



Interpretation of Polio Québec Logo

A brilliant sun with one gray ray amongst shining ones suggesting that we are a group that wishes to enlighten the polio world - to radiate outwards, ever mindful of the potential secondary effects of polio (the gray ray).



POST -POLIO SYNDROME

The Late Effects of Polio

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Information Booklet
written for Polio Quebec

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POLIO QUEBEC WARNING ABOUT SURGERY

- Be absolutely certain it is necessary.
- Get a second opinion if you have any doubts.
- Be assured that your doctor, surgeon and anaesthetist know you had polio. *It is extremely important that they be aware of previous surgical interventions* and know that certain anaesthetics and medications should be avoided for people with neuro-muscular disorders such as polio.

INTRODUCTION

If you had polio or know someone who did, you may be concerned or wish to have questions answered regarding the possible development of post-polio syndrome. Studies show up to 64% of those who had polio experience problems decades later. This brochure has been designed for those who had polio, and their families, to help relieve any general concerns that may have arisen, as well as to provide general information.

CAUSE

Why post-polio syndrome (PPS) occurs is not clearly established. There are many different theories. However the most probable theory so far is one which explains that the motor neurons spared by polio "sprout" to resupply muscle fibres that lost their innervation during polio, like a tree (motor neuron) growing many new branches (sprouts). These motor neurons then supply more muscle fibres than normal and so have to work harder. These new sprouts (branches) fall away after a number of years due to premature aging and exhaustion of the motor neuron caused by the increased demand on it. The muscles then lose their innervation (nerve supply), resulting in weakness. This degenerative process can also produce neuromuscular junction transmission defects (difficulties in communication between nerve and muscle) which may be the cause of muscular fatigue.

DIAGNOSIS

Diagnosis of PPS requires a careful history and physical examination. The following factors can increase the risk for developing PPS: (i) a greater degree of paralysis at the time of the original infection, (ii) a greater functional recovery after acute polio, (iii) a longer time since acute polio, and (iv) a greater age at the time of presentation to a clinic.

During a physical examination the strength of all the muscles is evaluated as well as the amount of movement at each joint. The determination of PPS is done via a process of elimination of other conditions that may cause similar symptoms. Currently there is no diagnostic test for PPS. However, previous motor neuron loss due to polio can be confirmed by electromyography (EMG) testing.

Certain conditions such as sleep apnea, fibromyalgia, and osteoporosis likely occur more frequently in people with previous polio than in the general population. Sleep apnea (difficulty breathing during sleep) can produce significant daytime fatigue, morning headaches, nightmares, snoring, waking during sleep, impaired cognition, and irritability. Sleep apnea can be diagnosed in a sleep clinic, and is treatable. Fibromyalgia can produce chronic, generalized pain, and has been found to occur in approximately 11 % of individuals attending a post-polio clinic. This condition can be treated with certain medications, aerobic exercise, and other

measures. Osteoporosis (loss of bone mass) likely occurs more frequently in both women and men with previous polio. It increases the risk for fracture, and is now treatable with several medications. Diagnosis and treatment of these associated disorders can result in improvement of symptoms in patients.

SIGNS AND SYMPTOMS

There are a dazzling variety of symptoms that occur in PPS. The main symptoms of PPS can be summed up under a triad - new weakness, fatigue, and new pain. PPS is defined as new weakness and/or abnormal muscle fatigue with or without generalized fatigue, muscle atrophy, or pain in those who have recovered from paralytic polio.

New weakness occurs with or without new muscle loss in about 20-40% of polio patients. This increasing weakness may provoke joint instabilities, resulting in various deformities which may also result in greater difficulty with walking.

Fatigue is clearly the most prominent manifestation of PPS. Two types of fatigue are reported: (i) generalized fatigue, and (ii) local muscle fatigue. Many experience a sudden onset of generalized exhaustion after brief physical activity, known as the "polio wall." Muscle fatigue is experienced as a gradual loss of muscle strength with continued activity, which improves with rest. Fatigue-related symptoms consist of increased sleep, decreased concentration, decreased endurance, requiring a change in lifestyle. In addition, patients with respiratory problems have a variety of other symptoms, such as increased shortness of breath, sleep disturbance, confusion, inability to concentrate, etc. These symptoms may be classified as follows:

General-increased weakness; increased fatigue, decreased endurance for usual activities; changes in lifestyle (e.g., need for bracing or ventilator); increased instability and falling; excessive weight gain; situational anxiety and depression (as a result of decreased endurance).

Neuromuscular-increased pain and deformity of joints; muscle pain; muscular twitching; increased or new muscle weakness; increased fractures (as a result of weakness).

Respiratory-increased shortness of breath; increased respiratory infections; difficulty in speaking; sleep disturbances; confusion, especially upon waking; inability to concentrate ..

New pain is the most prominent symptom in some patients. It is felt around certain joints and muscles. This pain is usually related to physical activity. Another type of pain described is a burning sensation, deep in the muscle and

... bone, and not directly related to any specific activity. This pain is the hardest to deal with.

(Excerpted from Holman, K. G" Post-Polio Syndrome: The battle with an old foe reswnes. Post-Graduate Medicine 7968, p.47 (1986)

WHO CAN HELP

As PPS has only recently become known to medical personnel as a distinct entity, many health professions are now becoming aware of the symptoms of the disease and the effect they have on patients and their families. Diagnostic criteria for PPS were established in 1997 by the PPS Task Force, led by Dr. Cashman, and more recently in 2001 by the March of Dimes following an international conference on PPS with the help of a steering committee.

Currently the treatment for PPS is directed towards reducing the symptoms (predominantly pain, weakness and fatigue) and improving functions. Together with a medical team, the patient works towards attaining these goals. Members of a medical team may consist of the following professions: general practitioner, neurologist, physiatrist, occupational therapist, physiotherapist, social worker, dietician, respiratory therapist, psychologist, psychiatrist, pulmonary specialist, orthotist, and nurse. They can be seen by a referral from a family physician.

General Practitioner-The family doctor is likely the first health professional to be contacted to discuss symptoms and concerns. PPS is presently a diagnosis of exclusion (all other possible diseases having been ruled out). The PPS person may be referred by a family doctor to a number of specialists and a great deal of time and testing may be required before a diagnosis can be made.

Neurologist-A neurologist is a doctor who studies and treats problems associated with the nervous system.

Physiatrist-A physiatrist is a medical doctor who specializes in the area of rehabilitation.

Pulmonary Specialist-A pulmonary specialist is a physician who is specialized in the evaluation and treatment of pulmonary disorders.

Occupational Therapist-The occupational therapist can provide the PPS person with the means to relieve symptoms by suggesting energy conservation techniques, adaptations to maintain a level of functional independence in the home/car/work place, as well as any vocational retraining that may be necessary.

Physiotherapist-A physiotherapist provides consultation regarding mobility, recommending canes, crutches or braces if required. A physiotherapist treats pain

associated with bursitis or tendonitis resulting from PPS. Special exercise programs are developed and adapted to special needs.

Orthotist-An orthotist fabricates and evaluates orthoses (braces) which can be used to control joint deformities, to control pain and to stabilize weak limbs.

Social Worker-The role of a social worker is to provide any advice and counselling the PPS person and his or her family may require. They have resources available to locate and refer the PPS person to appropriate community services, depending on his or her needs.

Dietician-Provides education regarding healthy eating habits. The dietician can suggest food groups which will provide the best energy sources while maintaining an adequate body weight. A reduction of body weight may be required to reduce fatigue as well as stress on joints.

Respiratory Therapist-Since the respiratory function may have been affected in a PPS person, a respiratory therapist may be required to assess the vital capacity and the blood gas values of the PPS person, as well as playing a role in any intervention for improved ventilation.

Psychiatrist-A psychiatrist is a physician and tends to the psychiatric needs of an individual. A psychiatrist's services may be required if a PPS person is experiencing difficulty in coping with this second traumatic illness.

Psychologist-A psychologist can help a person to accept and live with new difficulties by helping the individual come to terms with the problem.

Nurse-A nurse's role is to promote health and optimal functioning, as well as to assist people in coping with changes and crises in life.

ATTITUDES

To maintain a sense of well-being, one must keep a positive mental attitude to health. This attitude can be developed by planning a program that meets an individual's needs and changes in lifestyle.

Group counselling with other PPS people may help develop an acceptance of lifestyle change. The most important factor is to realize that you are not alone. Maintaining ones values, likes and self-worth will facilitate the process of developing positive mental attitudes. Finally, it is important for physical and mental well-being to have a balanced routine of work, rest and recreation.

ADJUSTMENT IN LIFESTYLE

Changes in lifestyle may become necessary as the effects of PPS begin to manifest themselves. New signs of weakness, pain and fatigue may require the PPS person to adapt to a different lifestyle. For example, a person who was once ambulatory with walking aids may now have to rely on a wheelchair for mobility. Not all adjustments are this major. Sometimes the person only has to allow for more rest periods or cut back on the number of hours of working, etc. Some helpful hints include: (i) make realistic goals; (ii) plan a basic daily and weekly schedule (not too rigid, but flexible enough to respond to body needs); (iii) identify priorities - these are the activities that are unavoidable and/or pleasurable (demanding activities should not be scheduled for times when you are most tired); (iv) use of aids such as crutches, braces or household adaptations may facilitate daily function.

SEX

The importance of one's sexual identity and personal intimacy with the partner/spouse should not be underestimated. An important fact to acknowledge is that acute polio and PPS do not have any effects on the reproductive system, potency and/or sexual enjoyment. If any problems arise, the PPS person should not hesitate or feel embarrassed about consulting a specialist in this area.

CARING FOR SOMEONE WITH PPS

Many people with PPS continue to function with only minor complications. However some are less fortunate and require assistance from a caregiver. General guidelines include home and outdoor adaptations to facilitate daily activities and conserve energy. The care given must determine potential abilities and yet recognize there are things a PPS person is not capable of doing independently.

Daily Activities. The caregiver must consider what is important to the PPS person and focus on time spent doing those activities, together with conservation of energy.

Hygiene and Personal Care. The caregiver should consider the time and energy put into hygiene and personal care, providing assistance to overcome any problems. Some useful tips or aids are: (i) grab bars around bathtub and/or toilet area; (ii) a bath bench to sit on to facilitate getting in and out of the tub (a handheld shower also helps); (iii) washing hair in the shower; (iv) using a terrytowel robe for drying.

Dieting and Eating Tips. PPS people require a good, balanced, general diet for a healthy body. It is important to avoid being overweight as this requires more energy from muscles, thus increasing fatigue. Increased weight places additional stress on joints which may lead to arthritis .

PSYCHOLOGICAL IMPACT ON THE PERSON WITH PPS

One important fact to consider is that there is no simple relationship between the severity of a disability and the degree of psychological impairment. Many people have lots of physical disabilities and their psychological dispositions remain unaffected. One must also consider the wide range of individual reactions to disabilities and their attitudes as well as their adaptability towards the disability. Common reactions to disabilities are:

- Introversion, spending time alone. Many PPS people may feel they are inadequate compared to the "normal" population.
- Increased anxiety, stress. This usually occurs because the individual with new symptoms may be afraid due to minimal medical knowledge and awareness.
- Frustration/depression. This is evident in some PPS people who had acute polio and are now faced with new disabilities that cause a great deal of emotional turmoil.
- More subdued. Often seen in PPS people whose independent functioning has become impaired. PPS is psychologically traumatic because (i) the symptoms arise unexpectedly; (ii) the cause is unknown; (iii) there is a lack of knowledge and understanding in the medical community; and (iv) there are feelings of isolation and desperation as the PPS person searches for answers; feeling of devaluation may occur.

PPS psychological sequelae can be divided into four stages that may or may not overlap.

- The first stage is one of mourning, which is a normal feeling. This may result in a PPS person rejecting the use of shoe inserts, braces, wheelchairs, respirator, etc.
- The second stage consists of devaluing physical appearance. This means placing more importance on emotional, personal and psychological aspects and less on appearance.

- The third stage deals with enlarging the scope of values, i.e., awareness that values in work, study and leisure are more meaningful than the value of the physical body in judging self-worth.
- The fourth stage deals with learning to value their potentials within the limits of a disability rather than judging themselves in relation to the "full function" population.

ROLE CHANGES AND IMPACT WITHIN THE FAMILY

The person with PPS may rely on the family for both physical and/or psychological support. The family must support the PPS person, be reassuring while taking over some of the tedious chores, yet help to maintain the autonomy of the PPS person. The family must keep in mind that this is only a physical disability. The PPS person remains cognitively intact, and is still a major part of the family and should be treated as such.

MISCONCEPTIONS

PPS is the return of polio? False. There is no return of the virus. In fact there is no evidence for the presence of a live virus.

PPS is a rapidly progressive disease? False. the progress of PPS is slow and is measured in years to decades, marked with plateau periods where no progression takes place.

PPS is untreatable? False. The symptoms can be treated by various methods and early treatment may help alleviate future problems.

PPS is psychosomatic? False. PPS is very real and its effects vary from one person to another and symptom relief requires professional intervention.

Patients with PPS should exercise vigorously to build up and strengthen muscles? False. In fact, vigorous exercise may weaken muscles even more. Low resistance exercises are favoured so as to prevent atrophy of disuse, and increase strength. However, some individuals should not engage in additional exercise/activity .

RESOURCES AVAILABLE

A variety of community support services exist that can be very useful, such as:

Montreal Neurological Institute and Hospital (MNIH) - Post-Polio Clinic staffed by Dr. Daria Trojan, physiatrist (514-398-8911) and Dr. Diane Diorio,

neurologist. Preferably referred by a family physician.

Polio Quebec Association organizes general meetings in the spring and autumn for all people who had polio and their families. Guest lecturers are invited and medical information is also given. The meetings are designed to offer information on various topics, to discuss and exchange different problems and to offer general and emotional support. The Association also publishes bi-annual newsletters and organizes social outings. For information see address and phone number on the back cover. Membership: \$12.00 per year.

CLSC- Local community service centre provides basic health care services and check-ups from a multi-disciplinary team comprised generally of doctors, nurses, physiotherapists, occupational therapists, and social workers. They also have visiting homemakers who provide help in the household and with personal care; for example, they can offer assistance in cleaning the house and bathing. They may also help with some shopping, banking and laundry. A service of visiting nurses can also be helpful to the patient who is not fully autonomous.

Parking. Special (movable) parking signs for disabled drivers are available on completion of a questionnaire from Societe d' Assurance Automobile du Quebec, Emissions des Vignettes, call Montreal 514- 873-7620 or toll-free (800) 3617620.

Meals-on-Wheels. This service brings hot meals to the person's home. Referral from the CLSC is required for the use of these services, and what is offered will depend on the individual's needs.

Travel and Lodging expenses for patients of the Polio Clinic can sometimes be supported by le Programme transport et hébergement pour les personnes handicapées. Contact your local CLSC.

For resources in or near Montreal see page 12.

PUBLICATIONS

Polio Folio. A bilingual newsletter for members of Polio Quebec published twice a year. (Tel: 1-877-765-4672)

Abilities. Canada's lifestyle magazine for people with disabilities. Issued quarterly (\$ 14.00/year, \$22.00/2 years). Write c/o The Canadian Abilities Foundation, Access Place Canada, College Park, 444 Yonge Street, Toronto, Ont., M5S 2T1. Tel(416) 977-5185; Fax (416) 977-5098 (mostly English).

Paraquad and *Paraquad Express.* Published 3 times and 6 times a year, respectively. Membership: \$25.00/yr. For those in a wheel chair; others, \$35.00/yr. Tel: 514-341-7272.

Polio Network News. An international newsletter for polio survivors, health professionals and resource centres, to exchange information, encourage research and promote networking among the post-polio community. Issued quarterly. 4207 Lindell Blvd. # 110, St. Louis, MO 63108-2915.

Current Trends in Post-Poliomyelitis Syndrome by D.A. Trojan, MD, M.Sc., and N.R. Cashman, MD. A monograph published by Milestone Medical Communication, 1996, which can be obtained through Polio Quebec Association or through International Polio Network, 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915 (Tel: 314-534-0475).

FINANCIAL COVERAGE

In general when seeking financial help for equipment, an application form completed by a medical professional is required. It is then evaluated by the funding organization. Some of the associations and what they offer are:

R.C.L. (Quebec) for the Disabled Inc. Tel: (514) 866-3689. Offers financial assistance for equipment and adaptations for those on a fixed income. Provides loans for wheelchairs, beds, and provides transportation to medical and rehabilitation appointments.

Office des personnes handicapées du Québec (OPHQ) Tel: 514-873-3905. Offers financial coverage for technical aids and adaptations at home and in the work place.

Private group insurances. Some companies may pay for aids and equipment. Contact your insurance agent.

Quebec Housing Bureau (Société d'Habitation du Québec). Provides funding for residential adaptations (Tel: 1-800-463-4315).

Crideat (Rehabilitation Institute of Montreal) Tel: 340-2085. A resource service where one can go to examine a large variety of apparatuses and have a demonstration of their use.

Polio Canada: gives access to many resources and links to organizations across Canada. Tel: 1-800-480-5903.

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Available Resources (mostly) Montreal

HOUSING: Logique. Owns and operates apartment buildings in Montreal that are "universally accessible" for everyone, including people who are handicapped. They also advise on renovations in the home for the handicapped and elderly. A few apartments are available with rent subsidies for those with limited incomes. Tel: 522-8284. Info-Logement has a listing of available adapted apartments. Tel: 514376-4757, ext. 2418.

RECREATION: Centre d'intégration à la vie active (CIVA), 525 Dominion, 3rd Floor, Montreal, Qc H3J 3B4. Tel: 514-935-1109. Membership \$25.00/yr. Offers swimming, wheelchair basketball, theatre, painting, outings, bocce, etc.

EQUIPMENT, SERVICE AND REPAIRS: Institut de Réadaptation de Montréal. Offers general and emergency repair service for electric wheel chairs from 8:30 a.m. to 11:00 p.m. Serves the Island of Montreal. Tel: 514-340-2085. Constance Lethbridge Rehabilitation Centre offers a technical support department. Tel: 514-487-1891. Adaptel. Private service is available 24 hours a day, including emergency help for scooters (cost approximately \$45.00). Tel: 514328-1892. Para-plus (tel: 514-739-8030) and Van Action (Tel: 514-342-5000) provide medical supplies and equipment, van conversions, lifts, consultations, rentals, etc.

MOBILE DENTAL CLINIC In Montreal and Laval and South Shore offers dental service in homes and institutions, public or private, to people unable to get to a dentist's office. Managed by Dr. William Dery, available 24 hours a day. Call S.O.S. Dentiste at 990-0911.

TRANSPORT ADAPTE. Transport Adapte offers transportation services in adapted buses and taxis through the following organizations:
STCUM (MUCTC) Tel: 514-280-5341; STL (Laval) Tel: 450-662-8316; STRMS (South Shore) Tel:450-442-8600. For the rest of Quebec, telephone numbers can be found on •• www.mtq.gouv.qc.ca ••. To gain accessibility to Transport Adapte a form must be completed by a doctor or rehabilitation professional. The above organizations charge the same price as the ordinary community transport ticket. There is an additional fee if the trip is outside the region designated by the transit corporation. A private company is Medicar, available 24 hours/day at \$40.00 plus mileage. Tel: 514-766-3342.