

The late effects of

POLIO



Polio SA

*The post polio support group
for South Australians*



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This book is dedicated to the survivors of polio.

Thank you to everyone who assisted in assembling this booklet. This booklet was compiled and funded by Polio SA Inc.

We are happy to supply further information regarding any topic of interest in this book.

Disclaimer: This booklet is for information purposes only and is not intended as a substitute for professional medical advice.

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ABOUT POLIO SA

Polio SA is a not for profit organisation operated by volunteers. All staff and members have had polio or have a family relative diagnosed with post polio syndrome (PPS). PPS is the late effect of polio, usually occurring 20 to 40 years after the initial infection. Not all people who previously had polio will experience new symptoms.

Our aim is to:

- provide information about the late effects of polio and PPS to members and the greater community
- provide a supportive network through consultations, referrals and social gatherings, and
- ensure that Polio SA members are aware of their rights regarding their disability.

We provide the following services:

- mutual support through group meetings
- access to discounted health services including massage and hydrotherapy (see our website for details of current services)
- newsletters keeping members up to date with local and international developments
- access to a wide range of relevant information, and
- connecting people with similar interests.

Country groups

Previously there were polio support groups in rural South Australia, however to our knowledge these are no longer active.

All Polio SA resources are available to our rural members, including books, fact sheets, past newsletters, and personal stories.

For information, call Polio SA on 0466 893 402, visit poliosa.org.au or email us at poliosa.office@gmail.com.

FOREWORD

This book is intended to be used as a quick reference information guide for people with the 'late effects of polio' (LEOP), and their families and carers.

I wish to recognise the efforts Matthew Lynagh and Richard Pember, who as fourth year Physiotherapy Students, updated the information in this book in 2011.

More recently, I would like to thank the Polio SA committee, who reviewed the document in February 2017 and made minor alterations to ensure the booklet is relevant today.

As an indication of unity with Polio Australia (who have adopted orange as their key colour), the 2017 edition of the "Blue Book" will now be orange. This new edition is also in line with our recent rebrand.

For our new members (those with PPS or caring for someone with PPS), I would like to encourage you to come to our monthly Polio SA meetings and consider nominating yourself for the committee.

We also produce a quarterly newsletter, to which you can subscribe to the email version on our website at poliosa.org.au/contact-us.

Happy reading!

Brett Howard

Polio SA President, 2017

INTRODUCTION

Acute poliomyelitis (polio) is increasingly a disease of the past.

Despite worldwide progress in eradicating polio, in recent years it has become increasingly apparent that new symptoms can develop years and decades after a patient suffered an episode of acute paralytic poliomyelitis.

There is a lack of consensus in terms used to describe these new health problems experienced by previous sufferers of polio, but the terms *Late Effects of Polio (LEOP)* and *Post Polio Syndrome (PPS)* are frequently used.

This booklet provides an overall understanding of polio, PPS and living with PPS.

THE HISTORY OF POLIO

Polio survived as an endemic pathogen until the 1880s when major epidemics began to occur in Europe. Soon after, widespread epidemics appeared in the United States.

By 1910, frequent epidemics became regular events throughout the developed world, primarily during the summer months. At its peak in the 1940s and 1950s, polio would affect over half a million people worldwide every year.

In 1952, early versions of the Salk vaccine, used to kill the polio virus, were successful with small samples of patients at the Watson Home for Crippled Children and the Polk State School.

1954 saw massive field trials of the Salk vaccine sponsored by the National Foundation for Infantile Paralysis.

In 1957, after a mass immunization campaign, there are only about 5600 cases of polio in the United States.

Throughout 1958–1959 field trials prove the Sabin oral vaccine, which uses a live, weakened virus is found to be effective.

In 1962, the Salk vaccine is replaced by the Sabin oral vaccine, which is superior in terms of ease of administration and it also provides longer-lasting immunization.

TYPES OF POLIO

Non-paralytic polio

Symptoms include headache, neck, back, and limb pain. Fever, vomiting, abdominal pain, lethargy, and irritability

Muscle spasms are nearly always present in the neck and back, hamstring muscles, and variably present in other muscles. Muscles are generally tender to the touch.

Paralytic polio

In around 1% of infections, the polio virus spreads along certain nerve fibre pathways, preferentially replicating and destroying motor neurons within the spinal cord, brain stem, or motor cortex in the brain.

This leads to the development of paralytic poliomyelitis, the various forms of which (spinal, bulbar, and bulbospinal) vary only with the amount of neuronal damage and inflammation that occurs, and the region of the central nervous system (CNS) that is affected.

Spinal

Spinal polio is the most common form of paralytic poliomyelitis. It results from viral invasion of the motor neurons of the 'anterior horn cells' in the spinal column, which are responsible for muscle movement, including those of the trunk, limbs and chest. The virus causes inflammation of the nerve cells, leading to damage or destruction of motor neurons. When spinal neurons die, previously healthy muscles become weaker.

Bulbar

Making up about 2% of cases of paralytic polio, bulbar polio occurs when the polio virus invades and destroys nerves within the bulbar region of the brain stem. The bulbar region is a white matter pathway that connects the cerebral cortex to

the brain stem. The destruction of these nerves weakens the muscles supplied by the cranial nerves, producing symptoms of encephalitis (swelling around the brain), and causes difficulty breathing, speaking and swallowing.

Bulbospinal

Approximately 19% of all paralytic polio cases have both bulbar and spinal symptoms; this subtype is called respiratory polio or bulbospinal polio.

Here, the virus affects the upper part of the cervical spinal cord (C3 through C5), and paralysis of the diaphragm occurs. The critical nerves affected are the phrenic nerve, which drives the diaphragm to inflate the lungs, and those that drive the muscles needed for swallowing.

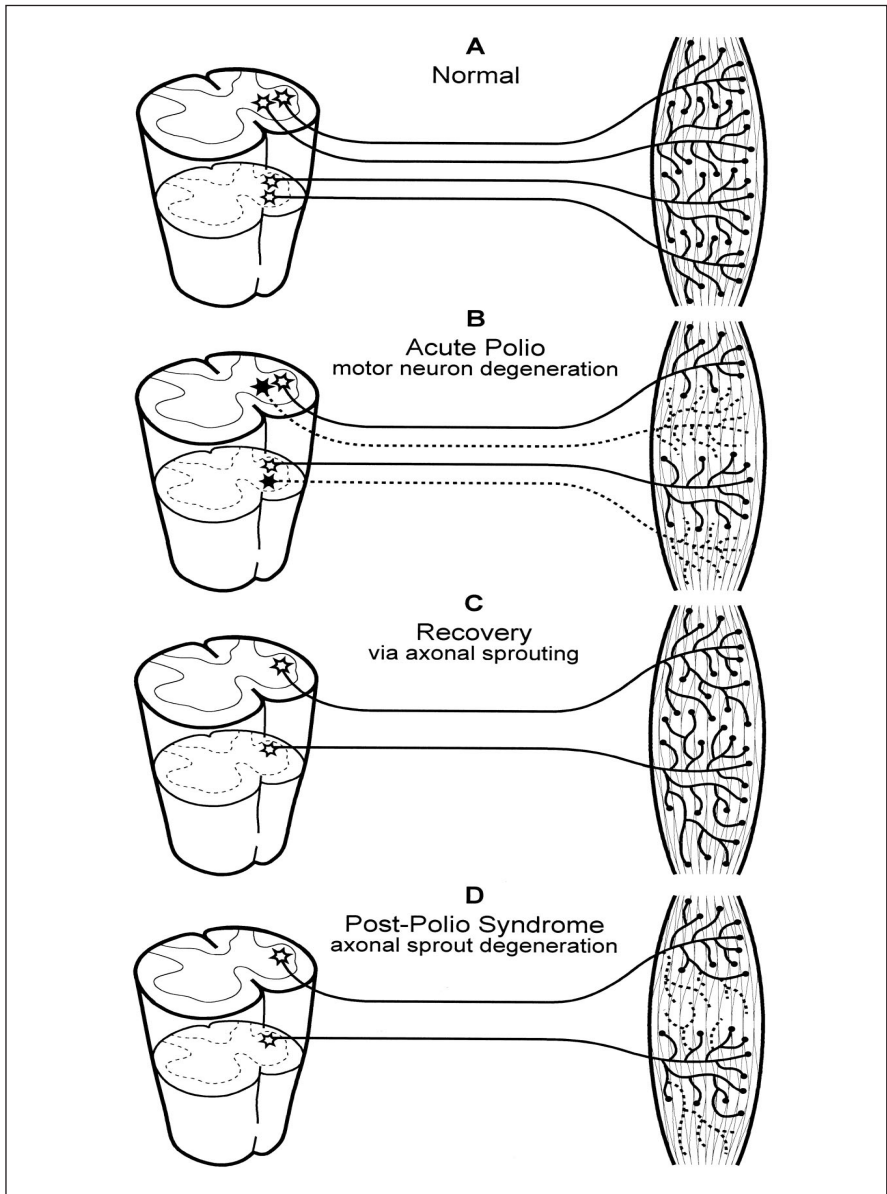
Approximately a quarter of individuals who survive paralytic polio in their childhood, develop additional symptoms decades after recovering from the acute infection. Particularly muscle weakness, extreme fatigue or paralysis.

PATHOPHYSIOLOGY OF POST POLIO SYNDROME (PPS)

Though the exact cause of PPS is unknown, many hypotheses have been formed.

The most popular hypothesis is the overuse of the motor units (specific muscle groups). Put simply, the new nerve endings can no longer work efficiently after a very long period of use (between 20 to 30 years) and therefore muscular fatigue, weakness and pain become present.

This theory is shown in the image on the right. *Example A* shows normal nerve function. In *example B*, we see a number of nerves are lost after experiencing polio. In *example C*, during the recovery phase, the remaining nerves sprout more nerve endings to supply the muscle that has lost its own supply. After decades, the sprouted nerve endings fatigue and degenerate causing symptoms experienced in PPS (*example D*).



Picture from Lambert, D, Giannouli, E and Schmidt, B, Post Polio Syndrome and Anesthesia, *Anesthesiology* 2005; 103:638–44

SYMPTOMS

The following symptoms are possible in PPS:

- Unfamiliar fatigue, which may be generalised fatigue (feeling total exhaustion) or muscle fatigue (a rapid tiring of the muscles that increases with exercise but improves with rest)
- New muscle weakness, which may include muscles originally affected by polio infection, as well as muscles seemingly unaffected at the time
- Pain in muscles and/or joints
- Breathing difficulties (chest infections)
- Swallowing difficulties
- Increased sensitivity to cold temperatures
- A declining ability to perform every day activities
- Difficulty sleeping
- Muscle atrophy
- Bulbar symptoms related to swallowing, speech and respiration

FATIGUE

Fatigue leads to the inability to perform self-care and work activities. People with an unstable PPS do not recover from activities as quickly as other people due to muscle fatigue. Fatigue is a general tiredness which in post polio syndrome is abnormal because it is not related to health or physical activity.

Fatigue can be due to poor sleep or overuse of muscles. It may also be worse after illness, surgery or bed rest.

What can you do?

Protect weakened muscles, rest regularly, reduce the energy required for mobility e.g. using orthotics, walking aids, wheelchairs etc., do not exercise into pain, stop before you become tired, seek assistance from others, and ask doctor or other health professionals for management strategies.

Overuse

Long-term overuse of muscles beyond their capacity causes fatigue of the muscle and pain. Learning how to exercise muscles within their limits will help. A neuro-physiotherapist can assist in developing a program for you.

EXERCISE

It is important to stay as active as possible and continue to exercise when you are experiencing the late effect of polio. People with PPS often experience loss in strength and weight gain.

A decrease in strength or excess weight can make tasks physically harder for you which may add to your fatigue. Exercising can also assist you in having a better night sleep, increasing your overall wellbeing.

Finding the right level of exercise for you can be a difficult thing to do at first. It is important not to over exercise as this may lead to muscular pain and fatigue however if you don't exercise at all your condition will also deteriorate. There is no recipe for the right amount of exercise as each person is affected differently by PPS. However with a little perseverance finding the right level is very achievable.

Tips for a successful program

- Seek advice from your physiotherapist, one who has knowledge of PPS, to work with you to devise an exercise program
- Start slowly, low to moderate exercise is advised
- To lose weight aerobic exercise (such as walking or riding a bike) is best. During the exercise you should feel warm, be perspiring and breathing heavily but without being out of breath
- Keep a record of how you feel after exercising. If you experienced any of the following it may be a sign you have done too much and should alter your routine:
 - pain during or after exercise
 - burning sensations in your muscles during exercise
 - fatigue lasting for more than four hours after exercise
- As you become fitter you can slowly increase the amount or intensity of exercise to 30 minutes a day (this can be broken up into 10 minute blocks if time is a concern)
- Strength training should only be every second day
- Vary the type of exercise, listen to music or exercise with a group so you don't become bored

Hydrotherapy as exercise

Hydrotherapy is a great way to exercise as it not only decreases the chances of injury (compared to on land) but is also a social activity. Hydrotherapy programmes provide exercise in a heated pool. The ideal pool is heated at 32.5°C. The warm water assists movement and gives buoyancy to enable people to do exercises designed especially for them by a physiotherapist. Ask Polio SA if there are hydrotherapy groups near you.

Other benefits of hydrotherapy

Water is a pleasant and encouraging way to exercise. Warm water promotes muscle relaxation and improves circulation. Programs can be devised to increase balance and the buoyancy of the water allows particular movements to be either assisted or supported. It reduces weight bearing and decreases mechanical stress on limbs, depending on the level of immersion. It is essential that the instructor or therapist is aware of the effected muscles and symptoms that you may experience.

PAIN

A very common symptom of PPS is muscle pain. This can be described as spasms, inflammation, muscle cramping or twitching, weakness or sometimes a crawling sensation that cannot be controlled.

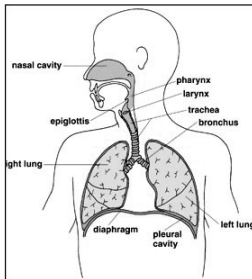
Pain is more often located in parts of the body that were affected by polio than in parts that were not. Many patients with PPS report cramping pain in the legs (most often the upper leg musculature) and aching pain in the neck and shoulders. The pain is typically reported to be widespread.

When the pain is brought on by physical activity it is known as overuse syndrome. This pain is exacerbated by stress and cold and is often increased when resting, at the end of the day, when it is least expected.

Chronic muscular pain can also occur with a small difference in the length of an individual's legs causing alterations in gait pattern. Most often such pain is felt in the outside upper third of the leg, specifically a muscle that runs down the outside of the leg from knee to ankle. The action of this muscle is to turn, twist, and flex the foot downwards. To compensate for a discrepancy in lengths, the muscle of the shorter leg works to stabilize the ankle in walking. This leads to muscle damage and formation of painful spots.

RESPIRATION AND SLEEPING

Respiratory problems are the most common health issues facing people with PPS. Many people have progressive muscle weakness as well as bulbar muscle dysfunction (muscles involved in speech, swallowing and chewing). Your respiratory system is responsible for breathing air and supplying oxygen to all of your bodies systems.



Respiratory problems may affect you during the day, such as; shortness of breath when walking up the stairs, or completing day to day activities. Because the muscles which help you breathe are weakened, they fatigue quicker than usual, making it harder for you to breathe. Regular breaks in activity, before you are short of breath, may help this.

Respiratory problems may also affect your sleep in the form of sleep apnoea or hypoventilation. This can disrupt your sleep and leave you feeling tired during the day. A disrupted sleep may also impact on your body's ability to recover.



Management

The use of continuous airways pressure (CPAP) can assist you in getting a better night sleep which will help you feel more awake and energetic the following day. CPAP (pictured) is a mask you wear while sleeping which opens up your airways allowing you to breathe better.

Regular exercise has also been reported to help sleep as well as levels of fatigue during the day (refer to *Exercise*, page 14).

If you are having trouble sleeping or are experiencing any problems with shortness of breath or breathing, see you GP as there are strategies out there to help you.

SWALLOWING DIFFICULTIES

Swallowing difficulties are another common symptom of PPS. It is seen in all types of polio, but is most common in people who had bulbar involvement during the acute polio phase.

Swallowing problems include:

- coughing and choking during eating
- sticking in the throat
- regurgitation of food
- difficulty managing secretions (e.g. saliva)
- each of these can result in secondary problems, such as pneumonia.

If you are experiencing these, a speech therapist may be able to help you by developing an exercise program to work on the speed, strength and coordination of the muscles involved in swallowing.

Tips to help improve your swallowing:

- avoid problematic food (e.g. dry, tough, chewy foods) or prepare it in a way that is easier to swallow (e.g. blend or chop finely)
- sit upright and keep your head faced forward, chin down
- take small bites
- chew slowly, and swallow before taking the next bite
- drink between mouthfuls
- eat when less fatigued
- eat the most difficult food first (when swallowing muscles are less fatigued)
- avoid turning your head either way when swallowing
- never put head back if you are having trouble swallowing, as this closes the food pipe

FALLS

Falls are particularly common in those with PPS. In addition to this, polio affected limbs are often osteoporotic making bones prone to breakage.

Caution should be taken on uneven and slippery surfaces, such as pavers, wet bathrooms and stairs. A fall can immobilise someone with PPS for a long time as healing can be slow.

Where possible, install assistive devices to improve areas hazardous areas – refer to *Assistive devices* section below.

ASSISTIVE DEVICES

The use of braces should improve mobility, reduce pain, and reduce overuse of the still well functioning parts of the muscles, joints, tendons, and ligaments. Use of lightweight knee, ankle or foot braces can have a beneficial effect and save energy.

Patients with PPS should be supplied with appropriate orthoses and braces on the basis of individual needs. To further improve energy efficiency, carbon-composite material is preferred. Besides orthoses, assistive devices to increase functional activity include walking sticks, crutches, manual and electrical wheelchairs, and motorised scooters.

Ramps and grab rails are useful in the bathroom and for outside steps. Use non-slip mats in wet areas to avoid falls.

SURGERY AND ANAESTHESIA

If you are planning to have surgery it is important to make sure your surgical team is aware that you have post polio syndrome. It is your responsibility to inform them of any previous reactions you have had to drugs used in surgery.

Inform your doctors (including anaesthetist) and dentists (for oral surgery) of any of your symptoms, especially respiratory (difficulties with breathing, sleep apnoea or shortness of breath) or difficulties with swallowing.

This is important because people with PPS may require smaller doses of anaesthetic during surgery, thought to be due to a combination of an increased sensitivity to muscle relaxants as well as due to general anaesthetic depressing the respiratory system.

As general anaesthetic depresses the respiratory system (making you take shallower breaths) and people with PPS commonly have a weakened respiratory system it is possible that the risk of complications during surgery may be greater. However, in procedures that requires local anaesthesia, such as dental, endoscopy, colonoscopy etc. more anaesthetic (up to twice as much) may be needed.

Surgery can still be relatively safe if you follow a few points to reduce the risks:

Pre-operative

- Talk with your doctors about your symptoms
- Ask doctors about what you can do to in the weeks leading up to the surgery
- If you smoke or drink, decrease the amount you are having
- Stay active before the surgery

Post-operative

- Follow the hospitals protocol to avoid respiratory infections. The protocol may include activities such as deep breathing,

coughing and huffing (similar to fogging up glass). Post-operative mechanical ventilation may be necessary to help with breathing after surgery.

- Be aware that for a few weeks your balance and level of mobility may not be at the same level as it was before the surgery, as postoperative sedation increases mobility problems for those with weakened muscles.
- Use walking aids/wheel chairs as they are prescribed

It is also important to note that post polio syndrome sufferers take longer to recover and as such your hospital stay may be longer than what is typical for that surgery.

Excessive bleeding can be a problem due to the relatively smaller blood volume in atrophied muscles that may delay healing in effected limbs.

Surgery will affect everyone differently so it is up to you and your doctors to figure out what will be the safest options for you.

IMPACT

Financial impact

It costs more to be disabled. Loss of employment; adaptive devices are needed e.g.; braces, scooters or wheelchairs. Modifications of the home, ramps, grab rails, higher toilets, all create extra expense. There is help available, ask your doctor or contact Polio SA for advice on how to access benefits.

Emotional impact

Anger, depression and anxiety are common. You should voice your feelings to your family, friends or a counsellor as if you isolate yourself from people they will not be able to help you.

Although you may not be able to participate in all the things you used to there will still be things you are able to do. Focus on these instead of the negatives.

Friends and family

Friends and family may not understand what you are going through. If you explain it to them and direct them towards educational resources they may be able to work with you better to help you make to most of things.

MEDICATION

There have been many trials on the effectiveness of different drugs on fatigue and pain caused by post polio syndrome. Immunoglobulin has been found to be encouraging but more studies need to be completed to further investigate this drug. Unfortunately no drugs to date have showed a real promise in helping these symptoms.

People with PPS have greater sensitivity to pain and often require more medication to achieve relief. They are more susceptible to adverse drug reactions including impairment of respiration and increased muscle weakness. Care should be taken when analgesics, muscle relaxants, sedatives, and cholesterol lowering medications are prescribed.

People with PPS must take their condition into consideration when drinking alcohol and smoking. Excesses of any kind, can lead to difficulties with breathing and create increased weaknesses in coordination and risk of falls. Overmedication is a risk factor as some prescriptions have side effects detrimental to people with post polio syndrome conditions.

HEALTH PROFESSIONALS

Doctor (general practitioner)

A doctor will help you manage your medications and will look at your symptoms and work out what is related to PPS and what may be due to something else.

Neuropsychology

A neuropsychologist deals with your mental wellbeing to help you take control of your life.

Neurophysiotherapy

They can assist you to improve your mobility, function, pain and quality of life.

Occupational therapist

Provides advice on fatigue management, task simplification, every day living, equipment and counselling related to coping with disabilities.

Orthotist

An orthotist can make and fit assistive devices to help you cope with pain, fatigue and improve your mobility generally.

Podiatrist

Diagnosis and treatment of disorders of the foot, ankle and lower leg.

Respiratory specialist

Aids to optimise your respiratory system.

Speech pathologist

Helps manage swallowing and speaking difficulties.

ADDITIONAL RESOURCES

Polio Australia website

polioaustralia.org.au

Books and publications

The Polio Paradox by Dr. Richard L. Bruno (no longer in print)

The Late Effects of Polio: Introduction to Clinical Practice by
Polio Australia

The Late Effects of Polio: Managing Muscles and Mobility by
Polio Australia

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