arthritis Care was commissioned by The Long Term Medical Conditions Alliance (LMCA) to provide training, support and supervision to the Self-Management Tutors (SMT). Supporting Arthritis Care's consultant in self-management programmes Jean Thompson is Jim Phillips the consultant trainer for the British Liver Trust. Both Jean Thompson and Jim Phillips have a long term medical condition themselves.

Organisations participating in this project and who are members of LMCA all represent people who live with long term chronic conditions. Alliance members include Action for ME, British Diabetic Association, Depression Alliance, Haemophilia Society, National Osteoporosis Society, National Endometriosis Society and The British Polio Fellowship. The exciting part of this project is that this course has never been trialed with these groups anywhere else in the world.

The first set of courses were delivered in the Autumn 1999 and the second set in the Spring 2000.

What the Lill project has set out to do:

Map existing self-management programmes, identifying areas of good practice, address common issues to assist organisations wishing to develop their own self-management programmes.

Provide a central co-ordinating role for information sharing, and facilitating partnerships for joint working.

Establish and convene a UK self-management Network which meets bi-annually.

Assist the LMCA organisations to set up, monitor and evaluate their own CDSMC, and help organisations to identify potential sources of funding.

Monitoring and evaluation is an integral part of the Lill project

The Psycho social Rheumatology Research Centre at Coventry University are evaluating the experiences of participants on the course both before attendance and at four and twelve months after attendance. The Centre has developed a wealth of knowledge from their research into the Challenging Arthritis Programme, which they can utilise and build on for the Lill Project.

Fundamentals underlying the self-management course

Social model of health/disability

It is lay led by people living with long-term conditions

It is group intervention

It is about sharing self-management techniques, not information giving

It is based on individual goal setting

It is a generic course working across conditions

It has a proven track record

It sees people with long-term conditions as a resource not a drain on the health service

It has the potential to challenge social exclusion

It complements traditional healthcare

It is based upon the principle of “can do”

It is unique

THE QUESTIONS MOST OFTEN ASKED ABOUT THE C D S M P ARE;

- 1 TELL ME MORE ABOUT THE COURSES. WHAT'S INVOLVED?
- 2 IT'S NOT ABOUT OFFERING PEOPLE A CURE, IS IT?
- 3 CAN ANYONE WITH A CHRONIC CONDITION BENEFIT FROM THE COURSE?
- 4 HOW DOES THE COURSE DIFFER FROM OTHER SELF-HELP GROUPS?
- 5 HOW SUCCESSFUL IS THE COURSE? CAN YOU GIVE ANY EXAMPLES OF THE WAY PEOPLE HAVE BENEFITED?
- 6 WHAT DO GP's/CONSULTANTS THINK OF YOUR METHODS? ARE THEY SCEPTICAL?
- 7 WHERE ARE COURSES AVAILABLE AT THE MOMENT?
- 8 WHERE CAN PEOPLE FIND OUT MORE?

EIGHTH INTERNATIONAL
Post-Polio AND
Independent Living
Conference
SAINT LOUIS, MISSOURI

Saturday, June 10, 2000

12:45 pm - 1:15 pm
PAVILION BALLROOM

*Celebrating the Tenth Anniversary of the
Americans with Disabilities Act:*

The Unfinished Revolution

Robert J. Provan, Provan & Associates, PC

Robert J. Provan, a 50-year survivor of childhood polio, is currently the owner of Provan & Associates, a law firm in Austin, Texas dedicated to pursuing lawsuits under the Americans with Disabilities Act and/or helping individuals to battle, through legal channels, an uncaring and non-responsive healthcare system.

A graduate of Slippery Rock State University in Pennsylvania, Bob attended the University of Texas School of Law. Immediately after law school, he went to work as a litigator for the Attorney General of the state of Texas. He left that post to become general counsel of Stephen F. Austin State University in Nacogdoches, Texas, where he stayed for 13 years. From there, Provan became general counsel for the Texas State University system, enjoyed a brief stint in private practice for a College Station, Texas-based firm, and then opened his own shop four years ago.

Provan is currently the subject of an A&E "Investigative Reports" program due to air in late summer spotlighting his personal commitment to and battle with HMO practices which discriminate against the disabled. His chief attack thus far has been his work in the *Zamora, et al. v. Humana, et al.* lawsuit pending in federal district court in San Antonio, Texas. That lawsuit focuses on the financial incentives employed by Humana and PacifiCare in their contracts with medical providers to discourage high-cost patients which, of course, means patients with disabilities who have chronic conditions and need frequent, and often expensive, medical treatment. The case is due to go to trial in November 2000.

Lighting of Spirit of the ADA Torch

Cyndi Jones, The Center for an Accessible Society

Robert J. Provan, Provan & Associates, PC

Bill Stothers, The Center for an Accessible Society

EIGHTH INTERNATIONAL
**Post-Polio AND
Independent
Living
Conference**
SAINT LOUIS, MISSOURI

Saturday, June 10, 2000

SESSION III

1:30 pm - 2:15 pm

PAVILION SALON B

Ventilator Users: Unanswered Questions*

Augusta S. Alba, MD; Audrey J. King, MA;
Edward Anthony Oppenheimer, MD

PAVILION SALON D

An Ideal Post-Polio Clinic: Philosophy and Design

Jessie K.M. Easton, MD; Karen Kennedy, MSW, CSW;
Wendy Malisani; Jack Martin, PT

PAVILION SALON A

**Guide to Developing a Post-Conference
Personal Plan of Action***

Linda L. Bieniek, CEAP; Linda Wheeler Donahue

8th International Post Polio and Independent Living Conference
Saturday June 10, 2000
1:30- 2:15 p.m.

SESSION III OPTIONS

VENTILATOR USERS UNANSWERED QUESTIONS

Speaker: Augusta S. Alba, M.D.

8th International Post Polio and Independent Living Conference
Saturday, June 10, 2000
Augusta S. Alba, M.D.
1:30 -2:30 p.m.

SESSION III OPTIONS

VENTILATOR USERS: UNANSWERED QUESTIONS

Short-term Noninvasive Ventilator Users (ER/ICU)

For what conditions in acute settings is noninvasive ventilation used? What is the success rate?

- BiPAP has been used in hypoxemic respiratory failure (RF), acute hypercapnic RF, chronic hypercapnic RF, post extubation RF, with an overall success rate of 60%.²
- Others report an overall success rate of 70%. Asthma exacerbations and status asthmaticus, congestive heart failure, acute respiratory distress syndrome (ARDS), severe pneumonia have been treated.

When should an acutely ill person be placed on noninvasive ventilation?

- Protocol guided noninvasive positive pressure ventilation NPPV: alert cooperative patient that meets at least two of the following: pH under 7.30, PaCO₂ over 55mm Hg, PaO₂ under 80mm Hg or an oxygen saturation under 92% on 100% non-rebreather masks, RR over 25 breaths per minute, severe dyspnea by the Borg Dyspnea Score or labored breathing⁷

What is inspiratory muscle strength training and when is it used?

- Use of inspiratory muscle strength training can facilitate ventilator weaning, when the individual on the ventilator had not been a long-term ventilator user prior to the acute illness.
- High intensity, low repetition program of 3-5 sets of 6 breaths per set using an inspiratory muscle trainer attached to the tracheostomy tube was provided. Training pressure targets were set at the maximal pressure with which patients should accomplish 6 inspirations. Patient were returned to pressure support ventilation for 2-5 minutes of rest between sets. Training pressures and spontaneous breathing periods were increased daily as tolerated.⁶

Long-term Ventilator Users:

Are ventilator users going home from the hospital?

- Fewer tracheostomized patients on ventilators are going home on mechanical ventilation, and more are being placed in nursing facilities in the past five years.

Can a nasal mask affect facial configuration?

- If a nasal mask with pressure on the perinasal region of the maxilla is used in children, care must be taken to assure that this region of the face does not become severely hypoplastic from the pressure caused by the counteracting force of the headgear to maintain the mask in position and to prevent leaks. By age four years about 60% of the adult face is developed. By age 12 years 90% of facial growth is completed. In the adult there may be some impact on the vascular bed irrigating the upper regions of the maxillomandibular structures.
- Recommendations include the yearly assessments of the individual child and the accumulation of more data on the long-term use of face masks at all ages.

Do persons who need artificial ventilation at night always use it as recommended?

- Patients with chronic respiratory failure from both restrictive ventilatory disorders or COPD may not use NPPV long-term. Of a group of forty, ten discontinued NPPV at six months and three progressed to tracheostomy. Of the twenty six patients who continued its use, they claimed to use it 7 hrs/night, but logged metered use 4.5 hours/night³

Does placing persons with ALS on artificial ventilation improve overall breathing ability?

- Amyotrophic lateral sclerosis: The average decline of FVC% and FEV1% was 1.7% per month and was not significantly altered by the initiation of NIPPV. There was a small, but significant drop in both of these PFT's when NIPPV was started. Improved survival with the use of NIPPV is not because of a decrease in the rate of decline of lung function with its use.¹

Can individuals with kyphoscoliosis be maintained in the home on long-term ventilation?

- Forty kyphoscoliotic patients with chronic hypercapnic failure have been ventilated successfully from 1-8 years with invasive and noninvasive positive pressure ventilation in the home.⁴

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An Ideal Post-Polio Clinic:

Philosophy and Design

Jessie K.M. Easton, M.D.

University of South Dakota School of Medicine
Sioux Falls, South Dakota

Each person who attends a clinic for polio survivors has a different set of needs and expectations. Some have braces and just need a new one, or information about the latest in assistive devices. Some have not seen a physician for years and need a complete history and physical examination, with referral to other sources for medical care of problems that can be treated. Most need information about their condition and what can be done to help. Some are not ready to make changes to accommodate altered ability, some are ready and can be helped with finding resources or applying for assistance. The clinic to serve this varied group of people needs a flexible approach and multiple resources.

Clinic models often depend on the personnel available in a community. A single physician may be interested in post-polio problems and see patients on a "triage" basis, referring them to physical therapist, occupational therapist, nutritionist, psychologist, social worker or orthotist and following them along as need arises.

Where resources are available, a multidisciplinary clinic can save the patients time and travel by having the various therapists present to examine and recommend on the same day. Some patients do not have the endurance to do this and may need to be seen on several days or be admitted to a residential-type facility (hospital or rehab unit) for a more leisurely, in-depth assessment and trial of equipment and new ways of doing things.

One essential for all models is the provision of information about the post-polio problems and their effects, for family members as well as patients. Video tapes and written material or audio tapes can be used, and loaner material to be taken home help to educate family and friends away from the threatening atmosphere of the clinic or doctor's office.

Follow-up is essential also. The recommendations made at the first visit need to be checked for effectiveness and whether they were done, new equipment need to be evaluated for effectiveness, forms for employers and insurance companies and government bodies need to be completed, and the staff and patients need encouragement to go on. Over time, needs may change and new approaches be required.

An Ideal Post-Polio Clinic cont.

Sioux Falls Experience

Beginning in 1987, McKennan Hospital sponsored a multidisciplinary clinic for post-polio patients, staffed by a physiatrist, physical therapist, occupational therapist and social worker, with referrals to nutritionist, psychologist, orthotist, or other medical specialists as needed. Over the years, some 170 patients had been seen in a monthly clinic. A few more had been seen individually by the physiatrist for a total of 184. Two thirds were women. Ages ranged from thirty to seventies and eighties. Most had a clear history of polio and were complaining of new pain, weakness and fatigue. A few had other causes (stroke, suspect muscle disease) and were referred for investigation. Some had medical problems that could be referred to their primary physician or specialist for management. Braces were recommended for some, and most actually got them and benefitted from wearing them, finding the newer models less objectionable than the remembered ones they'd discarded as teenagers. Fitting was sometimes a problem, as the orthotists wanted to correct everything at once. So did we, but soon found that it takes time to adapt to lifestyle changes and different ways of moving about. Most were able to walk and wanted to continue doing so. We did recommend wheels, either manual or powered, for distances where fatigue was a problem.

The local support group functioned as an adjunct to the clinic for those living in the area. Contact with other patients and exchange of information helped with adjustment to changing abilities.

Financial concerns needed to be addressed, for changing or stopping work, or applying for pensions (and the label of disabled) or for payment for equipment or home adaptations. A few referrals were made to Vocational Rehabilitation Services, but most were able to obtain Social Security benefits or to change their work on their own.

Continuity was important, and the person who functioned as coordinator of the clinic (in our case, the social worker) had to be knowledgeable about the patients, the post polio problems, and keep track of who, what and where, as well as making appointments and soothing agitated people who felt they needed to be seen now.

The most important lesson we learned was the need for patients to do things when they were ready, not necessarily when we thought they should. This meant a delay in solving problems at times, but overall a better success rate and more satisfied patients.

**GUIDE TO DEVELOPING A POST-CONFERENCE
PERSONAL PLAN OF ACTION**

Linda L. Bieniek, CEAP
LaGrange, Illinois

Linda Wheeler Donahue
Southbury, Connecticut

As a result of what you've learned and experienced during the conference, what do you want to *change in your life* during the coming year? This change *MUST apply to you* and not to someone else (since you cannot change another person). State your desired goal in **POSITIVE TERMS**.

1. GOAL. I want to ...

- | | | | | |
|----|---|-----|----|--------|
| a. | Is your goal realistic ? | Yes | No | Unsure |
| b. | Is your goal within your control ? | Yes | No | Unsure |
| c. | Can you initiate this change? | Yes | No | Unsure |

If you answer "No" or "Unsure" to any of the questions, then revise your goal. It needs to be realistic, within your control, and something you can initiate.

REVISED GOAL. I want to ...

2. SPECIFICS:

- a. **WHEN** do you want to achieve this goal?
- b. **WHERE** do you want this to happen?
- c. **WITH WHOM?** (if someone is involved in helping you achieve this goal)

3. **VALUES:** How will your goal **express what is important** to you?

4. **EVIDENCE:** *What will **tell and show you** that you have achieved your goal?*
 - a. How will **your life look**?
 - b. How **will you look** when you accomplish this goal?
 - c. How **will you feel**? (about yourself, life, or your accomplishment)
 - d. What **will you notice hearing** when you experience what you want?
 - e. How **will you sound** when you experience what you want?

5. **BENEFITS.** How do you expect to **benefit** from this change? How **will this goal improve your life**?

6. **POTENTIAL CONSEQUENCES:** What, if any **negative effects** might this change cause in **some part of your life**? In the **lives of others**? **Who may disapprove** of this change?
 - a. What part of your life?
 - b. How?
 - c. Others?
 - d. How it may affect them:
 - e. Reasons they may disapprove:

7. **CURRENT REALITY**

a. **WHERE ARE YOU** in relation to this goal right now?

- Thinking about it stage.
- Have already started to get information.
- Told others I want to do this.
- Uncertain about how I can experience this goal.
- Excited about the possibilities.
- Daydreaming about it.
- Involved in a crisis and need to make this change as soon as possible.
- Bored or frustrated with the status quo.
- Other:

b. What do **YOU NEED TO DO** in order to experience what **YOU WANT**?

- Obtain information about:
- Accept my needs or limits about:
- Gain Support (from whom or where):
- Obtain assistance with a health issue:
- Resolve a relationship issue:
- Organize my financial resources:
- Other:
- Other:

8. **RESOURCES & SUPPORTS.** What will help you achieve your goal?

Examples:

Internal - focused, good at seeing possibilities, ability to negotiate, spiritual

External - friends, supportive spouse, income, computer, accessible home

Strategies (what you DO) - pray, plan, prioritize, arrange for work accommodations, hire a cleaning person, say "NO" when tired, exercise

Internal:

External:

Strategies:

9. **OBSTACLES.** What may interfere with your goal? Slow you down? Distract you?

Examples:

Internal - shyness, fatigue, fear of how others will react to you, shame

External - work obligations, limited finances, taking care of a parent

Behavior patterns - avoid asking for help, judgmental of self or others, use alcohol to relax, eat unhealthy foods, smoke, overwork, help others while neglecting oneself

Internal:

External:

Behavior Pattern:

10. **NEEDS.** What **additional resources and supports do you NEED to overcome any obstacles and accomplish your goal?**

Examples:

Internal - grieve, being unable to walk, accept your needs

External - an accessible home, motorized scooter, housekeeping help

Strategies - consult local Independent Living Center for services, work with a therapist, hire a personal coach, get groceries delivered, ask church for volunteer help, read about relationship issues, organize your finances

Internal:

External:

Strategies:

11. **ACTION STEPS.** What do you **need to do?**

- a. What is the **first step** you will take?

When?

Where?

With whom?

- b. What is the next step you will take?

When?

Where?

With whom?

- c. What is the third step you will take?

When?

Where?

With whom?

EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference
SAINT LOUIS, MISSOURI

Friday, June 9, 2000

Learning About and From Post-Poliomyelitis: A Seminar for Physical and Occupational Therapists and Physical and Occupational Therapist Assistants

MORNING SESSION

- 7:45-8:15 am *Continental Breakfast*
FORT SAN CARLOS
- 8:15-9:10 am *Pathophysiology of Acute Poliomyelitis and Post-Polio Syndrome*
FORT SAN CARLOS
FREDERICK M. MAYNARD, MD, Upper Peninsula Rehabilitation Medicine Associates,
Marquette, Michigan
OBJECTIVE: Describe the pathophysiology of acute polio; compare/contrast with the
pathophysiology of other frequently occurring neuromuscular diseases; describe
the pathophysiology of the late effects of polio.
- 9:15-10:15 am *Pulmonary Problems: Signs and Symptoms and Screening*
PAVILION BALLROOM
(Plenary session for entire conference)
PETER C. GAY, MD, Division of Pulmonary and Critical Care, Mayo Clinic,
Rochester, Minnesota
OBJECTIVE: Describe the signs and symptoms of breathing problems of aging
polio survivors; describe appropriate screening techniques; explain interpretation
of results.
- PAVILION BALLROOM *Cardiac Problems: Signs and Symptoms and Screening*
(Plenary session for entire conference)
RUPERT D. MAYUGA, MD, Assistant Professor of Clinical Medicine (Cardiology),
Northwestern University Medical School, Chicago, Illinois
OBJECTIVE: Describe the signs and symptoms of cardiac problems of aging polio
survivors; describe appropriate screening techniques; explain interpretation
of results.
- 10:30-11:30 am *The Impact of the Polio Experience on PT/OT Management*
FORT SAN CARLOS
MARIANNE WEISS, MS, PT, Assistant Professor, Department of Physical Therapy,
University of Findlay, Findlay, Ohio
OBJECTIVE: Discuss the sociological, cultural, and psychological experiences of polio
survivors (and their significant others) and determine the impact of these factors
on participation in and response to PT/OT examinations and interventions.

EIGHTH INTERNATIONAL

Post-Polio AND

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Conference

SAINT LOUIS, MISSOURI

Saturday, June 10, 2000

SESSION IV (Plenary)

2:30 pm - 3:15 pm

PAVILION BALLROOM

**Report from March of Dimes International Conference
on Post-Polio Syndrome: Identifying Best Practices
in Diagnosis and Care**

... the role of the March of Dimes as convener of their conference
Michael Finnerty

... a review of the information
Frederick M. Maynard, MD

EIGHTH INTERNATIONAL
Post-Polio AND
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Conference
SAINT LOUIS, MISSOURI

Saturday, June 10, 2000

CLOSING SESSION (Plenary)

3:30 pm - 4:30 pm

PAVILION BALLROOM

Planning for the Future

... the perspective of a ventilator user, polio survivor,
and behavioral health professional
Linda L. Bieniek, CEAP

... the perspective of a researcher
Burk Jubelt, MD

... the perspective of a primary care physician and polio survivor
Marny K. Eulberg, MD

... the perspective of a clinician
Martin B. Wice, MD

... the perspective of a polio survivor and advocate
Joan L. Headley, MS

PATHOPHYSIOLOGY OF ACUTE POLIO AND POST-POLIO SYNDROME

Frederick M. Maynard, MD
U.P. Rehab Medicine Assoc., PC
Marquette, Michigan

PATHOLOGY OF ACUTE POLIO AND RECOVERY

Acute poliomyelitis is a viral infection that enters the body through the gastrointestinal tract. The central nervous system is the only place where permanent damage to the body results from the infection. Within the central nervous system, poliovirus can destroy nerve cells located in the spinal cord.

Motor nerve cells (motor neurons) consist of a cell body, a long tentacle (axon) extending from the cell body, and axon branches at the end. The neurons are located in the anterior (front) part of the spinal cord and are known as anterior horn cells. The axons leave the spinal canal and run through the body to reach targeted skeletal muscles. When an axon reaches a muscle, it successively divides into smaller and smaller branches, like twigs on a tree limb. Each terminal branch ends with a small bulbous enlargement (known as a neuromuscular junction) at the surface of a muscle cell (muscle fiber). Each nerve axon is connected to 100 to 2,000 muscle fibers, depending on the muscle's size and function. A nerve cell, its axon, and all the muscle fibers connected to it are referred to as a motor unit.

After the poliovirus invades the central nervous system, it can damage or destroy anterior horn cells. During the recovery phase after acute polio, strength increases in three ways. Some nerve cells are only temporarily damaged and over a few weeks recover their function. Other muscle fibers connected to dead nerve cells atrophy and are replaced by fibrous tissue and fat, while surviving muscle fibers hypertrophy (enlarge) in response to exercise. Third, the nerve cells that survived the poliovirus infection begin to compensate for the loss of neighboring nerve cells by growing new "sprouts" from the terminal axon branches. These sprouts make new connections with (reinnervate) muscle fibers that lost their connection with a viable nerve cell. Due to this compensatory process, surviving nerve cells may innervate three to eight times as many muscle fibers as normal¹, and reach up to 10,000 or more muscle fibers per motor unit. The result is giant motor units.

These compensations can result in apparent full recovery of normal strength. During the years of stable strength and endurance, polio survivors reach a steady state (equilibrium) of terminal sprout drop-off (denervation) and new sprouting (reinnervation). When this steady state is disrupted after many years, a critical threshold is crossed and new weakness occurs, marking the onset of post-polio syndrome².

While there is no agreement on the cause, or trigger, for the new degeneration of giant motor units, it is now known that changes in post-polio motor units occur at several levels and account for the symptoms of new weakness and increased muscle fatigability. First, the terminal axon sprouts deteriorate due to a tendency of giant motor units to revert to a more normal size. This

process is called fragmentation or peripheral disintegration. Second, insufficient acetylcholine (the neurochemical that is released at the junction when the electrical impulse from the neuron reaches the junction) causes defects of electrical transmission, resulting in a short circuit of the nerve's message to the muscle³. Third, muscle fibers may become smaller (disuse atrophy) and become less able to stay enlarged and/or contract as strongly. Also, a decrease in the flow of the nourishing neurotrophic factors from the cell body down the axon may negatively influence the muscle's metabolism.

TERMINOLOGY

Co-Morbidities

Co-morbidities, also known as secondary conditions, are other medical diagnoses and conditions, in addition to previous paralytic poliomyelitis, that may contribute to and compound a person's health problems and cause a decrease in the ability to carry out life's functional activities. For example, cancer or kidney disease may develop in a survivor of polio as a co-morbid condition and make the disabling symptoms of fatigue and weakness worse than they would be expected to be among people with only one of these conditions. Co-morbidities may be related to previous paralytic polio such as scoliosis, osteoarthritis, and aspiration pneumonia, or unrelated such as cancer and type 2 diabetes. It should be noted that polio survivors can develop the same diseases as the general population based on genetics, lifestyle behaviors, and circumstances.

Late Effects of Polio

The late effects of polio, or its synonym "post-polio sequelae," are specific new health and rehabilitative problems (secondary conditions) whose occurrences are likely to be a result of long-term residual polio-related impairments. An example of a common post-polio sequela is degenerative arthritis of the knee associated with progressive back-knee deformity (*genu recurvatum*) and residual thigh muscle (*quadriceps*) weakness. Knee pain and/or gait changes associated with a secondary knee arthritis may lead to new walking disability, another common late effect of polio. The majority of the late effects of polio can be specifically diagnosed and result from a patient's chronic muscle weakness.

The "late effects of polio" is a general term used to describe specific new health problems that are a result of polio-caused chronic impairments. Other examples are degenerative arthritis of overused joints, carpal tunnel syndrome and other repetitive motion problems, tendonitis, bursitis, failing joint fusions, over-stressed joints due to compensatory body mechanics, etc. Post-polio syndrome is considered to be a sub-category of the late effects of polio.

Many abbreviate post-polio syndrome as PPS, but this can be confused with "post-polio sequelae" because it has the same abbreviation. Post-polio sequelae refers to late-onset symptoms attributed to previous acute poliomyelitis, accounting for failure to maintain the level of recovery, and resulting in disability⁴.

Post-Polio Syndrome

Post-polio syndrome is a neurologic disorder characterized by increased weakness and/or abnormal muscle fatigability in individuals who had paralytic polio many years earlier.

The cluster of symptoms includes new weakness, intense fatigue, and pain in muscles and joints resulting in decreased endurance and diminished function. Less commonly, these symptoms include breathing and/or swallowing difficulties, cold intolerance, and new muscle atrophy. Generally, these problems occur after a period of functional and neurologic stability of at least 15 years following the initial episode of polio.

The symptoms can be divided into two groups: neuromuscular and musculoskeletal. The neuromuscular symptoms are believed to be caused by a progressive deterioration of motor neurons. This deterioration results in new weakness and abnormal muscle fatigability. The musculoskeletal symptoms are more likely caused by years of abnormal wear and tear. The result is muscle pain and pain from osteoarthritic joints, inflamed tendons, strained ligaments, and malformed joints.

The criteria for diagnosing post-polio syndrome include: 1) a prior episode of paralytic polio confirmed by medical history, neurologic examination, and, if needed, an electrodiagnostic exam to show changes consistent with prior anterior horn cell disease (exam is not required for limbs with obvious polio paralysis); 2) a period of neurologic recovery followed by an extended interval of neurologic and functional stability, usually 15 years or more, preceding the onset of new weakness; 3) the gradual or abrupt onset of new weakness and/or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, and/or pain; and 4) exclusion of medical, orthopedic, and neurologic conditions that may be causing the health problems listed above. New weakness (usually accompanied by diminished function) is the cardinal symptom of post-polio syndrome. Without a clear history of new weakness, the diagnosis cannot be made. In addition, the diagnosis cannot be made without excluding other likely causes of new weakness and other new health problems. For this reason, post-polio syndrome is called a diagnosis by exclusion.

Progressive Post-Poliomyelitis Muscular Atrophy (PPMA)

In the early '80s, the new problems of polio survivors were brought to the attention of the medical community, and the name game began. Earlier articles referred to "overwork weakness,"⁵ "late onset of respiratory failure," "loss of ambulatory ability,"⁶ and "delayed effects of poliomyelitis."⁷

To distinguish new, slowly progressive muscle weakness that is neurological in origin from musculoskeletal and/or wear and tear problems, Dalakas and colleagues (1984)⁸ used the term "late progressive post-poliomyelitis muscle atrophy." Progressive post-polio muscular atrophy (PPMA) is defined as progressive new weakness and atrophy in muscles with clinical or subclinical signs of chronic partial denervation/reinnervation compatible with previous acute poliomyelitis. The term PPMA is not often used today, giving way to "post-polio syndrome", a definition which continues to evolve and appears to be narrowing (i.e., new muscle weakness as a requirement).

POST-POLIO RE-REHABILITATION

Although residual motor impairment following rehabilitation from paralytic polio was long regarded as resulting in a static disability, study of the life course of people with a history of polio during the 1980s has shown that their disability frequently progresses.

Estimated to number 640,000 in the United States today, these individuals may comprise the country's largest disability group. Since the median age at onset of polio in most study samples is under 10 years, the majority of individuals became disabled as children. Population-based studies of persons who contracted paralytic polio have found 22% to 64% have developed new disabling symptoms.

Rehabilitation for polio survivors is an ongoing lifetime process. Polio survivors who went through rehabilitation after the acute episode of polio should be re-evaluated as their bodies' capacities change as a result of aging, wear and tear on joints due to unusual biomechanics, and overcompensation due to muscle weakness. New techniques may need to be learned to facilitate independence; new devices, to replace outdated and inefficient ones, may need to be used.

While the physical problems of polio survivors are similar to those of the elderly, some survivors seeking rehabilitation are younger, with different interests and lifestyles. The psychological issues of a person facing a recurrent disability are different from a "first time in your life" disability. Re-rehabilitation efforts may rekindle unresolved psychological problems that can interfere with adaptation to current circumstances. Previously learned coping styles, such as passing or minimizing, also may influence choices made by polio survivors.

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Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri
June 8-10, 2000

Pulmonary Problems:
Signs, symptoms, and screening &
Managing Pulmonary Problems

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INTRODUCTION

One could easily imagine why the polio epidemics from the early to mid-part of the 20th century had similar impact on the practice of pulmonary medicine as even the best-known infectious lung disease, tuberculosis. The modern day intensive care units are now primarily staffed by pulmonologists largely due to the huge need from breathing problems created by these two infectious diseases. Since acute polio infection has vanished from the developed world, we presently recognize pulmonary problems from polio as a late complication of residual muscle weakness and/or skeletal deformities such as kyphoscoliosis. During the following review, the initial discussion will note common patient complaints occurring at rest, with increased activity, and during sleep. Secondly, there are physical signs and clinical tests that help predict or further define these symptoms that should be explained. Lastly, the appropriate treatment methods can be identified and placed into perspective.

SIGNS & SYMPTOMS

Up to 6% of polio patients studied in one series required full-time ventilator support but larger percentages present to pulmonary physicians.¹ The most common respiratory symptom reported by polio patients is shortness of breath and may come from a variety of causes.² It is difficult to classify the subtypes of patients because the most profound abnormalities occur in those with severe kyphoscoliosis who invariably have muscle weakness as well. Shortness of breath during activities of daily living is most related to ventilation at polio onset, contracting polio after age 10, or having polio for over 35 years.³ Patients tend to adapt a breathing pattern of more shallow rapid breathing that tends to relieve the shortness of breath.⁴ Physicians will often further assess this by observing whether the patients worsen when lying flat - so-called 'supine dyspnea.' When the diaphragm muscle is severely affected and weak, this can be appreciated

further by observing for supine abdominal paradox where the abdomen will inappropriately collapse inward as the chest expands during inspiration. In those with severe chest wall muscle wasting and intact diaphragms, there may be an exaggerated outward motion of the diaphragm and the chest wall shows a 'paradoxical' collapse during inhalation.

Patients may also have sleep related breathing disorders, regardless of whether or not they report disturbances to their sleep. Daytime hypersomnolence is commonly reported, but morning headache, and nocturnal awakenings are also present.⁵ Patients who gain weight tend to have exercise intolerance, but this also predisposes them to more classic obstructive sleep apnea that is could be suspected when loud snoring is present.

CLINICAL TESTING

Traditional pulmonary function testing includes spirometry that assesses expired flows and volumes after a maximal effort. Polio patients classically exhibit restrictive physiology with reduction in lung volumes and a proportionate decrease in flows. Measurements of respiratory muscle strength, identified with maximal inspiratory and expiratory pressures (PiMax, PeMax), may also be reduced.⁵ Patients from a cohort study of those reporting a history of polio on average, have only a mild reduction in pulmonary function tests but those who specifically reported either respiratory muscle involvement at onset of polio or later developed kyphoscoliosis, have more profound abnormalities including elevated carbon dioxide levels on arterial blood gases, which portends a poorer prognosis.^{1,6,7} Cardiorespiratory exercise testing is useful in helping to separate out activity limitations from heart or lung impairment versus the often severe deconditioning that also occurs in these patients.⁸

Overnight oximetry and formal sleep studies (polysomnography or PSG) are used to prove whether polio patients have central hypoventilation, classic obstructive sleep apnea, or a mixed disorder.⁵ Patients with kyphoscoliosis with ill-defined symptoms should be considered for screening overnight oximetry. Those complaining of sleep disordered breathing symptoms as noted above, especially in the presence of moderate restrictive lung disease or daytime hypercapnia, should undergo a PSG study which can reveal profound nocturnal hypoxemia particularly during REM sleep.^{5,6}

TREATMENT

The mainstay of treatment for daytime shortness of breath is reconditioning with pulmonary rehabilitation. These programs usually include other helpful techniques such as cough assistance. The same data that suggests increased activity and possibly reduced hospitalizations for COPD patients seems to apply to restrictive lung disease patients.⁹

Oxygen therapy is generally contraindicated for patients with post-polio problems but ventilatory assistance with non-invasive techniques, primarily nasal nocturnal ventilation has

dramatic effects especially in patients with kyphoscoliosis.^{10,11,12} Corrective surgery to reduce spinal curvature can improve pulmonary performance.¹³ Careful attention to the cause of ventilatory insufficiency now offers patients marked increases in quality of life.

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CARDIOVASCULAR ISSUES AND THE POST-POLIO SYNDROME

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Cardiovascular disease (CVD) is the leading cause of death in both men and women in the United States. One of every 2.4 deaths is attributable to it. In addition, it results in substantial morbidity, accounting for more than 6 million hospital discharges per year in this country.

The actual incidence of CVD in individuals suffering from post-polio syndrome (PPS) is not known. However, there is reason to suspect that individuals with PPS might be at increased risk. Certain features of PPS such as generalized fatigue, generalized and specific muscle weakness, joint and/or muscle pain may result in physical inactivity - deconditioning, obesity, and dyslipidemia. Respiratory difficulties may result in hypoxemia. Any of these can predispose those with PPS to increased cardiovascular risk. Furthermore, most individuals with PPS are now at an age group where CVD such as heart attack, stroke, and heart failure become increasingly more likely. Common symptoms and signs of CVD include exertional chest discomfort, exertional and non-exertional shortness of breath, sudden shortness of breath and/or chest discomfort after lying down, swelling of the ankles and legs, heart enlargement, palpitation, loss of consciousness, and easy fatigability. It is evident that there are symptoms of CVD that overlap with common symptoms of PPS. This could present a problem since individuals suffering from PPS may not recognize cardiovascular symptoms by thinking that these may just be a progression or altered manifestation of PPS symptoms. The resulting delay in diagnosis can be costly. It is important to emphasize that CVD is often a "silent" disease without significant symptoms until its life-threatening or catastrophic sequelae appear suddenly. All too often, the first manifestation of CVD is sudden death, stroke, or a heart attack. The need to identify individuals at increased risk early enough to alter its catastrophic course cannot be overemphasized.

Available information on heart disease and PPS in the scientific literature is regrettably limited. Some interesting studies, however, may be of practical importance to PPS patients. One such study evaluated the cardiovascular autonomic function of subjects with antecedent poliomyelitis (Borg et al) and concluded that there was no significant dysfunction of autonomic nerves despite the presence of progressive muscle atrophy. This finding becomes important when one considers that many current methods for assessing cardiovascular function and fitness include evaluation of parameters such as heart rate, blood pressure, heart rate variability, valsalva response etc., all of which require an intact autonomic system. The study results suggest that individuals with PPS in general can use any of a number of standardized tests for cardiovascular risk assessment such as the exercise stress test without a decrease in test sensitivity, provided

that due consideration of the presence of muscular dysfunction is made. For example, an arm ergometer may be used instead of a treadmill as the method of providing the exercise in PPS individuals with lower extremity weakness. There are also non-exercise types of cardiovascular stress testing such as pharmacologic, vasodilator perfusion stress tests (dipyridamole or adenosine stress tests) used in conjunction with nuclear imaging, or a dobutamine - echo stress test. These are the preferred tests for those who cannot perform significant exercise.

Apart from cardiac stress testing, there are also an increasing number of ways to evaluate cardiovascular risk. Evaluation for coronary risk factors is of major importance to everyone with or without a history of PPS. Risk factors include cigarette smoking, hypertension, elevated LDL cholesterol (the "bad" cholesterol), low HDL cholesterol (the "good" cholesterol), diabetes, male gender (and post menopausal women), family history of premature coronary heart disease, the presence of peripheral arterial occlusive disease, and last but not least, obesity and physical inactivity. The presence of multiple risk factors results in more than just additive risk. Newer tests with possible utility in further defining increased risk for future cardiovascular events (i.e. heart attack, stroke) are currently under consideration. These include carotid artery duplex scanning, electron beam CT, ultrasound-based endothelial function studies, ankle/brachial blood pressure ratios, MRI techniques and testing for hs CRP - a possible marker of increased risk for coronary atherosclerotic plaque instability. Although there appear to be no large scale studies evaluating whether individuals suffering from PPS are at increased risk for CVD, it is probably safe to assume that there may be increased risk in certain individuals who have the traditional risk factors mentioned earlier. A study of 64 post-polio patients (Agre JC et al) found that 66% of the men and 25% of the women had hyperlipidemia with men also having low HDL cholesterol. These findings underscore the need to actively screen for dyslipidemia and/or hypercholesterolemia. In addition, deconditioning and obesity was found by Agre et al to be strongly associated with the presence of dyslipidemia. Therefore, it is important to address these issues in individuals with PPS.

In individuals with identified PPS symptoms consistent with cardiovascular deconditioning, there has been some hesitation in prescribing an exercise program to improve conditioning because of fears that traditional exercise regimens may lead to further loss of muscle from overuse. The prospect of safely and effectively training PPS subjects was evaluated by a number of investigators (Kriz JL et al, Jones DR et al, Owen RR et al). All investigators found that a carefully designed exercise program that avoided excessive muscle fatigue was able to provide positive results. Jones DR et al and Owen RR et al used lower extremity exercise. Kriz JL et al showed that PPS subjects can use upper extremity exercise (using an arm crank ergometer) for 20 minutes three times a week to achieve a significant improvement in cardiovascular conditioning (19% improvement in VO₂ max in the study). A very gradual training period of 16 weeks was used to allow all PPS subjects to reach a consistent exercise level and to avoid muscle damage from overuse. The results of these studies support the need to develop safe, effective, and easily accessible exercise programs for PPS individuals. This has the advantage of allowing the benefits of cardiovascular conditioning without the potential risk of further muscle damage.

Recommendations:

1. Determine if you have any of the common signs and/or symptoms of cardiovascular disease.

CVD signs: Enlarged heart, swelling of the ankles or legs, unusual/excess weight gain, wounds that do not heal well.

CVD symptoms: Chest discomfort (pain, pressure, squeezing, heaviness, etc.) especially if brought on by exertion and relieved by rest, shortness of breath with minimal exertion or upon lying down, palpitation or irregular heart beats, severe dizziness or loss of consciousness, sudden weakness or paralysis of one part of the body, sudden slurring of speech or loss of vision, frequent nocturnal urination, unusual and progressive fatigue, leg pain/discomfort with walking.

Consult your health care professional as soon as possible if you have any of the above signs and/or symptoms.

Signs and symptoms of a heart attack or impending heart attack: Continuous chest and or throat discomfort/pressure/pain/heaviness lasting more than 15 minutes even with rest and even after sublingual nitroglycerin. This may be associated with shortness of breath, sweating, dizziness, and palpitations. Discomfort may radiate to the left arm or jaw. **What to do:** Immediately proceed to the nearest Emergency Room or call the paramedics (911). If you have no severe allergies to aspirin, chew one tablet of regular 325mg. aspirin. This can help immediately by preventing or delaying further accumulation of blood clot in the arteries of the heart. In the Emergency Room you can be given powerful clot dissolving medications or if the facilities are available, emergency coronary angioplasty (a means of re-opening a blocked artery using a small balloon at the tip of a catheter) can be performed. These procedures can prevent an impending heart attack or reduce the size of a heart attack that has already started, thus reducing significantly the risk of dying as well as the risk of future complications. **Remember:** This is only effective if the blocked coronary artery causing the heart attack can be opened within the first few (preferably less than 3) hours of the onset of chest discomfort. So do not delay in getting to the ER!

2. Make certain that blood pressure, cholesterol/lipid profile, fasting blood sugar (FBS), body weight and an ECG are included in your annual physical examination. A chest X-ray would also be useful periodically to determine heart size and the status of the lungs. More frequent testing as well as additional specific tests (stress tests, echocardiograms, coronary angiograms, etc.) may be recommended as needed.

3. Avoid physical deconditioning and becoming overweight. Consult your health care professional for appropriate recommendations. In general, exercise has to be started very gradually and at a lower level and individually tailored to each individuals

physical status and needs. Care should be taken not to over exercise. Nutritional counseling is a useful resource.

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THE IMPACT OF THE INITIAL POLIO EXPERIENCE ON PT/OT MANAGEMENT OF THE LATE EFFECTS OF POLIO

Marianne T. Weiss, MS, PT

OBJECTIVE: Discuss the sociological, cultural, and psychological experiences of polio survivors (and their significant others) during their acute polio infection and rehabilitation; determine the impact of these factors on participation in and response to PT/OT examinations and interventions.

I. The influence of the cultural/sociological mind set during the polio epidemics of the 1900s; the need for replacing maladaptive thought patterns with an enlightened view of illness and disability

II. The influence of coping as a child with life threatening illness; the need for putting aside childish thought patterns and accepting emotional wholeness as an adult

III. The influence of isolation from family and friends; the need for opening up to significant others and for seeking/accepting support and assistance from them

IV. The influence of “it takes a village to raise a child”; the need for adapting to changes in the “cheering” section

V. The influence of having interacted with the medical establishment of the times; the need for re-establishing trust in medical/allied medical personnel

VI. The influence of personal belief systems; the need to adapt emotional responses to successfully cope with changing physical capacity

VII. The influence of financial support; the need to tap into unusual sources for funding medical and equipment needs

**THE IMPACT OF THE INITIAL POLIO EXPERIENCE
ON PT/OT MANAGEMENT OF THE LATE EFFECTS OF POLIO**

Marianne T. Weiss, MS, PT

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EIGHTH INTERNATIONAL
Post-Polio AND
Independent Living
Conference
SAINT LOUIS, MISSOURI

Friday, June 9, 2000

**Learning About and From Post-Poliomyelitis:
A Seminar for Physical and Occupational Therapists
and Physical and Occupational Therapist Assistants**

AFTERNOON SESSION

FORT SAN CARLOS

- 1:15-2:15 pm ***Guidelines to Implement Examination and Intervention Options***
MARIANNE WEISS, MS, PT
OBJECTIVE: Apply appropriate Preferred Practice Patterns from the *Guide to Physical Therapist Practice* to implement examination and intervention options and to measure outcomes for individuals exhibiting the late effects of polio.
- OR
- BETH KOWALL, MS, OTR, Post-Polio Resource Group of Southeastern Wisconsin; Occupational Therapy Association Research and Scholarly Activities Committee, Greenfield, Wisconsin
OBJECTIVE: Apply appropriate AOTA Practice Guidelines to implement examination and intervention options and to measure outcomes for individuals exhibiting the late effects of polio.
- 2:15-2:45 pm ***Outcomes Measures: A New Approach***
DAVID GRAY, PhD, Professor, Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri
HOLLY HOLLINGSWORTH, PhD, Program in Occupational Therapy, Washington University School of Medicine, Saint Louis, Missouri
OBJECTIVE: Present a new assessment battery that is reliable, valid, and sensitive to individual and environmental factors to measure community participation among individuals with mobility impairments.
- 3:15-4:00 pm ***Coping Styles and Personal Perspectives of Polio Survivors***
FREDERICK M. MAYNARD, MD
SUNNY ROLLER, MA, Research Program Manager, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, Michigan
OBJECTIVE: Incorporate the firsthand experiences related by polio survivors who are coping with aging with a disability into effective planning of PT/OT interventions.
- 4:00-4:45 pm ***Experience from Your Practice***
OBJECTIVE: Describe "best practice" intervention strategies; strategize about marketing services to polio survivors; apply lessons learned from treating polio survivors to the treatment of others who exhibit muscle weakness.

Eighth International Post-Polio and Independent Living Conference
Saint Louis, Missouri June 8-10, 2000

Physical Therapy Examination and Treatment of the Polio Survivor

by Marianne T Weiss, MS, PT

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The purpose of this presentation is twofold:

- 1) to describe the examination and treatment intervention that a physical therapist (PT) should be able to provide a polio survivor.
- 2) to inspire PT professionals to count themselves among those who possess the caring attitude, knowledge base, confidence level, and desire to provide skilled and appropriate examination and intervention services for polio survivors.

Certainly many health professionals other than PTs can help to lessen the impact of the late effects of polio. In some cases, the services of other professionals overlap those of the PT. However, this presentation will primarily address PT services.

I. WHY SHOULD A PT ACCEPT A POLIO SURVIVOR AS A PATIENT?

A. Treatment of polio survivors is within the scope of PT practice.

1. **Coordination, Communication, and Documentation**
2. **Patient/client Related Instruction**
3. **Direct Intervention**

B. There is a potentially large number of polio survivors who may actively seek PT services or could benefit from services if they knew they were available and accessible.

C. The polio survivor population has been underserved by physical therapy.

II. THE PHYSICAL THERAPY REFERRAL FOR POLIO SURVIVORS

III. REASONABLE EXPECTATIONS

IV. WHAT SHOULD A PHYSICAL THERAPY EXAMINATION FOR POLIO SURVIVORS ENTAIL, AND HOW SHOULD THE RESULTS BE INCORPORATED INTO TREATMENT?

- A. Comprehensiveness
- B. Interview Prior To Physical Examination
- C. Specific Tests And Measures And Recommendations For Treatment Intervention
 - 1. Aerobic Capacity And Endurance (Inclusive Of Exam Of Ventilation, Respiration, And Circulation)
 - 2. Anthropometric Characteristics
 - 3. Arousal, Attention, Cognition
 - 4. Assistive And Adaptive Devices, Including Orthotic, Protective, and Supportive Devices
 - 5. Community And Work (Job/School/Play) Integration Or Reintegration (Including ADL)
 - 6. Cranial Nerve Integrity
 - 7. Environmental, Home, and Work (Job/School/Play) Barriers
 - 8. Ergonomics and Body Mechanics
 - 9. Gait, Locomotion, and Balance
 - 10. Integumentary Integrity
 - 11. Joint Integrity and Mobility
 - 12. Motor Function (Motor Control and Motor Learning) and Muscle Performance (Including Strength, Power, and Endurance)
 - 13. Neuromotor Development and Sensory Integration
 - 14. Pain
 - 15. Posture
 - 16. Range of Motion (ROM) (Including Muscle Length)

17. **Reflex Integrity**
18. **Self-care and Home Management (including ADL and IADL)**
19. **Sensory Integrity (Including Proprioception and Kinesthesia)**

SUMMARY

Polio survivors who are examined by a physical therapist and agree to begin treatment intervention should ideally initially be treated with a frequency of between one and three times weekly. Treatments should be directed toward assisting the survivor to progress to the maximal degree possible toward the goals agreed upon after the initial examination. When maximal progress toward the initial long-term goals has been achieved, most polio survivors, just as do people having any other chronic disorder, benefit from periodic follow-up visits in physical therapy. The goals of follow-up visits are to: 1) re-examine the survivor's physical status to determine if progress has been maintained; 2) examine any new problems that may have arisen since the previous visit; 3) re-evaluate appliances and assistive devices; 4) revise home program interventions.

After the initial series of physical therapy sessions, follow-up visits may be scheduled monthly for two-three months. If the polio survivor is doing well, subsequent follow-up visits may be at three-month or six-month intervals. Of course, the polio survivor should be free to call to ask for a new physical therapy consultation if new problems arise or old problems resurface that can be addressed by physical therapy intervention.

Physical therapists can offer valuable comprehensive examination and intervention services to polio survivors that may significantly improve their quality of life. The ultimate goal of physical therapy intervention is directed at making polio survivors (and/or their care givers) as independent in their own care as possible, so their need for medical and allied medical services is minimized.

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EIGHTH INTERNATIONAL POST-POLIO AND INDEPENDENT
LIVING CONFERENCE

ST. LOUIS, MISSOURI, JUNE 8-10, 2000

GUIDELINES TO IMPLEMENT EXAMINATION
AND INTERVENTION OPTIONS

BETH KOWALL, MS, OTR
POST-POLIO RESOURCE GROUP OF SOUTHEASTERN WISCONSIN
FRIDAY, JUNE 9, 2000

- I. Considerations When Working with People with Post-Polio
 - A. Individualized Approach
 - B. Client-Centered Practice
 - C. Focus on Out-Patients
 - D. Optimal Level of Independence
 - E. Viewing the Total Person
 - F. Educate about Post-Polio
 - G. Awareness of the Post-Polio Literature
 - H. Disability Experience
 - I. Therapeutic Relationship

- II. Practice Guidelines
 - A. O.T. Process
 - B. Occupation-based Practice
 - C. Occupational Performance

- III. Referral

- IV. Evaluation
 - A. Acquire a Baseline
 - B. Gather Information
 - 1) Interviews
 - 2) Skilled Observations
 - 3) Standardized Tests
 - C. Functional Limitations
 - D. Performance Areas
 - E. Performance Components
 - F. Performance Contexts

- V. Intervention Plan
 - A. Collaborate with Client, Family or Caregiver
 - B. Short and Long Term Goals (sample goals)
 - VI. Intervention
 - A. Remediation/Restoration
 - 1) Intervention Strategies
 - B. Compensation/Adaptation
 - 1) Intervention Strategies
 - C. Disability Prevention
 - 1) Intervention Strategies
 - D. Health Promotion
 - 1) Intervention Strategies
 - VII. Outcomes
 - A. Functional Outcomes
 - B. Outcome Measures
 - VIII. Re-evaluation
 - IX. Discharge or Follow-Up
 - X. Conclusions
-

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Eighth International Post-Polio & Independent Living Conference
 Saint Louis, Missouri June 8-10, 2000

“Outcome Measures: A New Approach”

David B. Gray, Ph.D. and Holly Hollingsworth, Ph.D.

A different approach to assessing mobility-limited individuals was taken in a three-year project funded by the Centers for Disease Control and Prevention. Two new survey instruments were developed to assess participation in their environment: Participation Survey/Mobility (PARTS/M) and Facilitators And Barriers Survey/Mobility (FABS/M). The goal of the study was to construct surveys to be reliable, valid, responsive to change, and feasible to administer for the purpose of providing multiple indices of outcomes across a broad scope of personal and social activities for individuals with mobility limitations (NIDRR Long-Range Plan, 1999). Survey items were developed based on the interviews and focus groups of people who are mobility limited, their significant others and rehabilitation professionals. Items and formats were reviewed by focus groups and tested on small samples of people with mobility limitations (Gray, Gould, & Bickenbach, 2000). The surveys were pilot tested using a written, phone and in-person version. The results of these comparisons revealed that the surveys could be administered using all three approaches. After revising the surveys, they were sent to approximately 600 people with spinal cord injury, stroke, multiple sclerosis, polio survivors or cerebral palsy. The PARTS/M is composed of 25 different activities (See Figure 1) that correspond to the nine participation categories in the ICDH-2. Analysis of the PARTS/M surveys returned by 108 polio survivors showed internal consistency values for the P-evaluative scores (importance, choice and satisfaction) range from .39 to .77 with most values over .65. All but two of the test-retest values were over .68 with 18 of 25 over .74. Comparison of the cross population similarities and differences are being made. The FABS/M consists of 191 items that probe the situational specificity of activity limitations; request information on the type of assistive technology used in activities; and asks the respondents to categorize aspects of their environments as barriers or facilitators to participation that correspond to most of the major ICDH-2 environmental factors categories (see Figure 3). The values for internal consistency and test re-test for the FABS/M ranged from .73 to .97 with most being above .9. The PARTS/M and FABS/M have good psychometric properties for the polio survivor sample.

Indices for PARTS/M and FABS/M

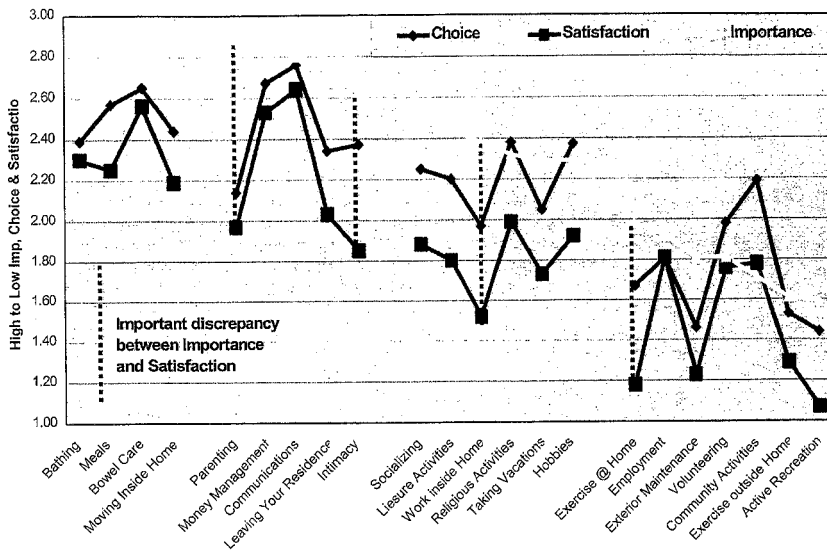
PARTS/M	Index of
<i>Participation Scales</i>	
P-temporal	frequency and preparation time
P-evaluative	importance, choice and satisfaction
P-assistance	personal assistance
P-environment support	assistive technology, accommodations
<i>Limitation Scales</i>	
L-access	environmental access
L-personal	impairment, fatigue, pain
FABS/M Scales	Index of
FB-Home	Building access, communication access, AT
FB-Community	Building access, surfaces, weather, crowds, noise, AT
FB-Work	Building access, surfaces, office adaptations, noise, AT
FB-School	Building access, surfaces, classroom adaptations, noise, AT
FB-Mobility Devices	Wheelchairs, canes, walkers
FB-Transportation	Types accessible - personal vehicles, cabs, rail, bus
FB-Attitudes	Service providers, teachers, co-workers, friends, sales people
FB-Benefits	SSI, SSDI, Medicare, health insurance, VR services

“Outcome Measures: A New Approach”

David B. Gray, Ph.D. and Holly Hollingsworth, Ph.D.

CDC CoreLite	Index of
BRFSS Demographic Secondary conditions Co-morbidities	Gender, ethnicity, age, employment, income, benefits, UTI, Skin ulcers, upper respiratory infection... Diabetes, Stroke,...

Evaluation of Participation by Polio Survivors



Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000

Coping Styles and Personal Perspectives of Polio Survivors

Frederick M. Maynard, M.D., Peninsula Medical Center, Marquette MI.
Sunny Roller, M.A., The University of Michigan Health System, Ann Arbor, MI.

A Review of the Past

Post-polio patients often experience their new physical symptoms as a recurrence of their original acute illness and many common symptoms are similar. Muscle weakness or the need for adaptive equipment can rekindle old memories of physical helplessness. Because many were young during their acute illness, they many mix age-related dependency issues with those resulting from physical impairments. Additionally, since most cases of acute polio occurred during epidemics, children were often isolated and separated from their families. Intense feelings of fear, rejection and/or guilt often accompanied an experience of abandonment and entrapment in a hospital. Furthermore, expression of these emotions by children in great distress was actively discouraged by the social pressures of hospital staffs, families and other patients. They were told to be good, to stoically accept whatever was being done to them, and especially not to cry.

The reemergence of intense repressed feelings can come as a surprise to both patient and professional during re-rehabilitation but must be acknowledged and managed when they occur. One woman reported with some astonishment that during her initial post-polio clinic visit she began to weep uncontrollably the moment she sat on the physician's examining table. Another gentleman revealed his unresolved fear of abandonment that immobilized him whenever his business travel required overnight stays away from his home and family.

During their initial polio rehabilitation, patients were encouraged to fight for recovery from residual weakness. "Use it or lose it" became a household motto for many of these children. They were also encouraged to overcome their disability through hard work and to set high goals for themselves. At the 1985 Conference, "The Post-Polio Experience", for Michigan polio survivors and health care professionals, a former director of the University of Michigan Respiratory Polio Rehabilitation Center reported that the children who did not set personal goals often died.

When maximum physical recovery was reached, polio survivors learned to cope in the world with whatever functional capacity was left. Characteristic attitudes and behavior often became part of their personalities as they reached their peak physical capacities by early adulthood. Until the 1980's, few were warned that a loss of functional capacity due to age-related erosion of physical reserves was to be anticipated. The alarm experienced by many post-polio patients who develop new functional limitations can add to their psychological difficulty in adapting again to disability. Since significant change in physical capacity is usually accompanied by strong emotional reaction, it is important that the difficulty of re-rehabilitation for post-polio patients is not underestimated by re-rehabilitation professionals.

Three Coping Styles

In the experience of the Post-Polio Program of the University of Michigan Medical Center, distinct patterns for polio survivors' emotional reactions to the need for re-rehabilitation have been recognized. These patterns appear to result from three characteristic styles of living with a chronic disability. A model for categorizing polio survivors has been developed that is based on these observations. Although it is limited by over-generalization, polio survivors have verbally validated the proposed categories at many post-polio conferences. A 1963 study of children with polio and their families also describes early coping behaviors that are compatible with this model.

The model designates polio survivors as Passers, Minimizers and Identifiers. These labels characterize typical attitudes and behaviors that were adopted in order to cope with long-term mild, moderate, or severe disability. Passers had a disability that was so mild it could be easily hidden in the normal course of daily social interactions. They could pass for non-disabled. Minimizers had a moderate disability that was readily recognizable by other people. They often used visible adaptive equipment or had to do physical tasks differently in order to optimally function. They typically minimized the importance of their physical differences. Identifiers were severely disabled following acute polio. They generally needed wheelchairs for independent mobility. Some also used respiratory

equipment. They needed to incorporate their disability into their identity in order to successfully cope with the major lifestyle adaptations required by their impairments. A close look at each group's coping style will clarify the typical patterns of emotional reaction that occur when polio survivors experience disabling late effects.

Passers

Passers worked diligently to hide their long-term disability. Many of their acquaintances probably did not know they were disabled in any way. Although intimate family members and friends may have known, on the whole, Passers became psychologically invested in hiding their disability from other people. Even today, they may not like to have to explain it or to talk about it. They do not want to think of themselves as having a disability. By using denial, they were able to put their disability out of existence mentally and physically and create an image that completely fooled the casual onlooker.

Passers may hide a paralyzed hand by keeping it constantly in a pants pocket or cover slightly imperfect body parts with stylistically camouflaging clothing. Passing is a coping style that requires constant vigilance and attention to the non-disabled disguise. Good Passers believe they cannot "blow their cover" or they might get stigmatized as part of society's disabled minority.

Based on an attitudes survey given to 100 polio survivors, the mildly disabled Passers were the group who was most distressed in having to adjust to the late effects of polio. They were more likely to be emotionally overwhelmed by the physical changes from the late effects than any of their more disabled post-polio counterparts. It is important for helping professionals to know that among people with a history of polio, it is the Passers who have the greatest resistance to making, and the most emotional difficulty in accepting, some of the relatively minor lifestyle adaptations that are needed to cope with the late effects of polio.

Passers who are confronted with post-polio sequelae often have their self-image threatened because they can no longer pass as non-disabled. Their disability has become undeniable and suddenly they must give into it. They may become frightened because they do not know how far it will progress. Typical thoughts may include: "Wearing a brace could lead to using two crutches, and a year later to a wheelchair, or who knows after that... and now that the disability is obvious, what will other people think...?"

When confronted with polio's late effects, Passers often must alter their self-perceptions and lifestyle in order to continue successful coping. Their former coping style may no longer be effective and new attitudes and behaviors must be learned. Clinically, Passers can often be fully rehabilitated because their new disabilities are less severe. They can often be reassured that modern orthotics, such as plastic braces, can be nicely worn under clothing and completely hidden inside shoes.

Passers may require an unexpected amount of understanding, patience and empathic support from health care professionals because of strong emotional reactions that are not only triggered by the impending public nature of their new disability, but also by memories of past polio-related experiences. What may appear to be an over-reaction to a minor physical change is founded in years of fearful cover-ups and a longing to be "normal." When their disability progresses from mild to moderate, they become undeniably disabled for the first time. This can be a harsh reality for them to finally face, accept, and adapt to. Using a new cane or crutch will publicly reveal a disability that can no longer be camouflaged. New coping techniques such as re-evaluating priorities, emphasizing the positive, and setting new goals can be invaluable tactics to employ during the process of re-rehabilitation.

Minimizers

Minimizers are post-polio people who have had a moderate disability that was always apparent to themselves and to others. They have coped with polio's first effects by minimizing the negative and accentuating the positive. Minimizers may say, "So what if I use braces and crutches and I can't walk in a normal fashion, look at all the other things I can do." Minimizers have adapted by de-emphasizing physical pain, deformity, and functional shortcomings. Many have pursued intellectual vocations and avocations in place of more physical or athletic activities. They often have been high achievers who have pushed themselves to their limits. Minimizers have learned how to tune out their bodies in order to ignore physical imperfections, a process called "devaluing physique". "I was always taught that no one would notice my orthopedic shoes if I wore a pretty smile on my face," reports on Minimizers.

This practical approach to living with an obvious physical disability has often been helpful for effective coping in a society which emphasizes physical beauty and prowess. However, Minimizers are often so adept at this form of denial that they recognize polio's late effects only when physical symptoms become unbearable and insurmountable. In order to survive and function at peak capacity they may have learned to use minimizing as a defense mechanism to such an extent that they became quite insensitive to their own pain, sadness, weakness, and

anger. This perception can occasionally generalize to become an insensitivity to similar conditions and feelings in other people, including persons with a more severe disability.

When asked to respond to the attitudes survey statement, "I feel uncomfortable around other disabled people," Minimizers endorsed it more than the other post-polio groups. They often had negative attitudes about severely disabled individuals as a group, particularly wheelchair-users. Therefore, they may feel that to personally begin using a wheelchair signals joining a social group that they have previously devalued and/or that implies defeat, helplessness, and not fighting vigorously enough against polio's disabling effects. Minimizers sometimes admit to difficulty being socially linked with someone in a wheelchair because the very association might somehow generate their own need to use one. It is useful for professionals to recognize these phobic-like reactions to wheelchair use when they occur and employ techniques for helping Minimizers change their perceptions of wheelchairs and wheelchair users. Indeed, these post-polio patients are the most likely to physically benefit from beginning to use a wheelchair.

Minimizers may have difficulty verbally describing new physical symptoms because they are skilled at ignoring and/or denying such problems. They need coaching and encouragement to fully focus on their body sensations and reactions and to become what might be called "wise hypochondriacs." Health care providers must listen closely to Minimizers for the slightest mention of new medical problems and give them permission to elaborate. Minimizers most commonly feel guilty about causing others, including health care professionals, inconvenience related to their new disability. These assumptions can block the progress of thorough and continued re-rehabilitation. Insightful health care professionals can help Minimizers embrace physical and lifestyle changes brought on by polio's late effects by helping the patient re-think and newly experience these disabilities, transforming them from burdensome affronts into simple facts-of-life.

Additionally, Minimizers are likely to have intense angry feelings about having to deal with new disabilities and re-rehabilitation. The classic question is, "do the virtuous fade first?" reflects a justifiable anger at having exercised and strained in daily routines for decades to come back from polio's acute attack only to become more debilitated later from what authorities call "overuse." Returning to rehabilitation can feel like an unfair defeat after a hard-fought struggle to overcome impairments and win the promised, sought-after and permanent exit from medical regimens and institutions.

Health care professionals can acknowledge and validate the Minimizer's anger as logical and can encourage living with that anger in healthy ways. Anger may manifest itself by slowing the re-rehabilitation process temporarily and creating resistance to starting new health care regimens. Alternatively, energy from anger may produce unrealistic expectations and/or impatience with their seemingly slow re-rehabilitation process. Anger can also give Minimizers the energy to make positive changes. However manifested, it is important that the health care professional not misinterpret anger or hostility as being permanent, personal, or irresponsible. It is a natural reaction to an alarming and serious situation which must be patiently dealt with and for which there is no cure.

In spite of many negative emotional reactions, Minimizers know how to set goals and achieve them with persistence and determination. The astute health care professional will encourage and help empower the Minimizer to use these qualities to re-focus on what is important in life; to take another look at how to be successful; to set new goals and achieve them in new ways. Health care professionals, family and friends must be patient in helping Minimizers work through understandable resistance, fears, and anger with re-rehabilitation. They must respect, remember, and sometimes remind Minimizers that they are experienced copers who have a well-proven capacity to see the positive in adversity and adapt effectively. As some Minimizers become more disabled, they may want to employ the key coping tactics of post-polio Identifiers.

Identifiers

Identifiers are people who have usually been sufficiently disabled since the onset of their acute polio to require wheelchairs for mobility. They have needed to more fully integrate their disability into their self-image in order to create successful and meaningful lives. Through identifying with others having physical disabilities, they have gained the strength to tolerate social prejudices and architectural barriers. Not surprisingly, many moved beyond their tolerations to become disabled rights activists who inspired environmental change and helped start the independent living movement.

Among the three groups sampled through the attitudes survey, Identifiers most strongly endorsed the statement, "high achievement is a requirement for survival as a disabled person." They also most intensely believed that taking an active role in the disabled rights movement was necessary to their future well-being in society, and that fully acknowledging their disability will help them cope with it more effectively.

With the onset of polio's late effects, many Identifiers confront the loss of their independence. The smallest functional forfeiture can be extremely distressing to a person who has been chronically severely disabled.

If breathing function becomes significantly impaired, death maybe a realistic threat. For Identifiers who have had to work diligently to lean to feed themselves and perform other relatively simple self-care activities, independence in daily living activities may be one of the most important accomplishments of their lives. Therefore, if post-polio sequelae threaten a decline in strength, they can be expected to appear extremely distressed.

Effective helping professionals need to anticipate the Identifier's concerns and recognize that their intense interest in autonomy and control of their environment is not pathologic. Identifiers have needed to develop a heightened concern about physical independence and about personal choice with how required help is given in order to attain high self-esteem and survive with their severe disability. When their freedom to control personal life activities is threatened by new physical limitation or even by temporary dependency imposed by a hospital setting, Identifiers may experience a threat to their whole life and purpose for living. This reaction often leaves Identifiers vulnerable to other's false perceptions of them as being overly controlling, difficult, and demanding people. In reality, they simply know what they need and are not too timid to ask for it. The informed health care professional will accept this and will do everything possible to let them continue to feel, and actually be, in charge of what happens to them.

Exceptions to the Models

As previously stated, each of these three coping styles is typically clustered around a mild, moderate or severe disability level. Of course, exceptions are not uncommon. Sometimes, those with severe disability demonstrate Minimizer attitudes. For example, an attorney who had exclusively used a wheelchair for mobility for over 30 years experienced sincere and deep-felt shock at a physician's matter-of-fact reference to his sever disability when explaining the wearing out of his upper extremities, his possible need for electric wheelchair use and the advantages of reducing his work day. The man had de-emphasized his obvious severe disability for years, successfully utilizing the coping style of a Minimizer. Some Passers, likewise, have been highly visible leaders in the post-polio movement, and Minimizers may share the Passer's fear of being stigmatized as part of society's "disabled minority."

Emotional distress is common to all survivors who experience a loss of functional abilities and an uncertain future. However, the greatest distress can be anticipated when a person's current functional capacities cause them to change from being a person with a hidden to a socially obvious disability and from being a walker to a wheelchair user. It must be remembered that each coping style can be successful. Any of them can assist a given individual in maintaining their highest functional level and their optimal social adjustment.

Successful Re-Rehabilitation

Passers, Minimizers, and Identifiers each adopted a characteristic coping style in the past that worked to create some of our generation's most successful and resilient survivors of physically disabling illness. The onset of new post-polio problems can present a challenge to their previously successful methods of coping and create significant emotional distress and pain. Health care professionals need to be aware of polio survivors' typical past coping styles and of their need to employ different tactics for coping during the re-rehabilitation process. Passers can no longer walk without a cane if they are now prone to falls. Minimizers cannot continue to ignore new pain and Identifiers may need respiratory aids in order to breath more easily.

Helping professionals can point out to polio survivors that it is possible to find opportunity in their time of change. Passers can "come out of the closet" or relax and enjoy a little more freedom with their very acceptable natural physiques and identities. Minimizers can also be empowered to live life with a great sense of wholeness through more fully recognizing, accepting, and integrating all aspects of their bodies. By relinquishing their struggle for physical independence and accepting new personal and technological assistance, Identifiers can gain the time and energy to develop new pursuits and cultivate other realms of interest. In this honest and supportive spirit of healthy transition, successful re-rehabilitation for polio survivors can be fostered.

EIGHTH INTERNATIONAL
Post-Polio AND
Independent Living
Conference
SAINT LOUIS, MISSOURI

Saturday, June 10, 2000

Learning About and From Post-Poliomyelitis: A Seminar for Physical and Occupational Therapists and Physical and Occupational Therapist Assistants

MORNING SESSION

BREAKFAST AND SESSIONS IN FORT SAN CARLOS

- 7:45-8:15 am ***Continental Breakfast***
- 8:15-9:00 am ***Revisiting the Traditional Methods of Gait Analysis***
JACQUELIN PERRY, MD, DSc (HON), Chief, Polio Service, Rancho Los Amigos National Rehabilitation Center, Downey, California
ANN E. HUETER, RPT, Post-Polio Clinic, Saint Anthony's Family Medical Center West, Denver, Colorado
OBJECTIVE: Apply observational gait analysis to the examination and intervention for polio survivors; implement motor learning principles for gait training of polio survivors; appropriately recommend orthotic interventions and/or assistive gait devices for polio survivors.
- 9:00-9:30 am ***Applicable Updated Assistive Technology***
ROBBIE B. LEONARD, MS, PT, Physical Therapy Program, Medical University of South Carolina, Greenville, South Carolina
BETH KOWALL, MS, OTR
OBJECTIVE: Review appropriate new assistive technology applicable to promoting independent living for people who experience the late effects of polio.
- 9:30-10:15 am ***Complementary/Alternative Therapies: How to Decide***
S. LAURANCE JOHNSTON, PhD, Falconwing Biomedical and Disability Research Consulting and Associate Member, Mountain States Paralyzed Veterans of America, Indian Hills, Colorado
OBJECTIVE: Discuss reasons why use of alternative medicine is now routine for many Americans; discuss a variety of alternative/complementary approaches relevant to physical disability.
- 10:30-11:55 am ***Practicing New Skills***
MARIANNE WEISS, MS, PT; BETH KOWALL, MS, OTR; ROBBIE B. LEONARD, MS, PT
OBJECTIVE: Experienced therapists will demonstrate and guide examination skills on volunteer polio survivors.

Revisiting the Traditional Methods of Gait Analysis

Jacquelin Perry, MD, DSc (Hon), Chief, Polio Service,
Rancho Los Amigos National Rehabilitation Center, Downey, California

Ann E. Hueter, MS, PT, Post-Polio Clinic,
Saint Anthony's Family Medicine West, Denver, Colorado

I. Walking uses a sequence of limb motion, determined by selective muscle force and passive joint mobility, to advance the body over the supporting foot.

II. Post-polio effects

A. Muscle weakness is the basic impairment of polio

1. Walking is preserved by clever substitutions

- a. Normal position sense
- b. Normal motor control

2. Gait deviations

- a. Post-polio syndrome changes are subtle
- b. Overt only if acute residual paralysis was marked.

B. Study of 44 polio survivors

1. Isometric strength classification

a. Standard was a non-exercise, age matched normals

- 1) Strong (< 1sd) (85%N)
- 2) Moderate (< 2sd) (45%N)
- 3) Weak (> 2sd) (15%N)

b. Random pattern of weakness

- 1) 19 combinations of S,M,W strengths.

c. Incidences of grade "weak" muscles

- 1) Hip extensors: 18%
- 2) Knee extensors: 45%
- 3) Ankle plantar flexors: 43%

3. Stride Characteristics

- a. Basic accommodation was a reduced velocity
- b. Both stride length and cadence decreased

4. Relative velocity

- a. Unrestricted normal 83 m/min
- b. Non-exercising adults 73 (87%N)
- c. Post-polio 53 (64%N)
(Equals a slow normal stroll)

III. Mechanics of Walking

A. Principles

1. Three basic tasks per stride (gait cycle)

- a. Weight Acceptance
- b. Single limb support
- c. Swing limb advancement

2. Each task requires specific joint motion and muscle strength

3. Polio survivors adapt by sacrificing mobility to protect their weak muscles
 - a. Each person's strength pattern is unique
 - b. Their modes of substitution are similar.

B. Weight Acceptance

1. Normal

a. Initial contact

- 1) Hip flexed 30°
- 2) Knee extended
- 3) Heel strike

b. Loading response

- 1) Heel is a rocker which initiates knee flexion
Anterior tibialis & toe extensors
- 2) Knee stability and shock absorption
Quadriceps
- 3) Hip posture preserved
Gluteus maximus, adductor magnus

2. Polio adaptations

a. Hip and knee extensor weakness

- 1) Stride length shortened
- 2) The rate of limb loading slowed
- 3) Forward trunk lean
 - a) Augments hip extensor strength
 - b) Knee moment reduced (0.09 vs 0.42)
(1) Quadriceps demand reduced
- 4) Rapid foot drop reduces the heel rocker
 - a) Knee flexion decreased (+4° to -35°)
 - b) Quadriceps demand reduced

5) Error

- a) Hip extensors inadequate:
Backward trunk lean
Increases knee moment
(quadriceps demand)
- b) Quadriceps inadequate
No LR flexion
Increases joint impact
(back, hip, knee)
Knee hyperextension
Pass / retract thigh

6) KAFO

- a) Locked knee joint
 - (1) Unstable knee
 - (2) Flexion, valgus, etc
- b) Off-set free knee joint
 - 1) Excessive hyperextension
- c) Ankle joint for stance stability

b. Anterior tibialis weakness

- 1) Initial contact
 - a) Foot slap follows heel strike
 - b) Toe strike if knee also flexed
- 2) Loading response
 - a) Rapid drop to foot flat
- 3) Error
 - a) Knee flexion stimulus reduced
- 4) AFO
 - a) Leaf spring
 - (1) IC: Foot supported at neutral
 - (2) LR: Allows plantar flexion to protect quadriceps

C. Single limb support:

1. Normal

a. Mid stance

- 1) Combined heel and forefoot contact
- 2) Ankle dorsiflexion advances body weight across the foot
- 3) Soleus & gastrocnemius moderately active

b. Terminal stance

- 1) Heel rise adds further progression
- 2) Forefoot support
- 3) Soleus and gastrocnemius intensity doubled

c. Calf muscles control tibial advancement

- 1) Tibial control stabilizes the knee indirectly

d. Pelvis stabilized by gluteus medius-minimus complex

2. Polio adaptations

a. Calf muscle weakness

- 1) Heel rise in terminal stance is lost
 - a) Elastic contracture may add some terminal stability
 - b) Otherwise heel rise delayed until opposite heel strike (50%gc vs 36.4%)
 - c) Stride length shortened
 - d) Ankle dorsiflexion prolonged (49%gc vs 44%)
- 2) Ankle dorsiflexion is curtailed with severe calf weakness (reduce DF moment)
- 3) Knee flexes as tibial stability is lost
 - a) Quadriceps demand prolonged
- 4) Tight "heel cord"
 - a) Substitutes for weak calf
 - b) Foot pulled into valgus (flat foot)
- 5) AFO
 - a) Dorsiflexion stop to replace soleus
 - b) Free ankle plantar flexion to protect quadriceps (LR)
 - c) Dorsiflexion assist if AT weak

b. Gluteus medius weakness

- 1) Contralateral pelvic drop
- 2) Ipsilateral trunk lean (if limb stable), Trendelenberg gait
'Cane' or 'Forearm crutch'

D. Swing Limb Advancement

1. Normal

a. Initial swing:

- 1) Rapid hip and knee flexion
- 2) Partial ankle dorsiflexion

b. Mid swing:

- 1) Hip flexion completed
- 2) Full ankle dorsiflexion

c. Terminal swing:

- 1) Knee extension
- 2) Hip flexion and ankle dorsiflexion maintained

2. Polio adaptations

- a. Hip and knee flexion usually adequate (grade 2+)
- b. Anterior tibialis weakness
 - 1) Drop foot
 - 2) Toe clears floor by increased hip flexion
- c. Quadriceps weakness
 - 1) Hip pass-retract for terminal swing knee extension
 - 2) Tibial momentum followed by inertia extends knee
- d. AFO
 - 1) Leaf spring for ankle
 - 2) no replacement needed for quadriceps

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Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri
June 8-10, 2000

**Applicable Updated Assistive Technology
PT/OT Seminar**
Robbie B. Leonard, M.S., P.T.
Medical University of South Carolina

Applicable Mobility Options

1. A word about manual mobility

2. Powered Mobility Options
 - a. Scooters
 1. Pros and Cons
 2. Types
 3. Accessories

 - b. Power Wheelchairs
 1. Front Wheel Drive
 2. Mid Wheel Drive
 3. Rear Wheel Drive

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Page 2

3. Seating Considerations

4. Functional Accessories

EIGHTH INTERNATIONAL POST-POLIO AND INDEPENDENT
LIVING CONFERENCE

ST. LOUIS, MISSOURI, JUNE 8-10, 2000

APPLICABLE UP-DATED ASSISTIVE TECHNOLOGY

BETH KOWALL, MS,OTR
POST-POLIO RESOURCE GROUP OF SOUTHEASTERN WISCONSIN
SATURDAY, JUNE 10, 2000

- I. Assistive Technology
 - A. Client-Centered Approach
 - B. The OT as Part of a Team Approach
 - C. Low -Tech vs. High - Tech

- II. Delivery of Service
 - A. Referral
 - B. Assessment/Evaluation
 - C. Intervention/Equipment Acquisition
 - D. Trial use of Equipment/Training
 - E. Follow-Up

- III. Activities of Daily Living
 - A. Self-Care
 - B. Communication
 - C. Environmental
 - D. Orthotics

- IV. Instrumental – Activities of Daily Living
 - A. Home Management
 - B. Community/Recreation

- V. Home Environment
 - A. Home Adaptations
 - B. Universal Design

- VI. Work Environment
 - A. Work Adaptations
 - B. ADA

- VII. Consumer Abandonment of Devices/Technology
 - A. "Meaning" of Device
 - B. Emotional Barriers
 - VIII. Funding Sources
 - IX. Conclusions
 - A. Awareness of Current Technology
 - B. Awareness of Research Literature/Internet Resources
 - C. Need for Standardized Assessments/Evaluations
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**Eighth International Post-Polio and Independent Living Conference
St. Louis, Missouri, June 8-10, 2000**

The Role of Alternative Medicine – Double-Blind or Double Standard

S. Laurance Johnston, Ph.D.

Consultant & Associate Member, Mountain States Paralyzed Veterans of America

Goal: The goal of this presentation is to attempt to further integrate alternative health-care perspectives to better the health of individuals with disabilities. It is not to advocate alternative or complementary medicine over conventional medicine.

Although this presentation focuses on alternative medicine, it is important to acknowledge the extraordinary contribution that allopathic (i.e., conventional) medicine has made to the health-care of individuals with disabilities over the last 50 years. Nevertheless, allopathic medicine has limitations in perspectives. For example, although there are few factors as important to chronic health as nutrition, only 24% of medical schools require a course in nutrition. This presentation will discuss the trends in alternative medicine, reasons for its popularity, the shift in world view concerning its use, and various specific therapies.

Definitions: Alternative medicine is vaguely defined. It represents a broad range of therapies that have been outside the purview of conventional medicine, including many non-Western and indigenous healing traditions. Health-care consumers define alternative medicine as “medical therapies that I paid for out of my own pocket, and did not feel comfortable discussing with my physician.” Physicians define it as quackery, because it was not taught as a part of a conventional medical school curriculum.

Trends in Alternative Medicine: In recent years, there has been incredible growth in the use of alternative treatments. *JAMA* has reported that 4 in 10 adults now use alternative therapies. Between 1990 and 1997, visits to alternative practitioners jumped 47%. Over that period, Americans visited alternative providers 629 million times compared to 386 million visits to primary care physicians. An estimated 90% of patients using alternative medical care are self-referred.

Although much of the criticism of alternative medicine comes from physicians, many desire additional training in alternative therapies. For example, in a recent survey, 49% of primary care, AMA physicians want training in homeopathy. 64% of U.S. medical schools now offer *some* courses on alternative medicine. Although the content of these courses is unclear, it is reasonable to assume that their inclusion is creating acceptance and respect for alternative medicine. Clearly, alternative medicine has become a key component of the nation’s health care. There is a health-care train leaving the station.

Reasons for Increased Popularity: The population as a whole, including individuals with disabilities, is desiring health care with a more holistic perspective than that currently offered by conventional medicine. Allopathic medicine is technology,

externally oriented. It tends to focus on fixing the symptoms, often ignoring the underlying causes from a mind, body and spirit perspective. Under the pretense of scientific objectivity and reductionism, allopathic medicine detaches itself from the patient's uniqueness. It operates by isolating and fixing the dysfunctional item in the absence of the big picture. In contrast many alternative traditions have more of a looking-inward, holistic perspective. Because most illnesses have mind, body and spirit contributions, truly effective treatments should consider all three.

Former Director of NIH's Office of Alternative Medicine, Dr Wayne Jonas summarizes some of the reasons for the surge in popularity of alternative medicine. These include "a rise in prevalence of chronic disease, an increase in public access to worldwide health information, reduced tolerance for paternalism, an increased sense of entitlement to a quality of life, declining faith that scientific breakthroughs will have relevance for the personal treatment of disease, and an increased interest in spiritualism." He also notes that there is growing concern about the adverse effects and escalating costs of conventional care.

Adverse Effects: Many people are turning to what they consider more "naturalistic" alternative therapies as the adverse effects of conventional, allopathic medicine are increasingly being documented. For example, *JAMA* has reported that 106,000 people died from adverse drug reactions in hospitals in 1994, making it the fourth to sixth leading cause of death in this country. In another example, almost two million individuals who enter hospitals in this country acquire infections that they did not have when they went there. Of these, 80,000 die. Finally, at the end of last year the prestigious Institute of Medicine concluded that medical errors result in 44,000 to 98,000 deaths each year. These statistics are especially relevant to individuals with disabilities who are often over medicated and prone to life-threatening infections. Statistics like this warrant a serious consideration of alternatives.

Medicine as the Prevailing Philosophy: Allopathic medicine is based on a "materialism" philosophy, represented by Newtonian physics. With this philosophy "physical matter is the only or fundamental reality, and that all beings and processes and phenomena are manifestations or results of matter." (see D. Eskinazi, *JAMA*, 11/11/98). Consistent with this philosophy, the body represents more or less the sum of its anatomical parts. Because consciousness plays no role in such a system, spirituality has been considered irrelevant to health. However, materialism and, as a result, its product allopathic medicine is a form of religion: "As it has not been demonstrated that physical matter is the only reality, materialism, therefore is akin to a religion, i.e., a system of beliefs held to with ardor and faith. Western allopathic medicine, therefore... reflects the dominant philosophical belief system of the society in which it developed."

Conventional Medicine's Lack of Testing: While it is true that many alternative therapies have not been well tested, the prevailing assumption that allopathic medicine represents scientifically well-tested procedures is inaccurate. For example, the Congressional Office of Technology Assessment concluded that only 10-20 % of conventional medicine techniques has been scientifically proven. Interestingly, Congress

has defined quackery as any unproved therapy (1984). Although this definition targeted alternative therapies, given the limited amount of conventional medicine that has a scientific basis, only one conclusion can be made: if alternative medicine is deemed quackery under this definition so must most of conventional medicine.

This double standard was evident in a recent New England Journal of Medicine editorial. After the authors slammed the use of the anecdotal evidence to support alternative medicine, they then proceed to draw broad conclusions about the risks of alternative medicine using 12 disparate case studies. Finally, a NIH Consensus Conference concluded: "While it is often thought that there is substantial research evidence to support conventional medical practices, this is frequently not the case...the data in support of acupuncture are as strong as those for many accepted western medical therapies."

Reasons that Have Kept Alternative Therapies on the Fringe in the Past: The current state of health care in this nation has been determined as much by politics, market-driven factors, and professional chauvinism as objective science. This approach has deprived all Americans, including individuals with disabilities, effective medical treatments. For a variety of reasons, it has been difficult for most alternative therapies to transition into mainstream treatments:

Economic: First, realistically, given the daunting economics that society demands for proving the safety and efficacy of any new treatment, few will make the transition regardless of merit. It can take almost \$100 million and over 11 years to get a new drug approved. The size of the market associated with most disabilities generally does not justify that expenditure and effort. Only therapeutics with a reasonably large market and deep-pocket financial sponsors (i.e., drug companies) have a chance. Furthermore, since many generic alternative modalities cannot be patented, economic incentives are lacking.

Over three billion prescriptions are filled each year in this country. Are these prescriptions being filled only on the basis of need? If so, why has drug advertising marketing increased in the past decade from \$12 billion to over \$13 billion now?

Furthermore, although the NIH has a program evaluating alternative modalities, it represents less than 0.5 % of the NIH budget. Given that alternative providers are visited 63% more than primary care physicians, it is a huge budgetary discrepancy, reflecting that NIH may have marginal relevance to much of the nation's health care.

Resistance by Organized Medicine: Most alternative treatments have had a history of suppression by the allopathic medical establishment. Example after example can be quoted. For example, the AMA pressured the FDA to ban acupuncture needles unless used in a research protocol. Even after most states had authorized its use, this ban lasted until 1996. Control issues remain to this day. For example, a prestigious NIH Consensus Conference recently concluded that although acupuncture now has many acceptable applications, the patient should first see a M.D. This ignores a differential in training in which physicians can practice acupuncture after 200 hours of training while non-M.D.'s must train over three years in an accredited school of oriental medicine.

In another example, founded largely to fight homeopathy, the AMA allied with the pharmaceutical industry (homeopathic remedies could not be patented), did everything in its power to squash homeopathy. Dogmatic opposition to homeopathy often continues to this day in spite of a growing base of evidence supporting its use.

Limited Scientific Perspectives: Third, alternative medicine often involves paradigm-expanding perspectives not well appreciated by western-trained scientists. Western scientists reject many alternative therapies because it offends preconceived notions about human functioning or because of inappropriate methods of assessment.

For example, for years, scientists dismissed homeopathy because it could not be understood by the biochemical processes that were used to explain most physiological phenomena. It required quantum physics, chaos and complexity theory. Similarly, although the explanation for acupuncture involving life-force ch'i was beyond the understanding of western science, it is now being explained by concepts involving subtle electromagnetic energy.

An Integrated Future for Health Care? There is not one system of medicine that is good and one system that is bad. To varying degrees, most have something positive to offer. Ideally, 21st century medicine will integrate the high technology, scientific reductionism perspectives of allopathic medicine and the naturalistic, holistic perspectives of alternative medicine. They should be complimentary not exclusive. For example, high-tech allopathic medicine should emphasize the diagnosis and treatment of problems in specific anatomical and physiological structures. It will be especially useful in emergency care and the care of people in the advanced stages of illness. Because more naturalistic alternative medicines will augment an individual's immune response, stimulating inherent healing potential, they will be especially effective in treating chronic illness.

Specific Alternative Medicine Therapies: This presentation will highlight aspects of the following alternative medicine therapies published in *Paraplegia News*:

- Acupuncture (*Paraplegia News*, September, 1998)
- Qigong (*Paraplegia News*, January & February, 2000)
- Homeopathy (*Paraplegia News*, January 1999)
- Ayurvedic Medicine (*Paraplegia News*, November & December, 1999)
- Craniosacral Therapy (*Paraplegia News*, November 1998)
- Magnetic Therapy (*Paraplegia News*, March & April 2000)
- Chronologically Controlled Development Therapy (*Paraplegia News*, July 1998)
- Dolphin-Assisted Therapy (*Paraplegia News*, July 1999)
- Human Energy Fields (*Paraplegia News*, March, May & June, 1999)
- Aromatherapy (*Paraplegia News*, to be published July & August, 2000)

EIGHTH INTERNATIONAL POST-POLIO AND INDEPENDENT
LIVING CONFERENCE

ST. LOUIS, MISSOURI, JUNE 8-10,2000

PRACTICING NEW SKILLS

BETH KOWALL, MS, OTR
POST-POLIO RESOURCE GROUP OF SOUTHEASTERN WISCONSIN
SATURDAY, JUNE 10, 2000

We will demonstrate an examination on a volunteer who has been diagnosed with Post-Polio.

- I. Introduction of the Volunteer
- II. Referral
- III. Evaluation
 - A. Gather Information
 - 1) Interview
 - 2) Observation
 - 3) Appropriate Tests/Assessments
 - B. Description of Functional Limitations
 - C. Performance Areas
 - 1) ADL
 - 2) Work/Productive Activities
 - 3) Leisure
 - D. Performance Components
 - 1) Range of Motion
 - 2) Manual Muscle Testing
 - 3) Endurance/Fatigue
 - 4) Hand/Pinch Strength
 - 5) Pain
 - 6) Psychosocial
 - E. Performance Contexts
- IV. Intervention Plan
 - A. Short Term Goals
 - B. Long Term Goals
- V. Intervention
 - A. Remediation/Restoration
 - B. Compensation/Adaptation
 - C. Disability Prevention

D. Health Promotion

VI. Outcomes

VII. Re-evaluation

VIII. Follow-up

