

Now called
Post-Polio Health

polio network news

Scoliosis and Seating

Carrie W. Clawson, OTR/L, ATP, National Rehabilitation Hospital, Washington, DC

Scoliosis, or curvature of the spine, is well-known to many polio survivors. It occurs in a large percentage of individuals due to muscle imbalance as a result of paralysis or weakness.

Changes in appearance as well as changes in the way the body functions can result from scoliosis; fortunately, these issues can be alleviated or ameliorated with proper treatment.

Complications

Problems associated with scoliosis include pain, decreased pulmonary function, decreased digestion, and reduced use of the arms.

In general, pain in thoracic (upper spine) curves is not a frequent complaint, but is much more common in lumbar (lower spine) scoliosis.¹ Pulmonary function may be compromised when a more severe curve limits the lungs' ability to expand, presenting particular danger for polio survivors who are often at risk for respiratory complications from other factors as well.² Severe scoliosis that affects the position of the head can cause individuals to aspirate food and liquid into the lungs. Pressure from the ribs and spine on the intestines and stomach affect their ability to function properly.

The ability to use the arms depends upon solid support from the trunk. As scoliosis affects trunk balance and positioning, arm use declines and is less efficient. Polio survivors know that energy conservation is key to living with the late effects of polio

and addressing scoliosis to optimize function of the arms is no exception. This is especially true for manual wheelchair users, who use their arms for mobility in addition to their daily activities. Because of the musculoskeletal alignment changes that occur with scoliosis, longterm wheelchair users with scoliosis are at high risk for orthopedic injuries and pain in the spine and shoulder areas.

Treatment of Scoliosis

One treatment of scoliosis is proper trunk support. (Other options often used include braces, corsets, and jackets, as well as internal structures such as rods in the vertebral column.) For wheelchair users, the wheelchair back and cushion can be modified for proper support. Addressing scoliosis through the wheelchair seating system begins with an assessment of the individual's sitting posture and ability to function. The position of the pelvis is always evaluated first, as changes in the pelvis affect the positioning of the trunk, head, and extremities (arms and legs).

When a person's pelvis sits higher on one side than the other, it is called a pelvic obliquity. If the obliquity is flexible, the scoliosis may be partially or completely corrected once the pelvis is level. This is accomplished by adding a pelvic build-up, or small pad, under the wheelchair cushion on the side where the pelvis is lower. Leveling the pelvis equalizes the pressure. For a fixed obliquity, a build-up is added under the higher

side of the pelvis to accommodate the deformity and better distribute pressure.³

For someone who does not sit in a wheelchair, a folded towel on a chair seat can be used to support or correct a pelvic obliquity. The towel should be placed so that it is under the lower side of the pelvis if the pelvis is flexible, and under the higher side if the pelvic obliquity is fixed. It can be difficult to make this determination; sometimes the towel is placed under first one side and then the other, using the more comfortable arrangement.

The next concern is the curvature and rotation of the spine and the position and mobility of the scapulae (shoulder blades). Lateral supports attached to the back of the wheelchair can be used to correct or support curvatures. A three-point system should be used to provide a balance between maximum force and pressure relief.

If a "c" shaped curve causes an individual to lean to one side, the first support should be positioned at the top of the curve, allowing at least two finger widths at the armpit. The second support should be placed on the other side

CONTINUED ON PAGE 2

inside this issue ...

Motor Neurons and Units	3
Five Ways to Find Peace	6
Sleep-Disordered Breathing ..	8
Have You Heard	9
More About Crutches	11

at the apex of the curve or slightly below it. The third support will be at the pelvis to prevent shifting. This is often accomplished by the contour of the cushion, hip guides, or the wheelchair armrest. If an individual has an "s" shaped curve rather than a "c," lateral supports should be positioned at the apex of each curve. Unfortunately, it is difficult to provide this type of lateral support to a non-wheelchair user. For some, a brace or corset can provide this effect.

For individuals with severe curvatures of the spine, a standard wheelchair back does not conform as needed for pressure relief and comfort. In these cases, a wheelchair back that is custom contoured to the individual offers the best solution.

Often gravity causes a flexible scoliosis to worsen when a person sits upright in a wheelchair. Tilting or reclining the wheelchair back a few degrees counteracts this and allows the lateral supports to be more effective. A wheelchair tilt occurs when both the back and seat of the wheelchair move; a recline occurs when only the back moves and the seat is stationary (as with most car seats).

Each has its advantages and disadvantages. A reclining back allows the hip flexors to be stretched and can provide a comfortable resting position, especially with the legs elevated. Tilting allows a person who uses a more complex seating system to sit in the same position at the hips and can prevent shifting or loss of proper position. For a person using a custom contoured back, a tilt is preferred over a recline, because reclining would change the position of the contoured back relative to the person.

A polio survivor with scoliosis investigating a mobility aid such

Nina Gilden Seavey, writer and director, signs the companion book to the 90-minute documentary, *A Paralyzing Fear: The Story of Polio in America*, at the opening in Washington, DC, on September 14, 1998, for Alan Fiala, PhD.

The film aired on many PBS stations in October 1998. *Polio Network News* invites comments from polio survivors or their family members on the documentary. Please send your thoughts to the International Polio Network.

The cost of the companion book is \$29.95, with an additional charge for shipping and handling. To place an order, call TV Books, LLC, at 800/331-3761 or contact a local bookstore.



as a scooter, must consider their seating needs. Many scooters and some wheelchairs cannot be modified to address scoliosis. An occupational therapist or physical therapist who specializes in seating can evaluate both positioning and mobility needs to recommend the appropriate choice of equipment. ■

Carrie W. Clawson, OTR/L, ATP, a Senior Occupational Therapist at National Rehabilitation Hospital in Washington, DC, specializes in wheelchair seating, mobility, and other assistive technologies. She has also been involved in the Post-Polio Clinic at NRH as the occupational therapist team member. She received a Bachelor of Science in Occupational Therapy from Virginia Commonwealth University/Medical College of Virginia in 1991. She is currently an Adjunct Clinical Assistant Professor at Shenandoah University School of Occupational Therapy in Winchester, Virginia.

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1. Parthasarathy, S.R., & Clawson, C.W. (April 1998). Taming the Curve: Scoliosis in Wheelchair Users. *Advance for Directors in Rehabilitation*, 7-4, 13-14, 76.
2. Halstead, L.S. (1998). *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*. Washington, DC: NRH Press.
3. Bergen, A.F., Presperin, J., & Tallman, T. (1990). *Positioning for function: Wheelchairs and other assistive technologies*. Valhalla, NY: Valhalla Rehabilitation Publications Ltd.

OTHER SCOLIOSIS RESOURCES

National Scoliosis Foundation, publishers of *The Spinal Connection*, 5 Cabot Place, Stoughton, MA (Massachusetts) 02072 (781/341-6333, 781/341-8333 fax, 800/NSF-MYBACK [673-6922], or scoliosis@aol.com).

The Scoliosis Association, Inc., publishers of *Back Talk*, P.O. Box 811705, Boca Raton, FL (Florida) 33481-1705 (800/800-0669).

Scoliosis Research Society (www.srs.org).

Post-Polio Motor Neurons and Units: What We Know for Sure

Neil R. Cashman, MD, University of Toronto, Toronto, Canada

Motor neurons are located in the brainstem and spinal cord. They send long processes called axons out to the muscle. In the muscle, the axon divides into terminal axonal branches that contact muscle fibers to trigger their contraction. The terminal axons communicate with the muscle fibers at the neuromuscular junction through release of acetylcholine, a chemical compound synthesized by motor neurons.

A normal motor neuron innervates from a few to thousands of muscle fibers, depending on the muscle. An eye muscle, for example, needs few muscle fibers compared with a leg muscle that may need up to 5,000 muscle fibers per motor neuron. A motor unit is defined as a motor neuron and all the muscle fibers it supplies.

Part of the recovery process from acute poliomyelitis involves terminal axonal sprouting of remaining healthy motor neurons to reinnervate muscle fibers that have become denervated by destruction of their motor neurons. These axonal sprouts can dramatically increase the number of muscle fibers innervated by the same motor neuron – in some cases, as many as seven to eight times normal.

This arrangement, good as it is over the short term, is not indefinitely stable. Over time, muscle fibers begin to lose their innervation. Imagine, for example, a tree trunk with many branches that has eight or nine times as many branches grafted onto it. The tree may be able to support those extra branches for a period of

time, but eventually they may begin to degenerate or fall off. This process is what we think is going on in post-polio syndrome, first proposed by David Wiechers, MD, and Susan Hubble, MD, in 1981.

What evidence do we have that supports that hypothesis? Muscle biopsies provide the strongest indication that there is some ongoing, terminal axonal degeneration. But listening over the years to people having this problem, my colleagues and I have concluded that post-polio syndrome is not simply a disease of slowly progressive new weakness.

We have proposed that the complaints – fatigue, lack of endurance, and a whole list of other symptoms originally collated by

Mary Codd, MD, when she was doing her work with Anthony Windebank, MD, at the Mayo Clinic – that wax and wane and can change from hour to hour or day to day or week to week are due to dysfunction in terminal axons rather than degeneration. If a terminal axon is in the process of degenerating, it is not here one day and gone the next. During an intervening period, the axon is not functioning 100%, but it is still there.

What is the evidence of axonal dysfunction? Electromyography can demonstrate a muscle that has been stimulated very rapidly, but then loses its force into the stimulation. If we stopped and waited a couple of minutes, the

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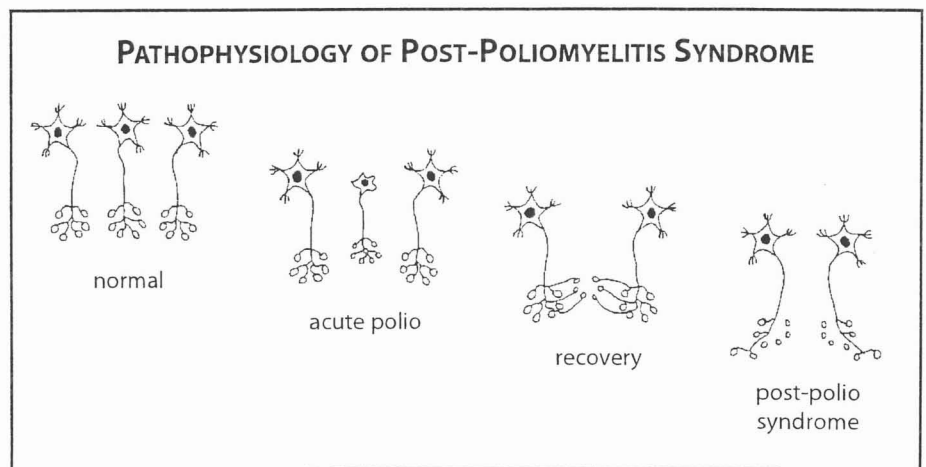


Figure 1. Normal: Three normal motor units are presented. **Acute Polio:** Invasion of one motor neuron by poliovirus produces degeneration of the affected motor neuron and denervation of associated muscle fibers. **Recovery:** Recovery after paralytic polio occurs through axonal sprouting from surviving motor neurons with reinnervation of muscle fibers. Muscle fiber hypertrophy may also occur (not illustrated). **Post-polio Syndrome:** Distal degeneration of enlarged motor units with denervation of muscle fibers is believed to be the most likely cause of PPS.

In *Current Trends in Post-Poliomyelitis Syndrome* by Daria A. Trojan, MD, and Neil R. Cashman, MD. Copyright 1996, Milestone Medical Communications, a division of Ruder-Finn.

muscle would restart at this high level, and we could show a decline with the stimulation of the whole muscle. Single-fiber EMG demonstrates the phenomenon called jitter, and increased jitter is a measure of dysfunction of terminal axons.

We can also use a stain for a special molecule called neural cell adhesion molecule. When muscle fibers are happy, when they are appropriately and correctly supplied by nerve fibers, they suppress production of this molecule. When they are unhappy, when their nerve fibers are not communicating with them, they express this molecule. We can see staining in 10-15% of the fibers, strongly suggesting that a large proportion of the muscle fibers are unhappy. They are not getting the proper connection with the nerve fiber.

Finally, in a series of experiments done by my colleague, Daria A. Trojan, MD, MSc, we broke down neuromuscular transmission with increasing rates of stimulation, in a technique called stimulation single-fiber EMG. With increasing rates of stimulation, there is increasing jitter indicating a defect in the transmission between the nerve and the muscle.

Thus, we have many lines of evidence to strongly suggest that the terminal axon is dysfunctional. It is not functioning properly on its road to complete degeneration. There is an intervening period of dysfunction, which may last for weeks to years.

Dr. Trojan and I have determined that part of the terminal axon dysfunction is due to a defect in the release of acetylcholine. An increase in acetylcholine may reduce fatigue and fatigueability and may increase strength. In an open drug trial of Mestinon

(pyridostigmine) in 1994, we measured fatigue in people with post-polio syndrome, and found a reduction in fatigue in the people taking Mestinon. In 1997, the North American Post-Polio-myelitis Pyridostigmine Study (NAPPS) found that Mestinon did not provide significant benefits with respect to quality of life, fatigue, or isometric muscle strength compared to a placebo, although a trend was noted

towards increased strength in very weak muscles.

We know there is terminal axonal degeneration. We also believe strongly that there is terminal axonal dysfunction not readily treated. We may be able to support the function of a terminal axon for years or decades, once we know why they are dysfunctional and how we can effect an improvement in this process. ■

RESEARCH FOCUSES ON BARRIERS TO PARTICIPATION

During the next two months, a random sampling of readers of *Polio Network News* will receive a comprehensive mail-in survey regarding lifestyles and activities. International Polio Network did not divulge your name to the researchers, and you will be identified only if you return the survey. However, we do encourage you to participate.

The project, headed by David B. Gray, PhD, in the Program in Occupational Therapy at Washington University School of Medicine in Saint Louis, Missouri, is funded by the Centers for Disease Control and Prevention. The goal of the three-stage research project, "Mobility, Disabilities, Participation and Environment," is to create a practical and useable assessment tool that can measure the effect of environmental factors on the participation of people with mobility limitations.

During the first-stage of the study, polio survivors and spouses from the Saint Louis area participated in interviews and focus groups to describe their activities related to transportation, employment, leisure activities, and home. They discussed what factors prohibited or helped them participate. The researchers, who also sought the opinion of health professionals who work with polio survivors, used the collected information in creating the mail-in survey.

The cross-disability study also includes people living with multiple sclerosis, spinal cord injury, cerebral palsy, stroke, and general mobility limitations.

POST-POLIO DIRECTORY 1999

will be available March 1, 1999. International Polio Network (IPN) will send forms to all clinics, health professionals, and support groups listed in the 1998 edition in early January. Please return the form (noting any changes in the information) to IPN as an indication of your willingness to stay updated on post-polio issues and to be listed as a resource for your geographic area. If you want to be added to this self-identified list, send your name, address, phone, fax, and e-mail to IPN.

Post-Polio Directory 1999 is available for \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only). (Many readers pay for the *Post-Polio Directory* when they renew their subscription to *Polio Network News*.)

IVUN RESOURCE DIRECTORY

1998/1999, an excellent networking tool for health professionals and both longterm and new ventilator users, will be available in November 1998. Sections include health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. The cost is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only).

Post-Polio Bibliography

◆ Bruno, R. (1998). Abnormal movements in sleep as a post-polio sequelae (CME article). *American Journal of Physical Medicine & Rehabilitation*, 77, 1-6.

Post-polio syndrome remains a diagnosis of exclusion and all possible causes for new symptoms in polio survivors must be eliminated. It is important to eliminate and treat a sleep disorder.

Sleep studies were performed in seven polio survivors to objectively document abnormal movements in sleep. Two patients demonstrated generalized random myoclonus, brief contractions and even ballistic movements of the arms and legs, slow repeated grasping movements of the hands, slow flexion of the arms, and contraction of the shoulder and pectoral muscles. Two other patients demonstrated periodic movements in sleep with muscle contractions and ballistic movements of the legs; two had periodic movements in sleep plus restless leg syndrome; one had sleep starts involving only contraction of the arm muscles.

◆ Parker, P. (1998). Late effects of poliomyelitis. *Mature Medicine Canada*, July/August, 52-54.

The summary article distinguishes between the relatively rare progressive muscular atrophy, the biomechanical problems of living with muscle weakness due to prior polio, and post-polio syndrome using the following criteria: "a history of paralytic poliomyelitis, a stable period of neurological status after recovery, residual neurological deficits due to the initial poliomyelitis, new subjective muscular weakness, generalized fatigue, and diffuse muscle/limb pain."

The article describes and discusses the major symptoms of fatigue, weakness, and pain. It states that the etiology is unknown; the diagnosis is one of exclusion and other causes for the symptoms should be vigorously investigated; that EMG cannot diagnose post-polio syndrome; and there is no 'cure.'

However, the prognosis can still be positive and the goal of treatment is to enhance the quality of life of individuals living with the late effects of polio.

◆ Wekre, L., Stanghelle, J., Lobben, B., Øyhaugen, S. (1998). The Norwegian Polio Study 1994: a nation-wide survey of problems in long-standing poliomyelitis. *Spinal Cord*, 36, 280-284.

The Norwegian Polio Study 1994 included 2,392 polio survivors. (The actual number in Norway is probably two to four times higher.) The response rate was 61%, which was considered low and was explained by the lack of a cover letter. When specifying new health problems, 85% stated that they had experienced increased weakness in muscles affected by polio, while 58% had experienced increased weakness in previously non-affected muscles. Other health problems related to polio were fatigue during exercise (80%), general fatigue (57%), joint pain (58%), muscular pain (58%), and cold intolerance (62%). The participants indicated an increasing need of aids, but 80% were still independent of help from others and 57% were still employed, fully or part time. Only 17% were satisfied with the public health services for polio survivors, while 67% of those who had undergone comprehensive examination at some central hospital were satisfied. This study indicates an obvious need of building up expertise in multidisciplinary evaluation and treatment of post-polio problems in countries where acute polio has been eliminated.

NOTE: There have been few large nationwide surveys of the polio population. Many surveys (and the results) can be criticized for having a small sample size and for surveying a select polio population, i.e., those who are patients at a particular hospital. Results of a nationwide survey in Denmark of 3,607 survivors were published in 1993. Data about USA polio survivors from the 1994 National Health Interview Survey (NHIS) will soon be available through the National Center for Health Statistics (NCHS).

◆ Willén, C., Grimby, G. (1998). Pain, physical activity, and disability in individuals with late effects of polio. *Archives of Physical Medicine & Rehabilitation*, 79, 915-919.

The aim of this study was to provide a description of pain and how it is related to the effects of polio, physical activity, and disability in individuals with late effects of polio. The analyzed group consisted of 32 individuals with a mean age of 56 years (range 37 to 73). Twenty-two individuals fulfilled the criteria for post-polio syndrome (as defined by Halstead and Gawne) and 10 had late effects of polio but did not fulfill the criteria for post-polio syndrome. More than half the individuals experienced pain every day. This study showed that the experience of pain is related to the level of physical activity.

One assessment instrument used in the study was pain drawing, a well-known method for describing different characteristics of pain. The aching characteristic was over-represented in all body parts, but in the lower limbs cramping pain was as common as aching pain. The cramping sensation might be an expression of muscle work that is overly strenuous. Interestingly, regarding the cramping sensation, there was no difference between the lower limbs that were polio-affected and those that were not. This may be due to overuse of the strong leg to perform many mobility-related activities. The authors note that muscles deemed non-polio-affected by the participants may include polio-affected muscles but with a high degree of reinnervation and thus normal or near-normal function.

The degree of muscle weakness was not related to the pain experience. This indicates that an individual does not necessarily experience more pain with more pronounced muscle weakness. On the contrary, it might indicate that those who are less affected by muscle weakness experience more pain, which can be a result of a more active life.

The authors recommend that individuals with late effects of polio who experience aching and especially cramping pain should adapt their level of physical activity in daily life. They also need to discuss their exercise habits with a physiotherapist. An activity diary and a pain drawing could be useful in these discussions. ■

Five Ways to Find Peace with One's Self and the World

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

For persons with disabilities like us, three principles are indispensable for peace: first, if I am going to live in peace with myself, then I must learn to live at peace with my disabilities. Second, if others are going to live in peace with me, then they too will have to learn to be at peace with my disabilities. And third, the more comfortable I am with my disabilities, the more others will be comfortable with me.

As I see it, peace with myself is harmony between where I am right now and where I aspire to be. I am not there yet. But I have peace in knowing I am still on the way. Peace with my disability is harmony between life as I want to live it and the demands that the disability makes upon my strength, energy, and endurance. I am always searching for a way of compensating for what I have lost by having goals that are attainable in spite of my losses.

Peace with others with me is harmony between what I do and say and what others expect from me. I should be open and clear about who I am and what I want. And they must not blindly expect me to follow their wishes.

Just how are we going to live in harmony with our disabilities and with others? As a result of my own experiences with disability, I have developed a five-step plan toward this harmony, and each step begins with a letter of the word "peace."

But I am going to start with the letter "A" because it is the most

important. "A" is for aim. Aim is the goal, the purpose of our actions. Aim as a verb is the lining up of our actions to reach our goal. Without worthwhile goals to aim for, life has no meaning.

If you want to help me get back on target, aimed again toward peace, there are things that I hope you will do for me and, of course, that I should be doing for you.

Be patient with my anguish and uncertainties. These feelings of mine are founded on real loss and real fears. Be positive and upbeat. Gently draw my attention away from dwelling upon what I have lost to recognizing the powers that remain. In your hopes for me, I can find hope for myself. Be enterprising and creative. Because I am unable to do the many things I used to do, help me to find a way to go on doing the few things that I can still do. Try to see and feel things from my perspective. Be warm and accepting. Be open and flexible.

If you want me to be at peace with you, don't pressure me to make your goals my goals. Once I have set my goal, even if you think it is wrong, don't reject me or try to block my path. If I fail to reach it, don't say, "I told you so." Just come over, give me a hug, and help me find another path to follow.

In my experience, the people who seem to adjust most easily to their losses are those with strong principles, because they more readily realize that what matters most in

life is not what one does but how one does it. And they seem to have an inner power that gives them energy to press on in the face of setbacks.

But what about the times we fail through our own fault – doing something stupid, unkind, lazy, or what we should not have done? Although guilt destroys peace, it also restores us to our senses. Peace is regained not by denying guilt or running away from it, but by acknowledging mistakes, learning from them, and accepting the consequences of our actions. Peace is being able to start again tomorrow regardless of what happened today.

Now the second step uses the letter "P" for powerizing prayer. We need to take time every day to withdraw into our inner selves in silence and attentiveness, making contact with the inner source of our energies.

If you are a believer, find and communicate with your God, the spirit in nature, the universal force. If not a believer, touch and draw on the powers of your inner self. Such prayer takes us into a world where disability doesn't matter. It refreshes our spirits, draws on our inner strengths, and gives us renewed purpose and energy. I highly recommend this process as an energizing step toward finding peace in our changing post-polio situations.

The third step is "E" for engage and enjoy. "E" is for the importance of spending our time engaged in meaningful activities.

"E" is for embellishing and emblazoning whatever we do with value and importance. "E" is for getting enjoyment out of whatever we do. Even if the only thing you can do is rest, then enjoy it. Put your heart into it. You have earned it.

Sometimes it is necessary to tramp through mud to get where we are going. So enjoy the squish, squish of the mud; be happier moving instead of being stuck. Be glad you are getting somewhere.

The fourth step is "C" for concern and communication. When we are concerned about others, reaching out to them with understanding and warmth, our troubles are lightened and fall more easily into perspective. Joy shared is joy doubled. Sorrow shared is sorrow lessened. Concern for others muffles pain for ourselves.

Peace also comes in fighting for a good cause such as standing up for our rights to protect what is necessary for our well being, particularly in the face of post-polio realities. But even in these situations, more attention to the concerns and needs of our adversaries can make accommodation and peace easier to achieve.

I am reminded of the little boy who once cut his finger and wound up with blood all over the place. But he went calmly into the bathroom to get a Band-Aid®. When his mother found him

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there, she said, "Why aren't you crying? Doesn't it hurt?" He said, "I didn't know you were home."

The little boy knew that crying was futile if no one heard him, so he solved the problem on his own. With his mother's help, though, that boy's finger would have been bandaged much faster, neater, and probably more effectively.

Finally, "E" is for embroidery, representing all types of leisure activities, hobbies, recreation, games, diversions. A peaceful life is a varied life. All work and no play usually adds up to pressure and anxiety and puts a strain on others.

These so-called steps are not steps to be taken one at a time or in any particular sequence; they are five important everyday ingredients for finding peace.

Peace is when the world is falling apart and you are not. Peace is when you are hurting but the pain doesn't make you quit. Peace is when you have to slow down but refuse to stop. Peace is having something to do and doing it with all you've got. Peace is having nothing to do but enjoying it. Peace is when you can enjoy whatever you do without regret for what you aren't doing. Peace is doing well what you would rather not do but have to. Peace is when you have done something wrong and have the courage to admit it and change.

Peace is when you are not afraid to say no when you would rather say yes. Peace is when you stop and commune with your inner self. Peace is doing something right when everything is going wrong. Peace is blowing off steam without burning anyone. Peace is time shared with another. Peace is clearing the tears from your eyes by wiping the tears from the eyes of another. Peace is when

you are in conflict and find a friend. Peace is shaking hands with someone you would rather sock. Peace is giving generously when you would rather be taking and receiving graciously when you would rather be giving.

In 1991 in Beijing, at an Asian and Pacific rehabilitation conference, the delegation from Hong Kong brought with them a supply of dolls as gifts. Each doll was egg-shaped without arms and legs. On the front were the words "Keep me down if you can." To show the spirit of rehabilitation, the dolls were weighted to return to the upright position if put on their sides. In this life of ours, we cannot escape being bowled over from time to time, but we can bounce back if we strive for peace with ourselves and those around us. ■

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Sleep-Disordered Breathing and Nocturia

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

This article is a follow-up of the survey of symptoms regarding sleep and bladder function that appeared in *Polio Network News* (Volume 14, Number 3). At a later date, *Polio Network News* will summarize a formal report of this study as well as list an Internet address for the same. Dr. Umlauf is still accepting the Sleep and Bladder Health Among Polio Survivors survey. The purpose is to explore the magnitude of obstructive sleep apnea (OSA) symptoms and nocturia in persons who had polio.

Having a good night's sleep is not an optional part of our lives; it is absolutely necessary to our health and well-being. Physically, sleep provides the body with time to rest and to recover from daily activities. All of us require a certain amount of dream sleep (rapid eye movement, or REM sleep) and deep sleep (slow wave, or delta, sleep) every night to function mentally. Any condition, whether it is pain, snoring, sleep-disordered breathing, restless legs, insomnia, or nocturia (excessive urinating at night), can fragment our sleep and result in daytime sleepiness.

One of the most serious types of sleep problems is obstructive sleep apnea (OSA), which can cause hypertension (high blood pressure) and lead to heart failure. OSA, a reversible condition, is associated with both snoring and nocturia. OSA occurs when the soft upper airway over-relaxes and closes off or obstructs the passage for air when the person goes to sleep. The sleeper may snore loudly and then suddenly stop. An observer, usually a spouse, may note that the sleeping person is trying to breathe but is unable to. After a number of tense seconds, some-

times 20 or 30, the sleeper will wake up, take a big breath, and resume snoring.

Often, the sleeper will not remember how many times these arousals occurred even though they may number in the hundreds. Here is the danger of sleep-disordered breathing: the sleeper may be unable to convey to a physician the exact nature and severity of the sleep problem.

Not surprisingly, nocturia is also frequently associated with poor quality of sleep. Getting up to void more than twice at night is considered abnormal because of sleep disruptions. For persons with mobility problems, having to urinate at night may also lead to falls or add to the difficulty of maintaining independence.

Although nocturia is usually assumed to be caused by either bladder instability or an enlarged prostate, it may also be a sign of OSA. In fact, recent studies have

found a mechanical and hormonal relationship between OSA and increased urine production at night. The mechanics of obstructed breathing characteristics of OSA cause the heart to perceive false signals of fluid overload. In turn, the heart produces a hormone-like protein that causes the kidneys to increase their output. However, because this relationship between sleep-disordered breathing and nocturia is not generally understood among health care providers or the public, persons who have both nocturia and signs of sleep-disordered breathing may not seek help for these symptoms or may not receive appropriate treatment when they do report them.

For more detailed information about general sleep problems, contact American Sleep Disorders Association, 6301 Bandel Road, Suite 101, Rochester, MN (Minnesota) 55901 (507/287-6006 or www.asda.org). ■

HEALTH INFORMATION FROM ...

Contact the **National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)**, 3 Information Way, Bethesda, MD (Maryland) 20892-3580 (301/654-4415, www.niddk.nih.gov) for a free copy of: *Fact Sheets* – KU-99 Impotence; KU-121 Urinary Incontinence in Women; *Booklets* – KU-03 Urinary Tract Infection in Adults, KU-22 Prostate Enlargement: Benign Prostatic Hyperplasia; and *Let's Talk About Bladder Control for Women Publications* – KU-109 Bladder Control for Women; KU-111 Menopause and Bladder Control; KU-113 Talking to Your Health Care Team About Bladder Control; KU-114 Your Body's Design for Bladder Control; KU-115 Your Medicines and Bladder Control.

The Simon Foundation for Continence, Box 815, Wilmette, IL (Illinois) 60091 (800/23-SIMON) publishes a quarterly newsletter, *The Informer* (with membership), and *Managing Continence: A Guide to Living with the Loss of Bladder Control*, available for \$10.95 plus \$1.00 shipping and handling.

The National Association for Continence (NAFC) publishes the quarterly newsletter, *Quality Care*, formerly *The HIP Report*. Contact NAFC, Editorial/Subscription Office, P.O. Box 8310, Spartanburg, SC (South Carolina) 29305-8310 (800/BLADDER, 864/579-7900, 864/579-7902 fax, www.nafc.org).

Agency for Health Care Policy and Research at www.hcpr.gov, click on the search button and type in "incontinence."

Have You Heard About ...

... **Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome** (ISBN 0-9661676-0-0) edited by Lauro S. Halstead, MD; co-edited by Naomi Naierman, MPA. Other contributors include: Ruth Wilder Bell, RN, DNSc; Nancy E. Bogg, M.Ed, CRC; Nancy Baldwin Carter, BA, M.Ed; Anne C. Gawne, MD; Kathryn R.B. McGowan, MA; Beverly Neway, MS, CRC; Rhoda Olkin, PhD; Liina Paasuke, MA, CRC; Julie K. Silver, MD; Laura K. Smith, PhD, PT; Tom Walter, BA; Grace R. Young, MA, OTR.

The appendix contains seven personal stories. 6x9 paperback, 256 pages. \$11.95 plus \$3.75 shipping within the USA and to Canada. Contact NRH Press, National Rehabilitation Hospital, 102 Irving Street, NW, Washington, DC 20010-2949 (202/877-1776, 202/829-5180 fax). The hardcover version (ISBN 1-886236-17-8) is \$25.00. Contact NRH Press for international shipping costs.

... **Black Bird Fly Away: Disabled in an Able-Bodied World** (ISBN 0-918339-44-8) by Hugh Gregory Gallagher, foreword by Geoffrey C. Ward. 6x9 hardcover, 320 pages. \$21.95. Contact Vandamere Press, P.O. Box 5243, Arlington, VA (Virginia) 22205 (703/538-5750, 703/536-9644 fax).

... **Anatomical Gift Whole Body Donation Guide** by Regina Lee — a consumer's guide to whole-body donation. \$24.50, includes shipping. Contact Consumer Education Services, Box 724261, Atlanta, GA (Georgia) 31139.

... the 7th International Conference on Home Ventilation – **Noninvasive Ventilation Across the Spectrum from Critical Care to Home Care** on March 14-17, 1999 at the Caribe Royale Resort Suites in Orlando, Florida. Polio survivors with respiratory problems will want to attend this important meeting. Ventilator users will be among the speakers as will health professionals knowledgeable about post-polio breathing problems. Topics of special interest to polio survivors are swallowing, nutrition, secretion enhancement techniques, sleep-disordered breathing, nocturnal hypoventilation, psychosocial aspects of long-term ventilation, and quality of life. Additional practical sessions will feature custom and commercial masks and ventilatory equipment. For registration information, contact American College of Chest Physicians (ACCP), P.O. Box 93826, Chicago, IL (Illinois) 60673 (800/343-2227, 847/498-1400, 847/498-5460 fax).

... Veterans Benefits/ Veteran Advisor

QUESTION: I served in the US Navy from October 1950 through October 1953. Eleven months later, in September 1954, I developed a fever and malaise together with muscle weakness. I was admitted to the hospital, and [doctors] diagnosed acute poliomyelitis. As a result, I am now paraplegic.

I filed a claim with VA for service-connection for this disease in September 1954. VA denied my claim [because] the poliomyelitis did not develop within 35 days following my discharge from the

Navy. I recently learned from another veteran that if a chronic disease develops within one year from the date you are released from active duty, service-connection can be allowed.

Was VA wrong in denying my claim? If so, how do I go about getting this error corrected?

ANSWER: Based on the information you provided, it appears VA improperly denied your claim. PVA Appellate Services recently obtained important favorable determinations on administrative review by VA's Compensation and Pension Service on this issue. In the past, VA relied on the provision in VA regulation 38 CFR 3.379, which specifies that for the purposes of service-connection the first manifestations of acute poliomyelitis had to occur within 35 days following discharge. PVA argued that this regulation was more restrictive than the statute.

PVA argued, and the Compensation and Pension Service agreed, that poliomyelitis is a chronic disease of the nervous system. Therefore, if poliomyelitis becomes manifest to a degree of 10% or more within one year from discharge, service-connection can be granted.

In your case, you can file for an administrative review of the initial denial of your claim or reopen your claim with new evidence. Contact your local PVA national service officer to determine which option benefits you.

For further information, contact Paralyzed Veterans of America National Office (202/872-1300 or www.pva.org).

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CONTINUED ON PAGE 10

... **My Body Knows What I Have To Say**, a dance performance by Sefa Jorques, New York, New York.

"I am a choreographer/dancer from Valencia, Spain. At the age of seven months I was diagnosed with polio and did not begin to walk until the age of three. However, as a teenager, I experienced an undeniable impulse to dance, and, seemingly out of an unconscious well, unusual shapes spontaneously emerged. At first, only still shapes appeared. I began accumulating an endless out-pouring of forms with no movement. The need to reveal the origin and meaning of these forms led me to develop my own vocabulary of movement.

"My body knows already what I have to say. The shapes are already there, waiting for me to free them. My dances are characterized by unusual, meticulous dance forms. The imagery of these forms varies from twisted, tangled, intertwining figures to more rounded, undulating, or elongated profiles. At times, separate parts of the body, such as arms, feet, hands, or fingers, take on a life of their own. At other times, portraits appear as if my body was broken into pieces and then put back together to create an illusory non-human form. Most of the movements are in slow-motion. The interplay of different shapes with their intrinsic movement creates complex meanings that defy any single interpretation.

"Since 1996, I have been a licensed massage therapist and a recipient of SomatoEmotional Release (SER). SER is a body-work technique developed by John E. Upledger, DO, OMM, which seeks to find and release excess energy embedded in the physical tissues. Through this hands-on technique an individual's body

moves very subtly into a position and the therapist simply follows the movement. When the body reaches the "therapeutic position," pain and/or emotional relief occurs. In this way, body movements can be analogous to the verbal healing of psychotherapy.

"While receiving this technique, I found myself in positions which I had previously discovered intuitively through my dance. I believe that my dance work is, at least in part, an emotional healing process of my early experience with polio."

"Cinc Mirades" – a dance program consisting of five solo pieces choreographed and performed by Sefa Jorques – will be performed December 11 and 12, 1998 at 8 p.m. at: Tribeca Performing Arts Center Borough of Manhattan Community College/CUNY

199 Chambers Street (between Greenwich and West Streets) New York City, NY (New York) 10007 212/546-8510 box office or 212/732-2482 fax

The theater is wheelchair accessible. Call the theater for ticket information.

The program is made possible by a grant from the Manhattan Community Arts Fund with public funds from the City of New York Department of Cultural Affairs.

This performance is also sponsored by the Tribeca Performing Arts Center.

... **May Media Meeting**, the national meeting to explore why disability issues, our issues, are not heard or discussed in the media.

Ragged Edge (formerly *Disability Rag*) and *Mainstream* are sponsoring a meeting in Louisville, Kentucky, May 21-23, 1999. The cost of the three-day meeting is \$200 per person, plus hotel (\$99 per night, double occupancy) and airfare. Continental breakfast and lunch will be provided. For more

information, contact May Media Meeting, P.O. Box 145, Louisville, KY (Kentucky) 40201 (502/899-9562 fax).

... **National Family Caregivers Week** (November 22-28), a great time to honor the over 25 million Americans who assist others.

The National Family Caregiver Association (NFCA) organizer of the week, reports that 80% of all homecare services are provided by the family. For ideas and materials to participate in National Family Caregivers Week, contact NFCA, 10605 Concord, Suite 501, Kensington, MD (Maryland) 20895-2504 (301/942-6430, 800/896-3650, 301/942-2302 fax, info@nfcacares.org, www.nfcacares.org).

... **the new post-polio groups in Japan**. Contact Mariko Koyama, President, Polio Association, 1-6-5-602 Minowa, Taiyo-ku, Tokyo 111, Japan (81/3-3872-7359) or Tae Shibata, Polio Women's Association, 23-5 Taibatake-higasimachi, Suma-ku, Kobe 654-01, Japan (81/78-796-0757).

... International Polio Network has published a **Polio and Post-Polio Fact Sheet** for the uninitiated which contains a listing of facts about polio and the epidemics, acute polio in the world today, including vaccine policy, and the late effects of polio. To receive 6 free copies, send a self-addressed #10 envelope with 55 cents postage to International Polio Network, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915. (International readers may request two free copies via mail, fax, or e-mail.)

More about crutches ...

Ergonomics, Inc.

Joyce C. Young, President
6058 Mad River Road, Dayton, OH
(Ohio) 45459 (937/434-2466 or
ergocrutch@aol.com).

For years, I sought ways to make my crutches more attractive.

When I used underarm crutches, I asked artistic friends to paint flowers on them, but when I began to use alumi-num forearm crutches, it

was impossible. Not only were they just plain ugly, but also they usually showed great signs of wear. I used to go through two or three pairs of crutches each year.

So, I researched other possible sources of crutch material and gathered several good friends to form a company to investigate the possibility of using the new composite materials that were proving very functional and popular. We incorporated Ergonomics, Inc. to design and develop improved products to assist people with physical conditions that restrict their mobility. Initially, we worked on improved design features, including streamlining and strengthening the crutch structure and reducing the number of parts.

Ergonomics entered into a Co-operative Research and Development Agreement with the US Air Force Materials Laboratory. Under this agreement, Ergonomics provided designs and desired performance characteristics for



improved forearm crutches, and the Air Force Laboratory applied its world-class expertise in materials technology and manufacturing to fabricate and test prototype crutches. As a result of this development effort, forearm crutches that are lighter, more comfortable, more durable, and cost effective than conventional designs have been produced. Testing on these superior crutches is expected to be complete in December 1998, after which they will be available for purchase on a custom-order basis.

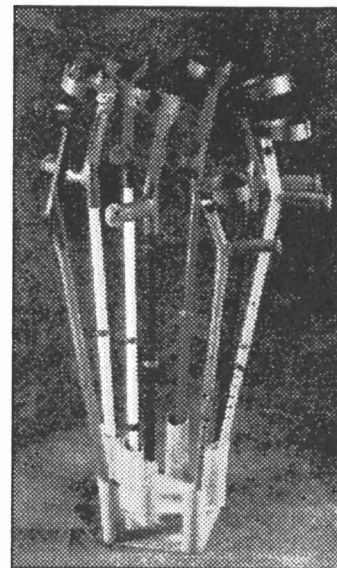
Unlike currently available forearm crutches (which have remained largely unchanged in design and material for decades), the new crutches will be ergonomically engineered and aesthetically pleasing. They will have graphite shafts and weigh approximately 50% less than ordinary metal crutches. The carbon fibers in the shafts are oriented so that mechanical vibration and shock transmitted to the user is minimized, and thus comfort for the longterm user is maximized. The Ergonomics crutch is more cost effective than standard designs because each is sized for the individual customer and have no adjustment pins, which are the major cause of wear and noise in conventional design.

Walk Easy

2915 South Congress Avenue,
Delray Beach, FL (Florida) 33445
(800/441-2904, www.walkeasy.com)

All Walk Easy forearm crutches are constructed of lightweight materials, feature a unique clip-on height adjustment mechanism, and come in an assortment of epoxy-coated colors. The crutches are designed to fit most adults ranging in height from 5' to 6'3" and are backed by a limited lifetime warranty covering defects in materials and workmanship.

Walk Easy also offers a full range of canes – small and large base quad canes in flat or inverted V-base design, orthopaedic canes with form-fitted handles, and folding canes. All canes are height adjustable, come in an assortment of colors, and carry a three-year limited warranty.



Edward L. Openshaw of Rumney, New Hampshire makes custom-built crutches for Thomas Fetterman, Inc., Southampton, Pennsylvania (888/355-6941).

When creating custom crutches, Openshaw is particular about the type and quality of the wood, making note of the grain and color. Many of his crutches are heat bent. All parts are handmade and to any dimension (height from top to floor and handle to floor; diameter and length of handle) or style a customer requests.

He offers a variety of weights, woods, finishes, and types of tops (leather sling, wood, cuff). ■

... Disability Product

Postcards, a packet of advertisements containing information about equipment. Send your name and address to Disability Product Postcards, P.O. Box 220, Horsham, PA (Pennsylvania) 19044-0220.

... **Weathershield™**, a convertible top for wheelchairs which provides protection from the weather. Contact Carolina CoverTech at 800/763-0243.

... the Web site **www.medicare.gov** created by the Health Care Financing Administration (HCFA). Sections include: What is Medicare? Managed Care, Who to Contact?, Publications, Wellness, Fraud and Abuse.

... **NeuroVista**, an online newsletter for neurology, health, and wellness information premiering fall of 1998. Log on to www.aan.com, the site of The American Academy of Neurology, the creator of the online newsletter.

... **President's Committee on Employment of People with Disabilities** at www.pcepd.gov, which provides visitors direct access to President's Committee publications, speeches and press releases, as well as to information on statistical data, workplace laws, job accommodations, interviewing, hiring and communicating with people with disabilities, among other topics. ■

Readers Write

"I am a post-polio quad who had my custom corsets made for over 40 years at Warm Springs. I could mail an older corset to them and they would do an excellent job of duplicating that existing corset. Now it is harder to find corset makers who make custom corsets. Most use a commercial-type general corset and these manufactured corsets are inferior in my opinion. Do you know of any other corset makers who could make a corset using an existing one as a model?"

Gene, North Carolina

"I have a 1989 Ford Econoline 150 van with 65xxx miles, new tires, rebuilt transmission, and dual air/heat for sale for \$8,900. It was modified for a tall person in a wheelchair with a six-inch dropped floor, a Sportster top, a Braun semi-automatic hydraulic lift. It will be available in January 1999. Call 573/445-7300 for details."

Dick, Missouri

"In an effort to plan a reunion and/or symposium, the Margaret H.W. Watson Foundation at D.T. Watson Rehabilitation Services is seeking the names and addresses of former Watson polio patients, alumni of the Watson physical therapy school, and 'Salk Soldiers.'

"Individuals who were involved with D.T. Watson in the past, including children who received treatment or training at the facility, or family members or friends who had a connection with Watson are invited to attend."

For more information, contact June Maier, D.T. Watson Rehabilitation Services, 301 Camp Meeting Road, Sewickley, PA (Pennsylvania) 15143 (412/749-2201, 800/922-4226, ext. 2201, junem@dtwatson.org).

"In 1954, at the age of 26, I contracted polio. To date, I have not had post-polio syndrome. Why? In reading the information, it appears that all of the research involves those with PPS. Have there been any studies of the still 'fortunate' polio survivors? Is it not reasonable to include this group in research? Would it be constructive to determine whether there may be scientific reasons for the difference between those with PPS and those without?"

Stan, New York

"I have had a CO (carbon monoxide) detector and finally had to disconnect it because of numerous false alarms, usually in the early morning hours. After some study, I determined that the erroneous alarms were caused by one or both of two factors – moisture added to the air by the humidifier attached to my ventilator, and gases generated by the recharging of my wheelchair batteries. This analysis was confirmed by a call to the consumer hotline of the detector manufacturer, Nighthawk Systems, Inc. (800/880-6788)."

LeRoy, Minnesota

If you had polio more than once and are willing to share your experience with others, send your name and address to International Polio Network.