

An introduction to who we are and what we do



The British Polio Fellowship is the largest charity supporting people with polio or Post-Polio Syndrome (PPS) in the UK. We were founded in 1939 by and for people with polio and continue to provide information and support to people with polio and Post-Polio Syndrome (PPS), their families and health care professionals.

The British Polio Fellowship provides a range of services. These include:

- Information, support and grants
- A holiday programme
- A network of local branches and groups across the UK
- A network of Welfare Volunteers
- Outreach programmes to find and bring together people with polio across the UK
- Fundraising
- Campaigning to raise awareness of PPS and other issues of relevance to our members.

We have over 8,000 members, and publish a popular members' magazine, *The Bulletin*, four times a year.

Why we've written this booklet

According to government statistics, there are around 120,000 people in the UK who have had polio and who may get PPS. For this reason, we have been raising awareness of PPS for a number of years.

This booklet contains information about PPS, its symptoms and diagnosis and, most importantly, what you can do to manage the condition and carry on living an enjoyable life.

Many thanks to...

We are indebted to Dr Ruth Bridgens for her summary of research findings on Post Polio Syndrome. We would also like to thank members of the British Polio Fellowship Expert Panel for their advice. We are grateful to the Berkshire Branch and Worthing and Sussex Branch as well as many individual members for their kind sponsorship of this guide.

Initial research by Dr Ruth Bridgens.

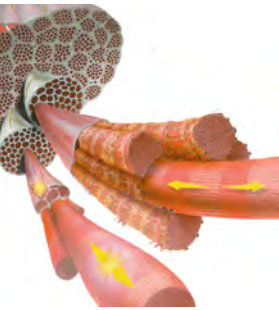
Content

Foreword

About polio	6
An Introduction to PPS	8
Changes to motor neurons due to polio and PPS	10
How is PPS Diagnosed?	13
What are the symptoms of PPS?Managing your symptoms	16
Adapting to having PPS	20
Living with PPS: more useful tips	25
British Polio Fellowship's definition of PPS	31
Some useful terms	34
Useful organisations and resources	39
Bibliography	41
Books	43
	47

Please note words shown in **green/bold** are explained in the section "**Some useful terms**"

About polio



To understand Post-Polio Syndrome (PPS) it is important to know a little about polio (poliomyelitis).

How do you get polio?

Polio is an infectious disease caused by any one of three types of poliovirus. It enters your body through your nose or mouth and develops in your throat and intestines. The poliovirus may go on to invade your **central nervous system**, destroying or damaging the nerve cells (**motor neurons**) that control your muscles.

What happens to your body when you have polio?

The polio illness can affect you in one of three ways:

- Approximately 95% of people have minor flu-like symptoms, such as feeling sick or being sick, a high temperature, sore throat and headache. They may not realise that they have polio.

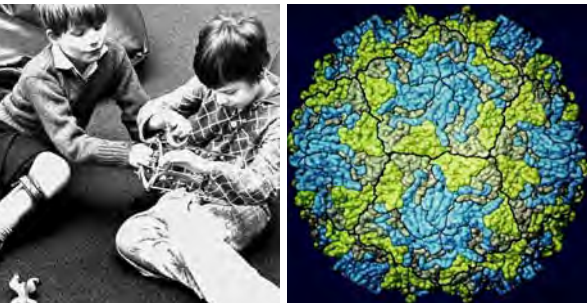
- In around 5% of people, the virus gets into their nervous system. For most people this will cause symptoms such as high temperature, stiff neck, back and muscle pain and headache. This is known as non-paralytic polio
- Around 1-2% of people will have some paralysis - they will have completely lost movement in the affected area of the body. This is caused when the poliovirus invades the nerve cells that control muscles, and leads to weakness, paralysis, muscle cramps and muscle pain. This is known as paralytic polio
- Sometimes the poliovirus affects the **brain stem**, causing difficulties with breathing, speaking and swallowing, facial weakness, or problems with the heart, lungs and intestines. This is known as bulbar polio

Polio is not thought to affect the sensory nerves, so people can still feel pain. Polio does not affect hearing or eyesight.

What happens to your body as you recover from polio?

- To begin with, some of the nerve cells which control your muscles will die or be left damaged
- Damage to nerve cells may be widely distributed throughout the body and so may not cause any noticeable weakness
- Muscles can often still be used and appear normal when tests are run even when perhaps 50% of the nerve cells are lost or damaged. This may be because the remaining muscles are working harder to compensate
- About half of the damaged nerve cells recover within the first month. During the following months or years, muscle strength may improve as the number of **nerve fibres** increase and **muscle fibres** grow larger.

An introduction to PPS



What is Post-Polio Syndrome?

Post Polio Syndrome (PPS) is a **neurological** condition that can occur in people who have had polio. After a long time without any significant change in their condition, people may develop new or increasing weakness, stamina problems, fatigue and pain.

PPS is often difficult to recognise as symptoms may develop slowly and may be mistaken for other conditions. Before making a diagnosis of PPS it is important to exclude any other conditions that could explain your symptoms.

We will look at the symptoms and management of PPS in this booklet.

A brief history of PPS

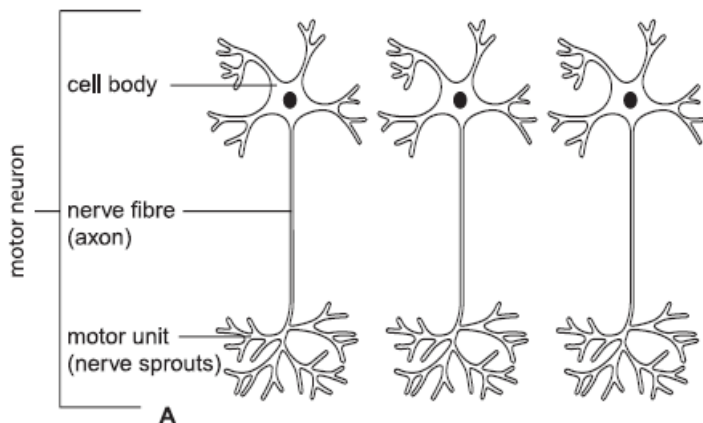
Studies from 1875 showed evidence of PPS, but it was not until the 1980s that doctors began seeing more people with polio developing increased weakness, fatigue and pain. For a long time neither patients or doctors were looking for, or prepared to accept, a connection with polio. As a result, little research was done into any longer-term effects.

By the 1990s there was enough evidence to suggest that these new symptoms were related to the effects of polio. Research took place to examine and understand the reasons for these symptoms. It is now known that people who had polio may develop new symptoms years later caused by Post Polio Syndrome.

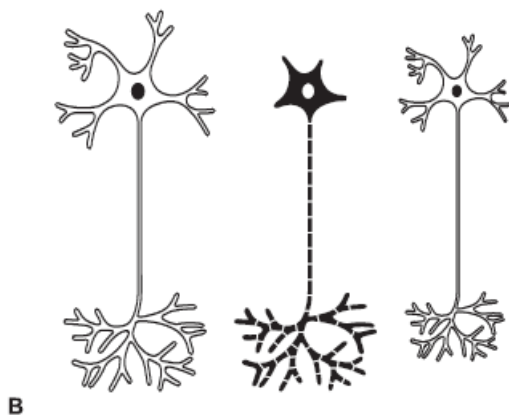
What else do we know about PPS?

- PPS can occur at any age and can be an issue for people who had either paralytic or seemingly non-paralytic polio.
- Research on who is most likely to experience PPS is not always clear and can be contradictory. Findings vary, but have shown that PPS may develop in a significant number of people with polio.
- It is suggested that PPS may affect more women than men.
- People who have had fatigue or pain in the years since they contracted polio, or where physical activity has caused extreme tiredness and pain, seem to be at increased risk of developing PPS, or may already be experiencing it.
- PPS also seems to develop more quickly in people who had polio during the epidemics of the 1950s.

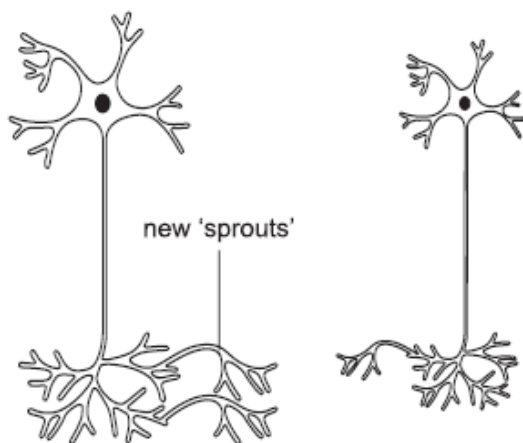
Changes to motor neurons due to polio and PPS



Normal
Normal healthy motor neurons.



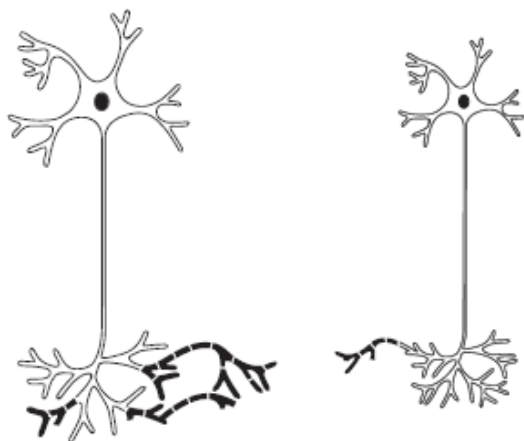
Acute Polio
Polio virus causes damage or death to varying numbers of motor neurons.



C

Recovery

Axons from surviving motor neurons, especially healthy ones, form new sprouts and restore nerve supply to disconnected muscles.



D

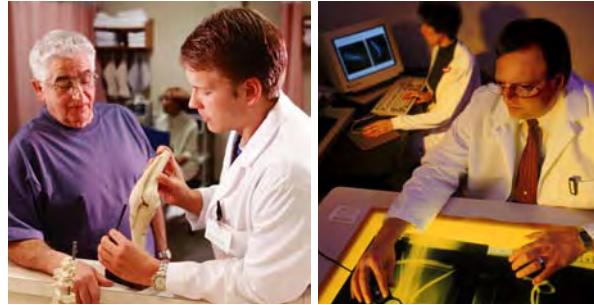
Post Polio Syndrome

New loss of nerve sprouts leading to new muscle weakness.



www.nhs.uk

How is PPS diagnosed?



Unfortunately there is no single test for PPS and it is important to make sure there is no other reason for the symptoms.

A number of factors will need to be considered before a doctor can tell you if you have PPS, including:

- Do you have a confirmed history of polio?
- If you don't know if you had polio, did you ever come into contact with anyone who might have had it?
- Do you have any physical signs of having had polio in the past?
- Have you had a period of recovery from polio when your condition has not changed for a long time?
- Are you experiencing new or increasing weakness, abnormal muscle fatigue or new loss of muscle bulk?
- Are you getting pain in your joints?
- Are you having problems with breathing, sleeping and/or swallowing, or not being able to tolerate the cold?
- Is there any other medical explanation found for these symptoms?

It may be difficult to get a diagnosis of PPS because many health care professionals know very little about the condition, or even about polio. Referral to a consultant neurologist, ideally with knowledge of polio and PPS, may be the best way to get a diagnosis and advice. The British Polio Fellowship has more information about PPS and a list of consultants with an interest in PPS and who you can ask your General Practitioner (GP) to refer you to.

The Fellowship's definition of PPS is included on page 34 of this guide.

What tests might I need to have?

If a GP suspects that you may have PPS, they should give you the following tests:

- Full Blood Count (FBC)
- Biochemical profile
- Creatine Kinase (CK)
- Thyroid function
- Inflammatory markers (ESR, CRP)
- Rheumatoid factor
- Anti-nuclear antibody (ANA)
- Uric acid
- Glucose
- Routine Kidney Function tests
- Liver Function test
- Serum Calcium
- Serum Vitamin D Status

If the results of any of these tests are abnormal, you are more likely to have another condition which needs investigation, but this does not rule out the possibility of you having PPS as well.

In addition you may be referred for X-rays if:

- Chest and spine
- Painful joints

If you have these tests and your GP is still not sure that you have PPS, you may be referred to a hospital consultant. At this stage you may have some or all of the following tests to rule out other possible conditions or confirm the likelihood of PPS:

- Electromyography (EMG) tests to see if polio has damaged your nerves and muscles
- Sleep studies if you are having problems sleeping or feeling unusually tired
- Cardiological tests to check your heart rate and function
- Magnetic Resonance Imaging (MRI) of your spine
- Lung Function Tests to see how well you can breathe in and out
- Tests to investigate swallowing problems

You should remember that you may have PPS as well as other conditions, so not every health problem or symptom experienced will be related to PPS.



What are the symptoms of PPS?



This section will give you more information about the main symptoms of PPS.

Weakness

New or increasing weakness is often seen as the most easily recognisable symptom of PPS. It can sometimes be difficult to separate weakness from muscle fatigue, which could be thought of as 'weakness that develops over time' or through usage.

Taken together, both weakness and muscle fatigue are normally considered essential symptoms of PPS. Both symptoms can occur in muscles previously affected by polio, but also in muscles where no damage has been obvious until now.

Muscle fatigue

Fatigue is often described as increasing physical weakness, increasing loss of strength during exercise and a heavy sensation in the muscles. This is common in PPS. It may lead to general

exhaustion or fatigue at the end of the day or it may even last for several days. Muscle fatigue can be a result of muscle overuse and this is thought to play a large part in PPS.

General fatigue

General fatigue is an overwhelming feeling of exhaustion, weakness and sometimes mental fatigue, which can be the result of muscle fatigue and muscle overuse.

Fatigue can also result from sleep disturbance, sleep apnoea (stopping breathing for intervals during sleep) or breathing problems. Rest usually relieves fatigue, unless it has been building up for days over a longer period, when recovery may take longer.

Muscle pain

Muscle pain is very common in people with PPS and is usually described as aching, especially after activity, or it can be felt as a burning pain, spasms or cramps. This pain may be the result of muscle overuse and may occur with **muscle twitching**, especially later in the day or at night.

Joint pain

Weak muscles can lead to unstable joints as they no longer hold the joints in the correct position. This can cause joint pain. Pain may also be caused by injuries to the **tendons** or **ligaments** due to overuse of unstable joints. Weakness and injuries around joints may also lead to pain due to compressed (pinched) nerves.

Muscle loss

Due to the original damage polio caused to the nerves that send messages to the muscles, people with PPS may experience new loss of muscle bulk. This causes wasting or loss of muscle tissue resulting from lack of use.

Sleep disturbance

Sleep disturbances can be common and may relate to **sleep apnoea**, breathing difficulties, pain, muscle twitching or general overtiredness. Sleep apnoea can be caused by the repeated shutting of the airway from throat weakness, sometimes made worse by weight gain. It can also occur when there are brief interruptions in the brain reflex that triggers breathing.

Breathing problems

If you needed help breathing when you had polio you may be more likely to have breathing problems when you have PPS. However, anyone with PPS can have breathing problems, caused by weakness of the **diaphragm** and chest muscles, **scoliosis** or **sleep apnoea**.

Breathing problems mainly occur at night, sometimes due to a combination of weak breathing muscles and brief interruptions in the brain reflex that triggers breathing. When you are sleeping your breathing normally slows down and you can't make a conscious effort to improve it. This may result in short periods when breathing stops, before automatic reflexes start you breathing again.

Breathing problems may develop very slowly. Early signs include frequent waking from sleep, sometimes with choking or gasping, nightmares, snoring, morning headaches, coughing, daytime sleepiness, difficulty speaking at length, lack of concentration and being out of breath when you exercise.

It is important for both doctors and people with polio to understand that breathing problems may develop. These should be assessed as they arise. If you are at all concerned about your breathing, please consult your GP to request a referral for an assessment. Important: In the winter, consider asking your GP for a flu vaccination if you are not already offered one.

Problems with swallowing

Weakness in the muscles you use for chewing and swallowing may lead to coughing, gagging or choking (**dysphagia**). You may also experience changes in your voice and in your speech such as hoarseness or a low volume or nasal sounding voice, especially after you've been speaking for a while or when you are tired.

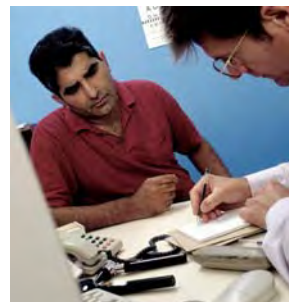
Swallowing problems are usually mild and progress only very slowly. Advice from a speech and language therapist may be helpful.

Cold intolerance

Sensitivity to cold, like many PPS symptoms, may be felt in one area of the body, for example in an arm or leg that may have a poor blood supply, or may be felt as a general cold intolerance, or intolerance to any large temperature change.

Other symptoms?

As there has not been enough research into PPS, there are many other symptoms such as urinary problems, that may or may not be related to it. When other possible causes are ruled out, PPS is sometimes thought to be the cause.



Managing your symptoms

There is no cure for PPS but you can learn how to manage it so you remain and feel as well as possible.

Once your doctor has diagnosed that you have PPS, you should ask for the following:

- An assessment of how PPS is affecting you, and steps you can take to help you feel better. This can include occupational therapy or physiotherapy
- A referral to a speech therapist for a swallowing assessment, if necessary
- An assessment of the emotional impact that PPS may be having on you, and treatment if necessary
- A review of how you are going to get about - walking aids, a wheelchair and a driving assessment
- An assessment of your practical needs at home and at work through occupational therapy or Social Services
- An assessment of care needs by Social Services
- An assessment of how PPS may affect your money situation. You may want to get a benefit checks or independent financial advice
- An employment-related assessment to look at your job or voluntary work options

Staying as healthy as possible means combining self-management techniques, such as pacing, with symptom management such as healthy eating and weight control, as described below.

We can help you find the right advice and find ways to manage your PPS that suit you. The following information may be able to help you:

Conserve it and preserve it!

When you first had polio, you may have been told “use it or lose it”, even if this meant you acted in a way which made you feel pain or very tired. We now know that it’s much easier and better for you to learn new ways of coping with PPS. This can be summed up as “conserve it and preserve it”. One way to conserve your energy is through pacing.

Pacing is very important

Everyone who reads this guide will be at a different point in their life, but will need to look at their work or home environment, and how they get about outdoors, from getting to the shops to travelling further afield.

It is very important that people with PPS save their energy - being active or exercising at the right level for them. That’s where pacing comes in.

What is pacing?

Pacing is a method of learning to recognise your own individual and manageable baseline of activity, so you always stop what you are doing before you become exhausted. By always stopping before you are tired, you may be able to continue for longer.

Pacing means that most activities can be broken up into smaller ones with rests in between.

For example, if you swap between several different jobs or repetitive activities you will be using different muscles and resting others. If a job cannot be broken up it may need to be

done a completely different way. You may need help from another person, or may realise that that job was not necessary after all.

For example, several smaller trips to a supermarket may be easier than one large shop, but if just driving to the supermarket and back is tiring then maybe it is time to have home deliveries.

When managing PPS symptoms it is worth considering the following: pace, change or stop.

In summary

Try to live your life so you feel as fit and healthy as possible most of the time, and then see how you can fit family, work, activities and friends into it. Adapting and finding new ways to do things has always been part of living with polio. The same goes for living with PPS.

Important

Asking for help when you need it is not a sign of weakness but simply being practical about a situation. Consider asking people to help you with chores while you save your energy for doing things that you actually want to do!

Planning your time

Here are some questions to help you pace:

- How much can I do in one day and what is most important?
- What do I really enjoy doing?
- What is not important and can be cut out?
- Have I allowed time to rest?

- Have I organised my home or workplace so that the things I need most often as the easiest to get?
- Have I arranged comfortable seating for any task that can be done sitting?

The *Pacing for activity and exercise* leaflet, written with advice from the Physiotherapy Department of the Lane Fox Unit at St Thomas's Hospital in London, includes further information about pacing and how to work out a baseline of activity.

Please talk to your doctor or physiotherapist before you start an exercise programme.

Controlling weight and eating healthily

Being overweight can be a further strain on weakening muscles and won't help your energy levels and general health. Losing weight is a good idea and can help reduce PPS symptoms.

While regular exercise is a good way of controlling weight, it might not be possible for you.

Following a sensible and healthy eating plan will help to reduce weight and improve health. It is important to eat a healthy, balanced diet including foods which provide slowly released energy over longer periods.

Trying new foods, food combinations or ways of cooking to widen the variety of tastes and textures and stimulate the appetite can be an enjoyable way to lose weight and improve your health. Your GP can also refer you to a dietitian.

Here are some more food and cooking-related tips, which also make use of the pacing techniques mentioned earlier:

- Plan meals ahead
- Break down cooking tasks into smaller, more manageable ones
- Set aside more energetic days for food preparation and cook extra amounts to freeze for less energetic days
- Get hold of cookery books focusing on meals that are simple and full of things that are good for you, but quick to prepare. (Your local library is a good source for a whole range of recipe books)
- Some kitchen equipment such as food processors, microwaves and slow cookers can be useful tools for helping you save time and energy
- There are a number of utensils available that are specially designed for those who do not feel strong, or who have difficulty using their hands
- Ready meals and tinned and packet foods are useful if you feel too tired to cook a meal from scratch, but they are often high in salt, sugars and fats, low in vitamins and minerals and contain food additives, so you should not eat them too often.



Adapting to having PPS

Why am I finding it hard to accept that I have PPS?

Tens of thousands of people in the UK have survived polio and have led active and independent lives, often after months or years in hospital and rehabilitation.

After working hard to recover from polio and being told that you will feel stronger with time, it can be difficult to accept new symptoms and face the problems and limitations they bring.

Don't be afraid to ask for help

Many people never talk about having polio. However, when you are diagnosed with PPS it is a good idea to talk about it with your friends and family, and explain the symptoms.

Family and friends may not realise that they are causing more harm than good by putting pressure on you to ignore your body's warnings. The only answer is to be patient, try to explain how you feel and carry on with what feels right for you. Talking about polio and PPS can be the first step towards asking for help when necessary.

You might find that your family has spent years trying to forget that you had polio because it was so painful at the time. It may be hard for them to think about and come to terms with all over again.

Speak to your GP if new symptoms are making you feel anxious or depressed. You can also get support from church or religious groups, social groups or clubs, or organisations such as Samaritans and Age Concern or your local British Polio Fellowship

Branch or group. Joining a support group is a good way to start learning new ways to cope with PPS. Group newsletters are often full of useful suggestions.

Many people who had polio have found that any change in life can be tackled and seen as a challenge. However, if PPS seems like one challenge too many, talking to family or friends, or consulting a doctor or a counsellor, can often help people living with PPS see things in a new perspective.

The importance of relaxation

Rest and relaxation are an important part of finding the right balance between activity and saving energy. Relaxation is important to ensure that energy levels are recharged.

Warm baths and showers can be relaxing, as well as massage and other alternative therapies.

Managing stress

Stress in itself isn't necessarily bad for you, but too much for too long can be damaging. It is helpful to be aware of the effects of stress on your health and how it can be successfully managed. Good support can help minimise stress.

If a situation is causing stress over a long period of time, it needs to be changed or thought about differently. If you are always thinking about other problems, it may be difficult to think constructively about managing PPS symptoms.

The following can help you to manage stress:

- Talk to someone - don't bottle up your feelings
- Accept offers of help

- Do one thing at a time - don't let tasks pile up
- Know your own limits and don't expect too much of yourself
- Let off steam in a harmless way - laughter is very helpful
- Try to spend time with people who are positive and you enjoy being with
- Practise slow, deep breathing
- Use relaxation techniques.

If you are experiencing long period of stress, anxiety or worry, discuss this with your GP.

Coping with feeling the cold

If you really feel the cold, then it's a good idea to wear several layers of clothing, more than one pair of socks or possibly use heating pads.

If you feel cold all over, sometimes a comfortably hot bath or shower is the only thing that will relieve the overall cold, shivery feeling you get from being out in cold or windy weather. Cold can also lead to temporary increased weakness and sleepiness, increasing the risk of accidents or falls.

If possible try to avoid draughty places or becoming cold to start with. It is easier to stay warm than to warm yourself up again if you have become cold.

Our factsheet, *Cold intolerance* includes further information about feeling the cold and practical ways to keep warm.

Can medication be used to manage pain and fatigue?

Ideally, pain and fatigue can be reduced with some of the tips above. However, if even the most ordinary daily activities cause pain, there are various medication options, from over-the-counter painkillers like aspirin,

paracetamol or ibuprofen, to stronger anti-inflammatory drugs and opiates. Over the counter remedies should not be used on a long term basis without discussion with your GP.

Whilst not an initial option, you may wish to discuss Gabapentin with your GP. This is a drug that was originally developed for epilepsy and nerve pain, not general pain. It has been of some use to people with PPS pain where other types of painkillers have not helped. Reducing pain may also help with sleep and fatigue.

Opiates such as codeine may cause drowsiness or depress breathing and have other side effects, including constipation. Muscle relaxants such as benzodiazepines, which are sometimes used for muscle cramps, may also cause drowsiness and increased weakness.

It is important to remember that while pain is being controlled by drugs, more damage may be done leading to more pain later if you do not look after your joints and your activities are not paced.

Drug-free alternatives for pain management include TENS (Transcutaneous Electrical Nerve Stimulation) machines. Some people have also found acupuncture or hypnotherapy helpful for managing pain.

For further information see our *What you should know about your medication* factsheet.

The side effects of medication

Unfortunately, all drugs have potential side effects.

Some people with polio have reported that certain drugs, or combination of drugs, taken for other health conditions have made their PPS symptoms worse or more noticeable.

As people get older, they are more likely to be prescribed medicine for a variety of conditions, such as arthritis and high blood pressure. Sometimes those taking a mixture of drugs for different health conditions can experience more severe side effects.

You may be more likely to experience side effects if you have had breathing problems, muscle weakness or paralysis, swallowing difficulties or if you are older.

You should discuss potential side effects with your doctor, particularly those that may cause or worsen the following symptoms:

- Fatigue
- Difficulty breathing
- Muscle weakness
- Dizziness and/or drowsiness, which may affect your balance, ability to drive and cause falls
- Depression or anxiety. These can change your perception of pain, making it seem worse
- Insomnia (difficulty getting to sleep or staying asleep). This can increase fatigue
- Increased cold intolerance.

If you do have any new symptoms, speak to your doctor as soon as possible. It may be possible to change your prescription. Never stop taking a particular drug without seeking medical advice.

With any drug, the balance between the benefits of taking it, the risks of not taking it and the risk of side effects needs to be taken into account.

For further information, see our factsheet, *What you should know about your medication - a guide for people with polio/Post Polio Syndrome*.

Mobility aids and orthotics

Various mobility aids, such as a walking stick, crutches, ankle braces, callipers, wheelchair or scooter, may make it possible for you to carry on doing many things that were becoming difficult or impossible.

You can get many of these aids free from the NHS. Before contacting your local supplier it is important to have some idea of what is available. You can get help with this from Disability Living Centres, assessment centres or suppliers.

Here are some options you might be given:

- A new brace to improve posture, stability, and balance, increase walking efficiency and reduce fatigue and falls. There are many new lightweight materials that are far more comfortable and less obtrusive than older models, whether you are thinking of crutches, braces or wheelchairs
- New backs, seating and cushions for wheelchairs to make you more comfortable and to stop you feeling so tired on long outings
- There are also a wide variety of adaptations for cars, such as hand controls and lifts for wheelchairs

Aids can be seen as routes to freedom and doing what you want rather than symbols of disability. Walking straighter and more easily with a walking stick may make you appear less disabled, and will definitely give you a better posture and more energy than struggling on without.

Living with PPS: more useful tips



Do I need a polio vaccination if I am going abroad?

There are three types of virus that can cause polio. If you have been infected with one type you could still get another. So, if you are going to a place where there is a risk of getting polio you should have a polio vaccination or booster to make sure you do not get it again.

You will also need to consider any other vaccinations or medications that are recommended for the place that you are travelling to.

Your GP or practice nurse should be able to advise. For more information see www.travelhealthpro.org.uk or www.fitfortravel.nhs.uk

IMPORTANT: In the winter, consider asking your GP for a flu injection if you are not already offered one.

Can complimentary therapies help?

There has been very little research into the benefits of individual complementary or alternative therapies such as acupuncture, homeopathy and hypnotherapy in relation to PPS.

However, as long as your therapist is properly qualified and you have spoken to your doctor about the treatments you are going to have, complementary therapies may be able to help with PPS symptoms where conventional medicine does not have anything to offer. This has been demonstrated by comments made by members of The British Polio Fellowship.

For further information see our factsheet, *Complementary Therapies*.

Going in to hospital

If you are going into hospital for either a local or general anaesthetic, please ask for our Hospital Pack. This guide contains important information that you should give to your anaesthetist.

If I have PPS am I more likely to get other illnesses?

People with polio or PPS will experience the same health issues as other people.

You may be slightly more likely to get some other common illnesses such as **osteoporosis** or **osteoarthritis**, but this is likely to be linked to having a limited ability to exercise, additional wear and tear of joints, or increased weight rather than directly to polio.

Where can I learn more about PPS?

Many people with PPS have done courses to help them learn how to manage their symptoms.

There are limited courses directly related to PPS, but you may find general chronic condition courses useful as these cover topics such as pain management. They also help patients cope with symptoms and feelings and advise about relaxation, energy management, exercise and nutrition.

Your GP or specialist should be able to advise you about these courses.

Further information

More information about the diagnosis and management of Post-Polio Syndrome for GPs and members of the public can be found on the NHS website.

To access this information please visit www.nhs.uk/ and click on "Go to the Health A to Z" and find Post-Polio Syndrome .

You may wish to refer your GP to this website when you go and see them.

British Polio Fellowship's Definition of PPS

Summary Level Definition

“Post-Polio Syndrome (PPS) is a neurological condition that can occur in people who have had polio. After an interval of several years of stability, people may then develop increasing weakness, stamina problems, fatigue and pain. PPS may respond to a range of therapies which might prevent further deterioration”.

Symptoms include the onset of new weakness or abnormal fatigue in previously affected or unaffected muscles; a general reduction in stamina; muscle and/or joint pain; muscle atrophy; breathing, sleeping and/or swallowing problems; or cold intolerance. Symptoms may lead to loss of endurance or function.

A diagnosis of PPS assumes the absence of any other conditions that could explain the above symptoms. Such conditions should be considered and excluded by appropriate investigations”.

Operational Definition

The following operational definition of Post-Polio Syndrome supports and expands upon the summary definition above. It is derived from consensus statements based on the extensive review of various medical and scientific literature, studies and previous definitions.

As there is no diagnostic test for Post-Polio Syndrome it is commonly defined by a **symptom complex** that includes new muscle weakness, decreased endurance, pain and fatigue.

The onset of PPS may be gradual or it can occur suddenly. It occurs irrespective of ageing. Symptoms may sometimes appear to be triggered by various events like surgery, falls or immobility.

The following are the main criteria that need to be considered in making a diagnosis of “Clinically Definite PPS” or “Clinically Possible PPS” and are also shown graphically in the table below:

- **Clinically Definite PPS**

"Based on various consensus statements, a diagnosis of “Clinically Definite PPS” comprises a confirmed history and/or physical evidence (however slight) of polio, a period of functional recovery and stability, new muscle weakness, or abnormal muscle fatigue, with evidence of neurogenic change, and the exclusion of any other possible conditions".

- **Clinically Possible PPS**

It is recognised that there are patients who have PPS symptoms, but there is less diagnostic certainty. This would include patients with the following characteristics - a possible history of polio where there may be no previous physical manifestation, new muscle weakness, or abnormal muscle fatigue, (with no evidence of neurogenic change), a complex of symptoms that are generally recognised to be those for PPS, and the exclusion of any other possible conditions.

Diagnosis criteria (See below for more detail on each of criteria)	Clinically Definite PPS	Clinically Possible PPS
Definite history / physical evidence of polio	●	
History of possible polio		●
Period of recovery and stability	●	●
New muscle weakness – with evidence of neurogenic change	●	
New muscle weakness – no evidence of neurogenic change		●
Appropriate complex of symptoms	●	●
No other disorder / medical explanation	●	●

Diagnosis criteria

1. Definite History of Polio / Physical Evidence

The patient's original medical records, history and/or physical evidence provide a confirmed diagnosis and history of the original polio illness.

2. History of Possible Polio

Some people may not have confirmation of prior polio or a physical manifestation of the illness, but do have some history and/or current symptoms, which taken together, indicate a **possibility** of polio.

For example, this could apply to a patient in whose family, or circle of friends, there was an incidence of polio, or who is known to have come from an area where there was a polio

epidemic or outbreak, and/or who suffered an illness that at the time was not diagnosed as polio.

3. Period of Recovery and Stability

Partial or fairly complete neurological and functional recovery after the original polio illness followed by a period of neurological and functional stability. As guidance only, the period of stability will generally be 15 years or more.

4. New Muscle Weakness – with evidence of Neurogenic change

Muscle weakness may be confirmed clinically by the presence of clear lower motor neuron features. When and if available / appropriate, EMG testing may confirm this and establish a baseline for repetitive testing or offer alternative diagnosis. Other tests that may be useful are nerve conduction tests to assess nerve damage, Manual Muscle Testing (MMT), reflex and exercise testing for endurance. Other causes of neuromuscular weakness will also need to be excluded by appropriate tests.

Although it is accepted that electro diagnostic testing has limitations in confirming neurogenic weakness, and will not provide a definitive diagnosis of new weakness, it may help to exclude some of the other common causes of neurogenic weakness as well as other, more rare, conditions.

5. New Muscle Weakness – no evidence of Neurogenic change

A patient who has a possible history of polio may be experiencing new weakness that testing cannot confirm to be neurogenic (see Point 4) but is consistent with the symptoms of PPS.

6. Appropriate complex of symptoms

These may include two or more of the following health problems occurring after the stable period: extensive general fatigue, abnormal muscle fatigue, decreased endurance, muscle pain, joint pain, new weakness in muscles previously affected or unaffected, new muscle atrophy, functional loss, breathing or swallowing problems, cold intolerance.

7. No Other Disorder / Medical Explanation

Exclusion of medical, orthopaedic, and known neurological conditions that might cause the health problems listed in Point 6 above, although these other conditions may co-exist with PPS. Depending on symptoms, the most obvious possible causes to rule out are orthopaedic problems related to the original polio; injuries, breathing problems, other neuromuscular diseases, and other diseases that commonly cause fatigue, such as thyroid problems, diabetes or heart disease.

EMG testing and other relevant tests (see Point 4 above) may be used as a means to exclude other known neurological conditions that may present similar symptoms.



Some Useful Terms

Your GP or consultant may use some of these medical terms when discussing your condition with you.

Term	What it means
Brain stem	The lower part of the brain attached to the spinal cord that carries the main nerve connections for the motor and sensory systems from the main part of the brain to the rest of the body
Central Nervous System	Coordinates the activities of all parts of the body
Diaphragm	A thin layer of muscle that separates the chest and abdomen and plays a crucial role in breathing
Dysphagia	A condition in which the action of swallowing is either difficult to perform or painful
Fasciculations	A small, local, involuntary muscle contraction or twitching, often seen in calf muscles
Ligament	A tough band of flexible connective tissues that links two bones together at a joint. They both strengthen the joint and limit its movement to certain directions
Motor Neuron	One of the units (neurones) that goes to make up the nerve pathway between the brain and a muscle that control movement

Term	What it means
Muscle fibre	An elongated cell that forms the muscles of the body and generates muscle tension with the help of motor neurons
Muscle Twitching	See Fasciculations
Nerve Fibre	A threadlike extension of a nerve cell that conducts nerve pulses
Neurological	A neurological disorder is one that can affect the central nervous system (brain and spinal cord), the peripheral nervous system or the autonomic nervous system
Osteoarthritis	A degenerative disease of the joints that causes pain, stiffness and restricted movement
Osteoporosis	A disease of bone, leading to reduced bone density, resulting in bones that are brittle and liable to fracture
Scoliosis	A medical condition in which a person's spine is curved from side to side, shaped like an "S" and may also be rotated
Sleep apnoea	A sleep disorder characterised by pauses in breathing during sleep
Tendon	A tough band of fibrous connective tissue that connects muscle to bone

Useful organisations and resources

International Centre for Post-Polio Education and Research

Website: www.postpolioinfo.com/centre.php

An American resource and website, with Post-Polio information aimed at both professionals and the public.

Post-Polio Health International

4207 Lindell Boulevard, #110
St Louis, Missouri 63108-2915, USA
Website: www.post-polio.org

Post-Polio Health International aims to enhance the lives and independence of people with polio through education, advocacy, research and networking. The website includes resources for the public and health professionals.

Post-Polio Network (NSW) Inc.

Website: www.polionsw.org.au

The Network provides advice, information and support to people with polio and PPS in Australia.

Polio Survivors Network

Website: www.poliosurvivorsnetwork.org.uk

This site contains useful information and a library of reference material and articles.

British Footwear Association

Tel: 01604 261126

Website: www.britishfootwearassociation.co.uk

The British Footwear Association is a trade association representing British Footwear manufacturers and British-based footwear brands. The site has information about hard- to- find footwear, a directory of companies and FAQs.

Disabled Living Foundation (DLF)

Tel: Helpline: 0300 999 004 (9.00am-5.00pm, Mon-Fri)

Website: www.livingmadeeasy.org.uk

The DLF is a national charity providing free, impartial advice about all types of equipment to older and disabled people, their carers and families. The website includes useful guides, information and a database of equipment.

Forum of Mobility Centres

Tel: 0800 559 3636
Website: www.mobility-centres.org.uk

17 independent mobility centres offering advice and assessment on driving, getting in and out of a vehicle and transporting a wheelchair or a scooter in a car. Some offer advice and assessment on wheelchair or scooter selection.

Motability

Tel: 0845 456 4566
Website: www.motability.co.uk

A national charity which assists disabled people on high rate DLA Mobility Component or War Pensioner's Mobility Supplement to fund a car, electric wheelchair or scooter. Motability oversees wheelchair and car schemes, and may provide adaptations and financial help towards vehicles and driving lessons.

See the British Polio Fellowship's: *Useful Organisations list* for further information

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