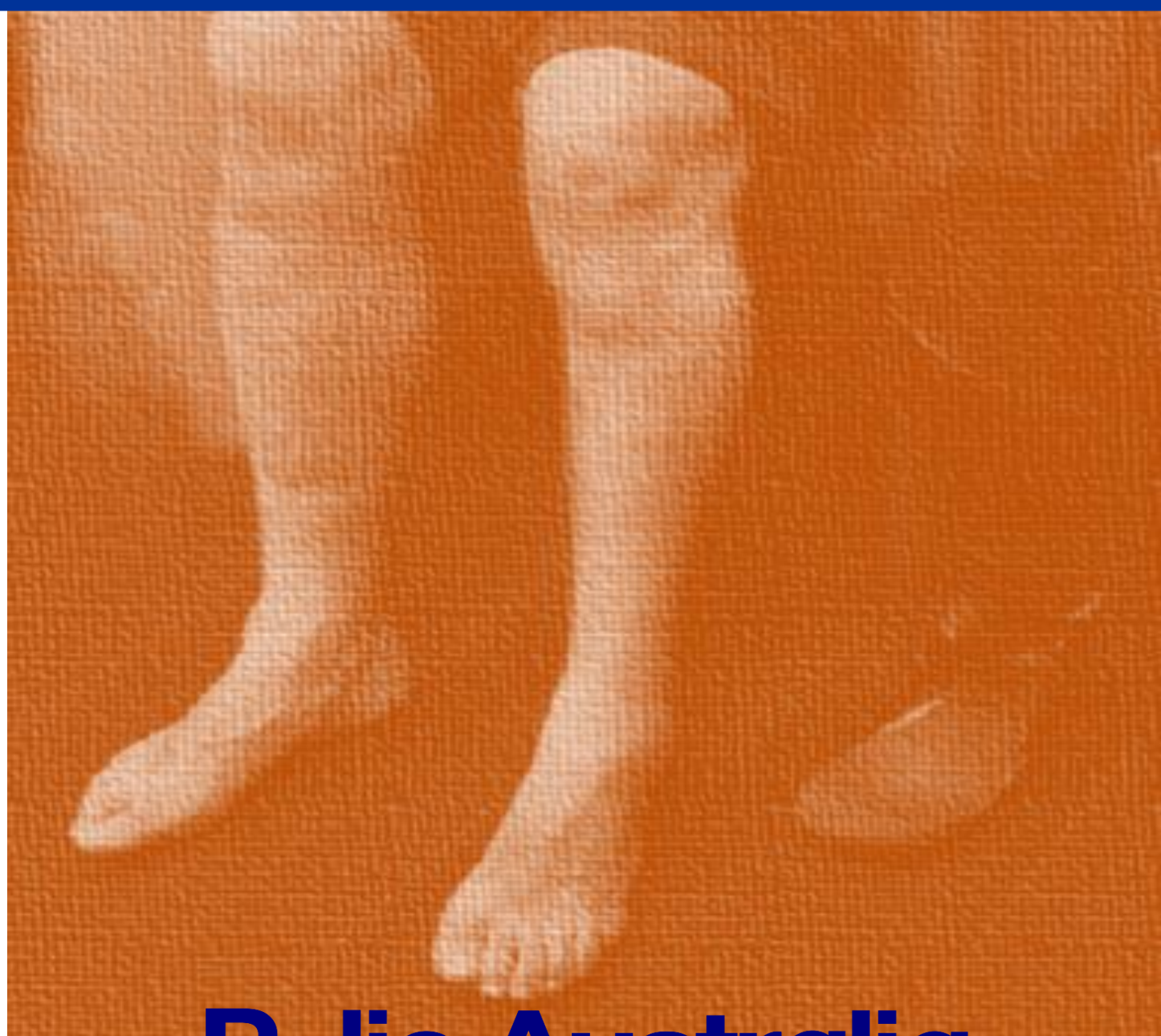


The Late Effects of Polio
MANAGING MUSCLES
AND MOBILITY

Clinical Practice For Health Professionals



Polio Australia
Representing polio survivors throughout Australia

www.poliohealth.org.au

Published by Polio Australia Incorporated
PO Box 500 Kew East Victoria Australia 3102
www.polioaustralia.org.au / www.poliohealth.org.au
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ISBN 978-0-9874392-1-5

ACKNOWLEDGEMENTS

Polio Australia's clinical practice module project has been many years in the making. A number of telephone conference discussions between members of Polio Australia's [Clinical Advisory Group](#) throughout 2011 worked up the concept and decided what should be incorporated into a practical resource series for managing the Late Effects of Polio (LEoP) / Post-Polio Syndrome (PPS). However, the project's progress has been slow because of a lack of financial backing. Polio Australia receives no government funding, nor were we able to secure any philanthropic project grants for this work. Understandably, there is only so much time busy health professionals can contribute on a pro-bono basis.

In 2012, Polio Australia was able to launch the first of the series – a clinical practice 'overview' module titled *"The Late Effects of Polio: Introduction to Clinical Practice"*, thanks to GSK Australia's medical team, who took it on as a volunteer project. This overview was a compilation of LEoP / PPS symptoms and general explanatory notes, resourced from work produced by international experts. It proved to be a valuable resource, especially for polio survivors who were able to share a printed copy with their treating health professionals and/or direct them to the [online version](#).

In early 2014, Polio Australia was approached by a private donor (who wishes to remain anonymous) looking to contribute to a discreet project. The donor agreed that *"The Late Effects of Polio: Managing Muscles and Mobility"* would be a worthy investment.

We were then able to engage one of our Clinical Advisory Group members, [Dr Natasha Layton](#) (OT), to work on producing this resource. As a seasoned researcher, and proponent of evidence-based practice, her approach was based on:

- Rapid evidence reviews of the literature.
- Using methods to seek out, evaluate and privilege 'practice wisdom', that is, evidence and knowledge which is not contained in the refereed literature.

- Use of inclusive methodologies to embed the consumer experience and consumer-valued outcomes in any research endeavour.

To create this resource, Natasha worked closely with a Clinical Reference Group comprising:

- [Ann Buchan](#), Neurophysiotherapist, Unley Physiotherapy, South Australia.
- [GM Jegasothy \(Jega\)](#), Senior Physiotherapist, Western Australia.
- [Melissa McConaghy](#), Director and Principal Physiotherapist, Advanced Rehab Centre, New South Wales.
- [Margaret Petkoff](#), Occupational Therapist, Polio Services Victoria.
- [Louise Thomas](#), Principal Physiotherapist, Neuromuscular-Orthotics, Victoria.
- [Dr Mary Westbrook](#), Psychologist (Ret), Fellow of the Australian Psychological Society, New South Wales.

A number of people from the post-polio community also contributed as *"Lived Experience Experts"*, providing valuable insights into the practicalities of living and coping with their chronic condition.

Polio Australia's [Kristy Rackham](#) (Registered Nurse, Health Education and Public Relations Consultant), was then tasked with editing and formatting the document, spending untold hours getting it print-ready. Additional content, editing, and proofreading were provided by [Gillian Thomas](#) (Vice President), and [Mary-ann Liethof](#) (National Program Manager).

Polio Australia would like to acknowledge and sincerely thank everyone who contributed to *"The Late Effects of Polio: Managing Muscles and Mobility"*.

The combination of skills, knowledge, experience, wisdom and energy has resulted in a rich and seminal resource that we can all be proud of. Most significantly, this module achieves its purpose of being a comprehensive, 'go-to' resource for Australian health professionals.

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FOREWORD

The opportunity of sharing strategies to assist survivors of poliomyelitis is a fundamental tenet in rehabilitation practice. This publication is a must read for all polio survivors and their treating team and carers.

The life journey of the polio survivor is a fascinating story of beating the odds, taking on new challenges and succeeding, and then, ultimately in later years, having to come to terms with increasing functional limitations but not wanting to give up the fight to remain as independent and autonomous as possible.

Our understanding of the pathophysiology of poliomyelitis and its late effects has improved significantly over the past two decades. It is clear that the combination of extra stresses on joints and muscles along with motor nerve decline (a little quicker than the ageing process) contribute to the three most common symptoms: fatigue, pain and weakness. These symptoms can be quite debilitating and it is essential that the polio survivor is given every opportunity to manage these symptoms and maintain a satisfactory lifestyle.

In the past, polio survivors were advised not to exercise in the fear that exercise may make their condition worse and even lead to significant harm. Fortunately, we now know that this is not the case. A sensible balance of prescribed exercise and recovery time incorporated into daily life along with appropriate physical and emotional support, ergonomic set-up and pacing can allow the polio survivor to continue to have a fulfilling life.

"Late Effects of Polio: Managing Muscles and Mobility" has been written by experts in the field of Neurological and Musculoskeletal Rehabilitation. It is an extremely well-constructed and focussed manual that will assist in the goal of keeping all polio survivors as mobile and independent as possible.

It is a privilege to write this Foreword and I encourage you to make the most of the opportunity to incorporate the principles espoused in this publication into the life of the polio survivor.

Dr Stephen de Graaff
Consultant Physician in Rehabilitation Medicine
Senior Rehabilitation Physician
Epworth HealthCare

CHAPTER 1: ABOUT THIS MODULE

Introduction

Polio Australia commissioned this clinical practice module for health professionals to inform the broader primary care community about good practice in the management of individuals living with polio, the Late Effects of Polio (LEoP) and/or Post-Polio Syndrome (PPS). The module will also be of interest to those working with individuals with other neurological or musculoskeletal issues, and those living with the late effects of disability.

Many polio survivors who have emerging symptoms still report difficulty in obtaining correct diagnosis and treatment. As time passes, an increasing number of previously 'stable' persons with a history of polio infection report unexpected new symptoms. The large number of survivors who are now experiencing new symptoms has transformed the problem from an individual predicament to one of social concern.

The module's content is drawn from three sources: the contemporary practice wisdom of Australia's current allied health polio specialists; the expert knowledge of those living with polio and its aftermath; and the evidence-based literature.

The framework of the World Health Organisation International Classification of Functioning, Disability and Health (ICF) [1] is used to structure the module, commencing with descriptions of affected body functions and structures, and principles of assessment. Following this, a range of interventions are described including physical treatments, task adaptation, and the use of assistive technologies, environmental interventions

and other supports. The module aligns with the contemporary best-practice drive toward person-centred care and a multidisciplinary approach to client management.

Person-centred care requires individualised goal-setting, tailored supports, and a strong understanding of the psychosocial aspects of adjusting to impairment. It is particularly important to note here that Australians ageing with polio have lived through both institutionalised and rehabilitative approaches to medicine and rehabilitation over the decades [2]. These experiences, not always positive, have influenced coping strategies and attitudes to professional support.

A common thread in the experience of polio and LEoP is that 'lived experience' has not always been acknowledged. The person-centred practitioner respects the 'expert by experience' and engages in collaborative processes with individuals and their families affected by polio, working together to achieve the person's desired outcomes.



Polio Australia

Established in 2008, Polio Australia is a national body governed by a Management Committee comprising representatives from the six State polio networks. Polio Australia is a consumer-founded, consumer-focused, not-for-profit, incorporated organisation representing the hundreds of thousands of Australia polio survivors who are now living with the late effects of polio.

Our Mission

Polio Australia is committed to standardising quality polio information and service provision across Australia for polio survivors. Polio Australia's vision is that all polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed life choices.

The purpose of Polio Australia is to:

- Educate and inform polio survivors, their families and carers, and the community at large, about the late effects of polio.
- Provide information, education and training to General Practitioners and a range of medical specialists and other health professionals to improve the diagnosis and management of the late effects of polio.
- Facilitate the provision of appropriate and consistent health, disability and aged care support services across all states and territories to improve the treatment and management of the late effects of polio.
- Provide outreach to culturally and linguistically diverse and Aboriginal and Torres Strait Islander polio survivors to ensure their diverse needs are being met in a culturally appropriate way.

- Advise governments on policy development and programs in relation to the late effects of polio.
- Stimulate research into the late effects of polio.
- Assist the State networks to support polio survivors and their families, friends and carers at the local level.
- Facilitate and encourage the co-ordination and further development of activities within and between the State networks.
- Support and promote polio immunisation at a national level, and provide assistance to the state Networks to do so at the local level.

There are currently very few health practitioners and/or services knowledgeable in the provision of best practice care for polio survivors. However, those health professionals who have participated in Polio Australia's activities have reported that, as a consequence, they have gained increased understanding and confidence in providing appropriate care for their clients.

Polio Australia's programs are intended to provide the resources that will extend this level of understanding across the range of Australian health professionals who make up the 'post-polio care team'.

An informed health sector will lead to more accurate assessment, diagnosis and management for people experiencing LEOp, with a corresponding decrease in Federal health expenditure.

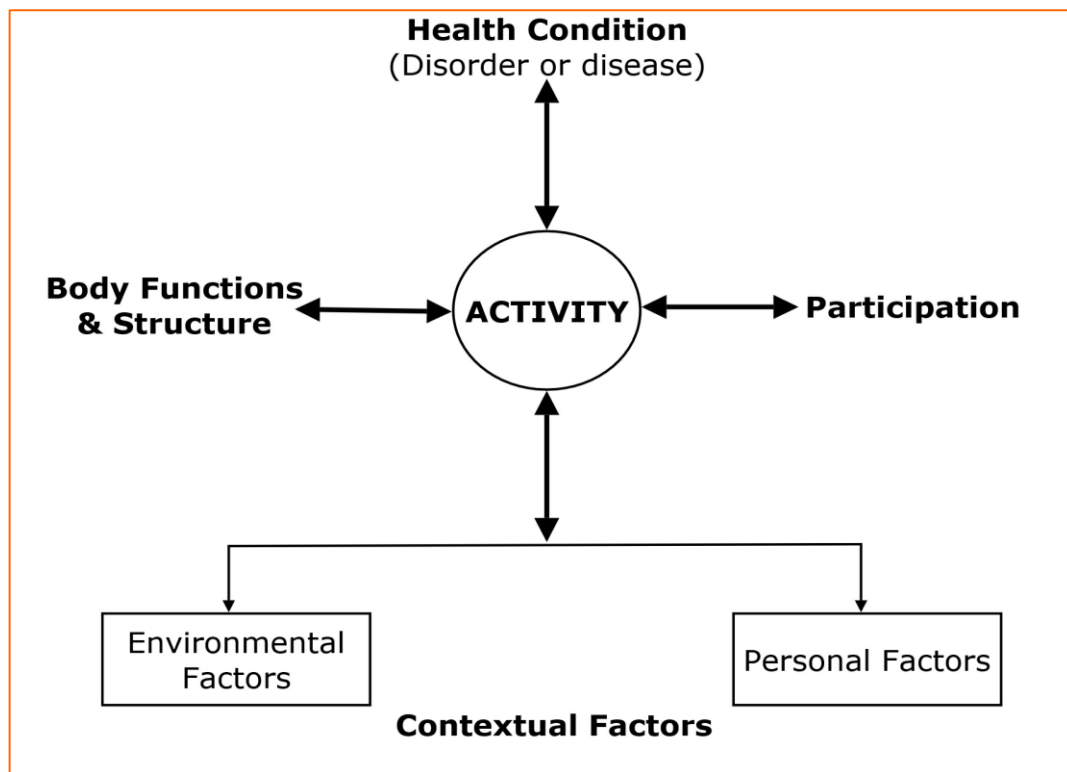


Figure 1: The Relationship of Key Concepts in Functioning, Disability and Health [1]

Module Summary And Structure

The World Health Organisation (WHO) view health as a state of wellbeing, beyond disease or impairment. As can be seen in Figure 1, an individual's function is an interaction between the health condition and contextual factors. Contextual factors include a person's innate features and capacities (known as personal factors), and by their environments. Beyond an 'absence of disease', the WHO enshrine the concept of activities (the execution of a task or action) and participation (involvement in a life situation). This holistic view places the person living with LEOp, and their personal aspirations and goals, at the centre of any assessment or treatment plan.

The Clinical Practice Module is therefore structured to link management of body structure and function issues with valued activities and participations. An important focus is also the range of environmental barriers and facilitators which impact outcomes, such as environmental adaptations, the introduction of assistive devices, and the use of personal support. The resourcefulness and capabilities of people living with LEOp is emphasised through sections on human adaptation to tasks and circumstances, and the voice of 'lived experience experts' throughout the module.

CHAPTER 2: POLIO PATHOPHYSIOLOGY

Background

During the peak epidemics of polio in Australia from the 1930's to the 1960's, significant numbers of Australians experienced paralytic polio (between 20,000 and 40,000 people). This figure must be increased 200-fold [3] to obtain the estimated number of infected cases during the same period. The original epidemic population is now an ageing one, and an increasing number of these individuals are now living with a range of symptoms and chronic conditions which may be attributable to the original polio infection, as well as the challenges of living with the effects of ageing with disability [4,5].

Whilst global polio eradication efforts have been effective in stemming outbreaks, in Australia we are also now seeing recorded incidences of younger people, particularly migrants from developing nations (or non-western nations), who contracted polio overseas. It may be anticipated that with an increasing global community, and ongoing immigration into Australia, in the years to come these people will likely present to

health professionals with various chronic conditions related to their initial polio infection.



Pathophysiology Of The Late Effects Of Polio (LEoP)

Acute poliomyelitis (polio, also known as 'infantile paralysis') is an anterior motor horn cell disease. During the initial acute infection, the polio virus infects spinal motor neurons and/or brainstem nuclei. This results in a widely variable distribution of weakness in skeletal and bulbar musculature, and residual impairment and paralysis ranging from minor muscle weakness to

total paralysis requiring interventions such as ventilation.

After motor-neuron destruction during the acute polio phase, surviving motor-units sprout axons to reinnervate the denervated or 'orphaned' muscle fibres. This process of denervation and reinnervation is ongoing over the muscle lifespan.

As a consequence, polio affected muscles have oversized motor units and increased muscle fibre density. Due to this process, people with LEOp may have experienced a prolonged period of stability of physical symptoms such as weakness and pain, often lasting several decades, before presenting to their primary care provider with what can feel like a resurgence of polio-like symptoms.

LEOp refers to: [6]

- Symptoms that are attributable to damage caused by the original acute poliomyelitis, including such aspects as residual weakness and musculoskeletal imbalance.
- Symptoms attributable to a failure to maintain the level of function achieved following the original acute infection, e.g., new weakness and fatigue (PPS).
- Secondary effects of chronic neuromuscular dysfunction, such as degenerative arthritis in overused joints and soft tissue diseases.

PPS refers to: [7,8]

- The neurologic disorder characterised by a constellation of symptoms including, but not limited to, increased weakness and/or abnormal muscle fatigability occurring many years after the initial polio infection.
- Generally considered a sub-category of LEOp.

It is estimated that up to 70% of people with LEOp will develop PPS. While the onset of PPS may be gradual, it can also be precipitated by trauma such as an accident or illness. The condition usually progresses slowly, yet sudden declines in health status can occur.

Symptoms of PPS are thought to manifest when the compensatory neuronal processes which sprouted following nerve damage

from the initial polio infection can no longer effectively innervate the muscles within their motor-unit territory, resulting in an unmasking of the neurological deficit caused by the original polio infection [9].

Diagnosis Of PPS

Diagnosis of PPS is performed via a process of elimination and is a solely clinical assessment, with no specific tests for the diagnosis of PPS currently available. Current criteria for the diagnosis of PPS [10] include:

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalised fatigue, muscle atrophy, or muscle and joint pain. Sudden onset may follow a period of inactivity, or trauma or surgery.
- Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.
- Symptoms persist for at least a year.
- Exclusion of other neurologic, medical and orthopaedic problems as causes of symptoms.

Aetiology and risk factors for LEOp are explored further in the *"The Late Effects of Polio: Introduction to Clinical Practice"* [6].

Inflammation Research

The concept of inflammation as a contributing factor to LEOp / PPS symptoms stimulated research into the efficacy of intravenous immunoglobulin (IvIg) as a treatment option. Pilot trial results were first published in 2006 [11]. Since then, Dr Kristian Borg (Karolinska Institute, Dandery Hospital, Sweden) and others, have continued to work with polio survivors to identify if IvIg can provide long term benefits and relief from the symptoms of LEOp / PPS.

At the European Post-Polio Conference in 2011, Dr Borg and his trial patients presented their findings with cautious optimism. In 2012, Henrik Gonzalez et al published their research findings in the "*Journal of Neuroinflammation*" [12]. At the 2014 European Conference, Dr Borg announced that Phase II/III of a wider study into IvIg as a therapeutic option for PPS would be implemented as a multi-national, multi-centred project in Europe, Canada, and the USA over the subsequent two years.

Clinical Commentary: Inflammation

In PPS, there is an ongoing denervation which may explain the increased weakness in muscles earlier affected by poliomyelitis. The denervation is compensated by collateral sprouting leading to an increase of the area of the motor units. [But], reinnervation cannot sufficiently compensate for denervation leading to whole or partial loss of motor units followed by a decrease of muscle strength. It is debated whether this deterioration is caused by further loss of motor neurons due to normal aging, genetics, deleterious over-use of remaining motor neurons, and/or an active disease process, perhaps involving chronic intrathecal inflammatory damage. These observations are supported by our and others' findings of and increased expression of pro-inflammatory cytokines particularly in the intrathecal compartment. The driving force of this inflammation has remained unclear. However, if the deterioration is indeed driven by inflammation, it should be accessible for therapy. [12, 13]

Clinical Commentary: ICD-10 Codes

The International Classification of Diseases, Clinical Modifications is used to code and classify morbidity data from the inpatient and outpatient records and physician offices. The codes can be found on the WHO website [14]. The final ICD-11 will be released in 2015. Relevant polio and post-polio codes from the ICD-10 [15] are:

- Z24: Need for immunization against poliomyelitis.
- A80-A80.9: Acute poliomyelitis.
- B91: Sequelae of poliomyelitis.
- G14: Post-polio syndrome.
- G47.30: Sleep apnea, unspecified.
- G47.31: Primary central sleep apnea.
- G47.33: Obstructive sleep apnea (adult) (pediatric).
- G47.36: Sleep-related hypoventilation in conditions classified elsewhere.
- G47.37: Central sleep apnea in conditions classified elsewhere.

Impact Of Ageing

Ageing With Polio

As those with a history of poliomyelitis get older, new disabling problems may emerge. New muscle weakness, atrophy and fasciculation can develop years and decades after a client suffered an episode of acute paralytic poliomyelitis. LEOp, PPS and Post-Polio Sequelae are used to describe this set of new health problems for these individuals.

Emerging evidence suggests that the weakness or fatigue in this population is due

to a reduction in the functioning motor-unit pool over time as the body naturally ages. It is thought that when a critical threshold is reached, motor neuron reinnervation can no longer keep pace with denervation. As a consequence polio-affected muscles become denervated and a disproportionate decline in function is observed by clinicians [16].

In 2013 Polio Australia conducted an extensive survey of 1,906 members which showed the problems experienced by people with LEOp. The results are seen in Figure 2.

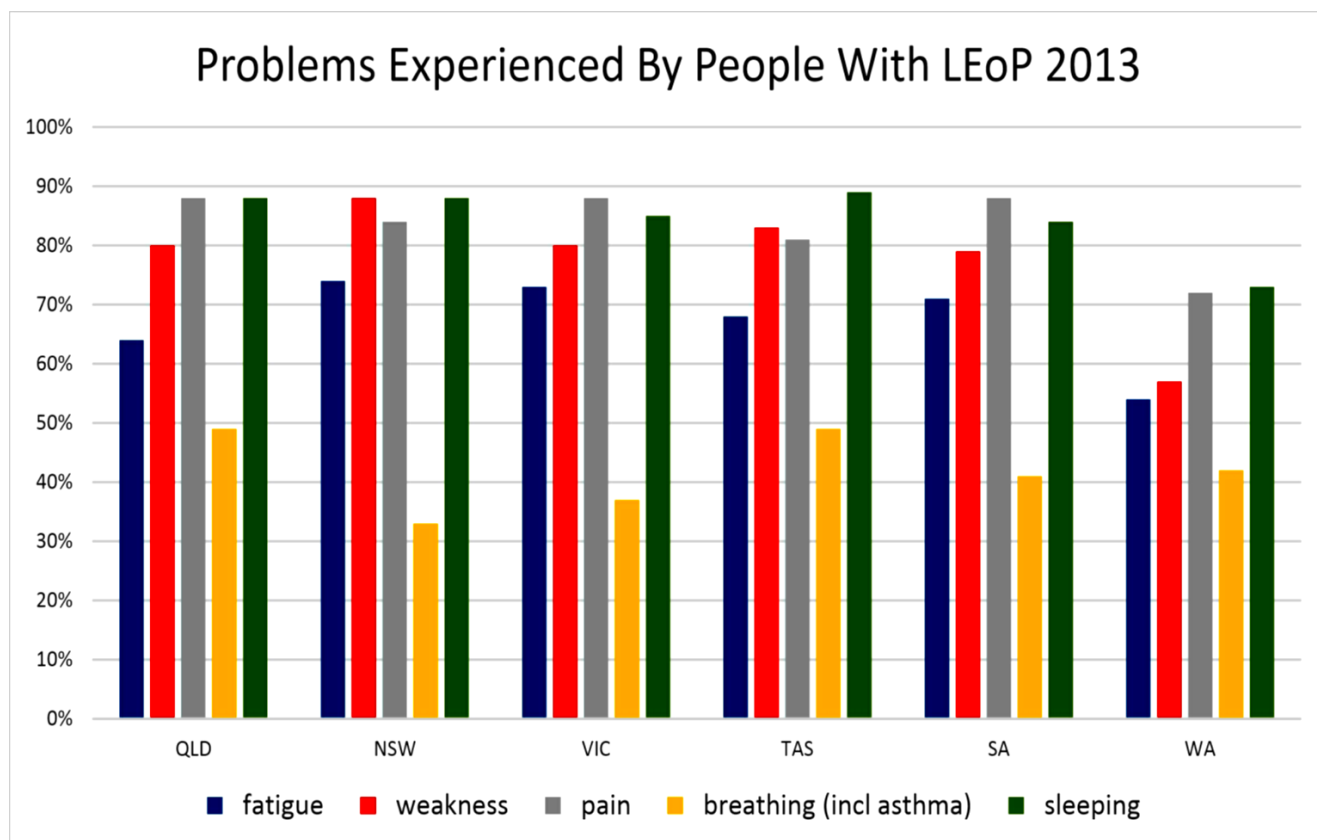


Figure 2: Problems Experienced By People With LEOp, 2013

Clinical Commentary

Key Characteristics Of Ageing

- Changes at cellular and sub cellular levels, measured by cell death.
- Changes in organ systems and measured by changes in organ output, for example a decrease in efficiency or output.
- Changes in performance of an individual, measured by decrease in functional activity.
- Psychological and social changes in an individual. These are measured by decreased ability to adapt to changing situations.

Ageing With A Disability

It is important to consider LEOp in the context of ageing generally, and ageing with a disability, in particular. Current theories in ageing include: programed theory whereby ageing follows a genetic timetable, and damage theory where ageing results from the cumulative consequence of free radical reactions resulting from toxins within the environment, or as a byproduct of cellular metabolism [17].

Clinical practitioners should strongly consider these age-related issues:

Frailty [18]

Frailty has been recognised as a medical syndrome with multiple causes and contributors. It is characterised by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death.

The integration of frailty measures in clinical practice is crucial for the development of interventions against disabling conditions in

older people. Two measures are available: the frailty phenotype and frailty index [19].

Reserve Capacity [20]

During maturation each organ system develops its capacity to carry out its functions. This capacity develops before birth and reaches its peak around age 18-20. Development of an excess capacity over basic survival needs enables the body to recover from minor and major injuries. Overall capacity is influenced by a combination of genetic and environmental influences. Over time, a gradual loss of capacity occurs, estimated to be 1% per year for individuals without disease. The age related loss in active motor units suggests 25% motor units become nonfunctional between ages 20 and 80 years. Upper limb strength generally decreases after the age of 40 at a rate of 1.5% per year. Beyond the age of 60 and in the 70s it decreases at 3% per year.

When reserve capacity drops below 40-50%, the risk of serious complications which threaten survival increases significantly. For individuals living without disability, this occurs after the age of approximately 70 years. Evidence suggests however that individuals who, for example, acquire a disability at 25 years of age, will lose capacity at a rate of 1.5% per year, reaching the threshold level of 40% by age 55-60 years. For individuals living with polio the rate of decrease is at least double this [21].

Neurophysiology [22]

Age-related neurological deterioration manifests through a decrease in central processing. An increase in response time may manifest due to slow processing of information by the brain. This can be compounded by a decrease in information about orientation and movement of the body in space due to a slowing of the 'feed forward

loop' within visual, somatosensory and vestibular systems. The resulting compromised effector pathway feedback loop leads to delayed or poor motor response such as poor coordination which in turn results in the loss of balance and falls. However, recent developments in the field of neurophysiology do indicate the ongoing capacity of the nervous system to adapt and respond over the life course. Metaplasticity endows synapses and networks with an ongoing ability to respond to an ever-changing environment. This has implications for the potential restoration of function through focused interventions to harness neurological potential.

Ageing Musculoskeletal Systems

The decreasing reserve capacity of body structures and functions may manifest as:

- Structural changes in bones, cartilage and elastic structures.
- Decrease in lung elasticity and vital capacity, and the loss of alveolar tissue.
- Reduced distribution of blood flow in the lung and to the muscles due to changes in the elastic tissue and cardiac valves of the heart.
- Increased joint stiffness and reduced muscle capacity leading to decreased stride length, trunk rotation, gait speed and increased stride width, segmental stiffness and poor co-ordination.

The pathophysiology of the ageing muscle includes:

- A limited capacity for motor unit re-modelling.
- Impacts of cellular changes such as loss of satellite cells, reduced oxidative capacity and decreased rates of protein synthesis.
- Hormonal changes in men (testosterone) and women (oestrogen).

These changes result in a reduction of the total number of strength and power muscles and their size, as well as a reduction in the number of endurance muscles.

Clinical Commentary: Future Pathways

The Late Effects of Disability Clinic at the Royal Perth Hospital, WA, suggests clinicians should set pathways for the immediate, short term (3-5 years) and long term (10 years) rehabilitation outcomes. These management plans or pathways take into account the range of ageing and polio-related factors outlined in this chapter, focusing on person-centered goals and on a range of remediation and adaptation techniques. The section on interventions within this module (Chapter 5) presents a range of treatment strategies to treat and manage the effects of ageing with a disability. [See also Appendices 1 and 2]

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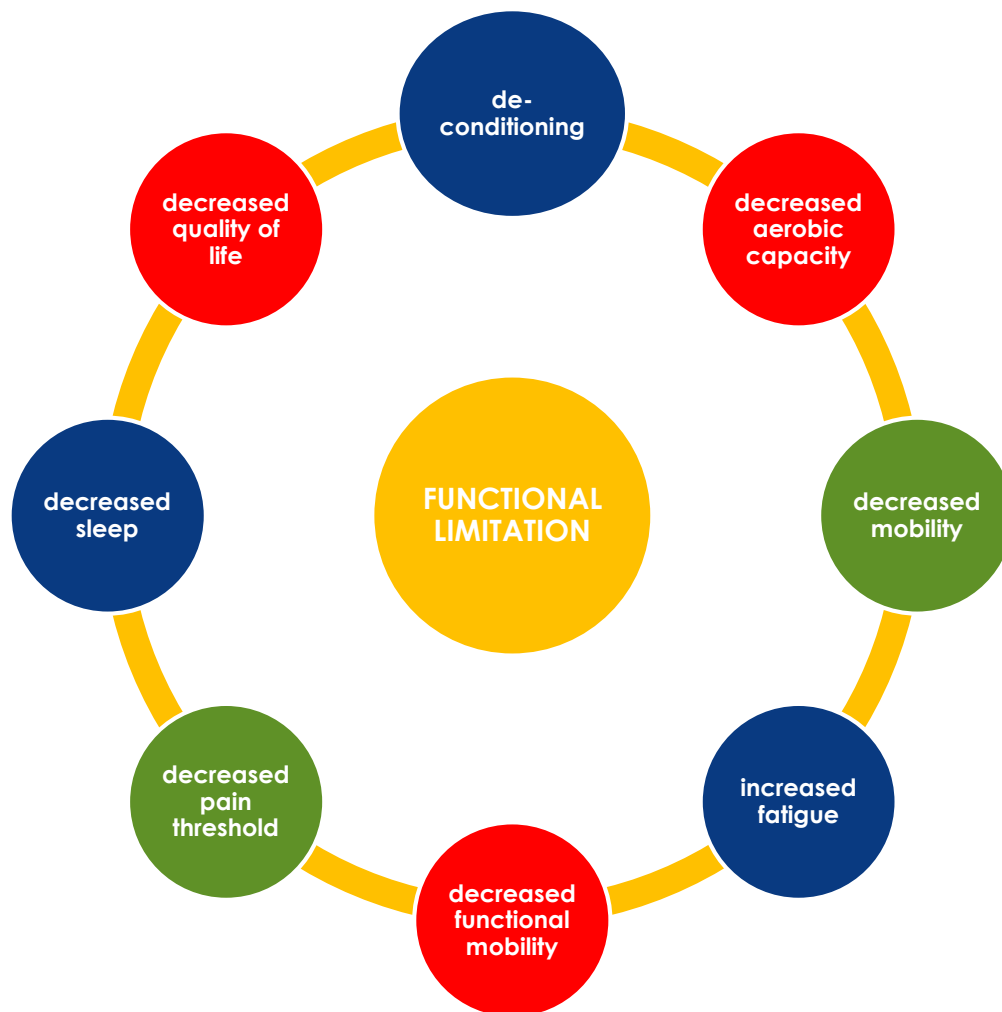


Fig 3: Functional Limitation Loop – depicts a range of issues leading to functional limitation [23]

This in turn leads to impaired muscle function, giving rise to compromised gait and balance, limited functional mobility and a higher risk of falls.

In terms of daily living, individuals may demonstrate a decreased ability to sustain loads such as carrying a bucket of water from the tap to the garden, or carrying the shopping from the car to the kitchen.

Psychosocial Considerations: Age And Stage

Individual factors such as gender and life experiences render every person unique, and the progression through the life course adds a further dimension of individuality.

Erikson [24] proposed a range of developmental stages and corresponding 'tensions' across the decades of life which will critically influence the happiness, satisfaction, and life goals of each person. The two final stages are:

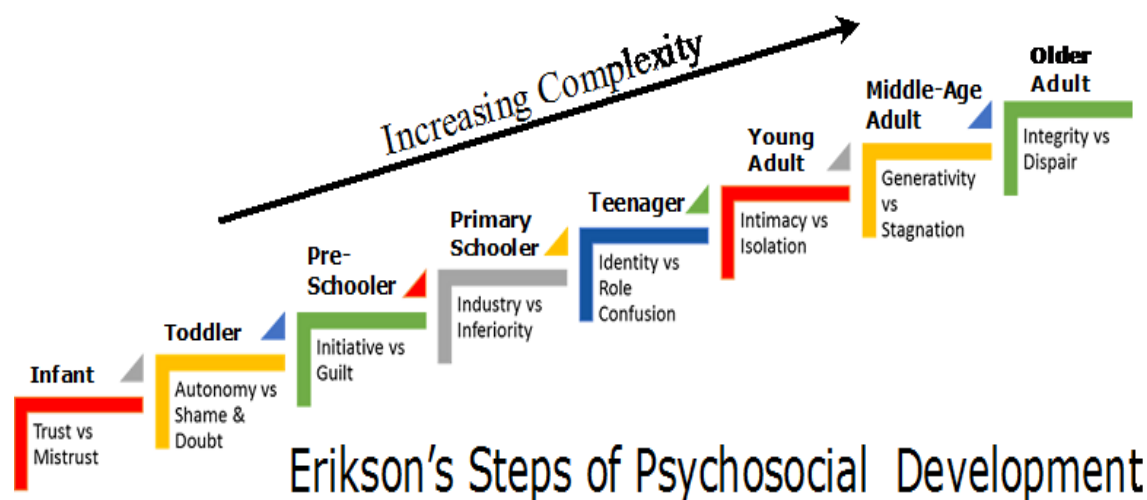
1. **Generativity vs stagnation:** the second stage of adulthood between the ages of 35-64. During this time people are normally settled in their life and know what is important to them. A person is either making progress in their career or treading lightly in their career and unsure if this is what they want to do for the rest of their working lives. Also during this time, a person is enjoying raising their children and participating in activities that give them a sense of purpose.

If a person is not comfortable with the way their life is progressing, they may be regretful about their decisions and feel a sense of uselessness.

2. **Ego integrity vs despair:** this stage affects the age group of 65 and on. During this time an individual has reached the last chapter in their life. Retirement is approaching or has already taken place. Ego-integrity means the acceptance of life in its fullness: the victories and the defeats, what was accomplished, and what was not accomplished. Wisdom is

the result of successfully accomplishing this final developmental task. Wisdom is defined as “*informed and detached concern for life itself in the face of death itself.*” [24]

Figure 4 provides a systematic framework for considering the range of factors which contribute to symptom management and healthy ageing. Each pathway or system, that is, self-care, lifestyle and wellness, is self-sustaining yet affects the other pathways in a positive manner.



Lived Experience Expert: Dinosaurs Have Something To Teach

Polio survivors sometimes feel like dinosaurs that everyone is happy to see die out. Some health practitioners take the view that it is not worth spending time developing treatments for, or conducting research into, the late effects of polio. Yet the experiences of polio survivors have implications for other disability groups. Parallels are being drawn between PPS and other viral infections. As people with disabilities such as spinal cord injury, cerebral palsy, spina bifida live longer it is apparent that they are prone to many of the overuse injuries that are part of the broader late effects of polio. This has led to questions being asked about what should be taught in initial rehabilitation to preserve body functions. In a 1996 editorial "New Mobility" magazine wrote, "The polios once showed us - the non-polio crips - how to live in the world with a disability... Now they may teach us how to grow old with our disabilities."

Dr Mary Westbrook [2]

Human Functioning

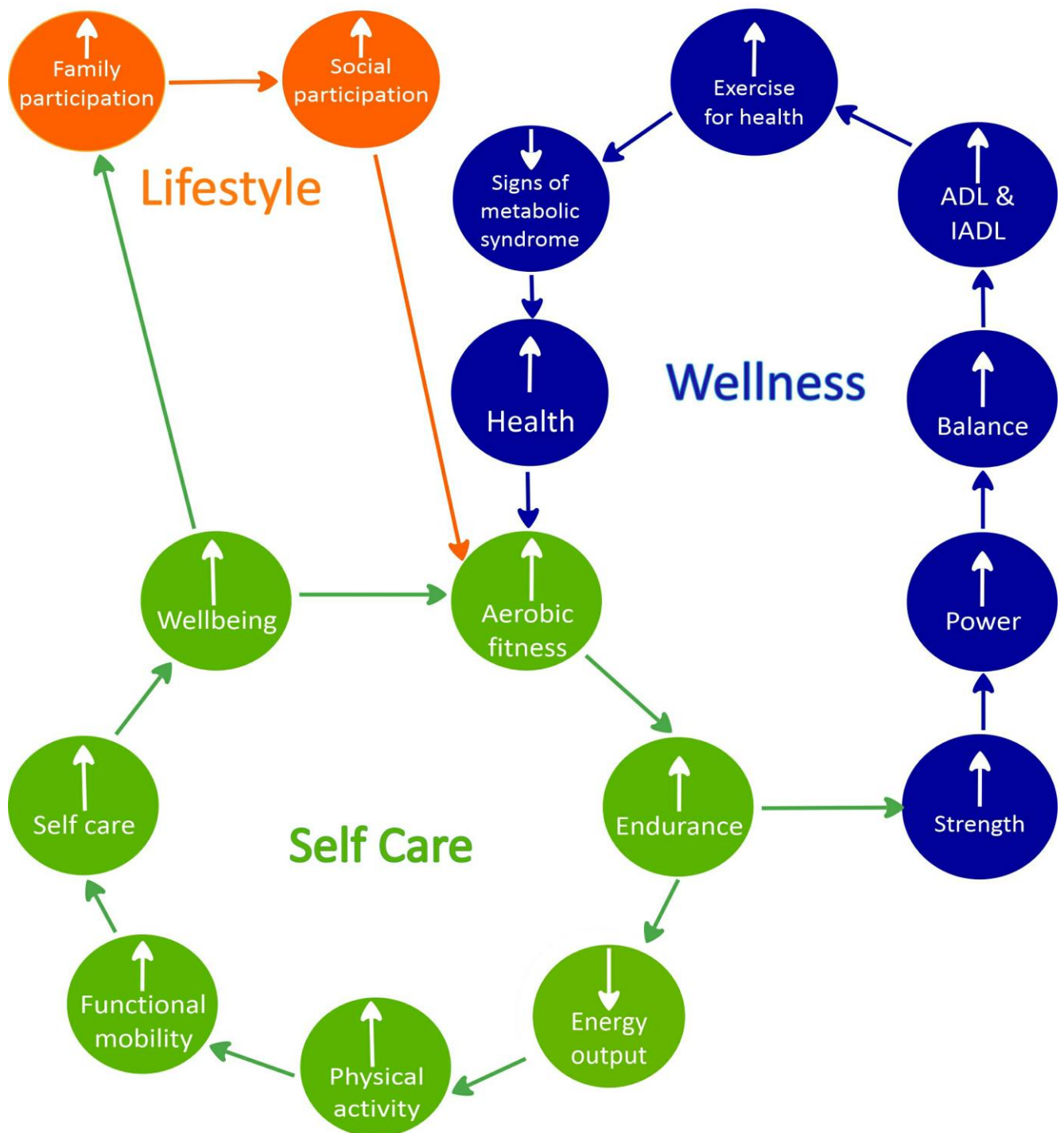


Figure 4: Systems View Of Human Functioning [25]

CHAPTER 3: ALLIED HEALTH PRACTITIONERS

The Post-Polio Interdisciplinary Care Team

Best practice in management of people with LEOp is still evolving. In the absence of specific medical or pharmacological treatments, management programs are key to analysing and minimising symptoms, maximising function, and supporting participation.

Medical practitioners acknowledge that an interdisciplinary approach is appropriate and recommended, as individuals are likely to have a wide variety of problems. As many symptoms result from motor unit degeneration, and/or attrition combined with normal ageing and overuse, treatment regimens and management strategies must be adjusted to the state of the condition [10,21].

People living with LEOp and people ageing with disability share many physical, psychosocial, and daily living challenges. However, several important and specific considerations apply to the LEOp group.

Firstly, some specific contra-indications and management strategies must be considered in assessment, the prescription of exercise, and planning for the future, with energy conservation, muscle overuse, and fatigue and weakness kept in mind.

Secondly, the psychosocial sequelae of a lifetime living with polio requires particular understanding and consideration from allied health practitioners.

During and after the polio epidemics, those who contracted the virus experienced a range of invasive and frequently traumatic

interventions such as full body splinting (often within institutional contexts) for long periods of time during their formative years. The rehabilitation model of the time encouraged persistence and the overcoming of physical challenges to attain independence. Therefore, this cohort often experience stress, grief, and difficulty in making decisions to change or relinquish long-held coping patterns. They can struggle to accept strategies, assistive technologies or task adaptations, and are likely to require carefully staged advice and long-term collaborative support.

The Allied Health Team

Due to the numerous and varied considerations for the management of LEOp clients, a range of allied health professionals may be required to make up the 'Post-Polio Care Team' with the client, General Practitioner (GP) and specialists. Best practice in a team approach includes coordinated planning for immediate and long-term needs, and seamless communication between team members to deliver services efficiently. It is essential that the client be considered a key member of the interdisciplinary team. The post-polio care team may incorporate these allied health practitioners:

- **Dietician/Nutritionist:** To provide education and management strategies regarding appropriate nutritional intake and weight management.

www.daa.asn.au

- **Occupational Therapist:** To assist polio clients to employ strategies to help maintain overall health and encourage the highest level of lifestyle independence. www.otaus.com.au
- **Orthotist:** To fit appropriate and well-fitting orthoses for clients who require them. www.aopa.org.au
- **Physiotherapist:** To assist polio clients to improve/maintain mobility, function and provide relief from pain. www.physiotherapy.asn.au
- **Podiatrist:** To assess and treat lower limb and foot conditions. www.apodc.com.au
- **Psychologist / Social Worker:** To provide counselling, education and support. www.psychology.org.au
- **Speech Pathologist:** To support the management of clients with speech (Dysarthria) or swallowing disorders (Dysphagia). www.speechpathologyaustralia.org.au

- **Registered Nurse / Nurse Practitioner:** To provide client advocacy, coordinate care plans across disciplines, provide chronic disease management and wound care in various settings including home, general practice and hospitals. www.nursingmidwiferyboard.gov.au



Image courtesy of Caulfield General Medical Centre

Clinical Commentary: Key Partners In Holistic Management

From a quality-of-life perspective, perhaps the most important thing a physician can do is to help patients preserve mobility and avoid falls and resultant injuries.

Physiotherapists and occupational therapists can be extremely helpful in treating patients with musculoskeletal pain, weakness, decreased endurance, impaired balance, and difficulty walking. They can recommend appropriate adaptive equipment, such as shower grab bars, a raised toilet seat, sturdy and lightweight braces, assistive devices such as canes and crutches, and footwear modifications such as heel lifts and lateral wedges.

Therapists can also advise patients on how to pace themselves to manage fatigue, which is especially important for those with LEOp. Home safety, work simplification, falls prevention, and appropriate exercise are also strategies that can enhance function. [26]

Who Provides Treatment?

Clients may wish to utilise practitioners from a wider range of complementary therapies including massage, acupuncture, osteopathy, chiropractic, naturopathy and more. These may in fact be delivered by some of the allied health practitioners previously listed. Additional treatments should be in consultation with the post-polio

care team. Knowledge and experience of LEOp and PPS should be considered when selecting a complementary therapist.

The following graph shows the results of a survey of 318 Australians living with LEOp in relation to which health practitioners they consulted [2].

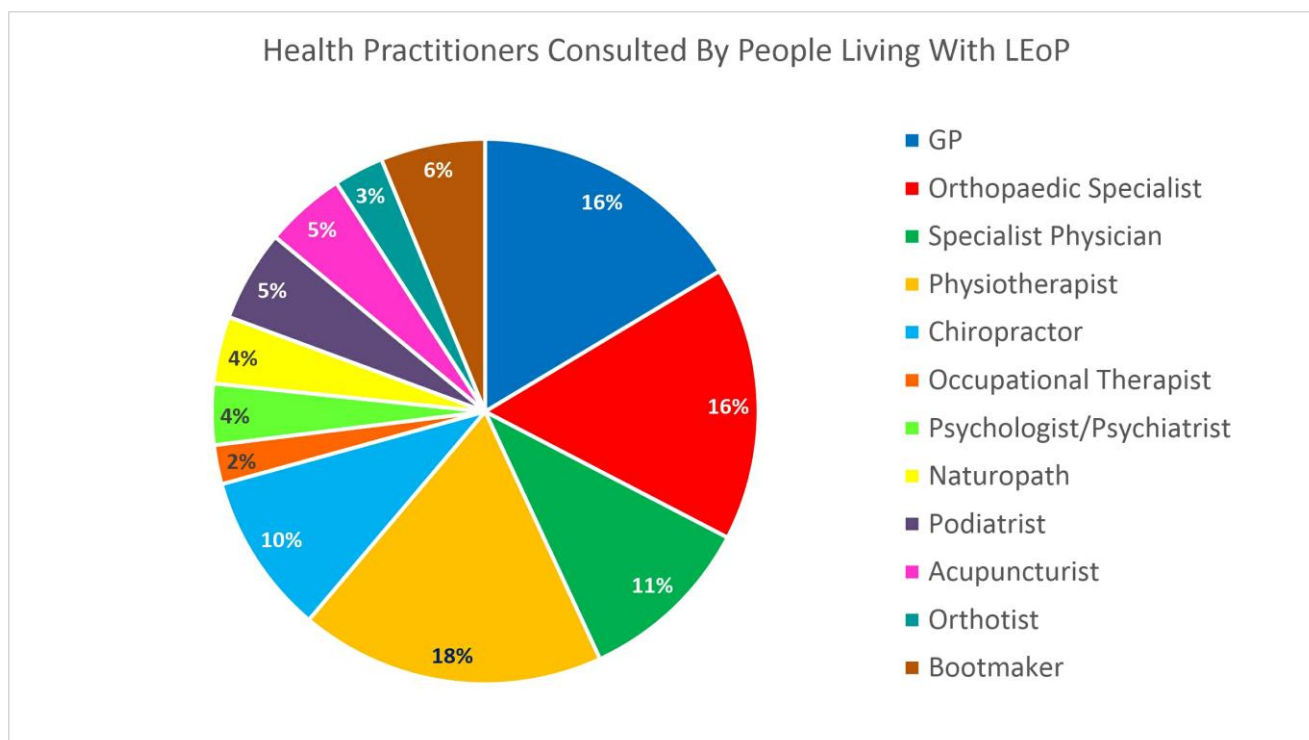


Figure 5: Health Practitioners Consulted By People Living With LEOp [2]

Useful Treatments For LEOp

A survey of 176 people with LEOp identified the following range of treatments that they had tried for relief of post-polio symptoms [2]:

- Counselling
- Dietary changes
- Exercise program
- Herbal remedies
- Hot baths
- Hydrotherapy
- Massage
- Pain relief medication

- Relaxation course
- Special shoes
- De-stress course
- Swimming
- Vitamin supplements
- Water aerobics
- Yoga

Of these modalities, only exercise programs had more negative responses than positive.

Lived Experience Expert: Weight Loss Combats Fatigue

*The last 10+ years have seen a noticeable increase in fatigue. So much so that after many blood tests, etc., I wished the doctors would find **something**. I didn't even care what the problem was, I just needed answers to the fatigue. Some years ago, I lost weight and found that to be a great benefit to my general health and wellbeing. I now try to keep my weight under control as it certainly helps combat fatigue.*

Maureen Grant, VIC

Complementary Therapies

In seeking solutions to problems such as immobility and pain, it can be difficult for individuals to evaluate what type of intervention to try and to locate impartial advice. A recent review of 'wellness interventions' provides some explanation of what different approaches offer.

Stuifbergen et al [27] suggest that it is important to differentiate between interventions with health promotion and wellness as the foreground interest, and those that are focused on disease and symptom management. A key difference is maximising health and quality of life vs control and management of disease and whether the person is viewed as a patient, or a motivated self-managing individual. The literature [27] noted that both wellness and disease management interventions may focus on enhancing similar behaviours, such as exercise or nutrition.

Lived Experience Expert: Complementary Therapies

My other favourite therapy for maintenance is remedial and lymphatic massage. It sorts out tense muscles and circulation issues. My massage therapist is highly qualified and has many years' experience working in a rehabilitation environment. She looks at the whole body and tailors her treatment accordingly. She is also experienced in Feldenkrais and lymphatic drainage. I have monthly treatments, but wouldn't it be great if it was weekly?! I also have an exercise program, as part of my maintenance program as well as vitamin and mineral supplements.

Anonymous

Health professionals who are asked by individuals living with LEOp about wellness alternatives must be mindful of the limited Western medical evidence base but also the likelihood that many interventions may have longstanding alternative and empirical evidence sources. Research into modalities including Tai Chi, Hatha Yoga, and Meditation [28] demonstrate subjective and objective improvements in fatigue, weakness, and pain management. It is likely that many alternative methods are indeed effective, but may not yet have been subject to rigorous scientific exploration.

It is advisable to suggest the following to clients who are considering a complementary approach to wellness or disease symptom management:

- The practitioner is qualified within a self-regulating or registered profession for whom the modality is within scope of practice.
- The selected practitioner has some knowledge of disability generally, and specifically of polio and its contraindications.

Many such complementary therapies are incorporated into Health and Wellness Retreats [29] run by Polio Australia and overseas, and are popular and well received by individuals living with post-polio. Wellness interventions at Retreats have included yoga (seated and supine), Tai Chi, Chi Ball, massage, and meditation. An additional activity that may be beneficial is Chi Kung (Qi Gong), a gentle Chinese exercise and movement modality which features slow and natural movements which contribute to stretching, breathing and improving mood.



Lived Experience Expert: Massage Helps

Modern physiotherapy came to the rescue with a physio who recognised that muscle damage was causing all my problems. She set about developing special exercises that did not stress my muscles. She taught a therapist to massage me.

Time has moved on and I use a combination of expert remedial massage (my therapist is a Feldenkrais trained physio who specialises in massage), which I need really every week but can only afford about every 3 weeks, Feldenkrais classes which I should do at home every day but don't because I rely on the group motivation, and gentle cardio and stretch exercises. I lift 1kg or 2kg weights, but my physio doesn't even like me doing that. I no longer have pain, as long as I have regular massage which seems to stop my muscles from going into spasm.

Christine Ducker, NSW



Images courtesy of
The Qi House - Acupuncture & Wellness Clinic
www.theqihouse.com.au

Lived Experience Expert: Acupuncture For Post-Polio

When I first went to my GP, she told me she didn't know anything about PPS. But, unlike some other medical practitioners, she showed an interest and willingness to learn. We've been on a journey together as she looks after me. She suggested I try acupuncture. I said I didn't like needles, so she uses laser for me instead. Once established, acupuncture lasts for about 3 weeks between treatments. The targets are usually for pain relief, relaxation, and sleep. It usually relieves the pain, helps me to relax and sometimes helps with sleep. I don't know why it works. I do know that if I'm late getting a treatment, the pain intensifies and I'm more fatigued. I recommend acupuncture for post polios be done by a GP who is aware of all their conditions and the possible effects.

Margaret Kinsella, VIC

CHAPTER 4: ASSESSMENT FOR LEO P AND PPS

A Holistic Approach

Assessment is the cornerstone of management for clients living with LEO P. A holistic approach assesses body functions and structures, psychosocial status, evaluates the impact of these upon the client's desired activities and participations, and considers the role of environmental barriers and facilitators for the client [1].

A longitudinal study of the course of functioning with late-onset sequelae of polio over a 5 year period identified minor declines in physical functioning (functional independence, perceived physical functioning, and walking capacity), but more significant declines in muscle strength and muscle overuse [30].

The difference in deterioration rates between walking capacity and muscle strength supports the concept of 'overuse' of muscles in daily life. That is, daily life functioning may be preserved at the cost of overloading progressively weakening muscles. This may impact the appropriateness of rehabilitation interventions, and suggests two main aims for multidisciplinary rehabilitation therapy:

1. Preservation or improvement of muscular capacity (muscle function and cardio respiratory function).
2. The reduction of physical demands in daily life activities.

It can often be difficult to separate the symptoms of LEO P due to the interwoven connectivity of physical and emotional states.

Lived Experience Expert: Post-Polio Care Team

NSW clients don't have a polio clinic like Victoria so it is hard to get a holistic assessment. In 2010 I attended the first Polio Australia Retreat where I saw an orthotic specialist for a new calliper and a physiotherapist for advice and gait retraining.

2013/14 saw me dealing with more pain. I needed a new assessment followed by more rehabilitation, including osteopathy, physiotherapy, gym, OT and hydrotherapy. The other useful 'therapy' for us is attending a support group. We can exchange information, hear other's stories, and enjoy interacting with people who understand the experience of living with LEO P.

I think many polios will tell you that they have 'trained' their health professionals about polio and LEO P. I always have handouts to give to health professionals so that I get the best advice and care possible.

Anonymous

Those with LEOp frequently report that the onset of post-polio symptoms has forced them, often for the first time, to recall and examine their acute polio experience [31]. Responses to these new symptoms of chronic, progressive disability often include anger, fear and confusion. Losing the abilities previously re-gained through strenuous rehabilitation may lead to feelings of bereavement resulting in social withdrawal, isolation, relationship hardships and a change in self-perception [32].

In order for health professionals to provide the best therapeutic advice, it is essential to have a good knowledge of the symptoms, and take the time to actively listen to clients. This will assist the practitioner to differentiate the underlying physical and psychological components [33].

The most appropriate method of providing a comprehensive and coordinated evaluation that addresses the full gamut of medical, functional, psychosocial and vocational needs is through the use of a multidisciplinary team.



Lived Experience Expert: Life Long Effects

I contracted polio at the age of about 18 months. Medical treatment was scarce due to my family's financial status and all I had was the local doctor, whose daughter had died from the disease. The effects have been lifelong and doctors generally have been ignorant of the effects, always looking for something like 'stress' to explain the appalling migraines and severe pain in which I lived. I'm actually in very good condition now at the age of 62, but there have been things happening which I now know are more likely to be related to the polio than merely age, which is the usual explanation. I don't think that makes them any easier to treat.

Christine Ducker, NSW

Clinical Commentary: Not Always Polio

One person presented to physiotherapy with unilateral lower rib pain, blaming her trunk weakness and scoliosis for this increasing debility. Investigation identified a gall bladder issue.

Musculoskeletal Assessment

The capacity to function with polio is the sum total of a person's ability to garner strength from movement patterns, rather than the use of individual muscles. Every person who has had polio has their own style of movement which is dictated by muscle combinations available and has been practiced throughout life. This pattern is likely to be the only movement template available to them.

In assessing the late effects of any disability, it is important to measure each presenting problem to be assessed against functional limitation and recorded against capacity one year ago or five years ago. This allows a forecasting of future directions. A range of standardised assessment tools exist, but may need to be adapted for the specific requirements of the polio client. A clinically valid approach is to identify the individualised tool for each client and use it consistently at each review. Suggested assessment intervals are:

- Initial assessment of presenting symptoms.
- Review at three months post-intervention.
- Regular ongoing reviews.

Neuromuscular Considerations

New muscle weakness can involve muscles known to have been affected by the original acute polio, as well as muscles that appeared to have been unaffected by the original acute polio infection. Even if muscle strength appears normal on clinical assessment, there may be significant denervation of muscle fibres. One study demonstrates that polio subjects with only 55% of the muscle strength of healthy subjects had manual

muscle testing results of normal strength [34]. Therefore, it is clinically important to note that one manual strength test will not show this denervation. Repeated tests are required to identify fatigue.

As discussed in the introduction, the change in muscle strength over time in the normal population over the age of 50 has shown a normal average decline of approximately one percent per year, while the LEOp population ages at double this rate, at approximately two percent per year [21]. In addition, polio clients often suffer from a significant reduction in neuromuscular innervations. This means they do not have an adequate 'reserve' to sustain the same level of function as unaffected individuals as they continue to age [16,35]. Inactive lifestyle can also increase the risk of muscle pain and fatigue in individuals who previously experienced paralytic polio [36].

Increasing muscle weakness can have a significant effect on the ability of a person to continue to have a satisfactory quality of life. Difficulties experienced are:

- Inability to be autonomous with ADLs.
- Reduced balance resulting in higher number of falls [37].
- Overuse of weakened and compensatory muscle groups leading to muscle pain.
- Asymmetric atrophy or weakness leading to contractures, pain, tension, and greater falls risk.
- Decreased muscle endurance and increased muscle fatigue.

The first subtle signs of LEOp or PPS may be new weakness and fatigue, and an increase in the time needed for recovery after muscle activity [38].

Loss of motor units and a decrease in muscle strength and endurance is not necessarily associated with impaired physical function, physical activity, or social participation. This non-linear association between denervation and function is possibly because of compensatory neuromuscular mechanisms. Diagnosis can be supported by electrophysiological examination including EMG, which usually reveals longstanding neurogenic signs [37].

Sensory Responses And Reflexes

A baseline assessment of sensory responses is recommended in order to screen for other pathologies in the nervous system. In the clinical setting, care is needed to differentiate peripheral compression neuropathies from spinal causes. Assessment includes:

- Quick, light touch along nerve roots.
- Sharp / blunt discrimination.
- Tendon reflexes.
- Cranial nerves: clients may not recognise or report breathing or swallowing issues but implied signs such as coughing during meals warrant a cranial nerve assessment.
- Current medications list: medications can impact muscle tone, endurance and strength.

Muscle Testing

Muscle testing contributes to the diagnosis of PPS and evaluates the muscle / nerve reserve available. An accurate muscle test helps ascertain which muscles are at high risk of weakness from overuse, how much a client should exercise, and which muscles can tolerate exercise.

Clinical Commentary: Exercise / Activity

Manual muscle testing can be predictive of both status over the next 5 years and the direction of likely change over 10 years.

Results from manual muscle testing can assist the allied health team to advise regarding exercise regimes, orthotics and other equipment. Exercise can help maintain and possibly strengthen muscles that are Grades 3+, 4, or 5 as long as a person doesn't overdo it. But exercise can be detrimental / harmful to muscles that are Grade 3 or less. A Grade 3 muscle can move the limb full range against gravity but it has only 15% to 20% of normal strength so it has very little endurance.

Grade 3 to 3+ muscles are considered at high risk because they can get weaker by both too little activity and by too much activity. A person with LEOp and Grade 3 to 3+ muscles has a daunting task of trying to find the correct balance to prevent losing muscle strength either from disuse or from overuse. If a Grade 3 muscle drops to Grade 2, and that muscle is essential to carry out a particular function, the client may experience a significant loss of function in that muscle group.

Grade 2 muscles may need some bracing support for added support and prevention of sprains and strains, particularly in the lower extremities because they do not have the strength to overcome gravity. Having said this, it is important to remember that the weight of braces should be carefully considered – heavy braces will wear down muscles.

Muscular testing also indicates any specific joint mechanisms at risk and the type of bracing which may be required if a muscle is too weak to perform its function, and is the basis from which to discuss lifestyle modifications such as use of powered mobility [34]. Figure 6 represents the Oxford Scale Of Muscle Testing.

A large number of the polio support network publications were reviewed, and contained 'lay information' about the nature and purpose of manual muscle testing. This indicated significant interest in the mechanisms of assessment and supported collaborative and informative approaches between allied health professionals and clients.

Oxford Scale		Muscle Being Tested
0	Zero	Has no muscle twitch.
1	Trace	Has some muscle twitch that can be felt.
2	Poor	Is only able to move the limb when gravity is eliminated.
3	Fair	Is able to move the limb against gravity.
4	Good	Is able to provide good resistance against the examiner.
5	Normal	Is as strong as the maximum resistance provided by the examiner.

Figure 6: Oxford Scale Of Muscle Testing (Grades)

Manual Muscle Test

1. Evaluate **passive range** of movement in order to show potential range. This should be done in fully supported position, gravity eliminated, to prevent false reading from tight muscles and trunk problems.
2. Evaluate **active range** to indicate muscle weakness and pain limitations. The difference between passive and active range is a quick guide to muscle strength. Polio-affected muscles develop tension slowly and need time to recover.
3. Evaluate **muscle tone** (noting any resistance at rest) throughout passive range, and observe trunk muscle tone. The assessor should keep in mind the difference between low tone in muscles (as seen in elderly clients or those complaining of fibromyalgia pain) and clients with pathological reason for low tone such as polio or comorbidities such as stroke, and muscular dystrophies.

In conducting a manual muscle test, a range of observations are clinically important. Static and dynamic strength [39] should be tested through the range noting any variation at the end of the range:

- **Static strength:** done slowly is always stronger than dynamic strength throughout the range (up to one full grade of difference). Static strength is tested at an angle of maximal force development, usually at a midpoint in range of the joint.
- **Dynamic strength:** should be tested through the full range. Recent or new lower motor neuron weakness / paralysis will present as equally weak in through range and static range. When a contracture is present, the strength on static hold is always stronger than the

strength through the range. It is important to test and record grades 1+ upwards. Clients can use lower grade strength in synergy with other muscles to produce functional movement. Grade 2 muscles generally do not change but appear stronger by recruitment of other muscles involved in achieving through range movement. From a rehabilitation perspective, Grade 3 muscles are likely to be strengthened, whereas a 5- percent change of improvement applies with Grade 2+ up to Grade 3.

Re-testing Muscles

Re-testing muscle strength at review is only useful in specific interventions. Generally, clients may achieve functional gains without showing any change in muscle strength, e.g. hip or knee muscles may not show any change in strength but the person may show improvement in walk tests; clients may report that they are able to climb steps with less effort but not show changes in muscle strength. Thus, the physiotherapist will save time and psychologically keep the client on track if muscle charts are re-completed at yearly intervals or once in every 2 years.

It is important to remember that changes can be minimal for clients living with LEOp, but an accumulation of small changes that are imperceptible functionally can cause major changes over time. Re-testing muscle strength against previously documented status can help with re-evaluating the problem and goals list. The data will help with a long-term planning process, encompassing possible changes in functional status and allowing the physiotherapist to coordinate with an occupational therapist and social worker regarding a future need for other supports such as mobility aids and structural changes to the home.

Clinical Commentary:

To Brace, Or Not To Brace?

After a detailed muscle chart of upper limbs, trunk and lower limbs has been done, the option to stabilise lax ligaments using bracing needs to be discussed by physiotherapists and orthotists. Changing joint alignment may make clinical theoretical sense but may trigger a fall. Also, clients often refuse to wear these braces. Unless the individual changes their 'gestalt' and brain template of established walking pattern, braces may be a very expensive waste of time.

Conversely, in the face of the dominant limb suffering musculoskeletal compromise, e.g. pain, weakness or arthritic changes, the need to stabilise one limb may be the only way to keep the person ambulating safely.

**Gnanaletchumy Maliga Jegasothy
(Jega)**

**Senior Physiotherapist,
Neurosurgical Rehabilitation and
Late Effects of Disability Clinic,
Royal Perth Hospital,
Shenton Park Campus (Ret 2014)**

Research in the field consistently points to a regime of 3 times per week over 3 months to show any change in muscle strength [39]. This change would be largely in unaffected muscles or muscles minimally affected at onset. Muscle weakness due to polio may not show change in muscle grade but will show change in functional capacity or reduction in fatigue / pain.

Torque Test

Torque testing is an additional method for measuring muscle strength and uses exercise equipment to electronically measure strength against an opposing force. This method is likely to become more common as robotics and computer-aided rehabilitation devices come onto the market.

Fasciculation Test

The presence of fasciculation is a further clinical consideration. Fasciculation or 'muscle twitch' refers to a small, local and involuntary muscle contraction, which may be visible beneath the skin. Fasciculation or 'muscle jumping' may manifest when a muscle is working against a strong unfamiliar resistance and when clients are tired. Fasciculation is a sign of overexertion and may manifest with delayed onset of up to a week after a non-routine increase in activity. One individual living with LEOp described fasciculation as "*a muscle going internally berserk*". Tapping the mid-point of a muscle belly may produce fasciculation and can indicate neuromuscular compromise. This is not a definitive test but a gross indicator and useful tool in quick testing. While this can occur in all people, the presence of fasciculation is linked to diseases of the lower motor neuron such as polio, and may interfere with quality of life.

Perceived Exertion Test

Broadly speaking, clients living with polio have difficulty assessing degrees of exertion, and clear guidelines must be provided as to what constitutes exertion. Perceived exertion should be measured over two to three reviews and is a good indicator of reduced muscle endurance / aerobic capacity. This test is particularly useful when self-reporting and muscle charts do not tally or when a muscle chart does not show change over time.

Speed Test

A number of factors such as joint and muscle stiffness / contracture in any of the trunk or ambulation muscles, will impact on the results of standardised speed tests.

The "*Timed Up-and-Go Test*" [40] is a useful tool to evaluate time taken to stand and take the first step. It is recommended that clients are invited to take their time for safety reasons.

Other tests which may be suitable include the two and six minute walk test. Clients should be encouraged to practise a slow walk for safety. Stride length, within limits, indicated by fewer steps in same time frame, may be a better indicator of improvement.

Functional Capacity Test

The capacity to function is the sum total of force generated by muscle groups and the ability to combine muscle groups to produce a movement pattern. This will be unique to each client. Additionally, on testing, clients with very weak muscle groups may show functional capacity far superior to clients with new muscle paralysis. Grade 2 strength muscle groups can enable an individual to stand and walk over flat ground and environments with which the client is familiar. This is in part due to the capacity of individuals to recruit, adapt and develop 'trick' movements over time.

Musculoskeletal Considerations

For some clients, function is achieved by using the abnormal musculature and joint movements which have developed over years of living with the effects of polio, e.g. the method of bracing through hyperextension to pick up items or perform a transfer. While such methods may be useful in day to day activities, they are likely to create ongoing wear and tear.

To protect joints and musculature for the long-term, careful collaboration with the client may be required to identify more sustainable methods.

Joint Deformities And Contractures

The impact of longstanding gait alteration due to weakness in part of the body impacts less affected limbs and joints. This additional wear and tear may lead to osteoarthritis, tendonitis, tendon tears, or bursitis in the compensating body parts. Use of the upper limbs in place of legs (for example through use of crutches, sticks or manual wheelchairs) also places more stress on the joints of the upper extremities, and this can result in damage to cartilage, tendons and ligaments in wrists, elbows and shoulders [41].

Range of motion testing and manual muscle testing will identify the presence of any contractures or tightening of soft tissue that result in a limited range of motion. The idiosyncrasies of individual gait patterns mean that some contractures are functionally supportive, e.g. Achilles tendon tightness which serves to stabilise the ankle, while others are problematic, e.g. inability to fully extend and lock the knee creates an unstable standing posture.

Scoliosis And Kyphosis

Testing joint mobility and muscle strength in individuals with marked scoliosis, kyphosis or kypho-scoliosis is essential, and a challenge. Understanding whether these deformities are idiopathic or secondary to polio muscle weakness and imbalance is worth noting. While the end result may be the same, the understanding may have an effect on future management.

Thorough assessment requires removing clothes to view the body part being tested.

The accepted start position for muscle testing (lying flat) will be difficult for clients with marked changes in spinal alignment. However, testing in the seated position may cause difficulties for an asymmetric spine when gravity is in play. To compromise, include a prone position with pillow support in lower abdomen and groin, or about 30 degree incline support, with a pillow under the knees to remove stretch on lower limb muscles.

Spinal deformities will restrict scapula movement thereby compromising shoulder joint range leading to functional restrictions. Therefore, testing shoulder joint movement independent of scapula movement is also recommended.



Compression Neuropathy

Nerves may be compressed by abnormal positions of the vertebrae or joints, e.g. carpal tunnel syndrome. Symptoms include numbness or tingling and progressive weakness. One study of 97 polio survivors noted an 80% prevalence of nerve entrapment, most commonly median neuropathy followed by ulnar neuropathy at elbow and then wrist, related to the use of walking aids and wheelchairs [42].

Additional Physical Assessments

There are a number of important secondary problems related to compromised musculoskeletal and neuromuscular systems as well as psychosocial issues that need to be taken into account for the post-polio client.

Respiratory Insufficiency And Complications

When polio survivors age they may encounter late onset respiratory failure due to weakening of respiratory muscles and deformities of the chest. The most common respiratory presentation is shortness of breath and sleep disordered breathing. A respiratory assessment investigates the nature of breathlessness and recovery time. This screens for any cardiovascular pathologies and provides a baseline to assess muscle and cardiovascular endurance, capacity for rehabilitation and post rehabilitation regimes.

A lung function test provides a valuable baseline for clients with scoliosis and/or bulbar weakness and indicates post-surgical management, including bed posture and rehabilitation intensity. This can be conducted by a respiratory physiotherapy or a respiratory physician.

Fatigue

The most common symptoms of LEOp include a triad of fatigue, deterioration in muscle strength, and pain [30,37]. Typically, fatigue related to LEOp will begin after a period of functional and neurological stability of at least 15 years following the initial episode of acute poliomyelitis.

LEoP fatigue is often associated with onset later in the day and with increasing severity toward the evening. It is important on assessment to exclude any other causes for fatigue such as anaemia or cancer. Current understanding suggests the aetiology of fatigue lies in the overuse or overwork of polio damaged nerves and muscles and can be categorised in two forms [8,38]:

- **General fatigue** (central fatigue): will often occur every day and progress throughout the day. General fatigue can occur following very minimal activity and is described as an overwhelming exhaustion with flu-like aching. It can include hot and cold flushes and sweating along with marked change in energy levels, physical and mental endurance.
- **Muscle fatigue** (peripheral fatigue or muscle weakness): is a reported decline in muscle strength upon exertion which may be described as muscle fatigability or lack of endurance. Post-polio individuals have described muscle fatigue as “a heavy sensation in the muscles”, “increased physical weakness”, and “increased loss of strength during exercise” [43]. Muscle strength often returns after a period of rest.

Pain

Pain, fatigue and weakness are commonly reported symptoms of LEOp (between 42% and 87%) according to descriptive surveys and clinical examination studies [5].

In normal pain responses, nociception detects something outside the normal boundaries of physiological activity that is potentially harmful to the body. The brain then produces the output of pain as a perception. Problems arise when those who have had polio override these warning signs and potentially accelerate harm to relevant tissues.

Muscle pain is very common in LEOp and is thought to be due to overuse of weak muscles or of other muscle groups which are compensating for weakened polio-affected muscles [38]. Joint pain can also be significant, typically caused by joint instability, anisomelia (unequal length of limbs), disuse of muscles, abnormal biomechanical movements, and degenerative joint diseases. Research shows that 10% of clients with LEOp have neuropathic pain, mainly caused by secondary disorders such as nerve compression or disc hernia [37].

Clinical Commentary:

Assessment Tools

In clinical practice, simple pain scales have been found to be useful such as the Wong-Baker Faces Pain Scale [44]. These are quick, user friendly and non-threatening. Descriptors of the pain (sharp, stabbing, aching, etc.) must also be captured. Having a baseline pain evaluation is useful at reviews, especially when pain reporting has not changed whilst other measures have improved. Pain assessment, in conjunction with sensory and muscle testing, is very important as a diagnostic tool. It is important to note that individuals with long standing physical disability frequently have a higher pain threshold.

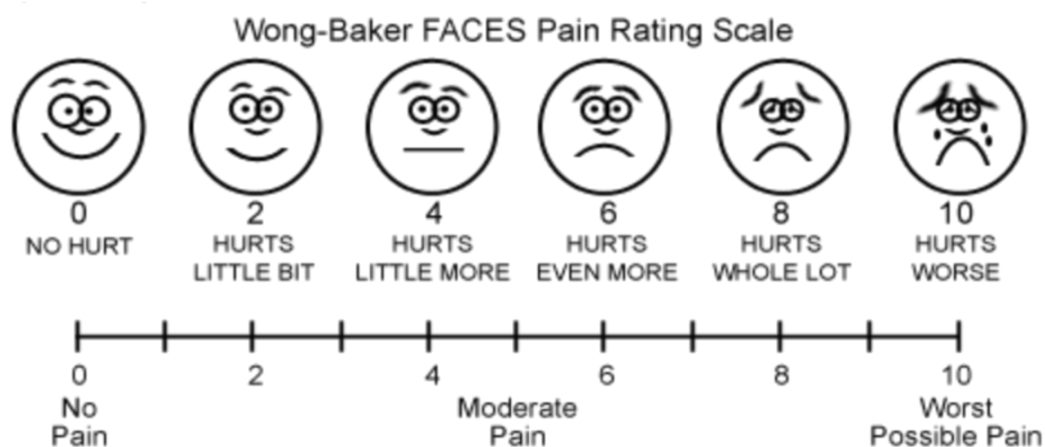


Figure 7: Wong Baker FACES Pain Rating Scale [44]

A classification of three classes of pain has been developed to facilitate diagnosis and treatment [45]:

1. **Biomechanical pain:** Pain resulting from poor posture is the most common type of LEOp reported pain. Weakness in polio-affected muscles (particularly the legs) often leads to poor muscular balance and skeletal alignment. Years of walking on unstable joints and tissues makes clients more likely to develop degenerative joint disease. Those with LEOp often experience shoulder pain due to the need for the body to compensate for weakened muscles or because of weight gain [46]. The majority of clients with LEOp will experience some degree of scoliosis. Nerve compression syndromes may develop from years of altered body alignment.
2. **Overuse pain:** The second most commonly reported LEOp pain results from overuse of soft tissue. Muscles unaffected by polio and those only mildly affected, tendons (tendonitis), bursa (bursitis) and ligaments are all vulnerable to overuse pain [45]. These structures are often overused to accommodate for weakened polio muscles resulting in strains, sprains and inflammation.
3. **Post-polio muscle pain:** Described as burning, cramping or a deep muscle ache. Deep pain is often characterised by muscle cramps, while superficial pain is sometimes associated with fasciculation, a crawling sensation, or extreme sensitivity to touch [47]. Many LEOp clients express deep frustration that this 'unbearable' pain is not understood by others, including health practitioners. Post-polio muscle pain is usually associated with physical activity and

typically occurs at the end of the day or at night. Muscle cramping and/or fasciculation is an indication of overuse of polio muscles [45].

Sleep Disturbance

Sleep disturbance is common in clients suffering from LEOp and is usually the result of a primary sleep disorder including obstructive sleep apnoea, central sleep apnoea and hypoventilation, joint and muscle pain, or muscle twitching [48,49]. Random muscle twitching at night can disrupt sleep and may be related to conditions such as restless legs syndrome, periodic movement in sleep, and generalised random myoclonus (muscle contractions involving muscles throughout the body).

Common clinical signs of sleep disturbance include:

- Tiredness upon waking.
- Daytime tiredness and/or sleepiness.
- Loud snoring.
- Headache upon waking.
- Irritability.
- Impaired intellectual function.
- Poor concentration.
- Fatigue.

The incidence of primary sleep disorders appears to be higher in LEOp clients compared to the general population. This may be due to chest and spinal deformities, weakened respiratory muscles and damage to the respiratory control centre following the primary poliomyelitis infection.

Dysphagia And Dysarthria

Symptoms include intermittent or constant swallowing issues related to decreased pharyngeal transit, bilateral pharyngeal weakness and decreased bolus control [50].

Speech problems may exist including the voice becoming easily tired and hoarse, and trouble coordinating breathing and voice production, e.g. during singing [51]. The incidence of new swallowing problems is between 6% and 22% of those LEOp [47], although this is likely underestimated as a loss of cough reflex and poor laryngeal penetration (passage of materials into the larynx) can occur without obvious symptoms [52,53].

The majority of clients who experience dysphagia and/or dysarthria have a confirmed history of swallowing problems in the acute phase of polio. However, even those with no history may have suffered sub-clinical damage to the bulbar nerves during the original infection. The severity of swallowing impairment can vary substantially between clients who often develop strategies to compensate for symptoms, such as tilting or turning their heads during swallowing, eating more slowly with smaller mouthfuls and avoiding foods that are difficult to swallow. Aspiration is reported to be rare, but there is evidence of slow progression of symptoms. Clinical history will help to determine whether clients are aware of bulbar symptoms and other symptoms that may be consistent with LEOp. Imaging such as video fluoroscopy, and a speech / language pathologist assessment may be very helpful to the primary care physician's evaluation of the cause of dysphagia.

Impaired Thermoregulation

Cold intolerance, particularly of the extremities, is a common symptom of LEOp. Between 46-62% of responders in post-polio surveys report cold intolerance [54]. Symptoms usually present during cold weather but can present even at mild temperatures and warm indoor surroundings.

Cold intolerance due to circulatory disturbance can be attributed directly to nerve and muscular damage caused by the polio virus. Virtually all clients reporting cold intolerance will have a normal core body temperature, however limbs with significant atrophy tend to be cool to the touch with a bluish discoloration and variable degrees of swelling. Generally clients do not recognise that their limb is cold until they touch it [41].

Cold limb(s) due to LEOp will not delay wound healing, unless other contributory factors are present such as peripheral vascular disease. However the symptoms may be an inconvenience and can become very uncomfortable and even painful. A baseline assessment of the integrity of blood flow is suggested, e.g. examining peripheral pulse points, dermatome sensation for hot / cold, and reperfusion rates.

Bladder Dysfunction

There many potential causes of bladder dysfunction in LEOp including [55]:

- Weak detrusor muscle may cause incomplete voiding. In this case voiding becomes more frequent and overflow incontinence may result.
- Weak sphincter / pelvic floor leading to stress incontinence (urine leakage).
- Autonomic nervous system imbalance giving rise to urge incontinence (difficulty inhibiting the desire to void) or difficulties initiating a void.
- Functional incontinence may occur due to being unable to reach the toilet in time as a result of restricted mobility.
- Oedema in the legs causing nocturia and urinary incontinence (common in those with lower limb paralysis). Fluid accumulates in the legs during the day and mobilises at night when the client lays down in bed resulting in a larger urine production at night.

- Problematic voiding habits such as suppressing the need to void leading to an overstretched detrusor muscle.
- Urinary incontinence can have a significant impact on a person's quality of life. Individuals may be embarrassed about their symptoms and avoid mentioning issues to health professionals [56]. They may also restrict social participation outside the home.

Treatment for urinary dysfunction varies depending upon the underlying pathology. Clinical decisions require input from an urologist and/or continence physiotherapist.

Comorbidities

Individuals with LEOp have paresis and are therefore less able to lead an active lifestyle, thus becoming more prone to certain types of comorbidity. Research shows that the lower levels and faster decline of physical functioning, and risk factors like inactivity and excess weight in those with LEOp, is associated with higher comorbidity levels.

Compared with the non-polio-affected population, people with LEOp have more cardiovascular disease such as myocardial infarction, hypertension and cardiac arrhythmias.

However it is worth noting that many polio clients have developed good cardiovascular fitness, especially clients using callipers and orthoses, or those who use manual wheelchairs or crutches, due to increased physical exertion.

The incidence of endocrine and metabolic diseases such as diabetes, hyperlipidaemia, and hypothyroidism are also higher in the LEOp population.

Surgical Considerations

Significant consumer advocacy is underway to educate the general medical and surgical professions on clinical recommendations for management of the LEOp client. Polio Australia's *"The Late Effects of Polio: Introduction to Clinical Practice"* [6] outlines these recommendations. Several adverse events related to anaesthesia and secondary complications of the surgical process have led to bulletins regarding specific surgical management. Of particular note is the impact of general anaesthetics and prolonged recovery time for LEOp clients (often 2-3 times longer than the general population).

While the client and his/her physician are primary sources of information in the event of surgery, allied health practitioners have an educative and supportive role in relation to potential surgery (including dental) for clients with LEOp. Allied health practitioners may offer valuable contributions such as:

- Self-advocacy support for clients to ensure PPS-appropriate medical care, documentation and liaison is occurring.
- Baseline condition documentation, e.g. contractures or spinal deformities, neuromuscular, and respiratory status, to predict requirements and precautions during and after surgery.
- Highlight potential psychological impacts of surgery and ensure supports are in place to minimise re-traumatising the client.
- Post-surgical planning including an increased propensity to post-surgical muscular weakness, slower recovery time and need for mobility aids.
- Discharge planning including arrangement for additional daily living supports.

Falls Assessment And Management

Falls risk analysis and prevention for community-dwelling individuals living with LEOp is of primary importance. Reduced muscle strength, relatively rapid muscle fatigue and impaired balance and gait are risk factors. Other risk factors include visual impairment, dizziness on standing, and the taking of certain medications [57].

Those with LEOp / PPS have more disease of the bones, muscles and tendons such as arthrosis and osteoporosis resulting in an increased risk of fractures after a fall [58].

A systematic assessment of risk behaviour and environmental hazards in the home under the direction of an occupational therapist has been shown to prevent falls and is indicated when physical symptoms suggest a falls risk [57]. Substantial literature now demonstrates a combination of personal and environmental strategies is effective to reduce falls risk and mitigate damage in the event of a fall. Reviews of medical literature provide strong evidence that exercise programs can also reduce fall rates in older populations but that the exercises are more likely to be for those with balance challenges [59].

Lived Experience Expert: Prevention Is Better Than Cure

I find that most polio survivors manage as they are until there is some 'crisis', i.e. a fall resulting in a fracture or a new severe pain episode. They then search for a quick fix so they can get on with their 'normal' lives. If we were all able to work around an attitude of 'prevention is better than cure', and perhaps a maintenance program, then we would all be better off.

Anonymous

Clinical Commentary: Falls Prevention For LEOp Clients

- Practice strategies to get up after a fall, such as turning over, locating firm supports and self-pacing.
- Have a back-up plan. Use body-worn personal alarms or mobile devices to call for help if it is difficult to get up from a fall, even in the absence of a fracture.
- A coded key safe box containing house keys should be installed on the outside of the house near the front door to ensure prompt access when help arrives.

Such exercises may include standing with feet together or on one leg while practising controlled movements that strengthen the core trunk muscles. The particular exercise program must be tailored to the capabilities of the individual under the direction of a physiotherapist who is familiar with the idiosyncrasies of LEOp / PPS.

In 2010, Alice Bickerstaffe MD, Anita Beelen PhD and Frans Nollet MD PhD, from the Department of Rehabilitation AMC, Amsterdam, The Netherlands, published a comprehensive research paper on "*The circumstances and consequences of falls in polio survivors*" [60]. The abstract follows.

Clinical Commentary: Falls In Polio Survivors [60]

Objectives: Many polio survivors have symptoms that are known risk factors for falls in elderly people. This study aims to determine the: (i) frequency; (ii) consequences; (iii) circumstances; and (iv) factors associated with falls in polio survivors.

Methods: A survey was conducted among 376 polio survivors. Participants completed a falls history questionnaire and additional information was obtained from their medical files.

Results: Of the 305 respondents, 74% reported at least one fall in the past year and 60% two or more. Sixteen percent of fallers described a major injury after a fall in the last year and 69% reported fear of falling. One-third of fallers had reduced the amount they walked because of their fear of falling. Most reported falls in a familiar environment (86%), during ambulation (72%) and in the afternoon (50%). Quadriceps weakness of the weaker leg (Medical Research Council (MRC) ≤ 3), fear of falling and complaints of problems maintaining balance were independently associated with both falls and recurrent falls, while increasing age and medication use were not.

Conclusion: The high rate of falls and consequences thereof merit the implementation of fall intervention strategies. To maximize effect, they should be tailor-made and target the fall mechanisms specific to polio survivors.

Psychosocial Assessment

Psychological symptoms including chronic stress, anxiety, depression, and compulsive behaviour are evident in LEOp clients. Depressed, anxious or stressed individuals with LEOp report a more severe physical deterioration, more pain with a higher rate of somatic complaints, poorer coping mechanisms, a reduced quality of life and greater social exclusion [31].

It is important for clinicians to consider the psychological impact of a chronic condition like polio as these symptoms are commonly overlooked. Importantly, psychological elements can exacerbate LEOp symptoms and often prevent clients from making the life changes necessary to achieve benefit from treatment programs [10].

People living with LEOp have lived much of their lives with residual impairment and through an era when few accommodations were available for people with disabilities [61]. They bring a range of treatment experiences from the acute phase of their illness, which may colour their attitude to hospitals and to health professionals [33].

Previous approaches to polio treatment have included ignoring pain and fatigue and to exercise as much as possible. Such strategies are now being regarded as possible contributors to the post-polio symptoms [5]. Post-polio clients and their families may therefore find it challenging to be advised to dramatically change their approach to managing their symptoms. This is a major obstacle for many individuals and often results in higher levels of unfulfilled treatment programs [31] and an unused stock of recently revisited and well-intended orthoses that are not a match with a long held self-image.

Research into coping amongst those with LEOp identified the critical role of coping style and collaborative approaches to management from health practitioners. Two main coping themes were identified with corresponding emotional states:

1. Focus on symptoms / maintenance of previous lifestyle: Characteristic of people who felt more helpless, depressed, and angry.
2. Accommodating of symptoms / lifestyle adjustments: Characteristic of those who adopted more helpful strategies and displayed personal acceptance and greater internal locus of control.

Research also showed that lifestyle and personal modifications were rated as more effective than many treatments and interpersonal strategies.

Lived Experience Expert: The Pain Of Polio

For those having survived acute polio, PPS means facing an unexpected second round of a disability they thought they had overcome. Fear and depression are common reactions particularly when health practitioners and families question the validity of patients' problems. Most of those with PPS or LEOp contracted polio in childhood.

Their hospitalisation sometimes involved years of separation from their parents who could only visit once a week. Children felt abandoned. They experienced painful treatments, many encountered emotional and even physical abuse in hospitals. The ethos of the times was to 'be seen but not heard', so that few ever talked about their experiences.

New symptoms late in life and the need to seek healthcare can often trigger traumatic, sometimes repressed, memories. There is fear that families will abandon them once again. Medical procedures may lead to panic reactions. Having to use orthotics again is perceived as failure after the early years of struggle to discard them. [62]

Dr Mary Westbrook

These findings highlight the need for health practitioners to tap into client knowledge when designing and evaluating appropriate rehabilitation programs [63].

Social Supports And Insight

Newly diagnosed clients frequently experience problems in communicating effectively about LEOp with their families and friends, and in obtaining help from them. The length of time required to obtain a diagnosis results in many LEOp symptoms being discounted by families and often health practitioners [2]. Intimate relationships between partners may also be affected due to the symptoms of pain, fatigue, and weakness which impact on an individual's self-image and sexuality.

The most successful approach to managing the complex psychological components of the LEOp involves all members of the interdisciplinary team being versed in recognising psychosocial issues and communicating concerns amongst the team to ensure appropriate treatment is forthcoming.

Further, the entire team must be skilled in understanding and working within any

psychological limitations by acknowledging the impact of past coping strategies, learned behaviours, and life course trajectory, and collaborate with the client for meaningful goals and achievable management plans.

Like physical symptoms, the incidence and severity of psychological symptoms in LEOp vary greatly between clients. The intertwining of fatigue, pain and muscle weakness, and cognitive changes such as concentration, short term memory lapses and word finding difficulties, often result in social isolation.

This can place intimate relationships and friendships under considerable strain and at risk of breakdown [64]. Social support assessment should include the burden on the daily living of family carers to identify key areas in which support, alternative approaches, and/or respite might preserve relationships and the health of both client and carer.

Lived Experience Expert: Coping With LEOp

There are no simple answers to post-polio problems and much research needs to be carried out into its causes and the effects of various treatments. However the literature suggests that much can be done to relieve symptoms and that the progression of symptoms can be slowed down or halted. People can do much to assist themselves by pacing and planning their lives in ways that conserve energy and avoid fatigue and muscle overuse. This often involves changing the habits of a lifetime, e.g. pressing on despite pain, never asking for help, never using aids in any circumstances, never asking for special treatment, and never talking to anyone about one's disability. The coping strategies which worked well for most of our lives and helped us achieve many successes now need to be changed as we tackle a new problem. We all need to reach our own individual decisions as to what most contributes to quality of life. Then we need to investigate and use the strategies, devices and lifestyle changes which may help us maintain these.

Dr Mary Westbrook

Adjusting To The Need For Support

People living with LEOp have often had many years battling alone to manage symptoms. As discussed in earlier chapters, a common characteristic is the tendency to 'drive' oneself further, and the reluctance to accept support [33].

Current disability theory acknowledges that rather than a discourse of independence

versus dependence, all humans live interdependent lives [65].

Framing support in this way opens a transactional way of thinking about the give and take of human relationships. Halstead [66] enacts this in Table 1 where individuals living with LEOp are invited to reconsider the support they use and to link this reflection to well-being goals.

Lived Experience Expert: Good Days, Bad Days

Allied health professionals only get to see us when we choose to see them. You may see us at our best, or at our worst.

Peter Willcocks, VIC



Table 1: Considering Support Tasks And Goal [66]

Task	Goal
Discuss your polio onset with the family you grew up in. Listen for each person's polio story. Become aware of your own story. See how this fits with your PPS story.	Use the story to develop strategies for maximising self-determination.
Examine how you 'own' polio and PPS. In what ways do you take control of living with PPS symptoms, and in what ways do you let things happen, wait for something or someone else to make the decision for you, or for 'luck' to decide?	Increase your feelings of control and power in your life. This results in a better sense of well-being.
Assess any symptoms you might have of depression or anxiety. Remember that everyone feels some sadness and some anxiety, so do not seek to have zero symptoms.	Become aware of any treatable emotional disorder and seek professional assistance. PPS is hard enough without an additional burden of a depression or anxiety disorder.

Task	Goal
<p>Take stock of your current roles and functions:</p> <ul style="list-style-type: none"> • What is the daily and weekly balance between work and play? • How much time per day and per week do you set aside just for relaxation? • Do you overdo things such that you wear out completely by the end of the day or end of the week? • Are there tasks you could delegate to others but don't? • Are you able to let go of some goals in order to conserve energy? • Could you trade a more intensive labor task for one involving less physical labor? • Do you have things to do each day and week that interest you and give you enjoyment? 	<p>Achieve greater balance in your life, avoid overdoing and then collapsing. Keep a more even level of energy throughout the day and the week.</p>
<ul style="list-style-type: none"> • Ask yourself if there is any possible AT device which could save labour, make tasks easier, conserve energy? • What keeps you from using them? • What tasks could be relegated to other people? • What tasks can you let go of altogether? 	<p>It's really true - you must conserve to preserve it.</p>
<p>If you had \$500 to spend on your house, what one change would make it easier for you to live there? Consider small changes that save energy, e.g. building a ramp to the front door, changing doorknobs to bars instead of knobs, finding a lower work surface in the kitchen and leaving a chair there, putting grab bars around tub and shower, making a sliding door self-closing, purchasing a remote control for lights and putting it within easy reach, putting lights on timers.</p>	<p>Don't use energy unnecessarily. Save your energy for more important things, such as your family and friends.</p>
<p>Think about the roles and functions in your household (provider, housekeeper, gardener, childrearing, romantic partner, emotional support). Consider how these are presently divided. Think about which ones must be done by family members (e.g. cuddling children), which could be shared or taken over by another family member (e.g. washing dishes), which could be hired out (e.g. vacuuming), and which might not need to be done at all now (e.g. putting the last five years of photos into albums).</p>	<p>Use good communication skills in the family to problem-solve how the family fulfills functions without overburdening any one person.</p>
<p>Evaluate your family's stressors and resources. Make a list of each, then try to make the stressor list shorter and the resource list longer.</p>	<p>A balance between stressors and resources leads to better coping. If stressors outweigh resources the entire family functioning suffers.</p>

Demonstrating the relevance of this work by Halstead, a study conducted by St Vincent's Hospital reported that fatigue impacts strongly on the daily activities of individuals living with LEOp [67]. The activities most frequently reported as being restricted by fatigue involved maintaining the home. These included:

- Housework (55%)
- Gardening (31%)
- Cooking (11%)

Once reflection on tasks and goals is achieved, the allied health practitioner can then guide the person with LEOp to identify relevant supports.

Sourcing Support

Practitioners such as social workers through their roles in casework, counselling, advocacy, community engagement and development, and social action, can address issues at both the personal and social level [68]. Governmental support systems are complex so specialist support to navigate formal and informal systems can be extremely useful. For those living with LEOp, support assessment will be intricately linked to life roles, e.g. breadwinner, and systems

like eligibility for disability or aged care benefits, multipurpose taxi cards, companion card, carers allowance, and the disability support pension, etc.

Lived Experience Expert: Seeking Information

Polio NSW is always endeavouring to give as much information to its members to encourage them to look after themselves so they can live with LEOp as best they can. Attitudes ARE changing out of necessity, I believe.

Susan Ellis
Vice President, Polio NSW

Self-Help And Empowerment

The voices of 'lived experience experts' who have contributed to this document illustrate the lengthy, individual and often painful journey undertaken to get the best out of life. They display the self-empowerment and tenacity required to traverse the ongoing impacts of polio and ageing with disability.

Lived Experience Expert: Strength In Numbers

After years of silence, never talking about polio, it was confronting. Invited to a network meeting, I couldn't bear the idea of sitting around a table with people in wheelchairs, badly affected by polio. That wasn't me, was it? Support groups have now become the rare place where we listen to each other, share management advice and tell of nurses, doctors and allied professionals who have been kind enough to ask about the foot, leg, arms that clearly had been paralysed. On being hospitalised, many polios have conducted clinics for trainee doctors and others.

Fran Henke,
Chair, Polio Reference Group,
Polio Network Victoria

An important feature of the literature and evidence base for polio is data from researchers and practitioners who themselves live with LEOp. Westbrook [2] is one such author, and Figure 8 from her research illustrates the importance of listening to lived experience.

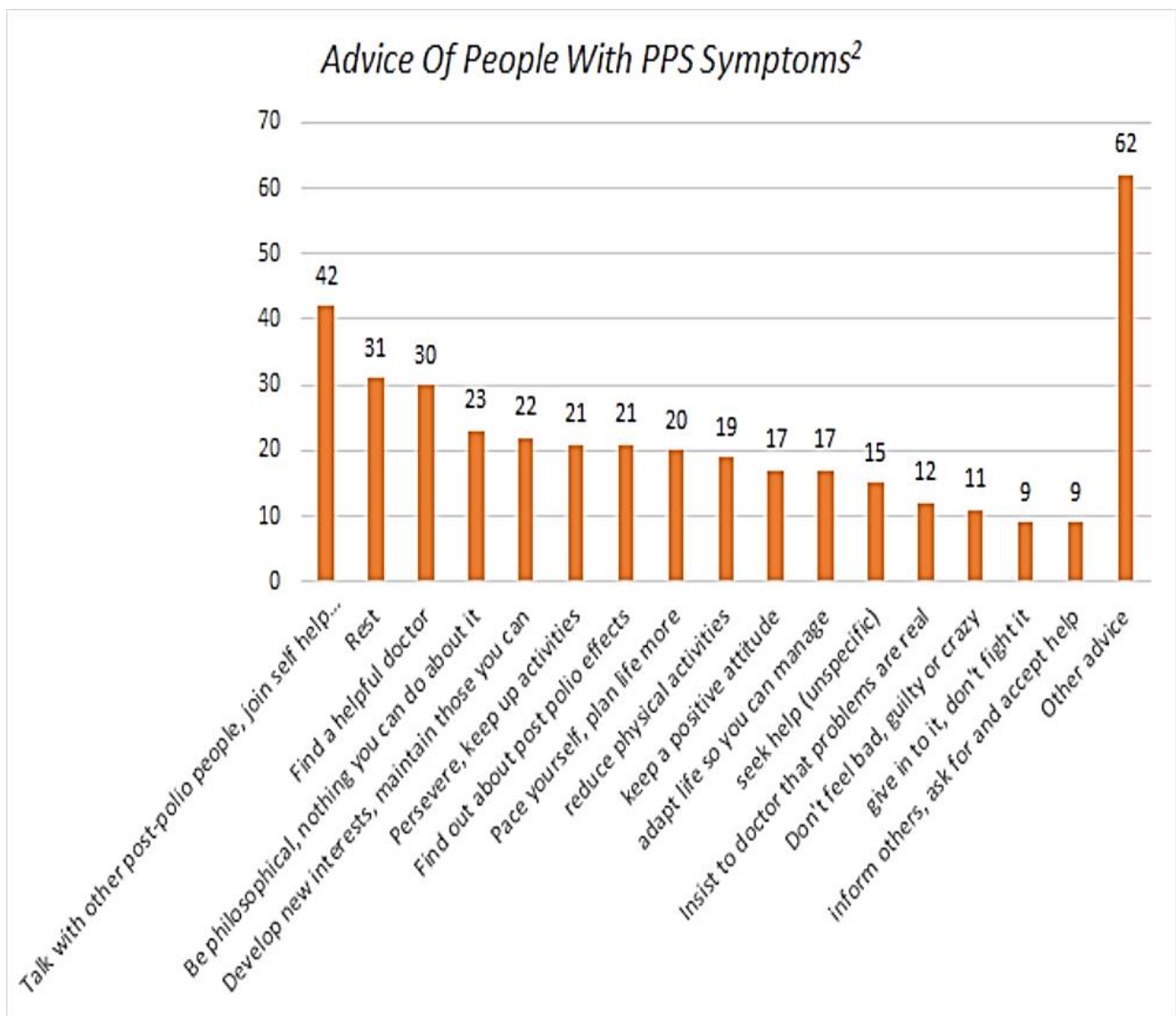


Figure 8: Advice Of People With PPS Symptoms [2]

CHAPTER 5: INTERVENTIONS

What Rehabilitation Means For LEOp

This chapter outlines a range of key interventions or strategies used to mediate the effects on polio-related body structure and function issues. Traditionally, physical treatments, whether mainstream or alternative, have been a key focus of management. The techniques outlined in this chapter are part of a holistic rehabilitation approach which attempts to modify or change the body of the individual living with LEOp. While this set of interventions represent an important range of options in post-polio management, a disability model best practice perspective suggests that the wider environment can and should be adapted to fit the needs of individuals living with disability by adapting tasks and barriers to make life easier. These concurrent interventions are outlined in subsequent chapters.



Post-Polio Precautions

People living with LEOp should be carefully monitored to identify signs of increasing muscle weakness and muscle pain in order to avoid undesirable effects, especially overuse of muscles that are symptomatically unaffected but found to have impaired neuromuscular function during clinical testing and assessment.

As discussed in previous chapters, overuse has been proposed as a cause of increasing muscular weakness. Some individuals with polio are anxious about exercising due to articles written against exercise, and early anecdotal studies which revealed loss of strength with exercise (due to excessive activity). A recent literature review published in *Lancet Neurology* [37] concludes there is no evidence that overuse will permanently damage muscles affected by polio, yet conversely, muscles affected by polio will readily atrophy with disuse, hence exercise may be indicated.

To avoid potential harm, exercise in post-polio patients should be carefully monitored and activity leading to excessive fatigue, muscle pain or joint pain should be avoided. Appropriate rest and avoidance of excessive exercise should be instituted if chronic muscular overwork is considered the cause of weakness.

Lived Experience Expert: My Best Approach

I believe that everyone has their own 'best approach'. The 'conserve to preserve' view was drummed into me early, but this didn't suit me so for most of my life I have chosen to take the attitude of 'do what you can while you can'. I have always believed in maintaining fitness through exercise. This has been achieved with a combination of swimming, aqua aerobics, then later hydrotherapy, stationary bike and walking for some cardio fitness, plus strengthening and stretching exercises acquired from the many physiotherapists I have known along the way. My goal for many years has been to exercise twice a week for 30-45 minutes. If I couldn't manage to walk or have a swim I would try to do the floor exercises and stretches.

I didn't count the incidental exercise of housework and childcare, which was a bit of a mistake, as this consumed much of my energy for many years and I underestimated this. In my early 40s there was a transition in my stamina and I had a period of about 6 years of being tired, unwell and experiencing increased pain and weakness. Each form of exercise I tried now seemed to lead to a new part of me breaking down and for a few years there was a pattern of build-up then injury. When this was diagnosed as post-polio I undertook a specific tailor made rehabilitation program, attending twice a week for eight weeks, and took a few months off work to rest. Much of the work was re-educating myself to my needs. For example, I learned that I now needed rest breaks during the exercise session, not just after.

I participated in a similar exercise program run by Polio Services Victoria five years later. Here I was guided to add the treadmill to my repertoire of exercise options, which was exciting for me. I had been told that I shouldn't 'waste steps'. The evenness and support of the treadmill enabled me to learn to take longer steps confidently and I strengthened muscles and improved my gait. I now do a form of Tai Chi for health and wellness and surprisingly do this standing, not seated, as my balance has improved.

While I do think people with polio have to be mindful of their capacities, I think it is equally important to focus on what we can do. Although we are often told that we can't increase muscle strength, my experience is that through trying something new I have increased some muscle strength probably in muscles that were not paralyzed but which haven't had much chance to activate. Exercise is an individual thing.

Anonymous

Clinical Commentary: Energy Output Hints For LEO / PPS Clients [\[69\]](#)

1. Cardiovascular or aerobic exercise is best for weight loss.
2. These exercises cause you to feel warm, perspire and breathe heavily without being out of breath and without any pain or burning sensations in muscles.
3. Whether a structured exercise program or part of daily life, any physical activity will burn kilojoules and improve health.
4. See your doctor for a medical evaluation before beginning a physical activity program and consult your physiotherapist for advice on the right program for you.
5. Choose activities that are fun, not exhausting. Add variety. Develop a repertoire of several activities that you can enjoy. That way exercise will never seem boring.
6. Wear comfortable, properly fitted footwear and comfortable, loose-fitting clothing appropriate for the weather and the activity.
7. Find a convenient time and place to do activities. Try to make it a habit but be flexible. If you miss your exercise time, work some physical activity into your day.
8. Use music to keep yourself entertained.
9. Surround yourself with supportive people to exercise with you, to remind you to exercise, or to give you time by yourself to exercise.
10. Start Slowly. Don't overdo it. Do low to moderate intensity exercises.
11. Acknowledge both your polio and non-polio limbs when choosing an exercise. You may have to work your polio limbs lighter than your non-polio limbs.
12. Early warning signs that the exercise is not beneficial are fatigue continuing for 4 hours afterward, pain and loss of strength.
13. Do not work muscles to fatigue. Take regular rests and use low resistance, i.e. light weight. You might start with 1-2 minutes of exercise followed by 1-2 minutes rest.
14. Strength exercises should only be performed on every second day.
15. You can increase the duration and intensity of your activities as you become more fit. Work up to exercising on most days of the week for 30 minutes. This can be done in 10 minute blocks throughout the day if time is an issue.
16. Monitor your response to exercise. You should find it light to somewhat hard.
17. Keep a record of your activities.
18. Reward yourself (with something other than food!) at special milestones.
19. Remember energy output (exercise / physical activity) is for life. Make it as much a part of your life as brushing your teeth!

Exercise

Contrary to earlier studies, research within the last 20 years demonstrates that modified exercise is beneficial for the polio population with or without LEOp and that it has no adverse effects. Although modified exercise has been shown to be beneficial, the current research is inconclusive regarding specific exercise prescription [37]. Thus, presented here is the combined clinical practice knowledge of the Polio Australia Clinical Advisory Group, supported by available peer-reviewed literature.

Prescribing Exercise

Individuals living with LEOp are extremely susceptible to muscle weakness and fatigue, therefore more caution should be taken with exercise prescription. Polio affected muscles are more likely to fatigue and have a prolonged recovery time compared to unaffected muscles. This may be explained by the increased workload on remaining motor units which are compensating for lost motor units that were destroyed by polio.

The first step in exercise prescription is an assessment and modification of any excessive demands on the body. This may include splinting, reduction of uneven stressors and reduction of workload. After modification of these factors, exercise forms the basis of management of patients with LEOp.

Absolute bed rest can accelerate muscle mass loss and strength at a rate of 1.5% per day, particularly affecting the antigravity muscles that maintain posture in standing. Most patients will benefit from appropriate physical activity and a large proportion

benefit from individually tailored specific muscle training [37]. It is important that these activities are well-paced and allow sufficient rest time to help minimise local muscle fatigue and facilitate strength recovery [26].

Lived Experience Expert: 'Thinking' Exercise

I am now back exercising 2 or 3 times a week. The old physio exercises are a great start, and having reconnected with some of my leg muscles, I am now trying to enliven the muscles that I am sure may never have been used.

These muscles are supporting my weak hip which has resulted in much less pain in the joint. As my exercise routine from an early age was on the basis of quality exercise and not quantity, it has been easy for me to understand the concept of not overdoing my exercise program.

After much practice, I have been able to use what I call 'thinking exercises', by focusing the brain on a particular muscle or muscles, thus not putting strain on my over-used arthritic joints. This process is extremely draining as the brain can only focus at that level for a minute or two. So far I have had pleasing results.

Maureen Grant, VIC

Strengthening Exercise

Clearly, no strength can be achieved in completely paralysed muscles after the acute period because neuromuscular damage is permanent. However, muscle strengthening may be performed in muscles with residual polio weakness. Note that strength gains may be slower or limited compared to muscles unaffected by polio.

Manual muscle testing must be performed before and during the exercise program to closely monitor changes in muscle strength (refer to Chapter 4: Assessment For LEOp And PPS), and the underlying cause of muscle weakness should be determined so that appropriate management strategies can be developed [21].

General recommendations for strengthening exercise are:

- Low resistance.
- High repetitions.
- Frequent rest periods of sufficient duration to allow recovery from muscle fatigue. [39]



Aerobic Exercise

Excessive cardiovascular exercise has been shown to increase levels of chronic fatigue. However, some amount of exercise is necessary for improving cardiovascular fitness. The correct level of exercise must be determined in order to gain maximal cardiovascular fitness without worsening levels of chronic fatigue.

The major principles are to exercise at a moderate (rather than maximal) intensity, have short sessions with frequent rests and have adequate recovery time between session days.

Lived Experience Expert: Pace Yourself

My experience of LEOp is that physical deterioration is from overuse, not a sedentary lifestyle. Intensive exercise programs can provide temporary relief from pain but I believe more permanent benefits are likely to be a result of healthy weight management, supported movement, use of assistive technology, an accessible environment and avoiding fatigue from overuse.

Peter Willcocks, VIC

Clinical Commentary: Cardiovascular Exercise

One study found the following program effective: 20 minute sessions with frequent short rests, 3 times a week, with at least one day off in between sessions. [69]

Hydrotherapy

Training in warm water has been identified as an effective treatment for muscle weakness and muscle pain [38,70]. Hydrotherapy programs can increase strength and coordination, improve ambulation and increase range of motion and flexibility. In clients where a neurological condition such as PPS impairs respiration, pool use may be contraindicated and requires careful assessment. This is because hydrostatic pressure exerts a compressive force on the chest wall, which increases with water depth and increases the work of breathing for the patient. With very close monitoring the hydrostatic pressure can be used as resistance to breathing and thereby a way to try and increase muscle strength [71,72].

Water can be experienced as fun, provide a feeling of weightlessness and relief from pain. Other physiological benefits of immersion in warm water include:

- Increased metabolic rate.
- Increased heart rate.
- Increased circulation to skin surface and muscles.
- Increased respiratory rate.
- Muscle relaxation.

Lived Experience Expert: Hydrotherapy

First, I decided to try one of the exercise classes at the pool. I knew I should be doing more exercise to keep from losing strength and endurance. I discussed the water aerobics class with the swimming instructor and explained my limitations. She encouraged me to adapt any of the exercises to my own abilities. She assured me that everyone in the class is very supportive of each other and that others also have physical difficulties. I tried it and liked it! I now attend this class for an hour twice a week on a regular basis. I enjoy it because everyone is so friendly and the instructor makes it fun! I discovered that I'm more flexible afterwards and have fewer joint pains, so it's been very successful! In the summer months, we use the outdoor pool where the sunshine and resort-like ambiance make it even more enjoyable. What a treat!

Anonymous



Recommended pool temperature is 32-33 degrees Celsius, and no cooler than 29 degrees Celsius to manage cold intolerance and gain benefit from the pain relieving effects of warm water. Water buoyancy can provide for assisted and resisted movements and stretching, although care must be taken not to overstretch.

Individual hydrotherapy assessment should include:

- Range of motion.
- Flexibility.
- Muscle strength.
- Endurance.
- Ambulatory skills.
- Transfers.
- Body shape and density: consider for safety and support, particularly in clients with neurological or musculoskeletal impairment.
- Psychological considerations: feeling safe in the water is paramount and requires a safe introduction. Introductory sessions must concentrate on stability, avoid water in / near the face and teach breath control and recovery.

Hydrotherapy treatment planning principles include:

- Core stability: consider as a pre-requisite for upper and lower limb strength retraining and function.
- Movement pattern alterations: while on land clients have habitual movements, when in water buoyancy allows for the introduction and learning of new movement patterns.

When prescribing hydrotherapy, consider pool temperature, easy access for the client, and the time of day when the client's energy is at its peak. Remind clients not to exercise to the point of fatigue. The combination of heat and exercising can be fatiguing.

Clinical Commentary: A Case Study

Presentation

A 70 year old male came to see me. This man had polio at 8 years old. He remembers having an awful headache prior to diagnosis. He spent 6 months in bed with plasters on both legs. He thinks he may have had it in his face too, as there is some current asymmetry. He was a rower from 16 to 22, so was pretty strong then. He has exercised very actively and regularly since. Recently, he struggled on a walk up the "Wine Glass Bay" route in Tasmania, but had to stop 100m from the top. He now gets generalised fatigue, his walking pace has slowed, and he can't take such a long stride. He notes some pain in the right hip, lower back, and left leg.

Assessment

He is doing 30 minutes daily on an exercise bike, but wanted further advice on exercise. On examination, subtle weakness was noted in the right hip, lower back muscles on the right, and subtle right ankle weakness. One manual strength test is not sufficient. Test three times to identify fatiguing effect and strength drop off.

Recommendations

Perform an MRI to exclude other possible conditions. Reduce bike activity to 20 mins only. Careful stretches after warm up. Regular rest times.

Ann Buchan
Neurophysiotherapist
South Australia

Exercise may need to be short (10 minutes) and then lengthened as endurance improves. A person should spend no more than 30-45 minutes in water above 32 degrees Celsius. The best benefits will be achieved in an exercise program 2 or 3 days a week.

Lived Experience Expert: A Cautionary Tale

My early adult years saw much walking and acceptance of muscle fatigue and pain as normal. In my early 40s I was fatigued for months with unshakable flu-like symptoms. My body was telling me something and I wasn't listening. After enforced rest and a slow recovery I returned to my old ways. Returning from a bike ride I would collapse, sleep for an hour or two and wake with the pain and twitching of overworked muscles. This I presumed was just a part of getting fit. By the age of 55 I was struggling with pain and breathlessness even to walk a few blocks. I was diagnosed with PPS and finally received some good advice on lifestyle. My 'learned' obsession to be as physically able as others in my youth had done much damage to the fragile network of motor neuron / muscle fibre connections.

Exercise for polio patients, and management of LEOp and PPS, poses very different challenges to other chronic problems such as MS, Cerebral Palsy, and even spinal cord injury, due to our fragile motor neurons. The challenge for physios is to differentiate between chronic conditions and design programs that will not lead to increased loss of function. While load bearing exercise can increase and help maintain muscle strength, it can also be detrimental for those with PPS and LEOp. One aim of a polio exercise program is to increase muscle fibre flexibility and avoid muscle fibres becoming knotted as a result of cramping. The challenge is to recognise which muscle groups are used to perform function. It all depends on the individual and the impact polio has had on his/her life.

Polio bodies will certainly benefit from exercise that promotes greater muscular flexibility, good circulation, and oxygenation. There may well be muscles in a polio body that are healthier than some and may be under-utilised. I agree that programs can be developed to make use of these muscles, but my concern is what happens when they too become overworked and fail?

For many polio patients, a program of healthy movement may have far greater and longer benefits than load bearing or repetitive movement. This has been my experience. My use of bracing, sticks, powered wheels and respiratory support has lessened the load on weakened muscles, reduced pain, and enabled me to become more active. I strongly recommend life as a healthy mover and if it hurts never do it again!

Peter Willcocks, VIC

CHAPTER 6: COMPENSATIONS

Redesigning Life

This chapter identifies a range of strategies to modify the 'task' component of the 'person', 'task' and 'environment' triad. Lifestyle re-design can be effective in reducing overuse symptoms. The narratives of individuals living with LEOp demonstrate that often lifestyle adjustments are initially experienced as restrictive. The allied health role entails a collaborative journey, understanding the specific occupational goals and values of polio survivors and supporting them to read their bodies, which tasks to prioritise, and what strategies and adjustments can make life easier.

Principles Of Self-Management

Fostering insight and self-reflection are primary goals to enable the person with LEOp to understand and predict his/her physical status over time. A baseline activity analysis over typical and atypical time periods is a useful starting point. Fatigue-mapping and diary-keeping are useful tools to encourage self-reflection and insight regarding activity levels and the response of the body. This will contribute to an overall conversation about role balance and the part played by self-education and self-monitoring in relation to fatigue and occupational performance. Key approaches include:

1. Attuning the person to his/her own bodies, tasks and environments through self-reflective checklists and simple biofeedback strategies.
2. An adult learning approach to impart knowledge teaching a range of self-help techniques in the areas of energy conservation, work simplification and joint protection.

Evidence from studies of post-polio life demonstrates a suite of strategies are often required. Lifestyle changes identified by Westbrook [2,73] include employing household help, investing in adapted furniture / equipment, modifying the home, pacing activities, planning life more efficiently, resting more, and reducing physical activity. Many of these strategies fall under the categories of energy conservation, work simplification, and joint protection.

Clinical Commentary: Stressful Activities

An activity is too stressful when: [66]

- There is a feeling of fatigue.
- The 'quality' of movement has changed.
- The 'quantity' of movement has changed.
- Engaging compensatory movements.

Energy Conservation / Work Simplification

People living with post-polio may present with both micro (daily) and macro (lifestyle) issues. Allied health advice may range from energy conservation techniques to occupational or vocational planning. Many individuals will find that modifying their work situation or early retirement is necessary. People may need to reduce and modify their physical pursuits and will find that pacing their physical activity and including periods of rest will increase what they can do [26]. Allied health practitioners may have conversations about tasks that can be eliminated or delegated and how to build in pacing and rest to minimise occasions where tasks require 'pushing through' causing rebound fatigue days afterwards.

Body Mechanics And Joint Protection

Good body mechanics use the body with maximum efficiency to reduce muscle weakness, pain and fatigue. It also reduces the predisposition to developing nerve compression problems such as carpal tunnel syndrome.

Bracing and pacing strategies are both suggested to protect joints during activity. Practitioners can teach the principle of using the largest joints available, i.e. holding loads in the arms rather than hands, or looping handles over forearms or shoulders rather than through fingers.

Clinical Commentary: Lifestyle Redesign Advice For LEOp [67]

To be able to conserve energy, clients need to understand and predict fatigue levels. Once this is achieved other simple techniques can be implemented.

1. **Fatigue mapping:** Be aware of fatigue duration and the time of day it occurs. Where possible structure the day so that rests / napping can occur during periods of fatigue.
2. **Pacing:** Plan the day around rest breaks so there is adequate time to recover following activity. Ensure enough time for task completion so you don't have to be rushed which will exacerbate a sense of fatigue. Resting the day before a busier day can also help.
3. **Prioritising:** Before beginning an activity, think about how important it is to complete it. Prioritise activities that are the most important.
4. **Delegate:** Give tasks to someone else wherever possible (role balance) to save energy for higher priority activities.
5. **Energy conservation:** When energy is available, ensure self-pacing. Try not to rush through tasks 'before energy runs out'. This may make fatigue worse.
6. **Awareness:** Be aware of physical and mental states and respect signs of fatigue or stress, i.e. muscle soreness, weakness, tiredness, reduced quality of movement, jaw clenching, facial grimacing, etc. Stop an activity if it causes symptoms.

Prolonged standing is stressful. Some polio survivors say it is harder for them to stand in one place than it is to walk. Sitting lessens the demand on the cardiovascular system and relieves the weight-bearing joints of the legs and the back. It takes 25% more energy to perform an activity standing than sitting.

Through activity analysis and forward planning, many activities can be performed while sitting, e.g. working on hobbies, dressing, shaving, hair care, showering. Activity analysis will also identify when sitting down causes the work surface to be too high; solutions include adapting the work surface or introducing equipment for working at the kitchen counter such as a propping stool or drafting chair. The role of assistive technology devices and home modifications will be discussed further in Chapter 7.



Lived Experience Expert: Lifting Advice

Lifting and setting down a load can be hazardous as improper movements can squander energy and cause back injuries. Take a moment to assess a situation before starting:

- How heavy is the object? Must it be carried, and how far?
- If your legs are strong enough, it is best to squat and lift with your legs, not your back.
- Always test the load weight first by pushing with your foot. Injuries occur when a load is heavier, or lighter, than expected.
- If the load does not push easily it's too heavy to lift safely, so ask for assistance.
- If the weight seems OK, stand with your feet apart for a more stable base. Then kneel or squat, pick up the load and stand up while keeping your back straight. Of course, a good rule of thumb for polio survivors is to ask someone else to lift.
- Remember: Don't hold your breath during the lift. Exhale when you exert yourself during an activity.
- If leg weakness prevents you from lifting with your legs, take extra precautions to avoid muscle overuse and back injury. Sit in a chair and estimate the weight by pushing it with your foot, crutch or cane. If it feels light enough, sit close to the load and bend forward from the hips, keeping your back straight, and lift the load onto your lap, then place it on a table, chair, or other surface. Do not stand up while holding the load.
- To lower a load that is located above your shoulders, test the weight first, keep the load close to your body and let it slide down onto your lap if you are sitting, or onto a table if you are standing.

**Grace Young, OT (Dec),
North Central Florida**

Lived Experience Expert: Enabled Living



Ten years ago my rehab specialist encouraged a return to activities that I enjoyed. I recommenced gardening, used tools wisely and took plenty of breaks. This worked wonderfully and the possums appreciated my endeavours. I now clean the car once a fortnight - I take it to a drive-through car wash and, with regular rest, I spend 4-5 hours vacuuming and polishing. When finished, I have oxygenated and stretched a few muscles, produced something that makes me feel good, and it is a family activity in that they get to dirty the car again. A few years ago, a relief physio (consulted at my 6 monthly endurance and strength assessment) was totally frustrated by my full paced enthusiasm and blurted out "Peter, you need to pace yourself - you have the same physical endurance as a 78 year old!". She immediately apologised and I shared the empathy of a mutual challenge. I was 58 at the time. I listened very carefully to the physio's message, but it was Occupational Therapists who managed my acceptance of a disabled parking permit, hand rails, walking sticks, a scooter and, 2 years ago, the freedom of a power chair. I no longer have the endurance I had at 58, but at 64 I am no longer living life as an exhausted 78 year old.

Peter Willcocks, VIC

CHAPTER 7: ASSISTIVE TECHNOLOGIES

Assessing For Assistive Technologies

Use of assistive technology (AT) devices is a well-evidenced and effective strategy to mediate between a person's impairment effects, their environment, and the tasks or outcomes they wish to achieve.

The history of AT devices reflects changing attitudes to human diversity over many decades. From wicker bath-chairs and commodes to leather and metal braces, AT devices have at times represented stigma and 'othering' of those living with disability.

More recently, the universal and inclusive design movements have shifted perspective and ask why common products are not designed to be used by all. This paradigm shift has seen ergonomic peelers, easy-access door handles and stepless shower surrounds become mainstream and easy to use for everyone. Likewise, technological developments such as wired-in home automation is replacing costly and specialised environmental control systems and, in some instances, the iPad is replacing communication devices.

That said, AT device non-use or abandonment rates of 30% - 59% indicate that not all AT devices are effectively provided [74]. A literature review by Wessels et al identified a range of factors leading to abandonment or non-use, and provide a set of key indicators to guide the practitioner in assistive technology assessment and provision [75,76].

Best Practice In AT Provision

State funding schemes which provide AT devices within Australia fund only the actual device, not the service delivery time for a health practitioner or AT supplier to engage in the required 'human factors'. There has been a policy push by peak allied-health-prescribing bodies to name the 'soft technologies' which accompany the 'hard technology' (or actual device) to remedy this issue.

International best practice identifies a series of service delivery steps to incorporate soft technology and therefore maximise outcomes and reduce non-use attrition rates [77]. These have been adapted for Australia (see below):

Best Practice In Assistive Device Provision [78]

1. Problem identification.
2. AT assessment with an AT practitioner, e.g. occupational therapist.
3. AT trial across multiple environments of use: adaptation, training.
4. AT prescription / recommendation made and application for AT funding.
5. AT provision including fitting, custom-setup, sign-off.
6. Clinical review and AT performance review.
7. AT re-evaluation including needs assessment of consumer and equipment lifecycle.

Common 'clusters' of AT provision for individuals living with LEOp may include appropriate bracing, adaptive devices (walking sticks, crutches, corsets), special seating and postural modification [45].

The concept of relying on mobility devices such as walking sticks and wheelchairs can be extremely traumatic for those with LEOp. It is suggested that clients test out a device to help enhance their enjoyment of an activity, e.g. visiting an art gallery or at an airport. Psychological support can also assist the client to evaluate his/her therapeutic choices (rehabilitation, orthotics, mobility devices, medications, speech pathology or surgery), and to decide between treatment or treatment abstinence.

Factors Influencing Successful Assistive Device Use

User-Related Factors

- Age and diagnosis.
- Client and family expectations.
- Emotional maturity of the client.
- Progress of the disability.

Device-Related Factors

- Device quality.
- Appearance.
- Availability of choice between devices.
- Portability.
- Weight.
- Ease of use.
- Presence of multiple devices.

Device Market Factors

- Opportunity to trial devices.
- Adequate training.
- Convenient delivery.
- Prompt supply.
- Ongoing support.

Lived Experience Expert: Suite Of Strategies Needed

Many of us had to adjust our activities and lifestyles, renegotiate job descriptions, find new ways to accomplish tasks, learn about assistive technologies, and acquire new skills. In every sphere of my life changes were needed, ranging from a small household device to a new van, scooter, and car lift that would all work together. Some were necessitated by newer PPS symptoms, and others were extensions of older long-term needs such as finding shoemakers to correctly alter my shoes. Many were specific to particular life tasks like attaching a child seat to the back of my scooter. In all cases I had to advocate for myself, know my rights, and feel confident in pursuing them. Instead, I felt overwhelmed. The main lesson is to tackle one thing at a time. Always. It's vital to keep perspective on the essentials (mobility), what makes life easier (having a new curb cut), what reduces pain (better desk chair), or fatigue (closer light switch), and what's nice (bagel holder). [55]

Environment Factors

- Social support.
- Suitability of the physical environment to the device.
- Opportunities within the environment for use.

Which AT Devices?

Australia's Independent Living Centres (ILCs - ilcaustralia.org.au) are the peak agencies specialising in independent living equipment. The ILC database is available online and contains thousands of specific products which illustrate the ISO 9999 categories. Phone and email enquiry services support consumers, carers and allied health practitioners with information and clinical reasoning around AT and related solutions. Many ILCs run drop-in and appointment services, and provide education events and outreach.

The remainder of this chapter focuses on information from clinical practice, and from experts by experience, regarding some of the main AT device areas used by people with LEOp.

The "*International Standard Assistive Products for Persons with Disability — Classification and Terminology*" [79] has been adopted in Australia as a comprehensive taxonomy of AT devices. Appendix 3 contains excerpts of this Standard relevant to people living with LEOp.

Mobility And Community Participation

Assistive products for mobility and community participation include all devices that help people move within their environment. These may be simple gait aids such as walking sticks, crutches or frames, and wheelchairs (both manual and powered) or scooters for those who require greater assistance.

Gait Aids

Are essentially used to address the following issues:

1. Reduced balance (and risk of falls).
2. Weakness.
3. Biomechanical concerns (joint pain, joint deformity, ligament laxity).

The level of support given by a gait aid can be minimal (single point stick) to maximal (gutter frame); it may be used at all times or only in certain conditions. Decision-making for the right assistive device should be done in conjunction with the patient and put in context with a thorough medical history, physical examination of strength,

balance, mobility, and functional level. It is essential the therapist understands the purpose of prescribing the aid, client goals for the device, and the environments in which it will be used.



Image courtesy of Caulfield General Medical Centre

When prescribing gait aids it is essential to consider the following:

1. Where will the aid be used?
2. What kind of gait aid is being prescribed?
3. How is the aid used / held?
4. What is the condition of the client's upper limbs (particularly hands and shoulders if long-term heavy gait aid use is being considered)?
5. How will the patient transport the aid, i.e. to the shops, on trains and planes etc?
6. What footwear is the client going to wear?

A period of gait training is often required to optimise a client's use of an aid. They should have a sound understanding of how the gait aid works and how to maintain it. They should be able to use the aid to mobilise in all the environments that they plan to walk in.

If clients are expecting to take their gait aids into the general community it is reasonable that they can negotiate steps and curbs, walk on slopes and uneven ground, side step and take steps backwards, as well as perform simple agility tasks. They also need to be able to walk at a speed that will enable them to cross at a set of traffic lights [80]. They may also need practice at getting into and out of cars and getting on and off public transport.

Clinical Commentary: Stick Hazards

Many physiotherapists no longer prescribe tripod or quadripod sticks due to tripping risks. Current clinical protocols suggest this level of support indicates a need for crutches or a frame.

Lived Experience Expert: AT For Balance

Balance has always been a major problem for me. Falling whilst walking has been my major challenge. Rather than falling over a damaged pavement, my falls have mostly been the result of tiredness resulting in the left foot not stepping up far enough from the pavement to not drag, resulting in my stumbling. When I am out of the house I usually use a walking stick for support and balance. Today I wear an orthotic if walking and this has allowed me to engage in mildly active holidays both here and overseas. Occasionally I manage to play 9 holes of golf thanks to a golf buggy that I push and use as a walking frame. I am fortunate to still be able to drive an automatic car, but I am no longer able to get up onto busses or trams even with the assistance of a walking stick or well-meaning people.

Maureen Grant, VIC

Walking Sticks

Walking sticks are most useful for people with mild or moderately reduced balance or who require a walking aid to assist their confidence in more challenging environments.

They are usually held in the hand on the side of the stronger leg and used with every step made by the weaker leg. Weakness or pathology of the upper limbs may limit which hand the device can be held in.

It is worth trying different types of sticks to address different concerns:

- **Wooden:** easily available and relatively inexpensive.
- **Metal:** more light weight and often adjustable.
- **Folding:** good for clients who travel and plan infrequent use of an aid.
- **Walking sticks with a seat:** useful for walking short distances and if needing to rest frequently. Weight can be an issue.

Walking stick handles also vary:

- **Crook handles:** less comfortable to lean heavily on, but can be placed over the arm when not being used.
- **Right angled / T-shaped handles:** generally more comfortable to lean heavily on.
- **Swan necked handles:** allow body weight to be positioned over the central shaft of the stick and should be considered for someone who relies very heavily on their stick.

- **Contoured / arthritis or Fischer handles:** are produced to fit a left or right hand and aid even weight distribution for painful hands – most commonly due to arthritis.

Crutches

Crutches are for people with more significant limb weakness, biomechanical abnormality or loss of balance. They are generally used in pairs and may require a period of gait training by a physiotherapist to achieve the most normal and energy efficient pattern: this can be a two, three or four point pattern with a step to, or swing through, cycle.

Lived Experience Expert: The New World Of AT

When a series of odd pains and new overwhelming fatigue started to hit in the late 1980s, I went through GP prescribed tests that found nothing – ever. Persisting, I was eventually told “it was all in my head”. I found a GP who is thorough and professional. I have stuck with him in order not to be caught out by one overlooking illness on account of likely LEOp. I started listening to myself.

The situation was worsening; the good leg seriously impaired from so many years of carrying the load. Made the effort to have a team assessment at Polio Services Victoria, two hours with Physio, Orthotist and OT. This led to wearing a carbon fibre GRAFO. Felt like a trussed chook, hated having a crutch. Then found the beautifully designed brace was protecting the ‘good’ hip as well as the more obviously polio-affected side. Opened my eyes and ears to many new issues: access to buildings and public transport, the wonderful world of mobility scooters; the struggle to afford aids and equipment.

Fran Henke, VIC

- **Elbow crutches:** most commonly metal and adjustable, but can be customised if required. They provide more stable upper limb support than a walking stick due to the hand grip to elbow section which enables the patient to brace their forearm during the stance phase of gait. The elbow cuff also allows the user to retain the crutch if they let go of the handle, e.g. when opening a door. Handles can be standard, contoured / arthritis or Fischer handles, or a gutter arm rest for those with hand paralysis or inability to weight bear on the hand due to pain.
- **Axillary crutches:** provide the most weight relief on lower limbs. Usually only used for clients with extreme weakness of the lower limbs, who are cardiovascularly fit, and have good upper body strength. While they don't provide an aesthetically pleasing gait, they enable a person with profound leg weakness to tackle flights of stairs and cover distance rapidly. Axillary crutch users must be taught not to lean on the axillary pad as this may interrupt blood flow and nerve supply to the upper limb. Clients using these crutches should also have an alternative means to ambulate as long term / heavy use is challenging for the upper limbs.

Walking Frames

Walking frames are generally considered for people with significant lower limb weakness and/or poor balance. The walking frame has a bigger base of support than a walking stick or crutch so provides inherent stability and enables the patient to off-load more of their body weight. There are many different types of frames, of which the most common ones are outlined as follows.

Clinical Commentary:

AT For Carrying

- Kitchen trolley on casters: to transfer dishes, glasses, silverware and food from the counter to the table and back, and carry items in the house.
- Rolling backpacks: initially marketed for students, are great for books, files and clothing.
- Lightweight shopping trolley or luggage cart: for shopping centres, supermarkets and strip shops, to carry purchases and transport loads between the car, house or office, and from room to room.
- Wheeled laundry trolley: for transporting items around the home and garden such as laundry, grocery bags, and garden plants.

- **Pick-up frames:** Standard pick-up frames are usually light weight and made from metal. They will have four rubber stoppers / ferrules at the end of their legs for slip prevention. They have foam or moulded plastic hand pieces and can either be adjustable in height, or purchased at a specified size. By design, pick-up frames only allow a patient to walk in a three point, restricted pattern. Patients should be able to negotiate single steps safely. For this frame to be functional, prospective patients need to have the upper limb strength and endurance to lift the frame for every step they take. If they tire quickly, they may benefit from using a wheelie frame instead.
- **Folding frames:** These are useful for people with limited storage space at home or who want to be easily able to transport their frame in the boot of a car. They are inherently less sturdy than a standard pick-up frame.

Case Study: Mobility Selection

A retiree living with the late effects of polio, Peter is planning for a likely change from ambulation with bilateral calipers, to powered mobility. Peter researches power-chair options online with the ILC, and with several AT suppliers. To apply for State AT funding, he must obtain a health professional assessment and medical letter. Peter collaborates with an OT familiar with the progressive nature of his impairment as well as its contraindications. In light of Peter's extensive community mobility goals, they explore the compromise between seating integrity and dismantle-ability. The collaborative decision is a folding power-chair able to be transported in vehicles.

- **Wheelie frames:**
 - Two Wheelie: has two wheels at the front and casters, skis or rubber stoppers at the back. Ideal for clients who require the stability of a frame but don't have the upper limb strength for a pick-up frame. These are most appropriate for slow and frail clients who only walk inside. An attractive feature of these frames is that they allow the patient to walk with a reciprocal gait pattern.
 - Three Wheelie: has one wheel at the front and two wheels at the rear. The front wheel is multidirectional to aid steering. They are easy to fold and fit into a car boot. Ideal for clients with reduced balance and confidence and can be used indoors or outdoors. They allow the client to walk with a reciprocal pattern, but provide less stability and customisation options than a four wheelie frame.
 - Four Wheelie: has two large multidirectional wheels at the front and two large unidirectional wheels at the back. It has various braking mechanisms and accessories. A good indoor and outdoor frame which can be used by low-level walkers requiring maximal support and stability, and high-level walkers who want a sturdy frame that will keep up with their pace.
- **Gutter frames:** have forearm supports in the form of gutters or troughs (a platform is also an option). These enable the client to bear weight through their forearms rather than their wrists and hands and are appropriate for people with severe wrist and hand pain or who have a fractured wrist or hand. They usually have four wheels, but may have two and this will be determined by the needs of the client.
- **Walking stick / crutch stoppers (ferrules):** interface with the floor with a rubber stopper / ferrule. Monitored closely for signs of wear and cracking. If the under-surface loses its bobbles / slip resistant rings it needs to be replaced. There are two main options:
 - Standard Ferrules: inexpensive, easily available.
 - Flexyfoot: provide improved grip and stability on uneven terrain, aid shock absorption, wear evenly.

Brakes

- **Pressure brakes:** works when the client bears weight through his/her arms down onto the frame. This causes the brakes to be applied to the rear wheels and prevents the frame from moving whilst leaned upon.

This mechanism works well for some clients, but can be a challenge for clients who are not heavy enough to activate the brakes, or who lean too heavily on the mechanism throughout the gait cycle.

- **Hand brakes:** appear similar to bicycle hand brakes and are on both sides of the frame. They are operated by the client squeezing the hand piece. These work well for some clients, but others with weak or painful hands find them a challenge.
- **Hand locks:** a brake lever that is applied to immobilise the frame. This is an important feature for frames with a built-in seat.

Seats

Built-in seats are useful for clients with limited endurance. They remove the anxiety of being unable to find a chair if tiring suddenly. Some agility is required to engage the brakes and then turn around to sit down. When choosing a seated frame check the weight capacity is adequate. The seat height should allow the client to easily rise from sitting to standing. Clients must be advised to use the brakes at all times when sitting.

Other Accessories

- Trays.
- Shopping baskets.
- Net / vinyl bags.
- Walking stick holders.
- Oxygen bottle holders.
- Sheep skin seat covers.

Wheeled Mobility

People who have difficulty ambulating, who are unable to walk for distances, or for whom the terrain is a problem, may elect to use wheeled mobility [81] devices as an alternative to gait aids. Wheeled mobility can be divided into manual wheelchairs, powered wheelchairs, or three and four

wheeled powered mobility scooters. Innovation is occurring rapidly in the powered mobility arena, with two wheeled devices using centrifugal force, such as the Segway (www.segway.com), now marketed for disability.

Assessing For Wheeled Mobility



Selecting the appropriate device requires careful decision-making, weighing up the physical issues at hand and into the future, the tasks which the client wishes to accomplish, and the environments of use. Assessment with an allied health practitioner who specialises in mobility devices, usually a physiotherapist or occupational therapist, is necessary if application is to be made to funding bodies, and desirable in order to attain the best possible outcome.

Collaborative assessment will include physical and cognitive assessment, discussion of the client's occupational goals, an environmental assessment, and forecasting of future needs. Pragmatic concerns such as price are also important. Cost varies significantly in all categories, and is related to the durability, lightness, aesthetics and adaptability of individual devices.

Manual and power wheelchairs and scooters are available through all State Funding Schemes, to eligible participants.

Assessment must also include an analysis of the daily, weekly and extended tasks or occupations of the individual. This includes the interface with tasks and activities:

- What transfer methods are used for the individual to move seamlessly and repeatedly through his/her daily environs?
- What reach ranges are typically and atypically used?
- How can the device support access to the range of work surfaces, rooms and spaces in which life roles are carried out, such as kitchen, bathroom, garden and café?

It is often the case that a few key tasks are priorities for clients in considering their mobility needs. Therefore, care is required to understand all the overlapping activities which contribute to meaningful participation, to ensure the mobility device supports as many of these as possible.

Device Considerations

Frequently, 'trade-offs' are required:

- **Flexibility:** A lightweight manual device vs effort of manual propulsion.
- **Power-packs:** Available for a range of manual wheelchairs but may add significant cost and weight. Manual chairs lack the suspension usually expected in a powered device.
- **Seating:** A stable and supportive seat may be too bulky to dismantle easily into a car. Lightweight seats can enable devices to be dismantled and stowed in a car boot, but multiple lifts and effort is required for this. Mid-wheel drive power-chairs offer excellent seating support and driveability, but may limit the capacity of the client to approach and use areas such as desks or workbenches, and are not ideal for transfers. Seating systems in power wheelchairs are significantly more

supportive, may have the option of tilt and recline, tilt in space, and raising seats.

- **Transportation:** It may be more practical to invest in a sturdier device with a ramp and car with low boot height, boot-mounted lift, or a trailer to transport the device.
- **Castors:** Large castors are suitable for rough terrain, but these can affect the turning circle and may impinge on footplate clearance and ease of transferring in and out.
- **Control:** Wheelchairs also feature far more adaptability in terms of suspension, posture and positioning, and alternate controls such as chin or switching controls.
- **Terrain:** Only the smallest three wheeled scooter can be used indoors, so careful planning is required to consider which mobility device will be required as circumstances change into the future.
- **Cost:** 'Tiller-drive' scooters are relatively cheap compared with power wheelchairs, however require more upper limb strength than a joystick and provide limited postural support.

Environments Of Use

A continuous 'path of travel' approach is suggested to map and understand the interrelated places of use for a wheeled mobility device. This might include paths of travel from room to room, across thresholds and surfaces, and in and out of private vehicles or public transport. Length of travel paths and their complexity are important factors in determining what powered support might be required given the fatigue, pain, muscle weakness and ongoing deconditioning which may occur in LEOp.

Lived Experience Expert: Balancing The Use Of Aids And Equipment

I use a range of equipment for different circumstances balancing three things – getting where I want to, keeping myself active, and safety. Good bracing is the most important contributor to my mobility and I have three types. I mainly wear a Helios below-the-knee brace which provides some knee support and some 'spring' in my step and flexibility and enough support for my usual daily activities. I have a free knee jointed long-leg brace which has a Helios below the knee and provides extra knee support. This is good for shopping or other activities which require standing. My third brace is a fixed ankle KAFO which I use for swimming in the sea and also for Tai Chi. It supports and protects my knee but allows extra freedom of movement as it doesn't have a full foot plate. It doesn't assist my walking as much as the Helios so I only use it for these activities.

I also have a manual wheelchair, a mobility scooter, a walker and crutches. The scooter is mainly for use in shopping centres, the wheelchair for distances when travelling pushed by someone else, but occasionally self-propelled, e.g. in galleries and museums. The walker is used at the swimming pool so that I am secure and it can also hold my bag and brace, or when doing things that require me to carry things, e.g. taking things to someone in hospital.

I have a set of forearm crutches which I also use in different ways. I don't use any in small indoor settings such as home and work. I use one crutch outside for short distances (less than 10 minutes) and for longer distances I use two.

Anonymous

Orthoses

Orthoses in polio management are used to assist with control of movement, correct or prevent joint deformity, compensate for muscle weakness, and improve energy efficiency.

A comprehensive biomechanical assessment is required to assess gait, lower limb strengths / weaknesses, joint mobility and the compensation strategies employed for movement. Orthoses are subsequently prescribed based upon this assessment.

Three key muscle groups are tested in the lower extremities to determine the most appropriate type of bracing needed to

substitute for the weak muscle groups: hip extensor muscles (gluteals); knee extensor muscles (quadriceps); and ankle plantar flexor muscles (calf muscles). Types of orthoses which can be prescribed based upon assessment include:

Lower Limb

- Foot Orthoses (or insoles): improve foot alignment, effect the alignment of the joints above, and often used to redistribute pressure and provide comfort.

- Ankle-Foot Orthoses (AFO): assist in control and stability of the ankle-foot region; have a role in influencing knee biomechanics, and substitute for weak ankle muscles including the calf muscle.
- Knee-Ankle-Foot Orthoses (KAFO): support the whole lower limb, substitute for weak quadriceps and compensate for severe muscle weakness and knee mal-alignment.
- Walking aids may be required in addition to orthoses, particularly in the case of weak hip muscles.

Spinal And Abdominal

- Rigid braces support kyphosis or scoliosis.
- Abdominal binders or corsets support weak abdominals and diaphragm, and assist with breathing, coughing, and back pain.



Image courtesy of Neuromuscular Orthotics
www.neuromuscular-orthotics.com.au

In 2007 Carolyn Kelley, PT, MS, NCS and Thomas DiBello, BS, CO, FAAOP published a

"Classification System" [82] for assessing individuals with PPS. The abstract follows.

Clinical Commentary: Orthotic Assessment For PPS [82]

Abstract:

Technological advances have given individuals with [PPS] and orthotists more choices in orthotic design and fabrication to sufficiently support and assist weakened lower extremities while walking, standing, and transferring. Stronger and lighter weight materials and components allow increased control and improved energy efficiency while ambulating and transferring. There are many challenges in recommending orthoses to people with PPS, as this patient population has worked extremely hard to overcome their impairments and functional limitations, and many will see the addition of an orthosis as a failure or clear evidence that they have gotten worse. There are few published guidelines to facilitate the healthcare provider's decision making process in the area of orthoses, and none specific to patients with PPS. Therefore, the purpose of this classification system proposal is to provide clinical guidelines for the recommendation of orthoses for individuals with PPS. When assessing a polio survivor for an orthosis, one must consider the following factors: previous orthotic use, pain, fall history, new muscle weakness, and fatigue levels. This article reviews existing evidence, presents and describes a classification system to facilitate healthcare providers in the clinical decision-making process related to orthoses and PPS, and discusses a patient case example of how the classification system can be utilized.

Footwear

Residual weakness, tight or lax musculature and foot size difference can lead to problems such as comfort, cosmesis, energy expenditure, balance and safety. Footwear is one aspect of management of foot issues. Should orthoses be worn, footwear may be required in a half size larger to accommodate. Podiatrists, orthotists, specialist footwear suppliers and other practitioners may recommend:

- Extra cushioning to keep the foot comfortable and take weight when the foot has tight muscles and joints and is very rigid (resists movement).
- Built up sections (internally or externally) to compensate for leg length discrepancy.
- Shock absorbing materials in the sole of the shoe if the problem is profound, and also involves the ankle.
- Reinforcing the shoe for extra support and stability to counteract foot flexibility due to weakness.
- Extra depth footwear and moulded uppers to manage hammer, claw or mallet toes or atypical foot shapes to avoid excess pressure or rubbing over the involved joints.



Image courtesy of Neuromuscular Orthotics
www.neuromuscular-orthotics.com.au

- Extra stability can be gained from shoes that have a broad, flat sole with a non-slip tread.
- Maintenance of uneven wear, e.g. the outer border of the heel, or if the nonslip tread is wearing thin.



Lived Experience Expert: Enabling With AT Devices

Denial of declining strength and mobility is a great issue for polio survivors as we were taught from an early age to ignore our limitations and push hard to be independent. While that attitude may have served us well in our formative years, now that we are ageing with LEOp we have to start listening to our bodies and dealing with, rather than ignoring, our mobility restrictions. Falling and breaking bones which may not heal satisfactorily or in a timely way is now a very important consideration.

For many, the answer will be mean using a wheelchair. We fight against it. We don't want to lose our hard-won independence and we see 'giving in' to wheelchair use as the thin edge of the wedge. The media and the general public don't help by referring to those of us who use wheeled mobility as being 'wheelchair bound' or 'confined to a wheelchair'. This negative language makes the transition even more traumatic. Whenever I am referred to in this negative way I always (hopefully gently) point out that I am enabled by my wheelchair. I could not participate in society to the extent I do without it, and my life is enriched by being able to contribute to the polio community.

My advice is to embrace the technology that is available today, and enjoy freedom of activity with safety and without exhaustion. If enough of us spread the 'enabled' message, perhaps the rest of the world will stop seeing us as 'confined'.

Gillian Thomas
Vice President, Polio Australia
President, Polio NSW

Lived Experience Expert: Solutions Focus

I truly believe that a holistic approach is needed and an assessment made... Many don't seek this advice and end up going round in circles trying to find help. After assessments the correct aids can be made which hopefully will improve gait and help with pain. An experienced orthotist is crucial here along with a physio who can help with walking patterns and balance, etc. Prior to purchasing major equipment, clients should get advice from an OT or from an Independent Living Centre. So they're not really optimising what is most beneficial for them or what is actually available to make life easier. I have always found OTs to be an absolute wealth of knowledge when it comes to suggesting ways of conserving energy and easier ways to manage our daily activities. But, it's a holistic approach that works here. I personally now have a smorgasbord of goodies to assist me and am only too happy and lucky to have them i.e. walking sticks with moulded handles, walker for night time trips to bathroom, bed pole to help turn over in bed, egg crate mattress overlay to help with pain, pick up stick which has stopped me knocking myself out trying to pick up 'stuff', a wheelchair for when I travel, an electric scooter with a hoist in the boot of my car that I can manage by myself to maintain my independence (it is wonderful and allows me to shop all day if I want OR do a beach front walk along the many pathways), a new, up-to-date calliper which has straightened my leg and my body alignment which has improved my pain levels. Fortunately, I have been able to fund these items myself.

Anonymous

CHAPTER 8: REDESIGNING THE ENVIRONMENT

Assessing The Home

Physical environmental barriers have a significant impact on participation rates for persons living with impairments and the effects of ageing. Redesign of the environment requires removing environmental barriers and enhancing facilitators and is a key intervention to minimise the lived experience of disability and maximise quality of life. Taking the holistic perspective offered by ICF, it is essential to observe the person in his/her home context to fully evaluate the relationship or 'fit' of a person with his/her occupations, goals and environments. Additionally, for those with LEOp the likely trajectory of the disease, the life roles and participation goals of the individual for the future should be considered [83].

The home environment is the context for much of people's lives. While a range of allied health professions may engage with clients at their home, occupational therapists are the primary profession trained in strategies to adapt the environment. Occupational therapy home assessments improve safety features within the home and adjust behaviour to enable people to move more safely in their environments [84].

Conducting A Home Assessment

Specific areas for review and potential adaption are:

- **Furniture:** review bed and chair for height, supports and indicators for accessories to support transfers (chair or bed blocks, transfer poles or bed sticks, weight transference and transfer strategies).
- **Reach ranges:** review door and window furniture for reach and manoeuvrability. Consider levers, pulleys or remote control (plug in controllers or ambient systems if renovating).
- **Domestic areas:** reorganise for fatigue management and energy conservation. Consider raised or lowered workstation area for use with propping stool or from seated position for cooking: butcher's blocks, elevated moveable chopping areas or kitchen trolleys may suffice instead of minor structural modifications. Utilise racks for stacking pans and plates to eliminate lifting. Store frequently used items between hip and knee height. Use an angled mirror against the wall over the stove to see what is cooking while seated. Front loader washer and dryer enables laundry to be handled from a seated position.
- **Storage:** Reorganise linen and supplies to minimise distance to walk to storage. Suggest multiple reaching aids in useful places, multiple scissors, sticky tape, and similar high use items in various locations to minimise time spent fetching these. Multiple telephone points or cordless phone to increase ease of communication.
- **Review access points:** External pathways and entrances, access to garden, washing line, external buildings and letterbox. Home modification funds are limited, but conversations about 'future-proofing' household access and maintenance may assist in decision-making regarding long-term housing options.

- **Path of travel:** Introduce a continuous path of travel to avoid gait and balance readjustments due to rough terrain, sloped surfaces, cluttered rooms, steps and variable surfaces. Screen for loose cables and electrical cords.
- **Flooring:** minimise surface changes such as carpet edging between rooms. Recommend non-slip or low-pile flooring options. Remove all loose mats or secure firmly with a non-slip underlay.
- **Wet areas:** raise hazard awareness for wet surfaces, lack of supportive footwear, fatigue or complex movement patterns, e.g. bathroom or shower areas. Consider non-slip treatments to flooring, addition of handrails in wet areas or adjacent to transfer points, and sturdy equipment such as a shower stool to improve balance while drying and dressing.
- **Lighting review:** educate regarding major contrasts in lighting to avoid visual challenges when moving from light to dark areas. Recommend night lights and/or sensor lights for common paths of travel, e.g. bathroom to bedroom, or bedroom to kitchen. Take time to adjust vision prior to starting on a journey at night.

Supports And Assistive Technology

Chapter 7 addressed the range of assistive technology (AT) devices which can augment functional limitations for the person with LEOp. Allied health practitioners should be alerted to the following important role of AT:

- **Ambient monitoring systems:** within dwellings are used to maintain people with complex conditions in the community. These include generic technologies such as mobile phones (GPS enabled) and remote video cameras, often marketed as 'smart home' technology. Monitoring technologies potentially decrease adverse incidents in the home as well as having a health technology function, i.e. enabling health conditions to be managed at home rather than in a health setting [85].
- **Video technologies:** enable remote consultations (also known as teleconferencing) with a general practitioner or specialist service and provide access to 'virtual' support where transport is not an option.
- **Powered bath hoist:** located on the floor can be used to elevate a person from floor level to sitting, either self-operated or by another person. While costly, this can be a useful backup.



Resources For Design

The following information draws extensively upon Australia's Independent Living Centres to help find necessary contractors, therapists and other useful information sources to assist with functional environmental redesign.

There are many resources that assist consumers, e.g. Therapy Choices (www.therapychoices.org.au) to make a choice of health professions.

To establish the quality of a profession and individual practitioners, check if the profession is registered with Australian Health Practitioner Regulation Agency (AHPRA), or is a member of the Allied Health Professions Australia (AHPA). Next, establish if the individual practitioner is a member of their professional association, as this provides some assurance about continuing professional development and quality practice.

Contact details are:

www.ahpra.gov.au

www.ahpa.com.au

For Consultants And Therapists

Association Of Consultants In Access Australia Inc.

The ACA is the peak national body in Australia for access consultancy. It works to achieve higher standards in accessibility in the built environment for people with disabilities. The website www.access.asn.au has an ACA consultant directory by postcode search.

Occupational Therapy Australia

OTs assess a person's ability to gain access to a particular environment. Assessments may be specific to an individual's situation or for a general public environment.

OTs may recommend alterations to the environment or to the technique and equipment used to access it. The private practice register of Occupational Therapy Australia www.otaus.com.au/find-an-occupational-therapist lists private occupational therapy services by specialty and by region.

Alternatively, OTs are employed at most community health centres and many public and private hospitals. Community-dwelling individuals wishing to have an OT review or home assessment are advised to contact their local community health service.

For Building Codes And Standards

Standards Australia

Standards Australia is an independent, not-for-profit body recognised as the premier non-government building code and standards organisation in Australia. It monitors what is considered viable and safe building. It is important to consider the standards when making modifications to the home to allow for the installation of AT or the adjustment of current infrastructure. There is advice on safe gradients, ceiling heights, etc. all designed to help make modifications as safe as possible. Standards Australia recommends that you review their FAQ (frequently asked questions) page before making any enquiry. Contact details are: www.standards.org.au/Pages/default.aspx
Toll free information service: 1800 035 822.
Email: mail@standards.org.au

The Australian Building Codes Board

This is a joint initiative by all levels of Australian Government and includes members from the building industry. It is a regulatory body that is constantly evolving to meet the needs and provisions of current technology. The Building Code of Australia, a good guideline for any modifications made to the home, is available on the website:

www.abcb.gov.au

General enquiries: 1300 134 631

Email: ncc@abcb.gov.au

Livable Housing Australia

Livable Housing Australia is a not-for-profit partnership between community and consumer groups, government and the residential building industry. They want to transform the way homes are designed and built, and they advocate the mainstream adoption of livable housing design principles in all new homes built in Australia. LHA's nationally-endorsed Livable Housing Design Guidelines describe the features that help make a home more livable and are available on their website:

www.livablehousingaustralia.org.au

Phone: 1300 738 913

State And Territory Equipment Schemes

VIC

State Wide Equipment Service (SWEP)

swep.bhs.org.au

NSW

Enable NSW

www.enable.health.nsw.gov.au

QLD

Medical Aids Subsidy Scheme (MASS)

www.qld.gov.au/health/support/equipment

WA

The Community Aids and Equipment Program (CAEP)

disability.wa.gov.au/services-support-and-eligibility/services-supports-and-eligibility-new

TAS

Community Equipment Scheme

www.dhhs.tas.gov.au/service_information/services_files/RHH/treatments_and_services/community_equipment_scheme

ACT

ACT Equipment Scheme (ACTES)

www.health.act.gov.au/health-services/community-based-health-services/rehabilitation-aged-and-community-care/village-creek-centre/act-equipment-scheme-actes

SA

The South Australian Domiciliary Equipment Service

des.domcare.sa.gov.au/des

NT

Territory Independence And Mobility Equipment Scheme

www.health.nt.gov.au/Contacts

Home Modification Resources

The NSW Home Modification And Maintenance Services State Council

This is a Government service for the frail, elderly or disabled which may assist with the installation of AT like grab rails, bathroom and kitchen modifications and even mowing your lawn. It also provides information and help to contact occupational therapists, carers and contractors. PDF versions of their brochures are available on the website in various languages. A 'nearest service' search feature is available on the website:

www.nswhmms.org.au

Phone: (02) 6622 8386

Email: info@nswhmms.org.au

The Victorian Home Renovation Scheme

Eligibility requires that you live in Victoria and are over 60, have a disability or are permanently caring for someone with a disability. Inspections are given by request after which a recommendation of changes / modifications and cost / quotes is given. A variety of modifications may be made via this scheme including: bench height adjustment, ramp construction, flooring changes, step-less showers and general maintenance:

www.dhs.vic.gov.au

Arrange a home inspection by calling Archicentre Home Services: (03) 9815 1900 or 1300 136 513.

Home And Community Care In Western Australia

The HACC program helps with minor structural changes for home safety and basic garden maintenance. It also assists with training clients to be better suited to independent living and can assist with taking some of the load off carers. There is a small fee to receive the HACC services and this fee is outlined in their downloadable brochure:

www.health.wa.gov.au/hacc/consumers/program.cfm

Phone Commonwealth Respite and Carelink Centre: 1800 200 422 for eligibility enquiries.

Information Services

The Home Modification Information (HMinfo) Clearinghouse is run by the University of Sydney. HMinfo translates high quality research specific to better design and building practice, containing extensive reviews of common issues:

www.homemods.info

Research publications by the HMinfo team at www.homemods.info/publications-by-hminfo/evidence are based on a systematic review methodology. The reviews are academically rigorous documents that are peer reviewed by specialist panels that are relevant to the topic. Additional publications are developed from this evidence base, including consumer and industry factsheets and checklists.

Factsheets

Consumer and industry factsheets are based on the Evidence Based Practice Reviews and provide information for consumers and industry professionals (includes a checklist) respectively on how to apply the best practice information gleaned from the research:

www.homemods.info/publications-by-hminfo/consumer

www.homemods.info/publications-by-hminfo/industry

Occasional Research Publications

Occasional research publications are produced by the HMinfo team based on methodologies other than systematic reviews. For instance, publications summarise industry relevant hot topics identified by the HMinfo Advisory Committee, or the Forum section of the website. These include articles on items such as thermostatic mixing valves or electrical safety within the bathroom and other specific research topics related to an industry related concern or known practice failure:

www.homemods.info/publications-by-hminfo/occasional

Summary Bulletins

Summary bulletins provide a concise overview of the issues relevant to a particular home modification topic. This information is intended to assist residents, carers, and home modification providers, to determine the most appropriate home modification approach for their personal, housing environment, and care circumstances:

www.homemods.info/publications-by-hminfo/summary

HMinfo maintains an electronic database with over 2,600 online and hardcopy materials relevant to the sector. Additionally, as a byproduct of the research, they produce annotated bibliographies of the best references for particular topics such as grab-rails, lighting and vision etc. to industry and other researchers:

www.homemods.info/publications-by-hminfo/annotated-bibliographies

CHAPTER 9: CONCLUSION



Focusing on muscles and mobility within the context of activity and participation, this Clinical Practice Module combines the evidence-based literature, the contemporary practice wisdom of Australia's current allied health polio specialists, and the expert knowledge of those living with the Late Effects of Polio (LEoP) and/or Post-Polio Syndrome (PPS). The intent is to inform health professionals and the broader primary care community regarding good practice in the management of individuals living with post-polio.

The range of strategies and interventions available to the health practitioner community include physical treatments, task adaptation, and the use of assistive technologies, environmental interventions and other supports. Optimal delivery of any and all interventions must occur within a collaborative, person-centred model, and utilising a multidisciplinary team approach. The person-centred practitioner recognises and respects the client as an 'expert by experience' and engages in collaborative processes with individuals and their families affected by polio, working together to achieve the person's desired outcomes.

People living with LEoP desire to live, work, relax, and play along with the rest of the Australian community. Life aspirations are not different, but the complexities of 'getting

there' may be greater. Allied health practitioners can contribute careful assessment, judicious use of available supports and interventions, and sensitive longer term planning, enabling full lives to be lived.

A Final Word From Polio Australia

Production of this comprehensive Clinical Practice Module brings Polio Australia one step closer to its goal of ensuring the national provision of standardised, quality polio information and services for polio survivors.

We commend the module to health professionals across Australia as we work in partnership with you in the support of and care for this nation's hundreds of thousands of polio survivors.

**Gillian Thomas
Mary-ann Liethof**

CHAPTER 10: APPENDICES

Appendix 1: Late Effects of Polio – Self-Assessment For Clients

LATE EFFECTS OF POLIO Self-Assessment for Clients

Can a Physiotherapist Assist You?

Answer the following set of questions to help identify whether the problems you are experiencing are ones that a physiotherapy assessment can assist with.

Circle the answer that best describes you:

1. Mobility

- | | |
|--|--------|
| 1.1 Have you noticed a progressive decline over the last one to five years, in your ability to move about as you have always done? | YES/NO |
| 1.2 Are you unable to walk as far (with or without aids like crutches) as you used to manage five years ago? | YES/NO |
| 1.3 Does 'getting about' tire you much more than it used to? | YES/NO |

2. Pain

- | | |
|--|--------|
| 2.1 Do you have problems such as joint pain, muscle pain, or increasing muscle weakness which have become worse in the last two years? | YES/NO |
| 2.2 Do you have trouble bending because your back hurts? | YES/NO |

3. Ability to Do Every-Day Things

- | | |
|---|--------|
| 3.1 Are you finding that your daily activities are becoming more limited by increasing breathlessness and fatigue? For example, do you find that you are unable to do the housework or gardening now, when it was not a problem a year or so ago? | YES/NO |
| 3.2 Are you unable to stand for as long as, say, two years ago? | YES/NO |
| 3.3 Do you have difficulty getting up from the floor, when this is something you have always been able to do? | YES/NO |
| 3.4 Are you unable to go shopping unless you get a close parking spot? | YES/NO |
| 3.5 Are you unable to stand for the usual length of time in a queue at the bank or check-out counter? | YES/NO |

4. Falling / Unsteadiness

- | | |
|--|--------|
| 4.1 Do you fall frequently at home? These may be relatively minor falls or trips, but seem to be occurring more often. | YES/NO |
| 4.2 Are you unable to carry objects, because you might fall and need your arms free to save yourself? | YES/NO |
| 4.3 Do you find walking downstairs now more difficult than going upstairs? | YES/NO |
| 4.4 Can you now only manage stairs if there are rails to hold on to? | YES/NO |
| 4.5 Are you unable to walk fast or run to catch a bus without falling? | YES/NO |
| 4.6 Is this something you have been able to do in the past, or never able to do? | YES/NO |
| 4.7 Are you having difficulty travelling by bus because you are unable to stand and balance on a moving bus? | YES/NO |

If you have answered **YES** to **any** of these questions, an assessment by a physiotherapist may help you regain some of this lost function or maintain existing function.

Source: G Jegasothy / N Fortescue, Senior Physiotherapists, Royal Perth Hospital, Shenton Park Campus, Western Australia

Appendix 2: Late Effects of Polio – Guide To Physiotherapy Assessment

LATE EFFECTS OF POLIO Guide to Physiotherapy Assessment

Name:

Phone:

Assessment Date:

Referral source:

Diagnosis:

Presenting mobility at assessment:

Must be documented - important for future reviews to look back at initial presentation.

Communication:

Noting clarity of speech and if patient had a documented, detailed list of symptoms.

Early History:

- Include history of polio - initial onset, which muscles were paralysed, how many muscle groups were involved?
- Patients may not have direct knowledge, depending on onset age. Quiz them about what they were told by family or what they remember. Could they move any limb? Could they lift their head off the pillow? Could they sit up in bed? Were they carried? Leading questions will tell you what paralysis may have occurred.
- Could they breathe on their own or were they put on ventilator assist, or required oxygen?
- On resolution of acute symptoms, what was the residual weakness?
- Ask about callipers - when used and when taken off?
- Ask about activities and games they played in junior years - this tells the physio which muscles were re-educated. Did they walk to school or were they driven?
- Ask about activities and games they played in high school - this tells the PATIENT about muscle capacity developed. Did they walk to school, did they cycle, catch public transport or were they driven?
- Ask about work - this indicates type of strain and stress. How did they get to work?
- For medical legal reasons, it is important to record if medical history recorded was information given by the patient during assessment. Avoid copying any information from medical referral, unless the patient has given the physio a copy of medical referral.

Social History:

- What are the patient's living arrangements, work status? Do they drive a car and/or catch public transport? Who does housework and/or shopping?
- What is the patient's current fitness regime or exercise program?
- Record how patient funds special equipment s/he is currently using. If wearing orthotics or callipers, who supplies these and how is this funded?

Mobility Status:

- Functional mobility - if patient is working, note higher skills, e.g. walking slopes, stairs, carrying objects and walking, i.e. dual attention tasks.
- Can patient climbing in and out of high vehicles and/or climb up ladders?
- Record how the patient does ADL (activities of daily living) and self-care. This is revealing, especially for those with marked paralysis.
- Physio may have to follow patient to the toilet to observe how they transfer, especially those with complex presentations and comorbidities. Patients often do not think that their transfer technique is unusual.
- For select patients, e.g. cognitive disability or severe scoliosis:
 - time functional mobility tasks, e.g. rolling, lying to sit, transfers, sit to stand, standing, include off the floor.
 - on and off the toilet - observed and time.
 - in out of car - description and timed.

Presenting Problems- Linked to Functional Limitations:

- Prioritise the problems - ask questions that would jog memory, e.g. pain - all the usual pain assessment questions, including analogue scale.
- With fatigue and pain, find out if patient is able to link this to activity.
 - Any sudden increased activity over previous 2 days?
 - How long a rest period is required before s/he recovers? Does s/he have days when s/he is washed out? Link this with activity.
 - Does heat / cold / taking medications help?
- Are there periods of fatigue when s/he 'freezes' during activity and/or is unable to continue walking?
- Does s/he get up in the morning with fatigue? Common for LED clinic consultants to recommend a full blood screen to assess biochemical stability.
- Does s/he get up in the morning feeling tired? Does s/he snore? Does family report that patient snores? Does the snore pattern have quiet periods in it?

Common Complaints:

- Patients may not think to articulate the following, as it has been part and parcel of their day to day living. Physio will have to ask the direct question "*do you experience . . . ?*"
- Joint pain, fatigue, night cramps, pain in legs or in feet, only at night. This pain is sometimes described as tingling pain or 'jumping legs'.
- Problems with frequently tripping or even falls.
- Problems with walking over grass versus walking on pavement. Difficulty with walking over kerbs / stepping over objects without changing stride length.
- Shuffling when approaching objects.
- Shortness of breath - examine for scoliosis.
- Continence issues.

Patient Goals Related to Functional Limitation:

- Very important to note and tie this to a function.
- Occasionally list physio goals. This is a good exercise, especially when patient has multiple, complex comorbidities, e.g. polio and severe rheumatoid arthritis / osteoarthritis with marked joint deformity.

Use of Other Health Professionals:

- Alternative health practitioners, other physios, and outcome of treatment.
- Current Medications.

Assessment:

- Timed Up-and-Go Test over 3 Metres
- Note if patient pushes off arm of chair, uses of orthotics and walking aids (modify using parallel bar for select patient).
- Note time taken to take the first step - this has prognostic value.
- 6 Minute Walk Test
 - take resting heart rate.
 - post exercise heart rate and heart rate 5 minutes later.
 - Heart rate and blood pressure are inaccurate if patient is taking medication for blood pressure control.
 - breathlessness scale - scale over 10 and Borgs perceived exertion scale.
- 2 Minute Walk Test (for appropriate patient).
- Wheelchair pushing for 6 or 2 minutes, as relevant - especially if this is the main mode of transport for patient.
 - observe pattern of wheelchair pushing and stress and strain on patients shoulder.
 - this can be due to physical layout of the wheel chair or patient technique and bad habits.
 - BUT whatever the reason, advise on correct technique in pushing wheelchair can correct many neck, back pain, and upper limb joint complaints.

Ambulation Pattern:

- Very brief problem list – note walking aids used, include orthotics and insoles.
- Observe gait during 6 minute walk test.
- Record which phase of gait is missing - not necessary to describe the whole gait pattern.
- If patient is complex then record starting posture, walking aid and side of use.
- Movement at hip, knee and ankle joints at mid and late swing phase.
- Movement at hip, knee and ankle joints at mid and late stance phase.
- Analysis can be done later. It does take experience to do gait analysis and draw a conclusion, while patient is walking.

Range of Movement (ROM):

- Orthopaedic or Oxford scale used by all physios to register passive and active range of movements.
- All limbs, neck and spine movements.
- Record both passive and active range. The difference between these ranges should give the physio an understanding of the problem the patient is faced with.
- Patients with specific complaint of spine / joint pain - target testing done, as per below:

Upper Limbs:

- rotator cuff strength - empty can test, lift off, external rotation
- impingement - Hawkins and Kennedy
- stability – apprehension
- stiffness as per passive and active ROM
- Neural Tissue Provocation Test (NTPT)
- muscle length

Hip:

- ROM active and passive
- FABER
- rotation at 90 hip flexion
- Ober's test
- muscle length

Knee:

- ligaments
- meniscus
- patella / femoral joint

Ankle:

- ligaments
- fore and hind foot mobility
- glides
- muscle length

Spine:

- active ROM
- posture
- palpation
- muscle recruitment – abdominals
- NTPT
- muscle length
- tendon jerks, if warranted

Tone:

- Severity indicated by + or ++, etc. Record muscle groups.
- Record resting tone / associated tone.
- Hypotonia or Low tone - to passive movement and feeling muscle belly, descriptive, no measures for this.

Sensation:

- As per neuro assessment - usually very quick, unless patient highlights specific complaint of loss of sensation.
- Light touch discrimination, sharp / blunt and proprioception.
- Use body chart to note above problems.

Muscle Strength:

- Note resistance through full active range and resistance against hold at mid-range.
- Note as 3/4+. The first number denotes strength through full range and second recording denotes resistance to hold.
- If patient does not achieve full range but does achieve $\frac{3}{4}$ range in good movement pattern, the strength is marked down. Patient must achieve full range.
- Avoid grading 3- and 3+. Movement against gravity is a good marker if recovery of muscle strength is an achievable goal. Rule of thumb, grade 3 and above can be strengthened but 2+ and below is unlikely to get higher grades.
- Routine test on all patients - helps clinical reasoning.
- Test patient in supine. Fully supported position usually eliminates error recording secondary to pain.
- Upper limbs can be tested in supported sitting, vital for patients with scoliosis.
- Patients with severe scoliosis – sitting may be the only choice.

		(R)		(L)	
		ROM	Strength	ROM	Strength
Shoulder	Flexion Extension Adduction Abduction Int rotation add Ext rotation add Int rotation abd Ext rotation abd				
Scapula	Elevation Depression Protraction Retraction				

		(R)		(L)	
		ROM	Strength	ROM	Strength
Elbow	Flexion Extension				
Wrist	Flexion Extension Ulnar deviation Radial deviation				
Fingers	Flexion Extension Lumbricals				
Hip	Flexion Extension Abduction Adduction Int rotation 0 Ext rotation 0 Int rotation 90 Ext rotation 90				
Knee	Flexion Extension				
Ankle	Dorsiflexion Plantarflexion Inversion Eversion				
Toes	Flexion Extension Lumbricals				
Trunk	Flexion Extension Lateral flexion R Lateral flexion L				
Neck	Flexion Extension Side flexion Rotation				

For Clients With Intellectual Disability - Modified MC:

- Position and test described, e.g. was patient tested in standing / support standing when testing lower limbs and sitting for upper limbs
- Note - was movement strength and control inferred from observation of patient's movement?
- Occasionally, for the above category of patients, an assessment of functional ability may have to do. The limb movements can be inferred from an analysis of the latter.

For Patients with Marked Scoliosis:

- Remember to remove clothing when testing shoulder joint movement.
- In kypho-scoliosis, shoulder joint limitation is secondary to scapula excursion.
- Patient must be tested through passive and active joint range in fully supported position.
- Trunk flexion, extension, lateral flexion, e.g. finger position in relation to knee joint and trunk rotation in unsupported sitting, is imperative.
- Observe how these patients bend down to pick up small objects from the floor. This can be used as a test.
- Patients often do not realise their tendency to compensate for movements. When these patients experience back or hip pain, inability to do 'their normal pattern' can cause falls.

Balance:

- Tested only if identified as a problem by patient or GP.
- Equilibrium test - in sitting and standing as relevant.
- Eye movements and tracking - slow and fast, visual fields.
- Tracking slow and fast, with head movements.
- Standing, Eyes open (EO) / Eyes closed (EC), normal and narrow base. Tandem standing and Single leg standing - both EO / EC.
- Include head rotation / answer questions with EO / EC to test dual attention capacity. Test prescribes 30 seconds, but continue beyond 30 seconds and up to one minute, for endurance.
- If there was a question of safety with use of a particular walking aid, include a Berg Balance scale - not routine requirement.

Problem Identification:

Use this section to rationalise and identify the patient's problem list, once all above tests are done. Attempt to explain patient's complaints using clinical rationalisation.

Management:

Use this section to list management strategies needed to address problems identified above.

Plan:

- How this is to be achieved? Record what has been organised / arranged, as ongoing therapy. If the physiotherapy is only an assessment clinic, detail and prescribe the exercise program the patient requires.
- Identify the muscles to be targeted and joints that need protection.
- Prescribe the endurance program and strength program.
- Stress % of one maximum considered suitable for the patient. Be as prescriptive as possible, as program may be supervised by a personal trainer, etc.
- Suggest a home program. Recommend equipment suitable for home use - this ensures that it is an all-weather program.
- Document orthotic and equipment that patient needs to have to reduce joint strain. Document name and contact of the orthotist and OT the patient was referred on to.

Further Investigations:

Record X-rays, sleep apnoea tests, and booked medical investigations. Document information sent to patient's GP.

Future Plan:

- As patient is often only seen once, it assists with reviews if future plan is worked out during initial assessment.
- Include life style activity suggestions which would assist maintain any of the gains achieved by rehabilitation.
- It may be worth recording suggestions that patient has rejected, especially for medical legal reasons, e.g. when reviewing a patient after a fall on public transport or in public area.

Review:

Record who will book review, e.g. physio, or if patient is to ring back on achieving a set exercise goal.

Source: *Physiotherapy Department Template used by Late Effects of Disability Clinic, Royal Perth Hospital, Shenton Park Campus, Western Australia*

Author: *G Jegasothy, Senior Physiotherapist, LED Clinic (Retired 2014)*

Appendix 3: Assistive Products For Persons With Disability ISO 9999:2011

Classes of AT devices	Subclasses of AT devices used by individuals with LEOp
04 Assistive products for personal medical treatment	
	04 03 Assistive products for respiration 04 06 Assistive products for circulation therapy 04 19 Assistive products for administering medicines 04 30 Assistive products for heat or cold treatment 04 33 Assistive products intended to manage tissue integrity 04 48 Equipment for movement, strength and balance training
06 Orthoses and prostheses	
	06 03 Spinal and cranial orthoses 06 04 Abdominal orthoses 06 06 Upper limb orthoses 06 12 Lower limb orthoses 06 15 Functional neuromuscular stimulators and hybrid orthoses 06 18 Upper limb prostheses 06 24 Lower limb prostheses 06 30 Prostheses other than limb prostheses 06 33 Orthopaedic footwear
09 Assistive products for personal care and protection	
	09 03 Clothes and shoes 09 06 Body-worn assistive products for body protection 09 07 Assistive products for body stabilization 09 09 Assistive products for dressing and undressing 09 12 Assistive products for toileting 09 21 Products for skin protection and skin cleaning 09 24 Urine diverters 09 27 Urine and faeces collectors 09 30 Assistive products for absorbing urine and faeces 09 31 Assistive products to prevent involuntary urine or faeces leakage 09 33 Assistive products for washing, bathing and showering 09 36 Assistive products for manicure and pedicure 09 39 Assistive products for hair care 09 42 Assistive products for dental care 09 45 Assistive products for facial care 09 54 Assistive products for sexual activities

Classes of AT devices	Subclasses of AT devices used by individuals with LEOp
12 Assistive products for personal mobility	
	12 03 Assistive products for walking, manipulated by one arm 12 06 Assistive products for walking, manipulated by both arms 12 07 Accessories for assistive products for walking 12 10 Cars, vans and trucks 12 11 Mass transit vehicles 12 12 Vehicle accessories and vehicle adaptations 12 16 Mopeds and motorcycles 12 17 Alternative motorized vehicles 12 18 Cycles 12 22 Manual wheelchairs 12 23 Powered wheelchairs 12 24 Wheelchair accessories 12 27 Alternative human-powered vehicles 12 31 Assistive products for transfer and turning 12 36 Assistive products for lifting persons
15 Assistive products for housekeeping	
	15 03 Assistive products for preparing food and drink 15 06 Assistive products for dishwashing 15 09 Assistive products for eating and drinking 15 12 Assistive products for house-cleaning 15 15 Assistive products for making and maintaining textiles
18 Furnishings and adaptations to homes and other premises	
	18 03 Tables 18 06 Light fixtures 18 09 Sitting furniture 18 10 Accessories for sitting furniture 18 12 Beds 18 15 Assistive products for height adjustment of furniture 18 18 Supporting handrails and grab bars 18 21 Gate, door, window and curtain openers/closers 18 24 Construction elements in the home and other premises 18 30 Assistive products for vertical accessibility 18 33 Safety equipment for the home and other premises 18 36 Furniture for storage
22 Assistive products for communication and information	
	22 09 Assistive products for voice production 22 21 Assistive products for face-to-face communication 22 24 Assistive products for telephoning and telematic messaging 22 27 Assistive products for alarming, indicating, reminding and signalling 22 30 Assistive products for reading

Classes of AT devices	Subclasses of AT devices used by individuals with LEOp
24 Assistive products for handling objects and devices	
	24 06 Assistive products for handling containers 24 09 Assistive products for operating and controlling devices 24 13 Assistive products for controlling from a distance 24 18 Assistive products to assist or replace arm, hand, finger function or a combination of these functions 24 21 Assistive products for extended reach 24 24 Assistive products for positioning 24 27 Assistive products for fixation 24 36 Assistive products for carrying and transporting
28 Assistive products for employment and vocational training	
	28 03 Workplace furniture and furnishing elements 28 06 Assistive products for transporting objects in the workplace 28 09 Assistive products for hoisting and repositioning objects in the workplace 28 12 Assistive products for fixing, reaching and grasping objects in the workplace 28 21 Assistive products for office administration, information storage and management at work
30 Assistive products for recreation	
	30 03 Assistive products for play 30 09 Assistive products for sports 30 12 Assistive products for playing and composing music 30 15 Assistive products for producing photos, films and videos 30 18 Handicraft tools, materials and equipment 30 21 Assistive products for gardening and lawn care for private use 30 24 Assistive products for hunting and fishing 30 27 Assistive products for camping and caravanning 30 30 Assistive products for smoking 30 33 Assistive products for pet care

International Organisation for Standardization 2011, *ISO: 9999:2011: The International Standard Assistive Products for Persons with Disability - Classification and Terminology*, 5th ed. [79]

CHAPTER 11: GLOSSARY

Active range of motion	Movements made actively by the patient.
ADL	Activities of daily living.
Alveoli	Small air sacs or cavities in the lung that give the tissue a honeycomb appearance and expand its surface area for the exchange of oxygen and carbon dioxide.
Anterior motor horn cells	Nerve cells from the spinal cord that innervate proximal muscles.
Arthrosis	Another name for osteoarthritis (OA), the most common type of arthritis. Arthrosis is caused by normal wear and tear on joints and cartilage.
Assistive technology	An umbrella term that includes assistive, adaptive, and rehabilitative devices for people with disabilities and also includes the process used in selecting, locating, and using them.
Atrophy	A gradual loss of muscle or flesh usually because of disease or lack of use.
Autonomic nervous system	A part of the vertebrate nervous system that innervates smooth and cardiac muscle and glandular tissues and governs involuntary actions.
Axillary crutch	A staff, ordinarily extending from the armpit to the ground, with a support for the hand and usually also for the arm or axilla; used to support the body in walking.
Axon	Long nerve fibre which transmits electrical impulses (information) away from a neuron's cell body.
Biomechanical pain	Pain resulting from poor posture/structural abnormalities.
Bulbar	Relating to the medulla oblongata i.e. the lower half of the brainstem, which is continuous with the spinal cord.
Bursitis	The painful inflammation of the bursa, a pad-like sac found in areas subject to friction. Bursae cushion the movement between the bones, tendons and muscles near the joints. Bursitis is most often caused by repetitive movement.
Cardiac arrhythmia	A problem with the rate or rhythm of the heartbeat. During an arrhythmia, the heart can beat too fast, too slow, or with an irregular rhythm.
Cardiovascular exercise	A general term for any form of vigorous aerobic exercise, which pushes the heart rate to a near maximum.

Carpal tunnel syndrome	A painful condition of the hand and fingers caused by compression of a major nerve where it passes over the carpal bones through a passage at the front of the wrist, alongside the flexor tendons of the hand.
Comorbidity	The simultaneous presence of two chronic diseases or conditions in a patient.
Cosmesis	The preservation, restoration, or bestowing of bodily beauty. In the medical context, it usually refers to the surgical correction of a disfiguring defect.
Denervate	To deprive an organ or body part of a nerve supply.
Dermatome	An area of skin that is mainly supplied by a single spinal nerve. There are 8 cervical nerves, 12 thoracic nerves, 5 lumbar nerves and 5 sacral nerves. Each of these nerves relays sensation (including pain) from a particular region of skin to the brain.
Detrusor muscle	The muscular coat of the urinary bladder, which, along with gravity and increased intra-abdominal pressure, facilitates emptying of the bladder during urination by its contraction.
Dynamic strength	The strength displayed during an active movement where there is change and in the muscle and joint during that action.
Dysarthria	Difficulty speaking due to central nervous system dysfunction.
Dysphagia	Difficulty in swallowing.
Effector	A nerve ending that carries impulses to a muscle, gland, or organ and activates muscle contraction or glandular secretion.
Electromyography (EMG)	A diagnostic procedure to assess the health of muscles and the nerve cells that control them (motor neurons).
Ergonomics	A science that deals with designing and arranging things so that people can use them easily and safely.
Evidence-based	Applying the best available research results (evidence) when making decisions about health care. Health care professionals who perform evidence-based practice use research evidence along with clinical expertise and patient preferences.
Fasciculation	A small, local and involuntary muscle contraction, which may be visible beneath the skin.
Flexor	Any muscle whose contraction serves to bend a joint or limb.
General fatigue	Fatigue not related to activity (also known as "central fatigue").
Genu recurvatum	Deformity in the knee joint resulting in the knee bending backwards, i.e. hyperextension / 'back knee'.

Gestalt	An organised whole that is perceived as more than the sum of its parts.
Helios	The Helios® orthosis is a custom energy loading graphite composite brace.
Hyperlipidaemia	An abnormally high concentration of fats or lipids in the blood.
Hypothyroidism	Abnormally low activity of the thyroid gland.
ICF	International Classification of Functioning, Disability and Health.
Ischemic	A decrease in the blood supply to a bodily organ, tissue, or part caused by constriction or obstruction of the blood vessels.
LEoP	Late Effects of Polio: Symptoms that are attributable to damage caused by the original acute poliomyelitis, including such aspects as residual weakness and musculoskeletal imbalance.
Locus of control	A psychological concept that refers to how strongly people believe they have control over the situations and experiences that affect their lives.
Manual muscle testing	Test of a person's muscle strength, or ability of the muscle to move a part of the body against resistance. A doctor or therapist will assess muscle strength in individual muscles, and the results show which muscles are weak and the pattern of the weakness.
Metaplasticity	Activity-dependent changes in neural function that modulate subsequent synaptic plasticity.
Magnetic resonance imaging (MRI)	A technique that uses a magnetic field and radio waves to create detailed images of the organs and tissues within a body.
Muscle fatigue	Or peripheral fatigue, present in muscles of the limbs, often progressive.
Muscle tone	The state of contraction or tension held within the muscles in a passive state.
Musculoskeletal	The human musculoskeletal system is an organ system that gives humans the ability to move using their muscular and skeletal systems. The musculoskeletal system provides form, support, stability, and movement to the body.
Myocardial infarction	Another term for heart attack.
Neurogenic	Caused by, controlled by, or arising in the nervous system.
Neuromuscular	The relationship between nerves and muscles.

Neuropathic pain	Pain caused by damage or disease that affects the somatosensory system.
Nociception	The encoding and processing of harmful stimuli in the nervous system and, therefore, the ability of a body to sense potential harm.
Nocturia	The need to wake and pass urine at night.
Nuclei	Central aspect of a cell around which all other elements are organised; cells in the brain or spinal cord from which nerve fibres form connections.
Oedema	The presence of an excessive amount of fluid in or around cells, tissues or serous (pertaining to serum) cavities of the body.
Osteoarthritis	Often called “wear-and-tear arthritis” it results from degeneration of joint cartilage and the underlying bone, most common from middle age onward. It causes pain and stiffness, especially in the hip, knee, and thumb joints.
Osteoporosis	A medical condition in which the bones become brittle and fragile – osteoporosis literally means “porous bones”. It occurs when bones lose an excessive amount of their protein and mineral content, particularly calcium.
Overuse pain	Pain resulting from overuse of soft tissue.
Paradigm shift	A fundamental change in approach or underlying assumptions.
Paresis	A condition of muscular weakness caused by nerve damage or disease; partial paralysis.
Passive range of motion	Movements made without effort from the patient, usually assisted by a practitioner/therapist.
Pathophysiology	A convergence of pathology with physiology. Pathology describes the abnormal or undesired condition, whereupon pathophysiology seeks to explain the physiological processes or mechanisms whereby such condition develops and progresses.
Perceived exertion test	Assesses the level of exertion during a movement.
Post-polio muscle pain	Described as burning, cramping or a deep muscle ache. Deep pain is often characterised by muscle cramps, while superficial pain is sometimes associated with fasciculation, a crawling sensation, or extreme sensitivity to touch.
PPS	Post-Polio Syndrome: The neurologic disorder characterised by a constellation of symptoms including but not limited to increased weakness and/or abnormal muscle fatigability occurring many years after the initial polio infection.

Practice wisdom	The accumulation of information, assumptions, ideologies, and judgments that are practically useful. Practice wisdom is often equated with 'common sense' and may or may not be validated when subjected to empirical or systematic analysis and may or may not be consistent with prevailing theory.
Reciprocal gait pattern	Describes how the arms move in relation to the legs to maintain better balance through a usual gait cycle.
Reinnervate	Restoration of function especially to a denervated muscle by supplying it with nerves by regrowth or by grafting.
Reperfusion	Restoration of the flow of blood to a previously ischemic tissue or organ (as the heart or brain).
Sequelae	An abnormal condition that occurs afterwards or results from a disease or pathological condition.
Somatic	Of or relating to the body, especially as distinct from the mind.
Somatosensory	Provides information about objects in our external environment through touch (i.e., physical contact with skin) and about the position and movement of our body parts (proprioception) through the stimulation of muscle and joints. The somatosensory systems also monitor the temperature of the body, external objects and environment, and provide information about painful, itchy and tickling stimuli.
Speed test	A functional test which measures the speed at which a task is performed.
Static strength	Sometimes known as "Isometric", is the strength held by the muscle during exercises where the length of muscle does not change; there is no visible movement of the joint.
Synapse	A junction between two nerve cells, consisting of a minute gap across which impulses pass by diffusion of a neurotransmitter.
Tendonitis	Inflammation of a tendon, most commonly from overuse.
Torque testing	Method for measuring muscle strength and uses exercise equipment to electronically measure strength against an opposing force.
Vestibular system	The sensory system that provides the leading contribution about movement and sense of balance (spatial orientation). Together with the cochlea, a part of the auditory system, it constitutes the labyrinth of the inner ear in most mammals.

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www.rehabmeasures.org/PDF%20Library/Timed%20Up%20and%20Go%20Test%20Instructions.pdf
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