HANDBOOK ON THE LATE EFFECTS OF POLIOMYELITIS

FOR PHYSICIANS AND SURVIVORS

EDITED BY
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FOREWORD I

Physicians have always learned from their patients, especially if they were seeking wisdom for total healing. This handbook for physicians and polio survivors is truly a document that comes from the partnership of patient and physician.

There are many new medical problems that people who had poliomyelitis twenty or more years in the past are beginning to experience. Many of these new problems are not unique to people with polio residuals, but there appear to be some that are. As with many areas of clinical medicine, particularly with chronic diseases and degenerative disorders, scientific research is slow and the questions are only recently being asked.

This handbook is not a scientific document but an attempt to convey to a wide group of medical practitioners useful information about clinical problems associated with old polio based on the experiences of others.

I credit the collective experiences of the many post-polios and physicians who attended and participated in *Rehabilitation Gazette*'s two international post-polio conferences, participants at Warm Springs Research Symposium, and, of course, my own patients.

Scientific and scholarly information, as it is available and pertains to the subject, has been included in the handbook, particularly for various clinical investigators and other serious thinkers who wish to pursue further reading on selected topics. I hope that this information will be helpful to polio survivors and their physicians alike.

Frederick M. Maynard, M.D.
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Ann Arbor, Michigan

FOREWORD II

The need for a polio "handbook" for physicians was first recognized by the impacted consumer of physician services: the polio survivor. Since the development of effective vaccines, poliomyelitis is a rare disease in the U.S., and medical graduates of the past 2½ decades have probably not seen a case.

The survivors of the polio epidemics of the 1950s have seemed medically stable and have lived productive lives. Some have required little intervention by medical practitioners. Some have continued their medical care at centers with orthopedic and respiratory specialists familiar with their problems.

In the past few years, however, new problems for post-polio people have developed. Progressive weaknesses of an arm or leg that had bourne the burden of functional activities have caused loss of independence. Pain, recurrent respiratory problems, and general fatigue have caused understandable fear that something more serious than aging was occurring to them. Their physicians did not understand. Dark hints of a "mysterious process," a "recurrence of polio," a "new disease" like ALS were frightening. With such an unknown, reassurance was not effective.

Several conferences have assembled research scientists and clinicians including post-polio people to address these concerns (the Warm Springs Research Symposium and *Rehabilitation Gazette*'s two post-polio conferences).

This handbook is a product of the conferences with input from many sources. All the answers are not here, but it is a beginning. Future revisions will be based on your responses and further sharing of information with investigators and medical practitioners.

D. Armin Fischer, M.D.
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INTRODUCTION

Both disabled individuals and medical experts agree that the medical profession does not well understand the late effects of polio and, consequently, physicians are not always meeting the current health care needs of polio survivors.

Although the Salk and Sabin vaccines have eliminated new cases of polio in the United States, an estimated 300,000 individuals with some degree of disability survived since the epidemics of the 1940s and 1950s. These disabilities vary from limited and localized muscle weakness to quadriplegia with total dependence on mechanical ventilation.

The majority of polio survivors have lived full and productive lives in their communities for nearly 30 years. Many of them have begun to experience new musculoskeletal problems, including increased weakness and pain, as they have grown older. These new problems often lead to losses in functional independence with activities of daily living. Many have had to return to using canes, crutches, or wheelchairs. Others who had been weaned from a ventilator during the acute stage of polio have now found it necessary to return to the use of ventilators when sleeping.

Throughout its 25 years as an international journal, *Rehabilitation Gazette* has been the "glue that held the polios of the world together" by collecting and disseminating information and creating a living network. Since the *Gazette* first published an article on polio aging problems in 1979, the matter has received national and international attention.

Unfortunately, the late effects of polio, including progressive muscular weakness, are not well known among most physicians. It is also difficult to distinguish them from other degenerative disorders of muscles, ligaments, and joints. Patients who develop new problems may be submitted to extensive tests unnecessarily. Many polio survivors have been labelled "hypochondriac" or "neurotic," have been given inappropriate prescriptions, or have been sent off for seemingly endless, expensive referrals. A frequent complaint of polio survivors is that the doctors do not appear to listen to them.

Since most polio survivors have lived with their disabilities for many years, they are often well-informed about their problems. Most well understand their responsibilities as good medical historians. They can also help educate their physicians about the types of new conditions they may be experiencing as the late effects of polio. Together, polio survivor and physician can find the most effective management plans.

This handbook is intended for physicians and other health care professionals who may be treating polio survivors for the first time. The handbook is also meant for polio survivors themselves. The use of medical jargon is kept to a minimum.

Polio survivors are to be treated differently only in regard to their specific limitations resulting from the residuals of polio. They are to be listened to with respect, since they are the ones who have lived within and taken care of their bodies for the last 25 or more years.

The editors also believe that techniques which are still effective for polio survivors today must be disseminated to modern medical staff who may be unfamiliar with the care of respiratory disabled and mobility limited persons.

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HISTORY OF POLIO

by Gini Laurie

Polio has occurred for thousands of years in all parts of the world. The bone formation of an Egyptian skeleton of the period of 3700 B.C. indicates the effects of polio, as does an Egyptian plaque from 1300 B.C.

Polio has had many labels: poliomyelitis, infantile paralysis, Heine-Medin disease, and poliomylelopathy. Poliomyelitis is a combination of two Greek words: *polios* or gray, denoting the gray matter of the nervous system, and *myelos* or marrow, denoting the myelin sheath around certain nerve fibers. There are three types: bulbar, spinal, and bulbarspinal.

The recording of polio as a disease dates from the late 18th century. By the early 19th century it was reported as being widespread in Europe and India. It was regarded as ubiquitous and caused by teething, foul bowels, or fever.

Three names are associated with the early recorded history of polio: Dr. Jakob Heine (1800–1879), an orthopedist of Germany, Dr. Karl Oskar Medin (1847–1928) of Sweden, and Dr. Ivar Wickman, a pupil of Dr. Medin, who experienced the great Swedish epidemic of 1905 and was the first to express the correct conclusion that person-to-person was the manner of transmission. (Ref 16.)

Presently, it is known that the infection is primarily an inapparent one involving the alimentary tract, that paralytic polio is a relatively uncommon complication, and that silent infection in childhood provides long-lasting protection. The disease is spread by asymptomatic persons through the shedding of the virus from the throat and intestinal tract. Dissemination of the disease is enhanced by poor sanitation, crowding, and low standards of personal hygiene such as those that are common in many tropical and subtropical areas. It is still a widespread problem of endemic proportions. (Ref 63.)

The early major epidemics in the United States were in the southeastern section in 1910 and in the northeastern section in 1916. In the latter, 27,000 persons, mostly children, were disabled and 6,000 died.

The epidemic of the summer of 1921 struck a future president of the United States and changed the history of polio. Franklin Delano Roosevelt became ill at his summer home in Canada. The following summer he learned to walk on crutches. He progressed slowly until 1924 when he tried swimming at Warm Springs, Georgia. Thereafter, he walked with braces and a cane. To share the hydrotherapy he formed the Georgia Warm Springs Foundation (now the Roosevelt Warm Springs Institute for Rehabilitation).

In 1938, during his presidency, FDR founded the National Foundation for Infantile Paralysis (March of Dimes) to organize laymen and scientists to conquer polio. At about the same time, similar organizations were started in Canada and Europe. (Ref 16.)

As the March of Dimes pushed the search for a vaccine and provided care for the survivors, waves of epidemics hit North America and Europe every summer. There were serious epidemics in the years 1936, 1937, 1941, 1944, 1946, 1949, 1951, 1952, and 1954. (Ref 78.)

During this time, the pattern of polio changed. No longer an infant's disease, it involved increasingly older age groups. As medical management and antibiotics improved, more and more people were saved, including those who remained permanently dependent upon ventilators to breathe. In the early 1950s, to care for them effectively and economically, the March of Dimes established and funded 16 regional respiratory and rehabilitation centers at teaching hospitals around the United States.

From 1953 to 1959, these centers acted as the hub of care, research and rehabilitation, and home care for survivors on ventilators. These centers were very successful in the rehabilitation of these patients, so that effective long-term maintenance care was taken over by responsible patients, families, and community resources.

Following the success of the vaccine and the widespread financial support of the public, the March of Dimes was forced to close the centers and curtail services. In 1959, there were 1,200 polio survivors on ventilators in the United States. (Ref 76.)

Immunization against polio began in 1955 with the development of the formalin-inactivated poliovirus vaccine (IPV) by Dr. Jonas Salk followed by the live, attenuated oral poliovirus vaccine (OPV) of Dr. Albert Sabin. OPV was first used on a scale in Russia in 1959 and in the United States in 1960--1961.

In North America, Europe, Australia, and some parts of Asia where either vaccine was used there was a spectacular decline in cases. In the United States, there were 28,000 cases in 1955 and in 1956, after one year of vaccine, there were 15,000. From then on the incidence plunged. Between 1973–1981, the average annual number of reported cases in the United States has been fewer than 15. (Ref 107.)

ADJUSTMENTS IN LIFESTYLE

To compensate for the functional limitations caused by the natural aging process superimposed on the residuals of polio and its late effects, adjustments in lifestyle may become necessary. A person who has walked normally may develop a limp or begin to need a cane. A person who has been ambulatory without aids may need braces and crutches. A person who has used braces and crutches may need to use a wheelchair. A manual wheelchair user may need to change to a motorized wheelchair. A power chair user may need further adaptive equipment.

These changes require psychological flexibility and an open mind. The adjustments are easier for those who can share the experience with other polio survivors through publications or participation in local mutual support groups. Survivors often gain valuable insights from other survivors who have benefited from techniques to achieve more energy, to improve chest expansion, to maintain independent mobility, to manage pain, to otherwise successfully adjust to some late effects of polio or to better cope with some new disability.

AGING AND WEAKNESS

The changes seen in the muscles of polio survivors complaining of loss of strength and decreased endurance may be partially the result of aging superimposed on previous residual nerve damage from polio. Recent research suggests that anterior horn cell populations (motor nerve cell bodies) may decline by up to 20% between ages 60 and 90. (Refs 154, 155.) This magnitude of cell loss would not be expected to cause clinical weakness in normal individuals. In polio survivors, with already reduced cell populations as a residual from acute polio, age-related losses of cells may produce enough weakness to interfere with normal activities such as walking or lifting.

There are several theories to explain the phenomenon of increased weakness or deterioration of strength occurring 20-30 years after the onset of polio, usually in limited muscle groups. There is no evidence that the nerve damage produced by the poliovirus becomes active again. Any progression of disability is not due to a recurrence of the polio infection, nor is progression always to be expected. The late weakness may

have nothing to do with polio, but may be caused by disuse atrophy following injury or illness, by pinched nerve roots and radiculopathies, by peripheral neuropathies, including compression neuropathies, or by disuse atrophy related to pain from chronic, strain-induced inflammatory disorders of muscles, tendons, and ligaments. These causes of increased weakness can be improved by rest, immobilization, traction, physical therapy, surgery, medications and other appropriate treatments.

Nerve cells previously damaged by the poliovirus infection may also be especially vulnerable to the aging process. Chronic overuse of weakened muscles at near-maximum loads may stress the metabolism of remaining motor neurons leading to further dysfunction of the motor unit. Further cell death creates a cycle of ever-increasing weakness. As motor neurons drop out, the person involved may exert greater effort, leaving the remaining neurons under even greater stress.

Some people have theorized that more men than women fall into this self-destructive cycle because men are more likely to try to exercise their way out of weakness. However, research results on the late effects of polio suggest that more women than men are currently complaining of new difficulties.

There is tremendous variability in the course of late post-polio weakness. It is far from inevitable in all polio survivors. A recent epidemiologic study done on all polio survivors in the city of Rochester, Minnesota, estimated that only about 20% of people who had polio are now experiencing increasing muscle weakness. (Ref. 158.)

The course of new post-polio weakness is usually very slowly progressive over many years. Keeping in good general condition and taking time to rest during repetitive activities may be the best advice for people who experience slowly progressive post-polio weakness.

Musculoskeletal problems that may occur as a result of long-standing muscle imbalance and weakness should be recognized and treated — not merely attributed to "getting old." Some of the more common new musculoskeletal problems among polio survivors include osteoarthritis of the spine and of peripheral joints, scoliosis, bursitis, tendonitis, osteoporosis, myofascial pain syndromes, foot and toe deformities, carpal tunnel syndrome and chronic postural strain to back and neck muscles producing chronic pain.

ALCOHOL

Alcohol should be avoided because it may inhibit swallowing, interfere with nutrition, and cause falls or other accidents. If there is any respiratory insufficiency, it is especially important to avoid alcohol use just before bedtime.

AMYOTROPHIC LATERAL SCLEROSIS

Although symptoms of post-polio progressive muscular weakness may seem to resemble more serious disorders, such as amyotrophic lateral sclerosis, there is no evidence that these two conditions are related.

Post-polio progressive muscular weakness develops very slowly over many years and is not steadily progressive. Amyotrophic lateral sclerosis usually progresses rapidly over 1 to 2 years and will often involve bulbar muscles. Spasticity and upper motor neuron signs are also common.

Clinical and electrodiagnostic evaluation by a neuromuscular specialist (a neurologist or physiatrist who is a member of the American Association of Electromyography and Electrodiagnosis is recommended) would be indicated to differentiate these conditions if new weakness develops rapidly in a polio survivor without other explanation.

ARTHRITIS

Degenerative osteoarthritis of many joints is common among polio survivors who have had residual muscle weakness, muscle imbalances, and joint deformities. Chronic strain on joints being used in abnormal ways, for example, weight-bearing with the upper extremities, often leads to early degenerative changes.

Problems with the shoulder girdle, wrists, and hands are frequently associated with using canes and crutches for ambulation for many years. Knee joint narrowing associated with back-kneeing (genu recurvatum) and other ligamentous laxity conditions occur frequently in post polios who have ambulated with residual quadriceps and hamstring weakness. Splints, braces, and other orthotic appliances, physical therapy, and anti-inflammatory medication can all be helpful.

Cervical osteoarthritis is particularly common in polio survivors because of abnormal head and neck use associated with upper trunk or arm weakness. Looking up at people from sitting low in a wheelchair can also lead to cervical disc degeneration, nerve root pinching (radiculopathy), and secondary weakness in the hands.

Diagnostic evaluation for this condition should include cervical spine X-rays, electrodiagnostic examination of the cervical paraspinal and upper extremity muscles, and a trial of cervical traction.

ATTITUDES — POSITIVE, WELLNESS

A positive attitude to health is maintained by planning a program adapted to individual needs and accepting the fact that some aspects of life will change with age.

In terms of positive mental attitudes and how they affect wellness, the following are the most important: belief and hope — belief that things can be better and hope for relief or improvement in the future; control and self-direction — control over the way disability is experienced and willingness to assume self-direction (these characteristics reflect self-esteem and self-confidence which are related to survival and success); good health — something to be tended to by proper diet, exercise, and rest and by avoiding excessive drinking, smoking, and similar social habits; the ability to plan ahead and think for the future; flexibility and adaptability — a willingness to reorder priorities; humor — especially the ability to see humor in one's own situation; and being open for whatever comes along in life — not blaming people but rather forgiving people and one's self.

COLDS

Polio survivors with respiratory insufficiency can be drastically affected by a single common cold. The old-fashioned remedies of fluids, humidity, and rest will do more for mucus and raising secretions than medications.

The onset of a minor respiratory infection in a ventilator-dependent polio quadriplegic should be dealt with as a serious and life-threatening problem, and treated with antibiotics, postural drainage, assisted coughing, and other methods for

mobilizing secretions. In people with marginal respiratory reserve, the benefits from the use of antibiotics outweigh the risks.

CONSTIPATION

Getting enough bulk-producing foods via the daily diet is imperative. In addition to a high fiber diet, Metamucil may be useful as a bulk producer. Stool softeners, such as Colace or Pericolace, can also be used. Regular use of stimulant laxatives, particularly Milk of Magnesia, should be avoided.

COR PULMONALE

Cor pulmonale refers to the development of congestive heart failure due to disease of the chest wall or the lungs. The common underlying cause is pulmonary hypertension (elevated blood pressure in the blood vessels of the lungs) due to low oxygen content in the blood.

This condition is not common in polio survivors, but it may occur in individuals who have marked chest and spinal deformity. In these cases, the lungs are often not ventilated evenly, causing impaired oxygen delivery to parts of the lung. Early signs are due to fluid retention — usually with ankle swelling.

Diagnostic studies may include electrocardiogram, chest x-ray, and arterial blood gas. Management requires oxygen therapy at least 12 hours (during the night), and often diuretic treatment plus salt restriction. In some cases, digitalis preparations and anti-arrhythmics are needed for irregularities in the heart beat. Potassium supplementation may be prescribed to replace that lost through the kidneys during the diuretic therapy.

The low frequency of this complication, even with those polio survivors with spinal deformities, may be due to the commonly associated paralysis of other muscles and the "enforced" rest of the heart.

DEPRESSION

When a person's level of functional independence is changed, some depression and sadness is normal. Polio survivors have

demonstrated remarkable adaptations over a long period of time. Returning to the use of a brace or wheelchair after struggling to overcome the necessity of using these 25-30 years previously may activate many longstanding emotional conflicts, particularly in relationship to independence. Counseling by professionals familiar with the physically disabled may at times be needed. However, psychosocial support through contact with others facing the same problems, such as post-polio mutual support groups, may help even more with life-style adjustments to increasing weakness and other late effects of polio. (See Pain.)

DIET

Weight control is a major problem for many mobility impaired people and can be expected to be a greater problem in middle age. Polio survivors will find that an overweight condition will aggravate problems with ambulation and functional independence in a wheelchair. Reducing diets must be nutritionally well-balanced with adequate protein, vitamins, minerals, and fiber content.

EVALUATION

Evaluation of any polio survivor should include a complete history, physical examination, and appropriate laboratory studies. X-rays may be needed to evaluate joint deformities. Muscle strength evaluation should be done by a registered physical therapist or other professional familiar with neuromuscular diseases. Repeat muscle testing is advised at least every 5–10 years even if there is no obvious change in strength.

If there is any history of impaired ventilation or any cardiorespiratory symptoms, ECG, chest X-ray and simple pulmonary function studies are indicated. A vital capacity test probably measures the respiratory bellows effect of the diaphragm and chest wall as well as any more complicated test. It should be done on initial evaluation and followed periodically as indicated. Arterial blood gases may be needed in case of marginal ventilation to evaluate oxygenation and CO_2 retention.

Individual problems with extremity and joint function may require consultation with a physiatrist or orthopedist experi-

enced in the management of skeletal deformities and muscle weakness. An experienced physical therapist or occupational therapist can assist with evaluation of functional losses and how best to adapt or improve a disabled person's ability to remain independent in activities of daily living.

EXERCISE

Muscle stretching and joint range of motion exercises are important whenever there is muscle weakness. Preventing tightness of the chest wall and abdominal musculature may be particularly important if there is limitation of respiratory capacity. General conditioning exercises or aerobic exercises to maintain cardiovascular endurance are good for polio survivors. The best endurance exercise for post-polios is swimming, which minimizes mechanical stresses to tendons and joints, but stresses the heart beneficially.

Conditioning exercises or any repetitive activity, including walking, which causes pain or a sense of muscle fatigue and increased weakness should be discontinued. Any exercise program should focus on building endurance, not strength.

An adequate exercise program will maintain the strength of previously involved muscles, and also avoid overloading those muscles which previously were not recognized as having been affected.

Muscles that are weakened by previous polio in general respond poorly to vigorous strengthening exercise programs. Very gradual strengthening exercises which are guided in intensity by the patient's level of fatigue and/or pain can lead to modest but significant improvements in strength. They should be focused on functionally important muscles.

FATIGUE

Marked fatigue after only moderate exercise or activity is a common late effect of polio. Fatigue and pain are usually indications of overuse. When either appears, activity should be discontinued or modified, and rest time added or increased. It is important for polio survivors to learn their own limits of strength or endurance and to avoid repeatedly going to that limit.

FOOT SWELLING

Dependent edema in partially or completely paralyzed lower extremities can produce foot and ankle swellings. Custom-fitted support stockings (e.g., Jobst brand) are recommended. Most pre-sized support hose do not help very much but may be worth a trial. It is important to avoid excessive constriction about the abdomen or upper thighs, since this can be associated with the development of blood clots in the lower extremities.

FROG BREATHING

Frog breathing or glossopharyngeal breathing (GPB) is a substitute method of breathing that can produce adequate ventilation for short periods, even when there is total paralysis of the respiratory muscles. (Refs 26, 28, 43, 94, 97.) It uses the tongue and pharyngeal muscles to force air by repeated swallowing into the trachea and lungs. The muscles of the tongue, soft palate, fauces, pharynx, and larynx must be functional.

Frog breathing is used effectively by many respiratory-impaired individuals with polio residuals for emergencies, transference, chest stretching and coughing, and to permit time off the ventilator.

Most individuals need considerable instruction and encouragement to learn this technique, as well as hours of practice to master it. To learn frog breathing, one says "gup" or "gulp" way back in the throat, at the rate of 100 times a minute with a stop every 12-15 seconds. To begin, it is advised to do this about once every 2-3 hours during the day for 5 minutes.

GENITO-URINARY SYMPTOMS

The poliovirus does not directly affect either the genital or urinary systems. During the acute febrile stage, the menstrual cycle may be disturbed and there may be retention of urine. Thereafter, fertility and urinary continence are usually normal. Occasionally, polio survivors have residual weakness of the bladder itself, which can cause partial or even complete urinary retention. If a post–polio person has recurrent urinary infections or high post-voiding residual urine volumes, consultation by a urologist for urodynamics and other studies is indicated.

HOSPITALIZATION

Hospitalization can be fraught with distress and anxiety for anyone, but even more so for polio survivors and others with disabilities.

Special needs created by a disability are not always sufficiently recognized or met by the acute care medical community. Moreover, there may be a lack of respect for a person who has been disabled for a long period, but who is an expert with regard to his/her own needs for maintaining normal body functions.

The medical community should allow attendants or family members to continue their care during hospitalizations and to remain in the same room when requested.

It would be best to discuss hospitalization arrangements prior to the need for admittance, such as when the polio survivor is well. This will enable the hospital to be prepared if there is an emergency, and to maximize the patient's comfort during a planned hospital stay.

HOSPITALIZATION, EMERGENCY

Management of an acute problem such as a respiratory crisis is often complicated by the lack of experience of emergency room staff with patients with partial respiratory muscle paralysis.

For example, an abdominal breather will not be able to breathe effectively except in the sitting or standing position when gravity allows the diaphragm to descend.

Respiratory equipment used by many polio survivors may also be unfamiliar to emergency room staffs of general hospitals. Cuirasses, pneumobelts, tanks (iron lungs), and many of the older ventilators used by post-polios may be viewed by ER staff as quaint artifacts of a past era. The tendency is often to replace such equipment with "modern" technology entailing endotracheal intubation and ventilation with a volume ventilator. This may be at times necessary, but can often be avoided by adjustments in existing equipment and/or the use of mouth positive pressure ventilation on a p.r.n. basis for several days.

If the personal and pulmonary care physician would become familiar with a post-polio's usual equipment, many inappropriate interventions during acute respiratory difficulties could be avoided.

HYPERTENSION

Nothing about polio is known to predispose to hypertension. If there is a history of high blood pressure in the family, a low salt diet should be started early in life and followed. Routine diagnostic work-ups and treatment of hypertension are recommended.

JOINT DEFORMITIES

Modern biomechanical and gait analyses identify excessive demands being placed on the joints and muscles. Overly strained tissues wear out. The appropriate therapeutic approach is to correct the deformities and reduce excessive strain by appropriate orthoses, changes in lifestyle, or selective reconstructive surgery.

Fixed lower extremity joint deformities require abnormal posturing to stand. This increases muscle stress. Backknee (hyperextension) is a frequent cause of pain. People use this posture to lock their knee(s) when the quadriceps muscle is paralyzed. This directs the weight bearing thrust onto the ligaments behind the knee joint. If the backknee deformity is only 10°, the stress is minimal and tolerated for a long time. A 20° deformity doubles the forces and threatens ligament stability as individual fibers yield to the strain the deformity progresses and pain follows. This can be controlled by a free knee orthosis with a hyperextension joint stop set at 10° to 15° of backknee so the person still has passive knee stability for weight bearing and yet can flex the limb to take a step.

Another disabling, yet frequently overlooked, problem is a tight heel cord (ankle equinus). This creates stress on the knee and causes deformity in the foot. To correct the foot with an orthosis, the ankle must be set in the equinus position and a compensating heel lift added. Surgical correction by tendon release is often the only satisfactory answer.

MEDICATION

Polio survivors are advised to avoid narcotic medications for any reason. Aspirin is always preferred as an analgesic for muscle and joint pain. There is a danger of suppression of breathing with any sedative, and many post-polios have night-

time problems with their breathing even without sleeping pills. There may be occasions when some medication is needed to help with sleep, but this should be prescribed cautiously and with full awareness of the potential hazard.

MISDIAGNOSES

Polioviruses are not the only agents capable of causing paralytic syndromes indistinguishable from classical poliomyelitis. Both coxsackievirus and echovirus can cause paralytic syndromes, and several other agents have been implicated in paralytic disease of the central nervous system (Ref 120).

The clinical picture of paralytic poliomyelitis can also be mimicked by other neuropathologic syndromes, including Guillain-Barre syndrome. (Ref 63.) There is a possibility that the symptoms of post-polio progressive muscular weakness may be misdiagnosed as amyotrophic lateral sclerosis (ALS), but studies do not reveal any relationship between the two. (See ALS.)

Because sensation is never affected or seen as a residual from acute polio, the appearance of pressure sores is unusual. If pressure sores do develop, it should raise the suspicion of another diagnosis, such as peripheral neuropathy.

Joints which bear disproportionate weight may develop pain and "premature" arthritic changes. Pain inhibition and disuse atrophy can often produce noticeable increased weakness and must always be considered a possibility among patients complaining of increasing weakness and pain.

MISDIAGNOSES, HISTORICAL

Many polio survivors who are now reporting the late effects of polio may never have had polio. During the epidemics of the 1950s, the National Foundation for Infantile Paralysis (NFIP) assumed many medical expenses for patients whose physicians reported diagnoses of polio. In order for their patients to receive the economic benefits from the NFIP, many physicians diagnosed other paralytic syndromes as polio.

The extent of those well-intentioned misdiagnoses is unknown. Therefore, statistics are skewed and the clinical picture of polio survivors is confounded.

MUSCLE WEAKNESS

Some polio survivors begin losing strength noticeably during middle age. The muscles most commonly affected are those that recovered well from the initial attack and have been used strenuously ever since. The most common complaints are: new weakness in muscles not previously recognized as being affected by polio, increased weakness with or without pain in muscles that were previously involved by acute polio, generalized fatigue and weakness, and post-exercise transient muscle weakness and/or muscle pain.

A decline of functional reserve due to aging or complicating problems (such as weight gain) may result in increased disability with a loss of some functions which were previously possible.

Polio survivors with deformities of the spine or limbs following acute polio may develop painful degenerative joint disease and/or nerve compression syndromes if weight bearing has been continued. Musculoskeletal symptoms of pain and weakness may increase.

Muscles that are weakened by polio in general cannot be strengthened by a vigorous exercise program and this may aggravate or enhance the development of weakness. (See Exercise.)

Muscle weakness generally is classified by the manual muscle test using a scale of 0 to 5 or an equivalent number of descriptive grades. Individuals with grades 5 (normal) and 4 (good) have been considered relatively uninvolved because they can function in a normal manner.

Quantiated comparison of polio survivors' strength with non-polio persons gives a different perspective. Post-polio manual grade 5 (normal) was only 75% of true normal. Grade 4 (good) strength measured only 40% of true normal. This low value has anatomical confirmation. A comparison of the spinal cord motor cells' destruction and pre-mortem strength showed that no weakness was noted on clinical examination unless more than half of the muscle's cells had been destroyed. Thus, both the normal and good post-polio muscles have more impairment than is suspected.

Muscles grade 3 (fair) and 2 (poor) cannot meet daily demands so they regularly are assisted by some substitutive posturing. As a result, polio survivors work abnormally hard ("good" equals 2½ times as hard as normal) to accomplish the same

activity: walking, sports, etc. The added strain may result in overuse damage.

If the strength loss is identified early and the muscles protected from overuse by a change in habits (e.g., an orthosis shift or change from a manual to electric wheelchair, etc.), the muscles can recover and be available for lighter tasks. Procrastination leading to chronic strain can cause irreversible loss.

OCCUPATIONAL THERAPY

The occupational therapist can play a vital role in the evaluation and treatment of the polio survivor. Assessment of upper extremity function, activities of daily living, and needs for assistive devices are important factors in determining the level of independence an individual has or can achieve.

Polio survivors often have a low tolerance for gadgetry. Modifications of the environment or new ways of performing activities are usually more acceptable.

A home or job site visit can enable the occupational therapist to prescribe equipment and provide training in its use. Observing performance of activities also enables the therapist to assess endurance and level of fatigue. Methods for task simplification can often be found.

Despite major strength and range of motion deficits, many polio survivors are remarkable in their ability to adapt. Therapists have and will learn many tricks from polio survivors.

OSTEOPOROSIS

Osteoporosis of the spine and long bones is very common in the more severely disabled polio survivors. Long bone fractures may occur with minimal stress and falls are common. Spinal compression fractures may cause back pain. Thoracolumbar support garments and spinal extension exercises may be helpful for progressive osteoporosis involving the spine. Postmenopausal women polio survivors in particular must maintain a large dietary calcium intake. Calcium supplements are often preferred over high calorie dairy products as a source of calcium.

OVERUSE WEAKNESS

Overuse weakness in muscles previously involved by polio was first described by Bennett. (Refs 14, 15.) Overuse weakness is a loss of maximal muscle force following strenuous activity which is persistent for days, weeks, or longer. Exactly what accounts for overuse weakness is not well-known and there may be several causes. It can develop in neurologically normal individuals after very intense exertion, and muscle fiber necrosis has been seen in these cases.

At what point of exertion this phenomenon develops in muscles chronically weakened after polio is not known. Early symptoms of overuse before lasting weakness occurs include post-exercise transient fatigue, post-exercise transient weakness, or pain in specific muscles after exercise.

OXYGEN

Oxygen therapy should always be used with caution. In the face of hypercapnia, oxygen therapy for polio survivors may eliminate the final mechanism for maintenance of respiratory effort and thus result in apnea. Maintenance of adequate alveolar ventilation is of primary importance. In case of severe hypoxia and respiratory failure, mechanical ventilation and oxygen may be necessary.

PAIN

Pain in the spine and extremities may be the most common medical complaint of polio survivors. There are many causes for pain, including disorders of nerves, bones, joints, and muscles. A diagnostic evaluation is indicated for any persistent pain which is limiting or for which medication is used. (See Pain, Low Back.)

Non-localized aching pain in many muscles is frequently described by polio survivors. Some survivors describe this pain as "flu-like" aching, while others experience it as similar to the muscle pains following acute polio. The origin of this type of pain is unknown and there appears to be no consistently helpful

treatment except rest. Heat, anti-inflammatory medication, and avoiding muscle exertion are recommended.

Survivors who develop chronic, disabling pain which cannot be explained in spite of expert evaluation frequently become depressed. Treatment of the depression may often decrease suffering even if painful sensations continue. A trial of anti-depressant medications is indicated if there are symptoms of endogenous depression (poor appetite, early morning awakening, lack of energy). Combining supportive counseling with physical therapy can more effectively establish better coping mechanisms for living with chronic pain. (See Medication.)

PAIN, LOW BACK

The low back is a common site of pain. This often results from using a backward-sideward trunk lurch to substitute for weak hip muscles. Abnormal trunk movements transfer body weight to the small facet joints at the back of the vertebra. They are not built for such strain. Concentration of back motion at one level in the low back following spine fusion or scoliosis is another cause of back pain. (See Pain.)

Weak abdominal muscles also predispose one to chronic back strain and back injury. A "Hoke" corset with its multiple cross straps and reinforcing steels often offers good relief. Individuals who depend on excessive lumbosacral motion for walking may not tolerate the corset.

Any abdominal binder, corset or girdle can help substitute for weak abdominal muscles. Physical therapy for heat, massage, joint mobilization, and stretching exercises can help control or resolve symptoms. A change in gait pattern, such as using crutches, may be needed to prevent recurrence or resolve chronic pain. Some people need to stop most walking and rely on a wheelchair. Abdominal fascial transplants to create anterior abdominal support may also be indicated on a selective basis.

PHYSICAL THERAPY

The physical therapist documents changes of strength and range of motion over time, recommends and monitors exercise programs, assesses equipment needs, recommends lifestyle

changes to reduce stress on the joints and muscles, and assists in the evaluation and treatment of respiratory dysfunction.

Intact sensation and proprioception allow polio survivors to substitute strong muscles for weak muscles, enabling many to walk well with many very weak groups of muscles. Changes in muscle strength and joint range of motion are good indications for further consultation.

Analysis of gait patterns may indicate why a patient is having certain problems. An evaluation of the functional status may reveal the need for additional assistive devices or lifestyle changes.

Polio survivors do not have as much reserve to call upon physically, and may have a more difficult time resuming activities after a long period of bed rest following surgery or severe illness. Extra effort may be necessary to prevent disuse weakness and avoid overuse weakness.

Renewed use of adaptive equipment may help the polio survivor retain his/her independence. Crutches or a cane may increase safety when walking. A knee-ankle-foot orthosis may control painful hyperextension of the knee and allow ambulation to continue.

Polio survirors who have been ambulatory may need to begin using a wheelchair part time. An electric wheelchair with special hand or mouth controls may be necessary for the polio survivor with limited endurance or strength in the upper extremities.

The need for lifestyle changes is dependent upon each person's individual problems. It is imperative that polio survivors learn to conserve energy.

POLIOMYELITIS, ACUTE

Acute poliomyelitis is a viral disease affecting the motor nerve cells in the spinal cord. There are three immunologically different types. Infection by one type doesn't confer immunity to the other two. Thus, the polio vaccine consists of the three types.

The acute attack is a biphasic disease. The poliovirus (enterovirus) invades the body through the mouth and lives in the gastrointestinal tract. From there, it gets into the blood stream, causing a fever and gastrointestinal upset lasting two to three days. Then, after one or two days, if the poliovirus invades the

central nervous system, paralytic symptoms ensue.

Symptoms of muscle aching, stiff neck, headache, and high fever occur. Paralysis soon follows. The extent of paralysis is always more severe during the febrile stage and regresses to a degree in convalescence. The muscle aching can be severe and should be treated with hot packs. The extent of paralysis will usually be evident by four to six weeks after the acute stage.

Approximately 8 cases a year in the United States are reported as vaccine-related. Since the Sabin polio vaccine is an attenuated live virus, it may cause paralytic polio in an incompletely protected individual. (See Vaccines, Polio.)

POST-POLIO SYNDROME

The term "post-polio syndrome" has been used to describe a variety of new problems thought to be a result of the late effects of polio. It has been used by some physicians to specifically describe the progressive muscular weakness seen in some polio survivors thought to result from further dysfunction or death of motor units. Since there is no agreement among medical experts about the meaning of the post-polio syndrome, its use is discouraged when other diagnostic terms can be more specific. The term "progressive post-polio muscular atrophy" is recommended for the diagnosis of progressive muscular weakness from new death or dysfunction of motor units seen in polio survivors.

PREGNANCY AND DELIVERY

Women with residuals of poliomyelitis can usually carry a pregnancy to term. However, pregnancy and polio can be complicated by the late effects of polio in some cases. Basic problems include: increased nutritional requirements; immobility from paralysis or contraction; limited strength and increased muscle fatigue; and breathing difficulties from bulbospinal polio.

All pregnant polio survivors should be on supplemental iron throughout pregnancy and the immediate postpartum period to maintain their hemoglobin and tissue oxygenation at normal levels. Any blood loss should be promptly replaced. If the patient has been advised not to take excess calcium because of previous kidney stones, she will need to consume four cups

of milk or dairy products daily to meet fetal requirements for calcium.

Immobility and decreased subcutaneous tissue may make pregnancy uncomfortable for paralyzed patients. Careful positioning and frequent changes in body position must be carried out and the head down body position should be avoided. The physical therapist can stretch out the hip musculature, especially the adductors, so the position of delivery will not be painful.

The patient may be unable to use stirrups for delivery because of contractions. An alternate position for delivery is left lateral. If the patient could not adduct her knees sufficiently and forceps delivery were indicated, a vacuum extractor could possibly be applied. If absolutely necessary, cesarean section should be performed.

Patients with mobility problems may be at increased risk for deep vein thrombosis in pregnancy lasting to six weeks postpartum. Minidose heparin should be considered (5,000 units subcutaneous every 12 hours) as prophylaxis against thrombosis. If minidose heparin is begun, weekly serum calcium levels should be checked, and at least two PTT values drawn to ensure the patient is not in the therapeutic range. Sites of injection may include abdomen or legs. Heparin does not cross to the fetus.

Patients with significant respiratory or mobility problems constitute a high risk group. They need co-management with an obstetrician or perinatologist and delivery at an appropriate center.

Women with partial muscle paralysis who do not require ventilatory assistance during normal daily activities should be evaluated. Both invasive and non-invasive tests of pulmonary function (vital capacity, blood gas, etc.) will provide valuable information for the second and third trimesters of pregnancy.

During uncomplicated pregnancy, vital capacity remains unchanged, and minute ventilation increases up to 40% by term. (Ref 109.) However, respiratory muscle paralysis prevents an increase in breathing, and progressive respiratory insufficiency in the last trimester may occur. Weekly follow-up tests of pulmonary function may be indicated in the late second or third trimester of pregnancy. Patients who have a previous history of decompensation under stress (excessive outside temperature, etc.) are at risk.

All upper respiratory infections during the second half of preg-

nancy of patients who are ventilator-dependent or have borderline respiratory function should be treated aggressively in the hospital.

If the patient is found to be underventilated by her own efforts, spontaneous breathing should be augmented with a portable positive pressure ventilator using a mouthpiece during the day and a lipguard strapped around the head during sleep. If the patient already has a tracheostomy, ventilation by positive pressure needs to be augmented as pregnancy progresses.

The family physician or obstetrician should refer the ventilator-dependent patient early in pregnancy to a high-risk, maternal-perinatal regional center which is equipped to care for patients with special needs. At least four weeks prior to the anticipated date of delivery, the obstetrical team (obstetrician, anesthesiologist, and nurse) should evaluate the patient to plan for a normal, uncomplicated delivery, forceps vaginal delivery, cesarean section, or emergency cesarean section.

Spontaneous labor and vaginal delivery proceed rapidly and uneventfully in most instances. The expulsive action of the normal uterine musculature is surprising when unopposed by voluntary musculature. Uncomplicated vaginal delivery can be accomplished with pudendal anesthesia. The patient should use oral positive pressure ventilation during labor. Nurses and physicians need to understand the equipment and be instructed in its use in advance. The anesthesiologist should monitor the adequacy of ventilation.

If forceps delivery is planned, pudendal anesthesia may provide adequate pain relief. Narcotics should be used only in minimal doses since somnolence in the supine position may lead to upper airway obstruction by the relaxed tongue and glottis. Low spinal anesthesia or epidural anesthesia carefully administered in small increments may be used for the patient's comfort, provided that the patient is monitored for adequate ventilation.

Cesarean section is not indicated except for obstetrical complications. Acute bulbo-spinal paralysis with intractable respiratory insufficiency may be an exception. However, in case of cesarean section, general anesthesia with endotracheal intubation and controlled ventilation is indicated, since regional anesthesia would block all accessory respiratory muscles. The patient will need controlled mechanical ventilation post-operatively and, therefore, may have to remain intubated with an oral tracheal tube for 12-48 hours afterwards under observation in an intensive care unit.

PROGRESSIVE POST-POLIO MUSCULAR ATROPHY

This is a specific medical diagnostic label useful to clinical neurologists. It describes patients with a history of polio who develop a rare type of progressive muscular weakness. Electrodiagnostic testing is a prerequisite for making this diagnosis, although there are no abnormal findings that are unique to this condition. This diagnosis should only be made by a specialist in neuromuscular diseases who is familiar with the problems of polio survivors.

RE-REHABILITATION

Rehabilitation is an ongoing process. Polio survivors who were once rehabilitated must be re-evaluated and learn new techniques to replace those that no longer work.

It is difficult for therapists to understand that, while the problems of polio survivors are similar to those of the elderly, psychologically the polio survivor is younger. The interests and lifestyles of someone twenty years older won't be the same, even though the physical circumstances are.

RESPIRATORY INSUFFICIENCY

Everyone's lungs change and deteriorate with age. If there has been impairment of the muscles, the normal changes due to age may cause new problems. Thus, while the number of people with polio has decreased, at the same time, the number needing breathing aids at night is increasing.

Limited respiratory reserve may reach a point where intermittent mechanical ventilation becomes necessary. Night respiratory aids allow the chest muscles to rest, so they can function during the day. If the breathing muscles are paralyzed or distorted by scoliosis, underventilation may occur during sleep, and CO_2 levels rise.

Symptoms associated with failing respiratory reserve are numerous, and, for the most part, non-specific. Symptoms presented are: fatigue or exhaustion from normal activities, reduced activity due to fatigue, anxiety, inability to fall asleep, restless sleep, awakening during the night with nightmares,

awakening in the morning with headache or slight confusion. Brain functions may become altered so that depression, inability to concentrate, dizziness, sleepiness during the day and blurring of vision can also occur.

Among persons with respiratory insufficiency, breathing patterns when awake are very shallow and become even more shallow when asleep. Breathlessness during activity even with such a simple task as speaking may also occur as early warning signs.

A combination of the above symptoms strongly signals the need for a respiratory evaluation by a physician specialist in pulmonary disease who has interest and experience with chronic neuromuscular disorders such as old polio.

However, not all requirements for assisted breathing are primarily night-time or in the recumbent position. Many people who have fair-to-good diaphragmatic function, but poor abdominals, will not be able to breathe effectively in the upright position without abdominal support.

RESPIRATORY THERAPY

The physician evaluating the ventilatory ability of a polio survivor should assess blood gas values and vital capacity. As aging occurs in the normal individual, vital capacity diminishes. This decrease in vital capacity is more serious in the aging polio survivor with limited musculature remaining to produce adequate ventilation. When vital capacity declines from examination to examination to a range of 600-400 cc H_2O, the appropriate intervention for improving ventilation must be considered.

A cardio/pulmonary physical therapist assists in the evaluation of residual muscle strength and in determining a program for increasing ventilatory capacity without mechanical ventilation. Early evaluation of residual muscle strength, thoracic mobility, and training in bronchial hygiene can delay a polio survivor's requirement for mechanical ventilation.

Polio survivors can have any mixture of residual muscles remaining so it is important to maximize the efficiency of these muscles by considering the most effective position. Testing the vital capacity in supine, sitting, and standing positions can clarify which muscles are functioning best.

The polio survivor with "poor" residual muscle strength may

require active assistance for breathing. The use of a pneumobelt, chest cuirass, or mouth positive pressure may be selected. (See Ventilators.) Some patients have experienced respiratory failure and have tracheostomies for mechanical ventilation. A phasing program should be designed to optimize the efficiency of the residual muscles. Special attention should be given to the positioning for breathing efficiency. Those who have not learned frog breathing should be instructed in this technique as part of the phasing program.

Polio survivors with limited chest expansion should be provided with a positive pressure unit at home to allow them to administer their daily chest stretching program.

Bronchial hygiene is important for any polio survivor with limited reserve. The polio survivor and family or attendant can learn postural drainage, manual cough, and suctioning methods. Polio survivors with adequate arm strength can perform a self-manual cough and postural drainage program.

REST

Rest is imperative for polio survivors. A nap during the daytime is recommended if generalized fatigue or malaise develops on a regular basis during normal daily activities. Fatigue often indicates overuse, which, in people with limited reserve, may become progressive. It is hard for some individuals to accept the fact that they cannot be as active as they were 20-30 years earlier. This is particularly important to recognize in polio survivors. When the use of braces and crutches to ambulate is associated with progressive weakness and fatigue, it may be time to seriously consider a wheelchair.

SEX

Sexual enjoyment and potency are unaffected by acute polio. Late effects of polio may lead to problems with positioning during sexual activity. Sexual counseling is available at most comprehensive rehabilitation centers. (Refs 36, 56, 57.)

SKIN PROBLEMS

Oily skin and dry skin are common to almost all people at one time or another. The conditions can be simply managed if properly recognized.

Oily skin has been long associated with many neurological diseases — polio, epilepsy, Parkinson's disease, etc. Gentle washing with soap and water is the best recommendation.

Flaking does not always mean dry skin. It can represent a condition called seborrhea or seborrheic dermatitis which is an oily condition. For seborrhea, daily use of a dandruff shampoo is advised. When facial redness and scaling are stubborn, a daily brief washing of the face using these shampoos as soap is recommended.

Spontaneous dry skin of the face is a far less common problem than oiliness. Dry skin does not need oil, but water. The simple solution is to decrease bathing, to decrease the temperature of the bath water, to use soap only where it is needed, and then to use just hydrating soaps or applications of water, and to trap that water with a moisturizing cream.

SLEEP

Body positioning during sleep is an important consideration for polio survivors with severe weakness, postural or joint deformities. If the polio survivor sleeps on his or her side, the arm should be kept in front, not under the chest wall which could cause numbness in the arm. If a person is skinny, a 2″ soft foam pad between the sheet and mattress may be more comfortable. Consultation with experienced rehabilitation nursing personnel can often solve unique positioning problems.

Difficulty falling asleep or insomnia has many causes. Depression is a common cause and can be treated by counseling. Sleeping pills should be used with great caution by any polio survivor with a history of respiratory compromise because sleep apnea may be a significant risk for these people. Insomnia, restlessness and/or morning headache may be warning symptoms of obstructive apnea or hypoventilation. (See Sleep Apnea and Respiratory Insufficiency.)

SLEEP APNEA

Sleep apnea or periods of temporary cessation of respiratory effort during sleep, may result in hypoventilation and CO_2 retention at night. This disorder may occasionally develop in polio survivors with moderate to severe impairments in respiratory capacity. The ear oximeter allows constant monitoring of oxygen saturation and has been used in sleep disorder clinics to diagnose this problem.

One form of sleep apnea involves temporary interruption of respiration at the central control area in the nervous system. This has been referred to as "Ondine's Curse," a reference to events in Giraudoux's play *Ondine.*

The other common form of sleep apnea is due to obstructive problems in the upper airways: this form is common in snorers.

SMOKING

Smoking is a significant health risk for anyone with respiratory insufficiency and/or a history of respiratory involvement by polio. Smoking causes mucus and more secretions to be mobilized by weakened expiratory muscles (coughing muscles). Other health hazards of smoking are well-known.

SWALLOWING

Anyone with respiratory insufficiency should chew slowly and swallow carefully to avoid choking. The best position for easy and safe swallowing is to sit up straight and lean the head forward. New symptoms of swallowing difficulties in polio survivors deserve full evaluation for dysphagia, which may rarely develop as a new problem in polio survivors with a history of bulbar involvement.

SWIMMING

The best form of general conditioning exercise for polio survivors is swimming. Water temperature should be warm to promote relaxation as well as flexibility of muscles and joints. Range of motion and stretching exercises are also very therapeutic done in warm water.

Adaptive equipment, such as floats, or specialized instruction available in swimming programs for the disabled may be needed to begin a swimming exercise program. Precautions to avoid overuse must still be followed. (See Overuse Weakness.)

TRACHEOSTOMY

Historically, persons disabled by polio in the United States have been managed with a tracheostomy less often than those in other countries or those disabled by spinal cord injuries.

Complications with tracheostomies are stomal infections, formation of granulation tissue which sometimes bleeds, tracheal stenosis, and loss of effective cough. Since the loss of effective cough may cause retained secretion, suction equipment is always necessary.

Most polio survivors with tracheostomies use uncuffed tracheostomy tubes (usually "metal Jackson's" with inner cannulas). If ventilators are attached to the tracheostomy tube, the volume or pressure is adjusted to compensate for the air leak which occurs with an uncuffed tube. This preserves the ability to talk, while providing adequate ventilation to the lungs.

In the case of respiratory failure due to chest infections, injury, or other causes, a "cuffed" tracheostomy tube may be required. When a polio survivor enters a hospital for other causes, there is a tendency to replace the patient's own familiar ventilator with a hospital ventilator and cuffed tracheostomy tube. This can be a frightening and alienating experience for the polio survivor, particularly if communication is lost. The person's physician should, whenever possible, orient the hospital staff to the person's ventilator needs before the person is admitted. This may require some orientation of the personal physician by the polio survivor.

TRAVEL/ALTITUDE

Persons with marginal respiratory reserve at sea level should be prepared to use respiratory aid if travelling to elevations above 3,000 feet. Evaluation of oxygen levels in the blood may be advisable before such a trip.

VACCINES, FLU, PNEUMOCOCCAL

Polio survivors with respiratory insufficiency are advised to receive the influenza (flu) vaccination according to U.S. Public Health Service guidelines and recommendations. Pneumococcal vaccine should be received by all polio survivors with limited respiratory reserve. At present, only the initial pneumococcal vaccination is recommended.

VACCINES, POLIO

The two types of trivalent polio vaccine currently in use are the oral polio vaccine (OPV) or Sabin vaccine, and the inactivated or killed vaccine (IPV) or Salk vaccine. The U.S. Public Health Service specific recommendations should be followed strictly. (Ref 110.) Generally, all persons between the ages of six weeks and 18 years should receive the oral polio vaccine. The World Health Organization recommends that unimmunized adults travelling to Third World countries be immunized with the Salk vaccine.

The advantages of OPV are the ease of administering on a large scale and to the very young, quicker and more long lasting protection, and extra protection to the wild polioviruses. There is a small risk that OPV will induce poliomyelitis in those receiving it, or in non-immunized contacts with the vaccine. For unknown reasons, persons over 18 years of age are more susceptible to vaccine-induced poliomyelitis. Parents who have never been immunized or have been only partially, and who have young children scheduled to receive OPV should receive a full course of IPV.

Anyone with a deficiency of the immune system, either genetic or drug-induced, as in cancer chemotherapy, should never be given live vaccine, nor should anyone who is pregnant.

The latest policy for immunization against paralytic poliomyelitis for persons residing in the U.S. is primary immunization of infants: 3 doses of OPV at age 2 months, 4 months, and 18 months; and primary immunization of older children and adolescents: 2 doses of OPV at 8-week intervals, followed by a third dose 6-12 months later. (Ref 110.)

VENTILATORS

The first mechanical ventilators were invented for acute polio patients. Generally, the polio patients could be ventilated by a wide range of devices, since there was little internal lung problem. This is less true as polio survivors age and lose respiratory compliance.

Ventilators suitable for use outside the hospital are dependable, and simple to operate and maintain. Most of them are small enough to be portable and operate on batteries (DC) as well as house current (AC). They are divided into two main groups: negative and positive pressure. The positive pressure ventilators are also divided into volume and pressure limited units. (Ref 159.)

NEGATIVE PRESSURE VENTILATORS. The tank (iron lung) units ventilate by enclosing the patient's whole body, except for the head in a chamber. A negative pressure is created in the chamber which is communicated to the chest cavity, causing air to flow into the lungs. These units are very dependable but are quite large, immobile, and limited to AC power.

Chest cuirasses or shells operate on the same principle as the tank. Instead of the whole body being placed in a chamber, the shell is placed over the chest and upper abdomen. The cuirass is then connected by hose to a negative pressure ventilator such as the Monaghan 170-C, Huxley, or Thompson Maxi-Vent. This system is portable, and with the 170-C, operates on batteries during power failures. The system is not as efficient as the tank and cannot overcome a stiff chest wall effectively. Care must be taken to obtain a proper seal between the cuirass and the chest, otherwise there will be a loss of pressure. There are also problems of fit as body weight changes or deformities develop.

The rocking bed ventilates by tilting. The bed moves in an arc of about 20 degrees, alternating head down with feet down. The abdominal contents then drop, causing inspiration, and move upward (head down), causing expiration. This unit also requires that there will be little airway resistance. Contrary to popular belief, motion sickness is rare since the patient is moving in only one plane.

POSITIVE PRESSURE VENTILATION. The pneumobelt or exsufflation belt is the perfect companion ventilation system to either the tank, cuirass, or rocking bed. The system includes an inflatable bladder, supporting abdominal corset, and hose.

The bladder is placed over the abdomen with a corset holding it in place. Positive pressure (30-50 cm. H_2O) is pumped into the bladder. The bladder then inflates, causing the abdominal contents to displace upward, and produces exhalation. The polio survivor must be sitting upright for inhalation to occur. When the pressure on the bladder is released, the diaphragm descends downward by gravity, thus facilitating inhalation. The preferred ventilator for the system is one of the newer portable volume ventilators since they have the ability to run over 18 hours on a single 12-volt battery. The pneumobelt is useful if the polio survivor has compliant lungs. Persons with a major degree of chest restriction or mucus production probably will not benefit from this system.

Pressure limited ventilators will deliver air until a pre-set amount of pressure has been achieved in the circuit. Historically, these were the primary ventilators in operation until the late '60s. They continued as the primary positive pressure units for polio survivors until the late '70s. These units are control cycled with the respiratory rate pre-set. Controlled ventilation generally has worked well on individuals with severe neuromuscular problems such as quadriplegia, since these people exercise little and usually do not have to change their respiratory rate.

- Thompson Bantam. The fixed pressure is for mouth, trach, and pneumobelt. This small unit works on AC or DC and comes with a battery charger. It may also be used with humidification. If power fails, it automatically switches to battery. It can be set from 7-30 breaths per minute. (Also chest shell for negative pressure.)
- Monaghan 170-C. This unit is designed for long term use. Humidification can be provided. For mouth, trach, and pneumobelt. (Also chest shell for negative pressure.)
- Huxley. This unit produces a smooth quiet breathing cycle. For mouth, trach, and pneumobelt. The range is 12-26 breaths per minute. AC power only. (Also chest shell for negative pressure.)
- Thompson Bantam CS. This unit operates with a battery for 3-4 hours. A sigh mechanism is included to provide the person with periodic deep breaths. (Sighing may be beneficial in preventing recurrent infections.)
- Thompson Maxivent. This unit operates on AC power only. A built-in alarm indicates disconnection from the individual.

Volume limited ventilators (portable) are relatively new in the field of home ventilation, first introduced in the late '70s. Volume

ventilators deliver a pre-set volume of air and adjust the pressure needed to deliver the air, depending on the airway resistance. These machines are available with either control rates or with a mechanism for the person to trigger breaths. These trigger mechanisms are called assistors and automatically deliver a breath if the person fails to trigger the machine. This is called an assist-control mode. These machines have longer running time on a single battery (18-24 hours). They usually have an internal battery that will run the ventilator for 60 minutes. They are also equipped with built-in alarms for disconnection or machine failure (low pressure) and for air blockage (high pressure).

- Life Products LP-3 and LIFECARE PVV. These identical ventilators are control-cycle units.
- Thompson Mini-Lung. This machine has the same clinical abilities as the LP-3 and PVV.
- Thompson M-25 assist. This unit has an assist control rate.
- Thompson M-3000. This unit has the standard features of a volume ventilator plus a sigh unit. The internal battery will run the ventilator for 2 hours.
- Life Products LP-4. This unit also has an assist control feature. It can also be used on an intermittent mandatory ventilator mode.

When using positive pressure, the delivery mode is critical. Tracheostomy tubes are the most frequently used mode. When using a tracheostomy tube, care must be taken to choose a tube that can be managed at home. An uncuffed tube is preferable since it allows the individual to phonate. Air loss is usually compensated for by increasing the tidal volume.

Many persons can be ventilated on mouth positive pressure entirely. A loose fitting mouthpiece can be used during the day. This mouthpiece can be placed on a moveable arm to allow it to stay next to the person's mouth.

Persons with no vital capacity can be ventilated during the night with a mouthpiece such as the Bennett Lipseal strapped to the mouth. Persons become conditioned to take sufficient air in their sleep from a cycled ventilator with a fixed rate and a pressure set high enough to compensate for leaks.

Intermittent mouth positive pressure also provides comparable tidal volumes to those produced by the negative pressure of the iron lung. Ventilators used for mouth IPPV can be set at much higher pressures than the iron lung so more air can be obtained.

VENTILATORS, EQUIPMENT MANUFACTURERS

Bear Medical Systems, Inc. 2085 Rustin Ave. Riverside, CA 92507 800-331-2327	Bear 33
The Cuirass Shop 1131 E. 16th Ave. Denver, CO 80218 303-832-2165	Cuirass Shell
J.H. Emerson Co. 22 Cottage Park Ave. Cambridge, MA 02140 617-864-1414	Rocking Bed Iron Lung Poncho Cuirass Shell Emerson Volume Ventilators, 3PV, 3MV
Life Products, Inc. P.O. Box 3348 Boulder, CO 80307 303-499-8761	Portable Volume Ventilators, LP-3, LP-4, LP-5
LIFECARE Services, Inc. 5505 Central Ave. Boulder, CO 80301 303-443-9234	Cuirass Shell Exsufflation Belt Pulmo-wrap Pneumobelt Portable Volume Ventilator, LP-3 Bantam PLV — 1000 Ventilator
Thompson Respiration Products, Inc. Div. of Puritan-Bennett Corp. 1680 Range St. Boulder, CO 80301 303-443-3350	Minilungs M-3, M-15, M-25, M-25 Assist Bantams GS, GT, Compact C MV Maxivent Portable Negative/Positive Pressure Ventilator M-3000XA Portable Volume Ventilator
W.S. Weingarten 401 E. 80th Ave. Denver, CO 80229 303-288-7575	Portable Iron Lung

VENTILATORS, HOME CARE

Mechanical ventilation in the home is totally different from intensive care unit ventilation in the hospital. The problems of cross infection do not exist in a home. Home users are experts in their own care, obviously since the polio survivors have been living at home successfully for over 25 years. Living at home with a ventilator not only saves money, it improves the quality of life.

A major problem with home care is financial coverage for equipment maintenance and repair. Another problem is adapting modern technology to techniques which have been effective for over 25 years. (Refs 79, 81, 83, 84, 85.)

WEIGHT

Body weight should be kept down, since excessive overweight can aggravate almost all mobility problems. Obesity may seriously interfere with breathing capacity and increase the risk of hypertension, cardiovascular disease, and diabetes. For polio survivors in a wheelchair, severe calorie restrictions, such as only 800 calories per day may be needed to avoid weight gain or induce weight loss.

International Polio Network (I.P.N.)

coordinated by

Gazette International Networking Institute (G.I.N.I.)

4502 Maryland Avenue, St. Louis, MO 63108 U.S.A. 314/361-0475

Origin

Rehabilitation Gazette, an international journal for independent living by people with disabilities, was started by Gini Laurie in 1958 for polio survivors in iron lungs to share their information and experiences.

The *Gazette* grew from a local newsletter to a renowned international journal and evolved to include other physical disabilities and the aging of all disabled persons.

In 1983, The *Gazette* celebrated its 25th year as a journal and information service, and was reorganized to expand its services. The new organization was named Gazette International Networking Institute (G.I.N.I.).

G.I.N.I. is incorporated as a non-profit [501 (c) (3)] organization. Donations are tax-deductible.

Rehabilitation Gazette

Published since 1958, *Rehabilitation Gazette* embodies and reflects the imaginative, practical, down-to-earth life experiences of its readers with disabilities.

It is a form of peer counseling and therapy by mail, an invaluable source of ideas, inventions, and adaptations that have been tried and found useful by others. Personal experiences in the *Gazette's* articles motivate other readers to live full and independent lives.

The *Gazette* is an invaluable tool for creative rehabilitation, providing health care professionals with additional insight into the interests and needs of people with disabilities. Readers include doctors, nurses, therapists, social workers, rehabilitation counselors, government officials, educators, and the relatives and friends of persons with disabilities.

The *Gazette* reaches 30,000–50,000 readers in 87 countries with translations in five languages. It is read by people who are disabled with

ALS, amputation, arthritis, cerebral palsy, head injury, multiple sclerosis, muscular dystrophy, polio, spinal cord injury, and stroke.

In 1986, G.I.N.I. began publishing two issues of the *Gazette* per year and offered membership in the G.I.N.I. organization. Membership benefits include a subscription to *Rehabilitation Gazette*, G.I.N.I.'s information service and library, and discounts on G.I.N.I. conferences and membership events.

Membership dues in G.I.N.I. are $25 per year for individuals and $35 per year for institutions. ($3 for postage outside U.S. and Canada.)

Polio Network

G.I.N.I. has maintained a worldwide polio network since 1958. Consequently, when an increasing number of polio survivors began to report new symptoms of pain, fatigue, weakness, and breathing difficulties, G.I.N.I. took the lead in organizing the first coordinated look at the problems with its 1981 polio conference.

In 1985, G.I.N.I. formally established the International Polio Network (I.P.N.) to link polio survivors and to encourage the formation of post-polio support groups.

G.I.N.I. publishes the *Polio Network News*, a quarterly bulletin for I.P.N. members and coordinates and maintains the national and international directory of post-polio support groups, clinics, and physicians.

Membership in I.P.N. is $5 per year for polio survivors and $15 per year for health professionals. ($3 for postage outside U.S. and Canada.)

Ventilator Users Network

Polio survivors who started using home mechanical ventilation in the 1950s formed the nucleus of G.I.N.I.'s International Ventilator Users Network (I.V.U.N.).

I.V.U.N. links ventilator users with each other and with medical personnel interested in home mechanical ventilation. These ventilator users include infants, children, and adults disabled by neuromuscular diseases or injuries affecting the respiratory system.

I.V.U.N.'s members receive a biannual newsletter featuring ventilator equipment and adaptations, glossopharyngeal breathing techniques, psychosocial aspects of long-term ventilator use, sleep disorders, organizations concerned with ventilator users, travel, etc.

Membership in I.V.U.N. is $5 per year for ventilator users and $15 per year for health professionals. ($3 for postage outside U.S. and Canada.)

Information Service and Networking

G.I.N.I. is a primary source of specialized information on do-it-yourself equipment, independent living, polio, spinal cord injury, and ventilators.

The library, with materials amassed over 35 years, is a special collection of books, periodicals, monographs and reports, pamphlets, clippings, and case histories.

Using the library's unique resources, G.I.N.I. answers questions on disability-related subjects, such as architectural and attitudinal barriers, civil rights, housing adaptations, wheelchairs, vans and lifts, etc. Questions about coping with disability are answered by referrals among G.I.N.I.'s international people network.

G.I.N.I. provides information on all aspects of independent living including attendants, education, employment, equipment, family life, sex, sports, and travel.

The information service is available only to G.I.N.I. members.

Polio Conferences

G.I.N.I.'s biennial polio conferences educate physicians, promote research, and provide information and psychological support to polio survivors.

Proceedings of the 1983 and 1985 conferences are available from G.I.N.I. (See Polio Publications section.)

G.I.N.I.'s Fourth International Polio and Independent Living Conference will be held June 4–7, 1987, at the Sheraton St. Louis Hotel. *Proceedings* from the 1987 conference will be available in 1988.

Polio Publications

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors.
Edited by Gini Laurie, Frederick Maynard, M.D., D. Armin Fischer, M.D., and Judith Raymond. 48 pages. 6″ × 9″. References. Resources. Glossary. ©1984. Paperback. ISBN 0-931301-00-9. $6 in U.S. and Canada. $8 overseas. Postpaid.

The *Handbook* is a compilation of information and the experiences of physicians and survivors who participated in *Rehabilitation Gazette's* two international post-polio conferences and Warm Springs' research symposium.

Topics include aging and weakness, arthritis, depression, diet, exercise, fatigue, frog breathing, muscle weakness, overuse weakness, pain, respiratory insufficiency, sleep apnea, tracheostomy, vaccines, and ventilators.

Proceedings of Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability, May 6-8, 1983, St. Louis, Missouri.
Edited by Gini Laurie and Judith Raymond. 72 pages. ©1984. 8½″ × 11.″ Paperback. ISBN 0-9313301-01-7. $16 in U.S. and Canada. $18 overseas. Postpaid.

Comprehensive source of information on the late effects of poliomyelitis for physicians and other health care professionals, and polio survivors. The *Proceedings* supplements the information in the *Handbook.*

Topics cover worldwide immunization, post-polio research, health maintenance, ventilatory equipment, long-term ventilator users, attendants, independent living.

Proceedings of Gazette International Networking Institute's Third International Polio and Independent Living Conference, May 10-12, 1985, St. Louis, Missouri.
Edited by Gini Laurie and Judith Raymond. 68 pages. ©1986. 8½" × 11." Paperback. ISBN 0-931301-02-5. $16 in U.S. and Canada. $18 overseas. Postpaid.

New information since the 1983 conference on the late effects of polio for physicians and other health care professionals, and polio survivors.

Topics covered include the role of exercise, the management of pain, need for respiratory support, psychological adaptations to changing respiratory support, post-polio research, polio immunization programs, ventilator-assisted living for spinal cord injured, muscular dystrophy, etc., the independent living movement world-wide, and attendant care programs.

Proceedings of Gazette International Networking Institute's Fourth International Polio and Independent Living Conference, June 4–7, 1987, St. Louis, Missouri.
Edited by Gini Laurie and Judith Raymond.
Publication date: May 1988.

Polio Network News and Post-Polio Directory.
Edited and compiled by Judith Raymond.
Quarterly bulletin of post-polio treatment and research, support group activities, and post-polio issues. Annual directory of physicians, health care professionals, post-polio clinics, and support groups worldwide. Available through membership in the International Polio Network (I.P.N.). Annual dues are $5 for polio survivors and $15 for health professionals. ($3 for postage outside U.S. and Canada.)

Rehabilitation Gazette: International journal of independent living by individuals with disabilities. Edited by Gini Laurie and Judith Raymond. $8 each postpaid for back issues. Post-polio features in the following back issues:

1986. Volume 27, Number 1. Coping with Disability and Aging: Poliomyelitis.

1985. Volume 26. Polio Survivors. Guidelines for Polio Support Groups.

1982. Volume 25. Second International Post-Polio Conference, St. Louis. 25 Years Later — Polio Survivors in Canada and U.S.

1981. Volume 24. International Post-Polio Conference, Chicago. Oral Positive Pressure. Homemade Cuirass Shell.

1980. Volume 23. Post-Polio Aging Problems. Respiratory Rehabilitation.

REFERENCES

1. Affeldt, J.E., Bower, A.G., Dail, C.W., Arata, N.N.: Prognosis for respiratory recovery in severe poliomyelitis. *Archives of Internal Medicine,* 38:290, 1957.
2. Affeldt, J.E., West, H.F., Landauer, K.S., Wendland, L.V., Arata, N.N.: Functional and vocational recovery in severe poliomyelitis. *Clinical Orthopaedics,* 12:16, 1958.
3. Alba, A., Khan, A., Lee, M.: Mouth IPPV for sleep. *Rehabilitation Gazette,* 24:47, 1981.
4. Alba, A., Nolan, A.: Advice for people with polio or other neuromuscular disorders. *Rehabilitation Gazette,* 23:10, 1980.
5. Alcock, A.J.W., Hildes, J.A., Kaufert, P.A., et al: Respiratory polio rehabilitation in Manitoba. *University of Manitoba Medical Journal,* 31:116, 1977.
6. Alcock, A.J.W., Hildes, J.A., Kaufert, P.A., et al: The physical and social consequences and rehabilitation of respiratory polio. *University of Manitoba Medical Journal,* 50(3):83-99, 1980.
7. Alexander, M.A., Johnson, E.W., Petty, J., Stauch, D.: Mechanical ventilation of patients with late stage Duchenne muscular dystrophy: management in the home. *Archives of Physical Medicine and Rehabilitation,* 60:289-292, 1979.
8. Alter, M., Kurkland, L.T., Molgaard, C.A.: Late progressive muscular atrophy and antecedent poliomyelitis. In L.P. Rowland (Ed.) *Human Motor Neuron Diseases.* New York: Raven, 303-309, 1982.
9. American Association of Respiratory Therapists. The Surgeon General's Regional Seminar on Home Care for Ventilator-Dependent Children and Adults. *AARTimes,* 8:32-83, April 1984.
10. Anderson, A., Levine, S., Gilbert, H.: Loss of ambulatory ability in patients with older anterior polio. *Lancet* 2: 1061, 1972.
11. Banaszak, E.F., Travers, H., Frazler, M., Vinz, T.: Home ventilator care. *Respiratory Care,* 26:1262-1268, 1981.
12. Barron, B.: Surviving and living with polio. *Rehabilitation Gazette,* 23:9, 1980.
13. Bennett, R.L.: The contribution to physical medicine of our experience with poliomyelitis. Editorial. *Archives of Physical Medicine and Rehabilitation,* 50:(9), 522-524, 1969.
14. Bennett, R.L., Knowlton, G.C.: Overwork weakness in partially denervated skeletal muscle. *Clinical Orthopaedics* 12:22, 1958.
15. Bennett, R.L.: Physical medicine in poliomyelitis. *Poliomyelitis.* Philadelphia, Lippincott, 261, 1952.
16. Berg, R.H.: *Polio and Its Problems.* Philadelphia, Lippincott, 1948.
17. Brook Lodge Invitational Symposium on the Ventilator-Dependent Child, October 16–18, 1983, Augusta, Michigan. Report.
18. Bruno, R.L., Myers, S.J., Cote, L.J., et al.: Abnormal vascular reflex activity in reflex sympathetic dystrophy syndrome. *Archives of Physical Medicine and Rehabilitation,* 64:483, 1983.

19. Campbell, D.M., Williams, E.R., Pearce, J.: Late motor neuron degeneration following poliomyelitis. *Neurology* 19: 1101-1106, 1969.

20. Cerny, R., Waters, R., Hislop, A., Perry, J.: Walking and wheelchair energetics in persons with paraplegia. *Physical Therapy* 60(9):1133, 1980.

21. Centers for Disease Control. Guillain-Barre syndrome: preliminary surveillance report, January 1978–March 1979. Atlanta, Centers for Disease Control, 1-13, 1980.

22. Centers for Disease Control. Poliomyelitis surveillance: summary 1977–1978. Atlanta, Centers for Disease Control, 1-28, 1980.

23. Centers for Disease Control. Poliomyelitis surveillance: summary, 1979. Atlanta, Centers for Disease Control, 1-20, 1981.

24. Cherniak, R.M., Adamson, J.D., Hildes, J.A.: Compliance of the lungs and thorax in poliomyelitis. *Journal of Applied Physiology,* 7:375-378, 1955.

25. Cherniak, R.M., Ewart, W.B., Hildes, J.A.: Polycythemia secondary to respiratory disturbances in poliomyelitis. *Annals of Internal Medicine,* 46:720-727, 1957.

26. Collier, C., Dail, C., Affeldt, V.: Mechanics of glossopharyngeal breathing. *Journal of Applied Physiology,* 8:580, 1956.

27. Curran, F.J.: Night ventilation by body respirators for patients in chronic respiratory failure due to late stage Duchenne muscular dystrophy. *Archives of Physical Medicine and Rehabilitation,* 62:270-274, 1981.

28. Dail, C., et al.: Clinical aspects of glossopharyngeal breathing: Report of its use by 100 post-polio patients. *Journal of American Medical Association,* 158:445, 1955.

29. Dalakas, M.C., Sever, J.L., Madden, D.L., et al.: Late postpoliomyelitis muscular atrophy: clinical, virologic, and immunologic studies. *Reviews of Infectious Diseases,* 6: (Suppl), S562-7, 1984.

30. Dauer, C.: The changing age distribution of paralytic poliomyelitis. *Annals New York Academy of Sciences,* 61:943-955, 1955.

31. Davis, H., Lefrak, S.S., Miller, D., Malt, S.: Prolonged mechanically assisted ventilation. *Journal of American Medical Association,* 243:43, 1980.

32. Debre, R., Duncan, D., Enders, J., Freyche, M., Gard, S., Gear, J., et al.: *Poliomyelitis.* Geneva, World Health Organization, 1955.

33. DeLorme, T.L., Schwab, R.S., Watkins, A.L.: The response of the quadriceps femoris to progressive-resistance exercises in poliomyelitic patients. *Journal of Bone and Joint Surgery,* 30-A:834-847, 1948.

34. Desmarias, M., Alcock, J., Hildes, J.: The Manitoba home care program for respiratory patients. *Canadian Medical Association Journal,* 75:654, 1956.

35. Dickinson, D.: Control of Respiration. *Poliomyelitis. Papers and Discussions Presented at the Fourth International Poliomyelitis Conference.* Philadelphia, Lippincott, 487, 1958.

36. Duffy, Y.: . . . *all things are possible.* Ann Arbor, A.J. Garvin, 1981.

37. Dunkin, L.J.: Home ventilatory assistance. *Anesthesia,* 38:644-649, 1983.

38. Dunnel, K., Adler, M.W., Day, I., et al.: Collaboration between health and social services: A study of the care of responauts. *Community Medicine,* September 22, 1972.

39. Dunnell, K., Ide, L.: An attempt to assess the cost of home care. In D. Lee, S. Shaw, (Eds.) *Impairment, Disability and Handicap.* London, Heinemann, 1974.

40. Dunt, D.R., Kaufert, J.M., Corkhill, R., Creese, A., Green, S., Locker, D.: A technique for precisely measuring activities of daily living. *Community Medicine,* 2:120-25, 1980.

41. Faber, H.: *The pathogenesis of poliomyelitis.* Springfield, CC Thomas, 1955.

42. Feldman, J., Tuteur, P.G.: Mechanical ventilation: from hospital intensive care to home. *Heart and Lung,* 11:162-165, 1982.

43. Fergelson, C., et al.: Glossopharyngeal breathing as an aid to the coughing mechanism in patients with chronic poliomyelitis in a respirator. *New England Journal of Medicine,* 254:611, 1956.

44. Fischer, D.A., Prentice, W.S.: Feasibility of home care for certain respiratory-dependent restrictive or obstructive lung disease patients. *Chest,* 82:739, 1982.

45. Giese, M.E.: Home ventilator care. *Pulmonary Medicine & Technology,* 1:17-23, June, 1984.

46. Gilmartin, M., Make, B.: Home care of the ventilator-dependent person. *Respiratory Care,* 28:1490-1497, 1983.

47. Ginzburg, M., Lee, M., Ginzburg, J., Alba, A.: Evoked giant sensory nerve potentials. *Electromyography and Clinical Neurophysiology,* 14:3-14, 1974.

48. Ginzburg, M., Lee, M., Ginzburg, J., Alba, A.: Possible mechanisms of evoked giant sensory nerve potentials. *Electromyography and Clinical Neurophysiology,* 19:33-40, 1979.

49. Glover, D.W.: Going home on a MA-1. *Respiratory Therapy,* 8:24-27, 1978.

50. Glover, D.W.: Three years at home on a MA-1. *Respiratory Therapy,* 26:1262-1268, 1981.

51. Goldberg, A.I.: Home care for a better life for ventilator-dependent people. *Chest,* 84:365-366, 1983.

52. Goldberg, A.I.: Home care services for severely physically disabled people in England and France. *International Exchange of Experts and Information in Rehabilitation Fellowship Report #20.* World Rehabilitation Fund.

53. Hackney, J.D., Sears, C.H., Collier, C.R.: Estimation of arterial Co_2 tension by rebreathing technique. *Journal of Applied Physiology,* 12:425, 1958.

54. Halstead, L.S.: Activity monitoring in chronic illness: time out of bed for tetraplegics during comprehensive rehabilitation. *Biotelemetry and*

Patient Monitoring, 5:77-87, 1978.

55. Halstead, L.S., Halstead, M.G.: Chronic illness and humanism: rehabilitation as a model for teaching humanistic and scientific health care. *Archives of Physical Medicine and Rehabilitation,* 59:53-57, 1978.

56. Halstead, L.S., Halstead, M.M., Salhoot, J.T., et al.: Human sexuality: an interdisciplinary program for health care professionals and the physically disabled. *Southern Medical Journal,* 69:1352-1355, 1976.

57. Halstead, L.S., Halstead, M.G., Salhoot, J.T., Stock, D.D., Sparks, R.W.: Sexual attitudes, behavior and satisfaction for able-bodied and disabled participants attending workshops in human sexuality. *Archives of Physical Medicine and Rehabilitation,* 59:497-501, 1978.

58. Hamilton, E.A., Nichols, P.J.R., Tait, G.B.W.: Late onset of respiratory insufficiency after poliomyelitis. *Annals of Physical Medicine,* 10:223, 1970.

59. Hayward, M., Seaton, D.: Late sequelae of paralytic poliomyelitis: A clinical and electromyographic study. *Journal of Neurology, Neurosurgery and Psychiatry,* 42:117-122, 1979.

60. Herbison, G.J., Jaweed, M.M., Ditunno, J.F.: Exercise therapies in peripheral neuropathies. *Archives of Physical Medicine and Rehabilitation,* 64:201-205, 1983.

61. Hildes, J.A., Schaberg, A., Alcock, A.J.W.: Cardiovascular collapse in acute poliomyelitis. *Circulation,* 12:986-993, 1955.

62. Hollenberg, C., Desmarias, M.H.L., Frihagen, L., Dale, A.: The late effects of spinal poliomyelitis. *Canadian Medical Association Journal,* 81:343-347, 1959.

63. Horstmann, D.M.: Control of poliomyelitis: A continuing paradox. *Journal of Infectious Diseases,* 146:540, 1982.

64. Johnson, E.W., Braddom, R.: Overwork weakness in facioscapulohumeral muscular dystrophy: Clinical notes. *Archives of Physical Medicine and Rehabilitation,* 52:333, 1971.

65. Johnson, R.T.: Late progression of poliomyelitis paralysis: discussion of pathogenesis. *Reviews of Infectious Diseases,* 6: (Suppl), S568-70, 1984.

66. Jones, D.R., Brink, L.S., Florence, D.W., Smith, N.P.: Effects of a comprehensive six-month exercise program on patients with chronic pain. Submitted for publication.

67. Kaufert, J.: Functional ability indices: measurement problems in assessing their validity. *Archives of Physical Medicine and Rehabilitation,* 64:260-267, 1983.

68. Kaufert, J., Kaufert, P.A.: Aging and respiratory polio. *Rehabilitation Digest,* 13:15-17, 1982.

69. Kaufert, J., Kaufert, P.: Disability and the aging process: The experience of respiratory polio patients. Tenth annual scientific meeting, Canadian Association on Gerontology, November 8–12, 1981. Abstract reprinted in *Gerontologist,* 21:248, October, 1981.

70. Kawamura, Y., Okazaki, J., O'Brien, P.C., Dyck, P.J.: Lumbar motor neurons of manual II. *Journal of Neuropathology and Experimental Neurology,* 36:861-870, 1970.

71. Kayser-Gatchalian, M.C.: Late muscular atrophy after poliomyelitis. *European Neurology,* 10:371, 1973.

72. Knapp, M.E.: The Kenny treatment for infantile paralysis. *Archives of Physical Therapy,* 23:668-673, 1942.

73. Knowlton, G.C., Bennett, R.L., McClure, R.: Electromyography of fatigue. *Archives of Physical Medicine and Rehabilitation,* 32:648-652, 1951.

74. Kurland, L.T., Molgaard, C.A.: The patient record in epidemiology. *Scientific American,* 245:54-63, 1981.

75. LaForce, F.M., Lichnevski, M.S., Keja, J., Henderson, R.H.: Clinical survey techniques to estimate prevalence and annual incidence of poliomyelitis in developing countries. *Bulletin, World Health Organization,* 58:609-620, 1980.

76. Landauer, K.S.: A national program of respiratory and rehabilitation centers. *Poliomyelitis. Papers and Discussions Presented at the Fourth International Poliomyelitis Conference.* Philadelphia, Lippincott, 1958.

77. Lane, D.J., et al.: Late onset respiratory failure in patients with previous poliomyelitis. *Quarterly Journal of Medicine,* New Series, XLIII, 172:551, 1974.

78. Langmuir, A.D.: Results obtained by means of vaccine composed of inactivated viruses. *Poliomyelitis. Papers and Discussions Presented at the Fourth International Poliomyelitis Conference.* Philadelphia, Lippincott, 1958.

79. Laurie, G.: California Attendant Programs. *Housing and Home Services for the Disabled. Guidelines and Experiences in Independent Living.* Hagerstown, Maryland, Harper & Row, 119-138, 1977.

80. Laurie, G.: Polio clinics and support groups. *Rehabilitation Gazette,* 25:21, 1982.

81. Laurie, G.: Post-polio symposium II — Oakland, California — November 14, 1981. *Rehabilitation Gazette,* 24:45, 1981.

82. Laurie, G.: Rehabilitation Gazette polio/respiratory resources. *Rehabilitation Gazette,* 24:36, 1981.

83. Laurie, G., Laurie, J.: Rehabilitation Gazette's Second International Post-polio Conference and Symposium on Living Independently with Severe Disability. *Rehabilitation Gazette,* 25:3, 1982.

89. Laurie, G.: Respiratory rehabilitation and post-polio aging problems. *Rehabilitation Gazette,* 23:3, 1980.

85. Laurie, G.: 25 years of experiences as polio survivors, Canada and United States. *Rehabilitation Gazette,* 25:24, 1982.

86. Longmore, P.K.: Learning to use a portable volume ventilator. *Rehabilitation Gazette,* 25:67, 1982.

87. Lutschg, J., Ludin, H.P.: Electromyographic findings in patients after recovery from peripheral nerve lesions and poliomyelitis. *Neurology,* 225:25-32, 1981.

88. McCord, W.J., Alcock, A.J.W., Hildes, J.A.: Poliomyelitis in pregnancy. *American Journal of Obstetrics and Gynecology,* 69:265-276, 1955.

89. McDonagh, M.J.N., Davies, C.T.M.: Adaptive response of mammalian skeletal muscle to exercise with high loads. *European Journal of Applied Physiology,* 52:139-155, 1984.

90. Mailhot, A., Maynard, F.: Age and the old polio: Do the virtuous fade first? *Rehabilitation Gazette,* 23:6, 1980.

91. Make, B., Gilmartin, M., Broday, J.S., Snider, G.L.: Rehabilitation of ventilator-dependent individuals: The concept and initial experience. (Abstract). *American Review of Respiratory Disease,* 125:139, 1982.

92. Maynard, F.M.: Define the issue. Rehabilitation Gazette, Rehabilitation Institute of Chicago: What ever happened to the polio patient? Proceedings of an International Symposium. Chicago, 159-167, October 14–16, 1981.

93. Maynard, F.M., Darnell, R.E.: Physiatry and physical therapy: models of professional interaction. *Archives of Physical Medicine and Rehabilitation,* 63:496-498, 1982.

94. Mazza, F.G., DiMarco, A.F., Altose, M.D., Strohl, K.P.: The flow-volume loop during glossopharyngeal breathing. *Chest,* 85:638-640, 1984.

95. Melnick, J.L.: Poliomyelitis vaccines: an appraisal after 25 years. *Comprehensive Therapy,* 5:6-14, 1980.

96. Melnick, J.L.: Toward eradication of poliomyelitis by combined use of killed and live vaccines. *Cardiovascular Research Center Bulletin,* 20:49-60, 1982.

97. Montero, J., et al.: Effects of glossopharyngeal breathing on respiration function after cervical cord transsection. *Archives of Physical Medicine and Rehabilitation,* 48:350, 1967.

98. Mooney, T., Cole, T., Chilgren, R.: *Sexual Options for Paraplegics and Quadriplegics.* Boston, Little, Brown & Co., 1975.

99. Moore, M., Katona, P., Kaplan, J.E., Schonberger, L.B., Hatch, M.H.: Poliomyelitis in the United States, 1969–1981. *Journal of Infectious Diseases,* 146:558-563.

100. Mulder, D.W., Rosenbaum, R.A., Layton, D.D.: Late progression of poliomyelitis or forme fruste amyotrophic lateral sclerosis? *Mayo Clinic Proceedings,* 47:756-761, 1972.

101. Nagi, S.Z., Burk, R.D., Clark, D.H.: *Report on a Survey of Respiratory and Severe Post-Polios.* Ohio Rehabilitation Center of the College of Medicine, Ohio State University, Columbus, May, 1962.

102. Nathanscn, N., Martin, J.R.: The epidemiology of poliomyelitis: enigmas surrounding its appearance, epidemicity, and disappearance. *American Journal of Epidemiology,* 110:672-692, 1979.

103. Nathanson, N.: Eradication of poliomyelitis in the United States. *Reviews of Infectious Diseases,* 20:940-950, 1982.

104. Newsom-Davis, J., Goldman, M., Loh, L., et al.: Diaphragm function and alveolar hypoventilation. *Quarterly Journal of Medicine,* 45:87, 1976.

105. Ontario March of Dimes: Post-polio workshop proceedings. Willowdale, Ontario, April 22, 1983.

106. Paul, R.R.: *A history of poliomyelitis.* New Haven, Yale University Press, 1971.

107. *Poliomyelitis. Papers and Discussions Presented at the Fourth International Poliomyelitis Conference.* Philadelphia, Lippincott, 1958.

108. Potts, C.S.: A case of progressive muscular atrophy occurring in a man who had had acute poliomyelitis nineteen years previously. *University of Pennsylvania Medical Bulletin,* 16:31-37, 1903.

109. Prowse, C.M., Gaensler, E.A.: Respiratory and acid-base changes during pregnancy. *Anesthesiology,* 26:381, 1965.

110. Public Health Service: Recommendation of the Immunization Practices Advisory Committee (ACIP) on poliomyelitis prevention. *Morbidity and Mortality Weekly Report,* 31:22-34, 1982.

111. Rabin, B.: *The Sensuous Wheeler.* San Francisco, Multi Media Resource Center, 1980.

112. Ratzka, A.D.: A European view of the conference. *Rehabilitation Gazette,* 24:44, 1981.

113. Ratzka, A.D.: Go positive with face mask and mouthpiece. *Rehabilitation Gazette,* 25:65, 1982.

114. Raymond, J.: Trends in home health care. *Rehabilitation Gazette,* 25:42-44, 1982.

115. Raymond, J., Laurie, G.: The polio conference: a blueprint of creative cooperation for all who are disabled. *Rehabilitation Gazette,* 24:32, 1981.

116. Raymond, M. (with contribution by Charcot, J.M.): Paralysie Essentiele de l'Enfance: Atrophie Musculaire Consecutive. *Gazette Medicale de Paris,* 225:1875.

117. Rehabilitation Gazette, Rehabilitation Institute of Chicago: Whatever happened to the polio patient? Proceedings. Chicago, October 14–16, 1981.

118. Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability. St. Louis, May 6–8, 1983. Proceedings.

119. Roos, R.P., Viola, M.V., Wollman, R., et al.: Amyotrophic lateral sclerosis with antecedent poliomyelitis. *Archives of Neurology,* 37:312-313, May 1980.

120. Sabin, A.B.: Paralytic poliomyelitis: old dogmas and new perspectives. *Reviews of Infectious Diseases,* 3:543-564, 1981.

121. Sabin, A.B.: Poliomyelitis vaccination. Evaluation and direction in continuing application. *American Journal of Clinical Pathology,* 70:136-140, 1978.

122. Sabin, A.B.: Vaccination against poliomyelitis in economically underdeveloped countries. *Bulletin, World Health Organization,* 58:141-157, 1980.

123. Sabin, A.B.: Vaccine control of poliomyelitis in the 1980s. *Yale Journal of Biology and Medicine,* 55:383-389, 1982.

124. Salk, J., Salk, D.: Control of influenza and poliomyelitis with killed virus vaccines. *Science,* 195:834-847, 1977.

125. Salk, J.: Immunization against poliomyelitis: risk/benefit/cost in a changing context. *Developments in Biological Standardization,* 43:151-157, 1979.

126. Salmon, L.A., Riley, H.A.: The relation between chronic anterior poliomyelitis or progressive spinal muscular atrophy and an antecedent attack of acute anterior poliomyelitis. *Bulletin of the Neurology Institute of New York,* 4:35, 1935.

127. Schaberg, A., Hildes, J.A., Alcock, A.J.W.: Upper gastrointestinal lesions in acute bulbar poliomyelitis. *Gastroenterology,* 27:838-848, 1954.

128. Schiffer, D., Palmucci, L., Bertolotto, A., Monga, G.: Mitochondrial abnormalities of late motor neuron degeneration following poliomyelitis and other neurogenic muscular atrophies. *Neurology,* 221:193-201, 1979.

129. Schonberger, L.B., Sullivan-Bolyai, J.Z., Bryan, J.A.: Poliomyelitis in the United States. *Advances in Neurology,* 19:217-227, 1978.

130. Schonberger, L.B., McGowan, J.E., Gregg, M.B.: Vaccine-associated poliomyelitis in the United States, 1961–1972. *American Journal of Epidemiology,* 104:202-211, 1976.

131. Schwartz, O.A., Bruderer, B., Pingleton, S.: Adverse hemodynamic effects of bronchodilators in acute quadriplegia. *Chest,* 82(A):253, 1982.

132. Shahani, B., Davies-Jones, G.A.B., Russell, W.R.: Motor neuron disease, further evidence for an abnormality of nerve metabolism. *Journal of Neurology, Neurosurgery and Psychiatry,* 34:185, 1971.

133. Sivak, E.D., Cordasco, E.M., Gipson, W.T.: Pulmonary mechanical ventilation at home: A reasonable and less expensive alternative. *Respiratory Care,* 28:42-49, 1983.

134. Sivak, E.D., Gipson, W.T., Stelmak, K.: Home care ventilation. *Chest,* 83:239, 1984.

135. Spencer, G.T.: Artificial respiration, Automatic ventilators, Special care units. In W.D. Wylie, H.C. Churchill-Davidson (Eds.), *A Practice of Anaesthesia.* London, Lloyd-Luke, 371-442, 1978.

136. Spencer, G.T.: Artificial respiration and care of the chest in the unconscious patient. In G. Cummings, S.J.G. Semple *Disorders of the Respiratory System.* Oxford, Blackwell, 1979.

137. Spencer, G.T.: Control of respirator-associated infection due to Pseudomonas Aeruginosa. *Lancet,* 2:871, 1974.

138. Spencer, G.T.: Disinfection of lung ventilators by alcohol aerosol. *Lancet,* 2:667, 1968.

139. Spencer, G.T.: How to make a cuirass shell that works. *Rehabilitation Gazette,* 24:49-50, 1981.

140. Spencer, G.T.: Polio vaccination for travellers. *British Medical Journal,* 1:148, 1975.

141. Spencer, G.T.: Pseudomas Aeruginosa cross infection due to contaminated respiratory apparatus. *Lancet,* 2:1325, 1965.

142. Spencer, G.T.: Rate of change of carbon dioxide tension in arterial blood, jugular venous blood and cisternal cerebrospinal fluid on carbon dioxide administration in man. *Journal of Physiology,* 170:555, 1965.

143. Spencer, G.T.: Respirators in respiratory failure. *British Medical Journal,* 3:780, 1969.

144. Spencer, G.T.: Respiratory insufficiency in scoliosis: Clinical management and home care. In P.A. Zorab (Ed.) *Scoliosis.* London, Academic Press, 315, 1977.

145. Spencer, G.T.: Tracheostomy and artificial ventilation in the treatment of acute exacerbations of chronic lung disease. *Lancet,* 1:854, 1964.

146. Spencer, G.T.: Tracheostomy and endotracheal intubation in the intensive care unit. In C. Gray, J.F. Nunn (Eds.), *General Anaesthesia.* London, Butterworth, 553-572, 1971.

147. Spencer, W.A.: *Treatment of Acute Poliomyelitis.* Springfield, CC Thomas, 1956.

148. Splaingard, M.L., Frates, R.C., Jr., Harrison, G.M., Carter, R.E., Jefferson, L.S.: Home positive-pressure ventilation: twenty years' experience. *Chest,* 84:376-382, 1983.

149. Splaingard, M.L., Jefferson, L.S., Harrison, G.M.: Survival of patients with respiratory insufficiency secondary to neuromuscular disease treated at home with negative pressure ventilation (NPV). (Abstract) *American Review of Respiratory Disease,* 125:139, 1982.

150. Stalberg, E.: The motor unit in neuropathies and myopathies. *Muscle and Nerve,* 252-253, May/June, 1981.

151. Surgeon General's Regional Seminar on Creating New Options for Ventilator-Dependent Children and Adults, May 7, 1984, Chicago. Report. In progress. (Chicago Lung Association).

152. Surgeon General's Workshop on Children with Handicaps and their families, December 13-14, 1982, Philadelphia. U.S. Dept. of Health and Human Services.

153. Taylor, J.R., Alcock, A.J.W., Hildes, J.A.: Hyaluronidase and renal calculi in poliomyelitis. *American Journal of Medical Science,* 230:536-540, 1955.

154. Tomlinson, B.E., Irving, D.: The numbers of limb motor neurons in the human lumbosacral cord throughout life. *Journal of Neurological Science,* 34:213-219, 1977.

155. Tomlinson, B.E., Walton, J.N., Irving, D.: Spinal cord limb motor neurons in muscular dystrophy. *Journal of Neurological Science,* 22:305-327, 1974.

156. von Magnus, H.: International symposium on immunization: benefit vs. risk factors. *Developments in Biological Standardization,* 43:218-219, 1979.

157. Walton, J.N., Irving, D., Tomlinson, B.E.: Spinal cord limb motor neurons in dystrophia myotonica. *Journal of Neurological Science,* 84:199-211, 1977.

158. Warm Springs Research Symposium on the Late Effects of Poliomyelitis, May 25-27, 1984. In progress (Roosevelt Warm Springs Institute for Rehabilitation).

159. Weingarten, W.S.: Respiration equipment — advancements over the years, equipment now in use and most recent developments. *Rehabilitation Gazette,* 21:34, 1978.

160. Weinstein, L.: Influence of age and sex on susceptibility and clinical manifestations in poliomyelitis. *New England Journal of Medicine,* 257:47-52, 1957.

161. Whiting, R.B., Dreisinger, T.E., Abbott, C.: Clinical use of exercise testing in handicapped patients. *Missouri Medicine,* 80:582, 1983.

162. Whiting, R.B., Dreisinger, T.E., Abbott, C.: Clinical value of exercise testing in handicapped subjects. *Southern Medical Journal,* 76:1225, 1983.

163. Wiechers, D.O., Hubbell, S.L.: Late changes in the motor unit after acute poliomyelitis. *Muscle and Nerve,* 4:524-528, 1981.

164. Wyatt, H.V.: Is poliomyelitis a genetically-determined disease? II. A Critical examination of the epidemiological data. *Medical Hypotheses,* 1:23-32, 1975.

165. Yarnell, S.K.: Delayed effects of poliomyelitis. *Physical Medicine and Rehabilitation,* 140:603, April, 1984.

GLOSSARY

Alveolar Ventilation — the amount of ventilation being moved to and from alveolar sacs. The amount of alveolar ventilation determines the partial pressure of carbon dioxide in the blood

Anterior — situated at or directed to the front.

Apnea — cessation of breathing. During sleep, transient apnea may occur.

Arterial Blood — that which carries oxygen to the tissues through the systemic arteries.

Atrophy — deterioration or loss of tissue, especially muscle tissue.

Bulbar — pertaining to or involving the part of the brain known as the medulla oblongata, which is at the top of the spinal column.

Carpal Tunnel Syndrome — a complex of symptoms resulting from compression of the median nerve in the carpal (wrist) tunnel, with pain and burning or tingling sensations in the fingers and hand, sometimes extending to the elbow.

Dysphagia — difficulty in swallowing.

Ear Oximeter — a photoelectric device for attachment to the ear, by which oxygen saturation of the blood flowing through the ear can be determined.

Edema — the abnormal accumulation of fluid in tissues, i.e., ankles and feet.

Electromyography — the recording and study of the intrinsic electric properties of skeletal muscle.

Endogenous Depression — depression which arises from within the individual.

Endotracheal — within the trachea (wind pipe).

Fascia — a sheet or layer of condensed connective tissue covering, binding, or supporting internal parts of the body.

Febrile — pertaining to fever or feverish.

Fibrillation — a small local involuntary muscle contraction.

Glossopharyngeal Breathing — a method of breathing by forcing air into the lungs using the tongue (glosso) and the throat (pharynx).

Horn Cell — a horn-shaped structure seen in transverse section of the spinal cord.

Hypercapnia — excess of carbon dioxide in the blood.

Hyperventilation — overbreathing resulting in lower CO_2 in the blood.

Hypoventilation — underbreathing resulting in higher CO_2 in the blood.

Hypoxia — decreased oxygen in the blood.

Intubation — insertion of a tube into any body orifice, often the nose, mouth, or trachea (windpipe).

Lumbosacral — pertaining to the loins and the sacrum (the triangular shaped bone of fused vertebrae forming the back of the pelvis).

Myofascial — pertaining to muscles surrounded by fascia.

Neuron — any of the conducting cells of the nervous system.

Neuropathy — any functional disturbance and/or pathological change in the peripheral nervous system.

Orthosis — a splint, brace, or other device.

Phonate — utter vocal sounds.

Postural Drainage — therapeutic drainage of lungs through positioning and rhythmic beating with the hands over the affected lung area.

Proprioception — ability to receive information from the sensory nerve terminals concerning movements and positions of the body.

Radiculopathy — disorder of the nerve roots.

Range of Motion — measurement of the amount of movement possible at a given joint.

Respirator — a term synonymous with ventilator, less commonly used today.

Scoliosis — a sideward curve of the spine.

Stenosis — narrowing of a duct or canal.

Stomal — pertaining to the opening of a tracheostomy, etc.

Thoracolumbar — pertaining to the thoracic and lumbar parts of the spine.

Tracheostomy — an incision into the trachea or windpipe and the insertion of a tube to facilitate breathing.

Ventilation — the act of moving air to and from the lungs.

Ventilation, Mechanical — breathing with the aid of a ventilator (utilizing either positive or negative pressure) to enable movement of air to and from the lungs.

Vital Capacity — the volume of gas that can be expelled from the lungs after breathing in as deeply as possible.

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