

Post Polio Syndrome

Management and Treatment
in Primary Care

(The Blue Book)



For Polio Survivors By Polio Survivors since 1993

POST POLIO SYNDROME
MANAGEMENT AND TREATMENT
IN
PRIMARY CARE

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FOREWORD

Original Edition

The Post Polio Support Group has, since its inception, striven to increase awareness amongst all medical professionals of Post Polio Syndrome (the Late Effects of Polio), which many Polio Survivors are now experiencing.

Around 60% of Polio Survivors have or will, at some stage, display some symptoms of Post Polio Syndrome. The medical profile of each survivor is unique and the diagnosis and the management of treatment are considered processes. This publication will provide all stakeholder groups with information that will place them at the leading edge of service delivery to those experiencing Post Polio Syndrome. It takes a multidisciplinary and holistic approach and is targeted towards helping to enrich the practitioner client relationship to the benefit of both.

As a Group we have been fortunate to have many good friends in the medical professions and to ensure the success of this project we have drawn on that goodwill across many disciplines. We have leaned most heavily on our writing team who have done such tremendous work over the past year. We are extremely proud of the final product and are conscious of the great debt all Polio Survivors owe to their rigorous work.

This publication represents a further development of our partnership with the Health Service Executive which has been an enthusiastic supporter of this initiative and has generously financed its production.

I am delighted to have the privilege, as former Chairman of the Post Polio Support Group, of introducing this forward looking publication and would like to pay a special tribute to my fellow Director, John McFarlane who has worked with me on this project, ensuring that the Polio Survivor perspective has been, at all times, the focus for the work.

Jim Costello.
Director & Trustee,
Post Polio Support Group.

FOREWORD

First Reprint

In 2007 we, as a Group, challenged ourselves to deliver a copy of the first imprint of this volume to everyone experiencing Post Polio Syndrome, each general Practitioner, each occupational therapist, each physiotherapist and each speech and language therapist. Furthermore as it was published on the Group's web site as a free download it quickly gained an international audience and has been reprinted with our permission for use as a primary reference source for the management and treatment of Post Polio Syndrome in many countries around the world, both in its original English text as well as translation. This slim volume has helped to keep the Post Polio Support Group of Ireland in the forefront of the care, and support of Polio Survivors through its innovative approach and original research.

Since 2007 knowledge and research has progressed, with the recognition, in 2010, in the World Health Organisation's International Classification of Diseases of Post Polio Syndrome, or as it should now be more correctly termed Postpolio Myelitic Syndrome (G14) as a distinct and incurable disease.

The ground breaking research being undertaken in to the condition around the world concentrates now, and in the foreseeable future on diagnosis and new developments in the care of Polio Survivors. This reprint of the original text deals with the practical reality of its management and treatment, those fundamentals have not changed and continue to bring relief to Polio Survivors and Postpolio Survivors around the world.

The Polio community and those caring for them are central to our mission. As research progresses and better treatments become available the reader may be assured that this Group will be in the vanguard of their promotion.

John R McFarlane
Chair 2010

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THE POST POLIO SYNDROME

Dr John Latham

Acute Poliomyelitis

Before discussing the Post Polio Syndrome it is worth reminding ourselves of the original disease poliomyelitis and its effects on the young patients who developed it.

Polio is mainly a disease of children and young adults caused by polio enterovirus type 1, 2 or 3. This much feared illness occurred in epidemics, usually in summertime in Europe and America. The last great polio epidemic was in the mid 1950s in Ireland (e.g. Cork 1956) as well as the rest of Europe and America.¹

The inactivated polio vaccine developed by Jonas Salk was available in 1955, and the oral polio (attenuated live) was available in 1962 developed by Albert Sabin. Following the widespread use of these vaccines, acute polio in the developed world has become a rarity.

It is estimated that there are approximately 7,500 survivors of polio living in the Republic of Ireland at present. Most of these people are middle aged and becoming elderly. Each general practitioner with a personal list of 2,000 may have 2 or 3 survivors of polio in his/her practice.

Infection

Polio is caused by an enterovirus of high infectivity whose main route of infection is via the human gastrointestinal tract. Infection is oral and the virus multiplies in the gut for one to three weeks when it is either contained by an immune response or a viraemic phase occurs. The virus is excreted in the faeces for a number of weeks and in saliva for some days. Infection rates are very high but it is likely that 95% of all infections are asymptomatic or cause a flu-like illness.

Acute Paralytic Polio

It is not known why some patients developed spinal polio while others suffered a flu-like illness with no neurological sequelae.²

Acute spinal polio is characterised by asymmetric paralysis of muscles served by motor units originating in spinal cord anterior horn cells which have been damaged or killed by the polio virus. This paralysis is often very sudden and sometimes very severe, usually involving the lower limbs and is often maximal after 48 hours. There is also a bulbar form of acute polio which causes paralysis of respiratory muscles and those of deglutition; this had a particularly high mortality and frequently required ventilation (tracheostomy and positive pressure ventilation or negative pressure ventilation, e.g. the body encasing “iron lung”).

During the acute phase of polio, strict bed rest was sometimes used to prevent further spread of paralysis.

Summary of neurological effects of acute polio:

- Spinal polio due to damaged or killed anterior horn cells,
- Acute paralysis of groups of muscles in limbs, or
- Respiratory muscles in acute bulbar polio leading to:
 - Respiratory failure.
 - Dysphagia.
 - Speech difficulties.

Recovery Phase

The recovery phase of polio requires that “orphaned” muscle fibres become re-innervated by axon sprouts and large numbers of hypertrophied muscle fibres may be innervated by small numbers of overworked surviving neurons. Some muscle fibres and groups of muscles may never be re-innervated and the remaining muscle groups will compensate by hypertrophying and working very much harder.

Patients underwent physiotherapy and mobilisation with stretching and sometimes splinting of affected limbs. This was to retrain affected muscles and help regain function. Orthoses were sometimes used to help

restore function and prevent wear and tear.

Most survivors with bulbar polio were weaned off negative/positive pressure respiration though some continued to use this intermittently. Some still use intermittent positive pressure ventilation.

Stable Disability

Polio was described as a chronic, yet stable, disease with a period of stable disability following rehabilitation in the recovery phase. The severity of disability varies greatly from almost imperceptible muscle weakness to significant weakness leading to reduced mobility and from no bulbar problems to intermittent dependence on assisted respiration.

Summary of Classic Phases in Polio

- Acute illness.
- Period of recovery.
- Stable disability.

Post Polio Syndrome

Polio was considered to be a chronic but stable disease once the acute phase was over and rehabilitation had restored a lesser or greater degree of function. However, it is now known that some survivors of polio develop new symptoms after many decades of stable functioning. The first descriptions of new muscle weakness in polio survivors, developing years after the initial illness, were published by the great French neurologist Charcot in 1875.³ It was not until the 1980s that the post polio syndrome was widely acknowledged; the term *post polio syndrome* (PPS) was first used at the first International Post-Polio Conference at Warm Springs Georgia in 1984.⁴

Diagnosing Post Polio Syndrome

PPS is a condition resulting in new symptoms in people who had polio years earlier but who have had functional and neurological stability for at

least 15 years. The symptoms may include the following:

- New muscle weakness.
- Fatigue.
- Muscle and joint pain.
- Atrophy of muscle.
- New difficulties in activities of daily living, particularly mobility related activities.
- Cold intolerance.
- Sleep impairment.
- Speech difficulties.
- Dysphagia.
- Respiratory dysfunction.

The cardinal symptom is new weakness.⁵

There is no laboratory test for PPS and in making a diagnosis all other causes of these symptoms must be excluded. Therefore careful clinical evaluation using history, observation and examination are the diagnostic tools required to eliminate other disease entities. These causes include:

- Natural effects of age.
- Bone or joint problems due to deformity or “wear and tear”.
- Other neurological disease.
- Medical disease such as hypothyroidism.
- Depression.

Since this is a diagnosis of exclusion, laboratory tests such as FBC and TFTs will be important. Diagnostic imaging such as joint X Rays or MRI scans of spinal cord may be useful in ruling out other causes.⁶

Referral to a consultant neurologist is usually essential for EMG, confirmation of the diagnosis and exclusion of other neurological and muscle disorders.

Causes of Post Polio Syndrome

There is no definite explanation for the new symptoms associated with PPS but the most widely accepted theory is that of *neuron fatigue*. In

this theory it is assumed that many motor neurons were destroyed by the original infection, leaving small numbers of overworked neurons to innervate many (orphaned) muscle fibres. With time and overuse, these few working neurons simply wear out leaving muscles denervated.⁷

Proposed aetiologies include:

- Motor unit dysfunction-degenerative change within motor units.
- Muscle overuse.
- Muscle underused.
- Loss of motor units due to age.
- Growth hormone or other hormonal effects.
- The combined effects of disuse, overuse, pain, weight gain or other illness.

Management of Post Polio Syndrome

There is no medical or pharmacological treatment of choice for PPS but there are many ways of managing polio-related difficulties, which should be symptom specific and involve a multidisciplinary team.⁸ A well informed general practitioner may be at the hub of this team which may include the following disciplines:

- Neurology.
- Physiotherapy.
- Occupational Therapy.
- Speech and Language Therapy.
- Respiratory medicine.
- Chiropody/Podiatry.
- Counsellors/psychologists.
- Dietetics.
- Pain specialists.
- Social workers.
- Nurse specialists.
- Orthotists.

The three main symptoms which need evaluation, treatment and

monitoring are muscle weakness, fatigue and pain.⁹ Other problems which require specific care and management are dysphagia and speech problems, which must be referred to a speech and language therapist.

Sleep disturbance is very common and sleep apnoea is more common in polio survivors than in the general population, even in those who did not have bulbar polio. This may be evaluated by a respiratory physician in a sleep laboratory. Continuous positive airway pressure (CPAP) using nasal or oral, or intermittent positive airway pressure (IPAP) at night may be used to improve oxygen levels and reduce symptoms of fatigue. This may be the case for a small number of people who did not require assisted ventilation during their acute attack of polio but who may have scoliosis or COPD or some other biomechanical problem affecting respiration.

Joint and limb deformities may require evaluation and sometimes treatment by an orthopaedic surgeon; collaboration between a physiotherapist and an orthotist may improve gait, control flexible conditions and rigid deformities with suitable orthotics.

The role of the occupational therapist (OT) is vital in assessing a patient's ability to perform activities of daily living and move about their home or work place. The OT will evaluate activities which cause pain and fatigue and will suggest the need for special equipment or adaptations to the environment. OTs will advise ways to avoid fatigue of muscles in line with the overuse theory.

Pharmacology

The physician should be aware that some drugs may aggravate the symptoms of PPS.

Benzodiazepines and beta-blockers are contraindicated; certain antiepileptic drugs such as phenytoin are also to be avoided.¹⁰ With regard to pain relief, caution must be observed when prescribing opiates which may precipitate respiratory depression.

Anaesthetists should be made aware of the special needs of people who are polio survivors: Smaller doses of anaesthetic agents may be required than in the general population and the same is true for the doses of muscle relaxants used in general surgery.

Management Programme

The secret of developing a truly holistic and multidisciplinary approach to PPS is to create an individual management plan for each person with PPS. The detailed descriptions of the physiotherapy management, the occupational therapist's role and the language and speech therapist's role which are included in this handbook, demonstrate the basis on which a polio survivor with PPS can be assessed and treated as an individual with very unique symptoms and problems. The goal of this management is to reduce pain and other unpleasant symptoms, increase and preserve mobility and enhance the person's potential to live an independent life at home, and at work.

The general practitioner should play a coordinating role with other specialties and deal with medical problems such as heart disease, osteoporosis and age related illness; but the physiotherapist, the occupational therapist and the speech therapist are usually the key professionals actively working with the person with PPS. A lifelong relationship with physiotherapy and occupational therapy is essential.

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OCCUPATIONAL THERAPY AND POST POLIO SYNDROME

Geraldine Foley and Róisín Nolan

Introduction

Approaches to the treatment of the late effects of disability have become increasingly multidisciplinary and occupational therapists are included in healthcare provision for persons with post polio syndrome.^{1,2} Occupational therapy has a long tradition of working with persons with disabilities and of facilitating adaptive outcomes in their daily living.³

Occupational therapists are concerned with how persons engage in purposeful occupations in the performance of activities of daily living, work/productivity and leisure activities.⁴ Occupational therapists seek to work from a client centered philosophy. This approach addresses the physical, psychological and social aspects of care and involves a collaborative process between clients, their significant others and healthcare providers in order to promote client participation, client decision making, exchange of information and respect for client choice.⁵

Occupational Therapy and Post Polio Syndrome

Occupational therapists help persons with post polio syndrome to modify their lifestyles in order to continue to perform activities that are most valued to them.⁶ Optimum function is best achieved through learning and using new skills and/or modifying existing life skills to accommodate for the residual and/or late effects of polio.⁷

Studies have shown that purposeful activity in many areas of occupational performance may be affected by the late effects of post polio including activities of daily living, work activities and leisure activities,^{1, 2, 8-13} which in turn affect quality of life.¹⁴ Personal care and mobility are considered primary components of activities of daily living. Work and

productive activities relate primarily to performance in the areas of home and job management. Leisure activities commonly include recreational activities and pursuits. It is often the case that leisure activities become a low priority for persons with post polio syndrome as reduced energy levels may be focused towards maintaining independence in essential activities of daily living.⁹ In addition, healthcare provision may not adequately address this component of occupational performance.

Performance Components affected by Post Polio Syndrome for Occupation

The common physical symptoms referred to as post polio syndrome include:

- fatigue,
- weakness,
- muscle atrophy, and,
- joint or muscle pain

and are seen in those who have a residual deficit from their paralytic poliomyelitis.¹⁵ In addition, persons with post polio syndrome may also demonstrate a number of psychological and social problems in relation to living with the chronic effects of post polio syndrome.¹ An occupational therapist seeks to address all performance components of occupational performance including both the physical, psychological and social effects of living with post polio.

The physical components addressed by occupational therapists include:

- range of motion,
- muscle strength, and
- endurance.

Limitations in these physical components may indicate the need for the provision of specific assistive devices, adaptive techniques and/or the implementation of energy conservation guidelines to optimise performance in activities of daily living.

Occupational therapists are primarily concerned with upper limb function for promoting independence in every day activity. Upper limb function is often impaired in the late effects of post polio. In addition, research has shown that post polio survivors with lower extremity weakness are at risk of developing upper extremities conditions such as arthritis and shoulder over-use secondary to long term use of manual wheelchairs and crutches.¹⁶ Hence, by evaluating how a person with post polio mobilises and uses assistive devices determines the type and use of appropriate aids and appliances.

Social and psychological responses to the chronic nature of post polio syndrome are also addressed by occupational therapists. Wenneberg & Ahlstrom¹⁷ found that post polio survivors demonstrated anxiety about the prospect of increased dependency on others. Westbrook & McIlwain¹ found that coping patterns that involved lifestyle and personal changes were more effective than coping styles which focused on symptoms and attempting to maintain previous activity levels. Hence, it is critical for occupational therapists to evaluate how psychosocial responses of persons with post polio to their changing health status affect their participation in all areas of occupational performance.

Areas of Occupational Therapy Intervention for Persons with Post Polio Syndrome

Occupational therapy healthcare provision for persons with post polio syndrome in recent years has been diverse,⁶ and intervention is most effective when initiated and accomplished on a gradual basis to facilitate adjustment to the effects of post polio.⁵ The most common areas of intervention include the following.

Energy conservation and work simplification

An occupational therapist incorporates knowledge of the following:

- person's daily routine,
- work demands,
- adaptive devices,

- home modifications and,
- assistive technology,

in order to reduce energy expenditure in every day activity.

An energy conservation program has been developed that includes education on:

- the neuropsychological basis of fatigue in post polio syndrome,
- the causes of excessive fatigue and,
- techniques to implement energy conservation.¹⁸

An energy conservation program may be used as a format for education about energy conservation and work simplification with persons with post polio.

Upper limb splints and orthoses

The provision of appropriate upper limb splints and orthoses is a focus of occupational therapy intervention.⁵ Upper limb splints and orthoses are used to support:

- weak joints,
- conserve joint integrity and,
- reduce pain caused by poor upper limb positioning and strain.

A mobile arm support is often used for polio survivors with severe upper limb proximal weakness. It is attached to a chair or wheelchair and has a ball-bearing hinge joint at the elbow with a forearm gutter.¹⁹ Provision of upper limb splints and orthoses remains dependent on adequate guidance on correct joint positioning, correct body posture and prescribed upper limb functional exercises in the context of prescribed periods of rest and work.

Assistive technology and adaptive equipment

Assistive technology is defined as any item of equipment or product, modified or customised, that is used to maintain or improve functional capabilities of persons with disabilities.²⁰ Assessment for assistive devices remains for the most part with occupational therapists. Kling *et al*² found that many polio survivors needed various technical aids to perform mobility related activities such as dressing, showering, toileting and cooking.

Standard aids and appliances for personal and domestic activities of daily living commonly include:

- toilet aids, bath/shower aids,
- recliner chairs,
- orthopaedic chairs,
- profile recliner beds,
- perching stools,
- handrails,
- long handled reachers,
- long handled personal care cleaning devices, and
- meal preparations devices such as adapted bottle and tin openers, electric knives, adapted cutting boards and plate guards.

Interventions that require a higher level of technical support may include home environmental control systems to operate various appliances, lights, phone, computer and Internet systems. In recent years assistive technology that requires increasing levels of technological support has become an area of specific expertise.

Occupational therapists may work as part of an assistive technology advisory team in the assessment for assistive technology support systems. In Ireland, the Clients' Technical Services of the Central Remedial Clinic, Dublin provides an assistive technology needs assessment for persons with varying degrees of disability. This service is a public health service and generally requires a referral from a health professional though not always.

Mobility

An occupational therapist is responsible for the assessment of mobility devices that do not include walking aids. This area primarily consists of assessment regarding the need for transit wheelchairs, manual wheelchairs, powered wheelchairs and scooters. Occupational therapists should advise against the use of manual wheelchairs as a primary mobility device and they should not be used as a prescription for exercise.²¹ Research indicates that post polio survivors are experiencing the long term effects of chronic musculoskeletal overuse where upper limb muscle group strength deteriorates at a rate higher than that associated with normal aging.²² McConnell²¹ points out that continuing to use manual wheelchairs remains a contraindication for post polio survivors as it fails to alleviate the chronic musculoskeletal overuse prevalent in post polio syndrome.

Environmental modifications to home area

Occupational therapists are commonly involved in advising persons with post polio on housing and home environmental modifications. Occupational therapists are usually required to assess a person's functional capabilities and the home environment for clients when they apply for a Disabled Persons Housing Grant. This grant is available from the Department of the Environment through local housing authorities and is provided towards the cost of long term home modifications to accommodate for the home occupier's disability.

Long-term modifications should consider appropriate accessibility throughout with emphasis on size and layout, and modifications should be carried out in close consultation with a client. Recommendations usually include advice on appropriate access and on building or converting existing home space to accessible shower rooms, kitchens and living areas. Hospital based occupational therapists' remit does not extend to occupational therapy assessments for Disabled Persons Housing Grant applications. This falls within the remit of community based occupational therapy or alternatively private occupational therapy.

Vocational rehabilitation

Many individuals with post polio syndrome are employed and hence advice and recommendations around workplace modification is a necessary feature of rehabilitation. In addition, the physical and emotional aspects of working whilst living with post polio syndrome may have a substantial impact and many persons with post polio may find themselves needing an occupational change in later life.²³ Occupational therapists may acquire expertise in the area of vocational rehabilitation where advice on appropriate access, ergonomics, assistive technology and adaptive techniques for work activities and/or alternative employment remain the primary focus.

Driving

Persons with post polio syndrome often experience difficulties driving as a result of limb weakness, reduced range of movement and muscle fatigue on prolonged activity. Occupational therapists may be involved in assessment of functional capabilities for driving and commonly refer clients to appropriate services that assess for the specific adaptations required for driving safely and without undue strain.

A driving assessment by a qualified driving assessor or an occupational therapist specifically trained in this area is appropriate for persons with post polio syndrome who are unable to control regular car controls to maintain independence in driving. In Ireland, the Disabled Drivers Association of Ireland and the Irish Wheelchair Association provide a driving assessment service for persons with varying degrees of physical disability. This is referred to as the Motorist Advice, Assessment & Tuition service (MAATS Program). Persons who hold a primary medical certificate are entitled to a number of cost exemptions on adapted vehicles.

Lifestyle changes: coping and adaptation

Persons with post polio syndrome may experience a number of psychological difficulties as illness alters self-perceptions and forces

those with post polio to deal with changing abilities.²⁴ Gordan & Feldman²³ point out that there are a number of strategies to assist persons living with post polio in maintaining functional abilities or in finding ways to accommodate for limitations. These include:

- examining the client's response to their disability and their issues in relation to accepting lifestyle modifications,
- providing knowledge about services available and,
- assisting in implementing lifestyle and work modifications.

Occupational therapists can provide valuable practical assistance, counselling and support in these areas.

Occupational Therapy in the Context of Irish Healthcare

Published literature is scarce on occupational therapy intervention for post polio survivors in the Republic of Ireland where the majority of occupational therapists work in the public healthcare sector. Occupational therapists also work in a private capacity and a listing is available from the Association of Occupational Therapists of Ireland (www.aoti.ie).

In the public health sector, most occupational therapists work in the community or hospital setting, both of which focus on the rehabilitative process for persons with post polio syndrome. Community occupational therapists work within the community care services of the Health Service Executive (HSE) and work from community care centres of the HSE. Clients may self refer to community occupational therapists but the majority of persons with post polio syndrome are referred to community occupational therapists by other healthcare professionals. Access to hospital based occupational therapists usually requires referral from a consulting doctor in the hospital in question.

Both hospital and community based occupational therapists are involved in assessing for aids and appliances. However, aids and appliances can only be provided by community based occupational therapists through community healthcare funds. Provision of appropriate aids and appliances from community services is dependent on post polio survivors having a medical card. Though persons without a medical card are entitled to the assessment for appropriate aids and appliances by

occupational therapists, they are not entitled to the provision of same.

Persons living with post polio may find themselves having to privately fund aids and appliances on recommendations from occupational therapists. While the Department of Health and Children recognises post polio survivors as persons living with a long-term neurological illness,²⁵ persons with post polio syndrome are unable to avail of entitlements under the Long Term Illness Scheme in relation to the provision of aids and appliances from community healthcare services.

Public waiting lists for community occupational therapy intervention are common throughout the Health Service Executive where healthcare services for persons with post polio syndrome remain inadequate.

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PHYSIOTHERAPY AND POST POLIO SYNDROME

Dara Meldrum and Deirdre Fitzgerald

Introduction

Physiotherapy is a cornerstone of management of prior polio and post polio syndrome. There is an increasing evidence base for the effectiveness of physiotherapy in alleviating PPS associated physical problems.¹ Patients with prior polio or post polio syndrome should have access to regular physiotherapy assessment, and treatment should be made available when needs are identified. These needs are likely to change with time, thus patient-centred, lifelong physiotherapy is recommended.

Assessment

A comprehensive and detailed assessment is necessary at the first consultation to establish a baseline from which future changes can be evaluated and a treatment plan developed. An assessment will usually have three components;

- neurological,
- musculoskeletal, and
- cardiorespiratory.

A detailed subjective history should be taken first and important aspects of the subjective history are shown in Box 1.

BOX 1: SPECIAL QUESTIONS IN THE SUBJECTIVE ASSESSMENT.

1. What was the age of the patient at polio onset- Was diagnosis confirmed at the time or at a later date?
2. What was the severity at polio onset- what muscles were affected?
 - Was the patient hospitalised?
 - Was the patient ventilated?
 - Was any surgery performed?
3. What was the course and extent of recovery and what was the patient's functional status at peak recovery?

Questions 1-3 are pertinent to assess the risk of post-polio syndrome. Significant risk factors for developing post-polio syndrome include a longer time since onset, adolescent and adult onset, severe weakness at onset, and a greater functional recovery.

4. What is the patients history of the use of aids and appliances both during the course of recovery and presently? (Patients may have required the use of aids and appliances during the recovery period but discontinued their use). Aids and appliances may include;
 - Wheelchairs, powered or self propelled
 - Gait aids – Walking frames, sticks, crutches
 - Orthotic devices-callipers, splints, braces (see p.33)
5. What, if any, are the patient's new symptoms?
 - Onset
 - Location
 - Type
 - Pain- muscle or joint?
 - Fatigue – differentiate between a subjective feeling of overwhelming exhaustion and need to rest and motor fatigue which is an inability of muscles to maintain maximal activity.
 - Muscle weakness/cramps/fasciculation/atrophy
 - Respiratory problems
 - Breathlessness/Difficulty breathing
 - Difficulty expectorating
 - Sleep apnoea, daytime sleepiness, headache
 - Use of mechanical ventilation
 - Musculoskeletal degenerative changes
 - Intolerance to cold.
 - Falls
 - Alteration in Gait

Neurological

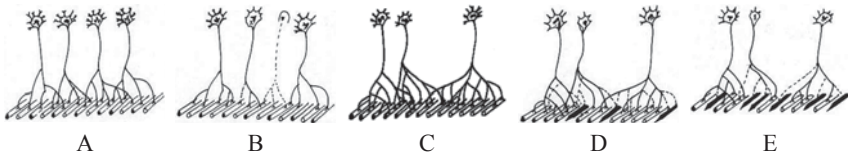
A standard neurological exam should be performed with particular attention paid to skeletal muscle strength. Common findings are summarised below in Box 2 (Although muscle strength is also an integral part of the musculoskeletal examination, it will be considered here). Prior polio patients may have significant weakness as a result of the initial acute illness. Weakness is asymmetrical and can affect different muscle groups within an individual to varying degrees.

BOX 2: NEUROLOGICAL EXAMINATION- POSSIBLE FINDINGS

New weakness in previously affected or unaffected muscles
Decreased muscular endurance
Gait changes
History of falls
Decreased function
Other lower motor neuron signs – decreased tone, reflexes and muscle atrophy

According to the Halstead criteria, the gradual onset of *new* neurogenic weakness in previously affected or unaffected muscles is one of the cardinal symptoms of post polio syndrome.² The gradual decline in muscle strength is thought to result from isolated degeneration of enlarged motor units (see Figure 1 below). However, those not meeting the criteria for post polio syndrome may also experience new weakness as a consequence of disuse, trauma, chronic wear and tear and/or pain. New weakness has been found in 38% to 71% of patients studied, with both previously affected and unaffected muscles involved. This weakness can be progressive^{3, 4} at a rate of 1% to 2% per year.⁵ New weakness manifests as muscle atrophy and decreased mobility, endurance and function. Those who had made a significant functional recovery despite significant weakness can experience a huge deterioration in function on the loss of a relatively small proportion of strength.⁶ Gait may be altered as a result of new weakness⁷ and falling can be a problem, particularly in those who have lower limb muscle weakness.⁸

Figure 1: Diagram showing the neuromuscular effects of polio and post-polio syndrome



- (a) Normal motor units showing healthy motorneurons, their axons and the muscle fibres they innervate.
- (b) Initial polio virus with varying numbers of motorneuron death and denervation of their muscle fibres (dotted line).
- (c) Recovery from polio. Axons from surviving motorneurons sprout new fibres to innervate the denervated muscle fibres.
- (d) Early post-polio syndrome. New loss of nerve fibres and muscle fibre denervation.
- (e) Late post-polio syndrome with further loss of nerve fibres and muscle fibre denervation.

Reduced muscular capacity in prior polio patients leads to a higher relative effort during daily activities and higher requirements of energy expenditure.⁹ The energy cost of walking has been shown to be significantly higher in subjects with PPS than in healthy subjects and is strongly related to the extent of muscle weakness in the lower extremities. PPS subjects can use up to 40% more energy than healthy controls per distance covered.¹⁰

Manual muscle testing using the MRC (Oxford) grading of skeletal muscle should be performed periodically.¹¹ More objective examination of muscle force using a dynamometer or similar device is highly desirable. This provides much more sensitive information and allows more early detection of muscle weakness.¹² Some systems such as isokinetic dynamometers and strain gauge tensiometers also allow detailed examination of muscle endurance (motor fatigue) which may be required if the patient complains of fatigue. Care should be taken when assessing muscle strength not to over fatigue the patient or induce muscle cramp. Also the physiotherapist should pay particular attention to trick

movements that might occur secondary to muscle weakness, and note surgical procedures such as joint fusion or tendon transfers that may have occurred in the past and affect strength testing.

Musculoskeletal

A standard musculoskeletal examination should be performed with assessment of areas of pain identified in the subjective assessment. Range of movement of joints should be recorded objectively and a detailed postural examination performed as deformity can change with time. A detailed biomechanical evaluation should be incorporated as complex biomechanical problems are frequent.

Pain is one of the most commonly described symptoms in prior polio patients with 38% to 86% reporting muscle pain and 42% to 80% joint pain. Risk factors for pain are summarised in Box 3.

BOX 3: RISK FACTORS FOR PAIN

Female gender	Weaker lower extremities
Weaker at time of onset	Younger at time of onset
Higher activity / mobility levels	Higher exertion on activity

Nerve compression syndromes, including carpal tunnel syndrome commonly occur.⁶ Muscle pain (myalgia) is more frequently reported in the lower limbs¹³ and can be due to cramps, fasciculations or muscle overuse. It can occur at rest but is mostly reported on activity.¹⁴ Those with muscle pain have been shown to have higher severity and duration of fatigue, and lower scores on the SF-36.¹⁵ Joint pain can be due to overuse of joints, the use of mobility aids and abnormal biomechanics. Conditions associated with chronic musculoskeletal wear and tear such as osteoarthritis, bursitis, tendonitis and myofascial pain are common. Pain in the legs and low back occurs more commonly in patients who are independently ambulating, while upper limb pain affects those who use crutches or manual wheelchairs.^{6, 16} The shoulders, knees, lower back, and ankles /feet are the most frequently reported sites of pain.¹⁷ Pain is more commonly reported in those with higher activity intensity levels and higher perceived exertion ratings suggesting that polio survivors who are more active experience more pain.¹⁷ Many also experience significant

discomfort due to cold intolerance. The patient will complain that their limbs are cold, and cold exposure produces weakness.

Cardiorespiratory

Reduced pulmonary function results from the virus affecting the medullary respiratory centres, the muscles of respiration and the cranial nerves.¹⁸ It may be compounded by thoracic cage deformity, e.g. kyphoscoliosis, and obesity. As many as 42% of patients with prior polio may complain of new breathing problems.¹⁹

Patients who required ventilatory support at polio onset and those with polio onset after 10 years of age are at higher risk of developing new breathing problems,^{18, 19} and also complain of more fatigue. However, patients who did not require ventilation at polio outset may also develop new breathing problems. One report found that 33% of ambulatory prior polio patients who were free from cardiorespiratory disease and did not have any significant chest wall involvement at the outset of polio complained of shortness of breath, and that those with shortness of breath had a significantly lower percent predicted FEV1 and FVC.¹⁸ A patient's cardiorespiratory status may appear normal at rest, but impairment cannot be ruled out unless formal exercise testing has been carried out.^{18, 20}

The cardiorespiratory assessment should include a careful history, measurement of peak flow, oxygen saturation, and interpretation of the results of pulmonary function tests.

In patients complaining of fatigue, morning headache, sleep disturbance, difficult arousal, daytime somnolence, impaired concentration, memory and irritability, chronic alveolar hypoventilation and sleep apnoea should be suspected and patients referred to respiratory specialists.²¹

Forced expiratory techniques such as coughing and huffing to assess a patient's ability to expectorate secretions effectively should be assessed. In patients who are using ventilatory support, physiotherapists may be involved in assessing the patient's and/or carer's ability to apply and manage equipment. Ventilatory support may be in the form of oxygen therapy, non-invasive positive pressure ventilation (oral, nasal or combined), or in extremely rare cases, negative pressure body ventilation (the iron lung).

Cardiorespiratory endurance can be assessed subjectively by asking the patient how far they can walk without getting breathless or with the Physiological Cost Index.²² Formal exercise testing can be performed where specialised equipment is available.⁹ The American College of Sports Medicine's²³ recommendations for exercise testing of patients with prior polio and post polio syndrome are shown in Box 4.

**BOX 4: THE AMERICAN COLLEGE OF SPORTS MEDICINE'S
RECOMMENDATIONS FOR THE EXERCISE TESTING OF PATIENTS WITH PRIOR
POLIO AND POST POLIO SYNDROME.**

Optimally utilise available muscle mass.
 Avoid use of a painful and/or recently weakened limb during an exercise test.
 Use equipment that does not require complex motor co-ordination.
 Use submaximal exercise tests (elicit at least a "somewhat hard" rating of perceived exertion and terminate testing when the "hard" rating of perceived exertion is reported (24,25).

Mobility

A detailed assessment of transfers and mobility including gait analysis should be carried out as the majority of post polio patients complain of difficulty mobilising and going up stairs. Walking speed will probably be significantly slower. Spontaneously chosen walking speed is much closer to maximal walking speeds in prior polio subjects compared with healthy controls, indicating that prior polio subjects may perform daily activities at close to maximal capacity.¹⁴

Some of the more common biomechanical abnormalities in post polio are detailed in Box 5.

BOX 5: COMMON BIOMECHANICAL DEFICITS IN POST POLIO ^(27,7)

Genu Recurvatum.
 Knee flexion contracture.
 Inadequate dorsiflexion in swing.
 Dorsiflexion collapse in stance.
 Genu valgum.
 Mediolateral ankle instability.

Gait analysis should include an evaluation of any orthoses or callipers to ensure correct fit, state of repair and suitability. Orthoses that were prescribed years ago may no longer be suitable for the patient and new orthoses have the potential to improve gait, decrease the energy cost of walking,²⁸ and subjectively improve the ability to walk.²⁹ It is imperative that the physiotherapist liaise with the orthotist or prothesist in this instance. Gait aids should be frequently assessed for wear and tear and metal fatigue and replaced where necessary. The physiotherapist may need to liaise with the Occupational therapist with regard to the need for provision of a wheelchair.

Carers

A meeting with carers is recommended to assess carer need and perhaps provide additional information pertinent to the patient. Of particular importance is the assessment of carer manual handling skills where there is a higher level of patient dependence.

Outcome measures

The following outcome measures have been used in research involving post polio patients and may be of use in assessment.

- The Rivermead Mobility Index.³⁰
- Dynamometry, Maximum voluntary isometric contraction (MVIC) or isokinetic dynamometry.³¹
- Timed walk.²⁶
- Physiological Cost Index.^{22, 32}
- Nottingham Health Profile.³
- Visual analogue scales for pain and fatigue.¹⁷
- Fatigue severity scale.³³
- Short-Form Health Survey (SF-36).^{15, 34}
- The Piper fatigue Scale.³⁵

Physiotherapy Management

Management of New Weakness

The management of the new weakness in the post polio population with exercise has been controversial. Some early case reports (1915-1957) suggested that exercise resulted in further damage to already vulnerable motor units and resulted in increasing weakness. Other early studies (1948-1966) found, however, that progressive resistive exercises produced improvements in muscle strength.³⁶

Recent studies have found that appropriate, carefully monitored, exercise programmes can be of benefit to prior polio patients.^{16, 37-41} One randomised controlled trial found an improvement in voluntary strength of the thumb muscles after 12 weeks of moderate intensity training 3 times per week. Moreover, it was found that training did not impact on the viability of the motor neurons of the trained muscles.³⁸ A study investigating a higher intensity programme, using maximal isokinetic and isometric exercise on a Cybex resulted in an increase in Quadriceps muscle strength and some changes in fibre size.⁴⁰ Two other studies have examined the effect of moderate intensity exercise,^{39, 41} and found overall increases in muscle strength but each of the studies described some individuals who showed a decrease in strength and/or increased pain.

It is recommended that individuals should learn to monitor and manage weakness and fatigue before commencing an exercise programme and that 'additional exercise should be completely avoided in patients who are too weak and fatigued and are already spending most of their energy simply performing activities of daily living'.¹⁶ Furthermore, **muscle overuse**, manifested as an aching on exertion should be avoided and regarded as a warning sign. Recommendations for muscle strengthening are summarised below in Box 6.

Box 6: GUIDELINES ON THE USE OF STRENGTHENING EXERCISES

<p>Prior Polio subjects can increase muscle strength with appropriate individualised exercise programmes</p> <p>An individual prescribed an exercise programme should be monitored for deterioration in muscle strength, increased pain or increased fatigue</p> <p>Individuals should learn to monitor and manage weakness and fatigue prior to commencing an exercise programme</p> <p>Muscle overuse, manifested as an aching on exertion should be avoided</p>
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Aerobic exercise

Prior polio individuals have been shown to require greater energy expenditure in everyday activities such as walking and cycling.^{9, 10} Cardiorespiratory de-conditioning of prior polio subjects has been reported especially in those who are non-ambulatory.⁴² Dean and Ross¹⁸ reported an improvement in energy cost and movement economy following modified low intensity (55-70% of age predicted maximum heart rates) aerobic training on a treadmill 30-40 minutes, 3 times a week for 6 weeks.

Management of pain

Management of pain is dependent on the aetiology and aggravating factors present with each individual. It is important to identify the type of pain presenting as described and tailor treatment appropriately. Physiotherapeutic management of pain should be cognisant of any pharmaceutical management of pain, e.g. injection or analgesia. Interventions that may alleviate pain are summarised in Box 7.

BOX 7: PHYSIOTHERAPY INTERVENTIONS FOR PAIN MANAGEMENT

Identification of the cause of pain
Modification of activity levels
Weight reduction
Use of aids and appliances to relieve or support weak muscles and joints
Electrophysical agents
Stretching exercises / Strengthening exercises
Postural re-education
Correction of gait problems
Hydrotherapy

Modification of lifestyle and activity levels

Muscular aching and cramping are thought to be as a result of muscle overuse and should be avoided.¹⁶ Reduction in activity levels, regular rest periods (pacing), weight reduction and use of assistive devices can help.⁴³

Activity levels have been shown to correlate highly with pain therefore a reduction may be of benefit. Maintaining a healthy weight is advisable as one study demonstrated that a higher BMI was associated with a higher risk of joint pain.¹⁵ Education about posture and back care may help to minimize aggravating factors.

Appropriate use of aids and appliances

Aids and appliances should be provided with the aim of improving abnormal body mechanics, and correcting and minimising postural and gait deviations mechanically. An appropriate orthosis has been shown to significantly reduce overall pain levels.²⁹ A “comfy” grip crutch may improve the wrist and hand position.

Use of electro-physical agents

Heat has been shown to help to relieve pain.¹⁴ Stretching can be helpful but should be used carefully as particular patients may benefit from shorter muscle length and associated reduced range of movement that improve stability. TENS is also recommended.

Hydrotherapy

Exercise in water is recommended for management of pain in prior polio individuals.¹⁶ Water provides a resistance but minimises stress on muscles and joints. The properties of water allow assisted, resisted or supported exercise, often enabling those limited by weakness on land to exercise with minimal assistance. The heat in hydrotherapy pool may also be beneficial. Prior polio patients who exercised in water for up to 8 months demonstrated a positive functional impact, a subjective positive experience, less pain, and a lower heart rate at a submaximal work level in a controlled trial, lending evidence to this form of treatment.⁴⁴ Hydrotherapy may also result in increased strength without exacerbating fatigue or pain.⁴⁶ It is essential that the individual’s overall physical condition is assessed prior to commencing a hydrotherapy programme.⁴⁵

Management of cardiorespiratory problems

The aims of respiratory care are to avoid hospitalisation, tracheal intubation, and respiratory infections although it should be emphasised that these are rare occurrences.⁴⁷ Chest physiotherapy can be provided to assist with the removal of secretions, and teach manual and assisted cough techniques.¹⁹ There is some research evidence for the provision of inspiratory muscle training in patients already using intermittent positive pressure ventilation.⁴⁸

With regard to increasing cardiovascular endurance there has been little research investigating the effect of exercise programs. One study on hydrotherapy showed that a 40 minute hydrotherapy program, performed twice a week over eight months had the effect of lowering heart rate during submaximal exercise.⁴⁴

Conclusion

In conclusion, patients with prior polio or post polio syndrome present with complex physical problems. Ongoing physiotherapy assessment and treatment are likely to have long-term beneficial effects in maintaining these patients at optimum physical performance.

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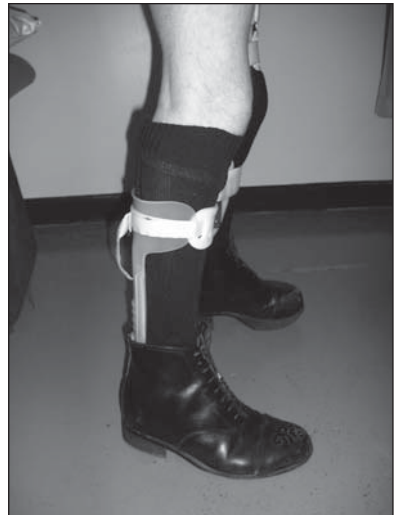
THE ROLE OF THE ORTHOTIST

Brian Kinsella

The role of the Orthotist, is that of biomechanical back up to the clinical team. From the point of view of the person with post polio, the Orthotist provides orthoses (splints). These include insoles to persons' shoes, foot orthoses, ankle-foot orthoses (AFO), knee ankle foot orthoses (KAFO) (short or long callipers), and spinal jackets. In some cases, orthopaedic footwear is also prescribed.



Example of a knee-ankle-foot orthosis (KAFO) worn with a custom made shoe



Example of an ankle-foot orthosis (AFO) worn with a custom made shoe

Old style orthoses of sidebars and T-straps are not so common anymore. The majority of AFOs and KAFOs (callipers) are now made to a cast, and use lightweight plastics. These orthoses are normally lighter and fit directly inside footwear. This often means footwear does not have to be adapted and walking is made easier.

The Orthotist, when making orthoses, considers skeletal alignment, joint integrity and ease of walking.

THE ROLE OF THE SPEECH AND LANGUAGE THERAPIST

Ciara McWeeney

Introduction

The most relevant changes brought about by Post Polio Syndrome (PPS) to the Speech and Language Therapist (SLT) are in:

- swallowing²
- voice

There is wide variability in reported prevalence rates of dysphagia³ and dysphonia⁴ for polio survivors, ranging from 20-60%.⁵ It is probable that these changes may relate to residual weakness of the oral, pharyngeal, or laryngeal muscles from the original insult or as a result of further neuronal degeneration associated with PPS that appears with increasing age or continual use of the surviving motor neurons.⁶ It is important to note that clinical experience in Ireland has not significantly supported these high prevalence rates.

This chapter reviews the findings of studies on PPS that relate to swallowing and voice, and provides information on the role of the SLT in the evaluation and treatment of polio survivors who present with these difficulties.

Swallowing

The most frequently used definition of dysphagia is

“difficulty moving food from mouth to stomach”.⁷

Some SLTs have used an alternative definition that expands the meaning of dysphagia to include all of the behavioural, sensory, and preliminary

motor acts in preparation for the swallow. This definition encompasses the cognitive awareness of the upcoming eating situation, visual recognition of food, and all of the physiological responses to the smell and presence of food such as increased salivation.⁸ Accordingly, dysphagia affects the most basic of socio-biological functions – the ability to eat and drink.⁹

Some people who contracted polio during the epidemic of the 1950s are now experiencing increasing muscle weakness, including swallowing difficulties, particularly those who suffered bulbar polio.¹⁰ In addition, these polio survivors may not necessarily have had any swallowing difficulties in their initial bout of polio.¹¹ Some of the signs for dysphagia include:

- unintentional weight loss,
- loss of interest in eating,
- coughing or choking when eating,
- food sticking in the throat, and
- difficulty swallowing tablets.¹²

If one or more of these signs are present, the person should be referred for a more complete swallow examination that may include an instrumental swallowing assessment (e.g. videofluoroscopy (VFSS), flexible fiberoptic examination of swallowing (FEES)). The swallowing difficulties displayed by these polio survivors include:

- unilateral and bilateral pharyngeal wall weakness,
- reduced tongue base retraction, and
- reduced laryngeal elevation resulting in reduced closure of the laryngeal vestibule.¹³

All of these disorders can cause residue to remain in various areas of the pharynx, with the risk of aspiration¹⁴ after the swallow. Often, postural changes selected to match the person's swallow physiology will facilitate a better swallow with reduced risk of aspiration. In most cases, aggressive exercise will fatigue the mechanism rather than strengthen it.¹⁵ Therefore, compensatory strategies¹⁶ are the procedure of choice.

Assessment and Treatment of Swallowing

The clinical swallow examination (CSE) and VFSS¹⁷ are the two most frequently used techniques for swallow evaluation and management.

The CSE typically involves case history, medical note review, a clinical assessment and mealtime observation.¹⁸

VFSS is one of several instrumental procedures designed to assess safety for oral feeding and to determine if there are swallow strategies that may reduce the risk of aspiration. The purpose of these techniques is to examine oropharyngeal physiology during bolus¹⁹ flow from the oral cavity to the stomach. VFSS enables visualisation of the main structures in one image, can follow the bolus from the mouth to the stomach,²⁰ and is non-invasive.

VFSS consists of ingestion of radiopaque substances of various consistencies with concurrent videofluoroscopy. It has two purposes:

- (1) to define the abnormalities in anatomy and physiology causing the person's symptoms, and
- (2) to identify and evaluate treatment strategies that may immediately enable the person to eat safely and/or efficiently.²¹

VFSS is designed to assess not only *whether* a person is aspirating, but also *why*, so that appropriate and efficient treatment can be initiated.

The SLT should take the opportunity during VFSS to examine the effectiveness of at least some of the treatment options that fit the polio survivor's swallowing difficulties.

In general, the introduction of treatment strategies begins with the use of postural techniques, followed by swallow manoeuvres, and finally, diet changes if necessary. The rationale for this sequence of interventions is based on the muscle effort required by people and the ease of application and learning of the various procedures.

Postural techniques are easily used, even for those with some degree of restricted mobility and have been demonstrated to effectively eliminate aspiration on liquids and other foods. Postural techniques redirect food flow and change pharyngeal dimensions.

Swallow manoeuvres, on the other hand, require ability to actively follow directions and voluntarily manipulate the oropharyngeal swallow as it is ongoing.

Another less widely used and less available imaging instrumentation procedure that provides information on swallow physiology and the bolus as it is being swallowed is FEES. This requires the transnasal passage of a flexible laryngoscope into the hypopharynx. Food and liquid are presented, the ensuing events observed and therapeutic interventions applied.²² Individuals are examined in postures typical of those in which they normally eat. This is important as posture has a significant effect on swallowing ability.²³ It should not replace VFSS because the oropharynx cannot be observed with this method and is indicated when laryngeal dysfunction is suspected.²⁴ A complete CSE must precede an instrumental examination. The SLTs ability to infer findings from the CSE and also the projection of possible findings directs the choice of technique.²⁵ It is important to choose the instrument that provides a field of view that reveals the most salient findings.

The problems associated with eating, drinking and swallowing are managed on a case-by-case basis, dictated by the findings of all examination procedures. Throughout the course of the disease and at every SLT review, the polio survivor should be counselled regarding the findings and the likely prognosis for progression. Problems should be anticipated and supportive measures employed to obviate complications such as aspiration, inadequate nutrition, and dehydration.

Multidisciplinary management of dysphagia ensures that individuals receive careful, in-depth assessment and treatment/rehabilitation of their swallowing disorders, and of their underlying aetiology. Members of the team usually include a combination of the following: the SLT, GP, radiologist, otolaryngologist, neurologist, nurse, pharmacist, dietician, occupational therapist, and physiotherapist. Respect for each other's expertise and good communication between members of the team are crucial to success.²⁶

Voice/Speech

A small number of polio survivors (again, prevalence data that is reported in the literature is variable) present with hypernasality, soft speaking voice, intermittent dysphonia, and hoarseness.²⁷ Dysphonia, if it occurs, is sometimes treated with voice amplification devices.²⁸ A SLT will be

able to give advice regarding the most suitable amplification device for the individual.

Conclusion

Polio survivors who have new or progressive swallowing and/or voice difficulties should be referred to their local speech and language therapy service for appropriate evaluation, treatment and follow-up. SLTs are based both in hospitals and health centres. There is also a number of SLTs working in private practice (see Irish Association of Speech & Language Therapists website).¹

The role of the medical team in patient education is critical. Although there is no cure, individuals and their families need information in order to make appropriate decisions about their care. There is also a need for appropriate staging of intervention, that is, sequencing of management so that current problems are addressed and future problems anticipated. This staging should be based on knowledge of disease progression and provision of that information to polio survivors and their families in a timely fashion. A balance must be struck between providing intervention too early - before the individual is ready – and providing the intervention too late – when secondary complications have arisen. Finally, degenerative disease is not synonymous with loss of hope. It is the task of the multi-disciplinary team to be honest, realistic, and hopeful as our patients and their families cope with the day-to-day challenges they face.

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- 2 Refers to the entire act of swallowing from placement of food in the mouth until the material enters the stomach.
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- 13 J Logemann, *Evaluation and Treatment of Swallowing Disorders* (2nd ed., 1998, Texas: PRO ED).
- 14 When food or liquid penetrates the airway below the vocal folds; aspiration can occur before, during, or after the pharyngeal response
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- 19 The food, liquid, or other material placed in the mouth for swallowing.
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APPENDIX 1

POLIO SURVIVOR INFORMATION

THE LATE EFFECTS OF POLIO

Do any of these sound familiar?

- Muscle and joint pain?
- Lack of strength and increased muscle weakness?
- Extreme fatigue?
- Breathing problems often related to difficulty sleeping?
- Swallowing problems?
- Severe intolerance of cold?
- Decline in ability to enjoy everyday activities such as walking?

If you have one or all of these symptoms, you may be suffering from the Late Effects of Polio, which may be subsequently diagnosed as Post Polio Syndrome, an internationally recognised and researched medical condition. The effects can be debilitating but there are a number of ways in which you can manage your condition, and that is where the Post Polio Support Group can advise and help.

Since the 1960s, new cases of paralytic polio have been extremely rare in Ireland. But there is a whole generation of Polio Survivors for whom the legacy of their polio is being felt many years later.

The Post Polio Support Group

The Post Polio Support Group has a variety of programmes to assist Polio Survivors in coping with their condition. These include the supply of Aids & Appliances and Assistive Technology, and Services, such

as; Physiotherapy, Occupational Therapy assessments, Counselling, Chiropody, Respite Care, Building Adaptions and others. The Group publishes information booklets, both for the medical profession and survivors, and you can access information from the Group's newsletter and website. The Group continues to look at new ways to improve assistance to Polio Survivors.

The Post Polio Support Group is here to support you. It can put you in touch with other Polio Survivors through local social support meetings, area meetings, annual general meetings, as well as seminars, conferences and other events. There are more than 7000 Polio Survivors in Ireland. Around 60% of survivors may be experiencing the Late Effects of Polio (Post Polio Syndrome).

Medical Advice

Polio Survivors concerned about the Late Effects of Polio should contact their Doctors for advice or referral to a Consultant. There may be an appropriate Neurological Consultant in your area. The Neuromuscular Clinic in Beaumont Hospital, Dublin, has assessed survivors over many years. Neurological clinics have been planned for other locations in the future.

What can you do to manage it?

Be strong, at the moment there is no cure for what you are going through, though there are a lot of things you can do to maintain your lifestyle -- with a lot of resolve from yourself and a little help from us. You will have to make changes but the results will make it worthwhile:

- **Energy Management** — Strike the right balance between rest and activity.
- **General Health** — Give your body the best chance it can have by living healthily.
- **New Aids** — New lighter callipers and other aids may make your life easier for you.
- **Greater Care** — Always seek professional advice before taking

prescription or over the counter medication or remedies.

- **Specialist Treatment** — From Physiotherapists, Occupational Therapists, Speech Therapists, Orthotists, Counsellors, Chiropodists, and others.
- **Specialist Consultations** — with Neurological, Orthopaedic, Rehabilitation and Respiratory Consultants, amongst others.
- **Psychological Support** — From Psychologists and professional Counsellors.
- **Peer Support** — Other Polio Survivors can be of great assistance to someone coping with the Late Effects of Polio. The Post Polio Support Group enables this effectively.

Make sure that you and your family understand the problems associated with the Late Effects of Polio and how it can be managed. Work with them and the professionals you may be referred to, as you continue to enjoy life and keep the independence you have fought so hard to attain. The supports are there for **YOU!** Make sure **YOU** use them to the full!

Contact

Post Polio Support Group,
Unit 319 Capel Building,
Mary's Abbey,
Dublin 7.

Tel (01) 889 8920.

Fax (01) 889 8924.

E-mail info@ppsg.ie.

Web www.ppsg.ie.

Registered Charity No 11356.

I wish to enquire about membership of the Post Polio Support Group

Name _____

Address _____

Tel No _____

E-mail _____

Please return to

Services & Information Co-ordinator,
Post Polio Support Group,
Unit 319 Capel Building,
Mary's Abbey,
Dublin 7.

Registered Charity No 11356.

APPENDIX 2

QUANTIFYING THE AGE PROFILE OF THE POLIO SURVIVOR POPULATION

REFERENCED TO JANUARY 2006

More than 7,000 members of the Irish public survived infection with paralytic poliomyelitis. Theoretical studies based on epidemiological data indicate that up to 60% of these are suffering or will suffer from the Late Effects of Polio.

Analysis of a sample of the Polio Survivor population drawn from the membership database of the Post Polio Support Group indicates that the age spread of the Polio Survivor population is as follows, based on indicated dates of birth

Date of Birth¹	
before end 1929	5%
after 1930 and before the end of 1939	16%
after 1940 and before the end of 1949	31%
after 1950 and before the end of 1959	23%
after 1960 and before the end of 1969	3%
after 1970	2%

The size of the Polio Survivor population, based on the above data and distributing those not replying proportionately throughout, should be as follows with numbers of those likely to display Post Polio Syndrome shown in brackets;

¹ 20% did not state dates of birth. Non traditional Irish surnames predominate with dates of birth since the mid 1960's. The Post Polio Support Group data may not reflect the age distribution of the broad Polio Survivor group.

Aged over 76	437	(262)
Aged over 66 but less than 76	1400	(840)
Aged over 56 but less than 66	2638	(1583)
Aged over 46 but less than 56	2013	(1208)
Aged over 36 but less than 46	262	(157)
Aged less than 36	175	(105)

APPENDIX 3

POST POLIO SYNDROME WEBSITE LINKS

The following websites may be of interest to those wishing to learn more about the condition;

Post Polio Support Group, Ireland.

The Group sets up linkages between Polio Survivors so that no one feels isolated or alone. The Group provides support programmes and raises funds to help it to continue a high level of support to Polio Survivors. In particular, there is a focus on the provision of aids, appliances, therapy services and other services which promote the dignity of Survivors and assist them to live independent lives.

www.ppsg.ie

Lincolnshire Polio Network.

Extensive information service for Polio Survivors and Medical Professionals, and offers an expanding catalogued library of full text articles on Post Polio Conditions plus resource directories and newsletters.

www.ott.zynet.co.uk/polio/lincolnshire/

Post-Polio Health International USA.

Information source for Polio Survivors, Ventilator Users and Medical Professionals. Publishers of Post-Polio Health and Ventilator Assisted Living.

www.post-polio.org/

National Institute of Neurological Disorders & Strokes

Information page for Post Polio Syndrome (PPS): Description, Cause, Diagnosis, Treatment, Exercise etc.

www.ninds.nih.gov/disorders/post_polio/detail_post_polio.htm

British Polio Fellowship

Information about this British Polio Survivor support group. Post Polio Syndrome, Q&A, publications, library, news and message board.

www.britishpolio.org.uk/

PPS CENTRAL - Post Polio Related Info on the Internet

Search or browse this comprehensive listing of PPS [post polio, post polio syndrome] internet resources, original papers, surveys and polls.

www.skally.net/ppsc/

POLIO ERADICATION WEBSITE**WHO (World Health Organisation)**

Information on the Global Polio Eradication Initiative

www.polioeradication.org/

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POST POLIO SYNDROME

MANAGEMENT AND TREATMENT

IN PRIMARY CARE

This publication is an initiative of the Post Polio Support Group. It is designed to promote a professional partnership in the support of the Polio Survivor and hopes to facilitate the multidisciplinary and holistic approach that he or she should expect at primary care level

It is aimed at those providing medical care to the Polio Survivor and aspires to inform the various practitioners that are actively managing and treating the survivor's condition.

Many Polio Survivors are experiencing the debilitating effects of Post Polio Syndrome years after their initial infection causing.....

*muscle bone and joint pains muscle weakness extreme fatigue
breathing problems often related to sleeping difficulty swallowing
problems severe intolerance of cold a general decline in mobility*

The Post Polio Support Group acknowledges with thanks the support it has received to produce this publication in particular the professional work of the voluntary writing team and the financial backing of the Health Service Executive

Mission Statement

“Our Mission is to create awareness and to provide information regarding the late effects of polio among Polio Survivors, statutory agencies and the wider medical profession, and to ensure that the needs of Polio Survivors relating to their condition are met to enable them to live with dignity”

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This publication is an initiative of Polio Survivors Ireland. It is designed to promote a professional partnership in the support of the polio survivor and hopes to facilitate the multidisciplinary and holistic approach that he or she should expect at primary care level. It is aimed at those providing medical care to the polio survivor and aspires to inform the various practitioners that are actively managing and treating the survivor's condition.

Many polio survivors are experiencing the debilitating effects of Post Polio Syndrome years after their initial infection.

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Mission Statement:

We address the diverse needs of polio survivors, advocating for them, educating healthcare professionals, and providing a comprehensive range of person-centred services and supports.