



By Frances Quinn, Vice-Chair of the British Polio Fellowship Expert Panel and Trustee

## 1. Introduction

**This factsheet is for anyone who had polio or has Post Polio Syndrome (PPS) who would like to learn more about pain and how it can be managed.**

Pain has the potential to make dramatic changes to people's lives, affecting both their physical and emotional wellbeing and their ability to remain active and independent.

Pain management aims to reduce how often pain is triggered and the severity of pain when it occurs. In some cases, pain may even be eliminated. With successful pain management, people who had polio or have PPS can get on with living as full a life as possible.

People who had polio will all have had different experiences and developed different ways of coping. It is important to find which pain management methods work best for you.

### Post-Polio symptoms

People who had polio years ago may now be experiencing new symptoms. These can include new or increased muscle weakness and fatigue with or without other symptoms like muscle and joint pain, muscle atrophy or wasting, breathing or swallowing difficulties or cold intolerance.

There is more information on PPS in other British Polio Fellowship factsheets.

## 2. Pain and pain types

Pain is usually the body's way of telling us that something is wrong. Most pain experienced is caused by actual or threatened damage to the tissues in our bodies, such as muscle and bone.

Most of the tissues and organs of our bodies are served by a network of sensing nerves. These nerves are not the same as the ones that aid muscle movement - the motor neurons - that can

be damaged or destroyed by the polio virus. The sensing nerves pick up information about any damage, or threat of damage. Chemicals are released, which excite nearby nerve fibres. Messages about the damage are then carried to the brain by the spinal cord. In specialised areas of the brain, the messages are interpreted as pain coming from the area affected by the damage.

Short-term pain, such as that from a punch, is called **acute pain**. It usually has an identifiable cause and often has visible signs, such as redness, heat and swelling. It can normally be relieved by treatment.

Pain lasting longer than 3 months is referred to as '**chronic pain**' or 'persistent pain' and can be continuous or recurrent (coming and going). Most people with chronic pain have some level of pain all the time and feel more intense pain in response to movement, changes in temperature or when they are ill, upset or anxious.

Many people living with chronic pain may find the pain impacts on other areas of their lives. This could include feeling isolated, lonely and excluded from mainstream society. They may struggle to maintain relationships with friends and family, employers and colleagues. Loss of employment, withdrawal and depression are commonplace.

Pain is not always sensed by the brain at the location of the cause of the pain - this is called '**referred pain**'. An example is sciatica where a problem in the lower back causes people to experience pain in their legs.

### Responding to pain

No matter what is causing the pain, each person's experience and how he or she responds to it is unique. You are the only person who will fully understand your pain. Irritation, anger, frustration, hopelessness, a sense of unfairness and other unhelpful feelings commonly experienced by people with chronic pain can increase tension in muscles and joints, which can cause more pain. They also increase tiredness,

make focusing away from pain more difficult and can prevent you from enjoying positive experiences.

However, pain may also be a wake-up call, helping you to see the positive side of making changes that will reduce the pain. You may discover new activities which are fulfilling without being as physical.

Many things influence our experience of pain and its emotional effects, such as personality type, coping strategies, home and work environment and the availability of supportive networks (family, friends and support groups).

Our core beliefs can also make a huge difference. Core beliefs are strongly held beliefs about ourselves, other people and the world, which develop over time, usually from childhood and through the experience of significant life events or particular circumstances. Examples of negative core beliefs are “I am powerless” or “I am unlovable”. These are potentially very destructive if not challenged and worked through. Anxiety and depression can also have a significant effect on the levels of pain people experience. Working to manage these problems can also reduce some aspects of pain. Being in pain is in itself stressful and distressing and you may wish to be referred to a counsellor, psychologist or other relevant professional.

#### **Other causes of pain**

It is important to remember that there could be something other than polio or PPS that is causing your pain. Also, if you had polio and are experiencing pain, this does not necessarily mean that you have developed PPS. Even if you have been diagnosed with PPS, the cause(s) of your pain should be thoroughly investigated. The pain could be the result of any number of factors, from the benign to the very serious.

Many people who had polio have other conditions that can also cause pain.

Osteoporosis is common and this can cause painful fractures. Osteoarthritis is also frequently a problem for people who had polio. Arthritis pain can be caused by the inflammation of joints, which can cause swelling and loss of movement.

Our factsheet, *Polio and Bone Health*, gives more information about osteoarthritis.

**It is very important that you talk to your GP about any pain you experience to get it thoroughly investigated.**

### **3. Examples of polio/PPS-related pain**

For people who had polio, pain may be caused by a number of factors.

Pain can be due to the increasing deterioration of nerves and muscles which characterises Post-Polio Syndrome. Important factors are the overuse of polio affected muscles or of the muscles compensating for weak muscles. This pain can also be felt in muscles previously not considered to be affected by polio as PPS involves new weakening of muscles that may have only been very mildly affected. Sometimes there is polio damage that does not become obvious until later in life.

Abnormal posture, gait and body movements (biomechanics) can put strain on joints, limbs and the back. Any worsening of posture or difficulty with movement can put new strain on joints throughout the body leading to instability and new or increased pain.

The long-term use of walking sticks, crutches, callipers and manual wheelchairs can cause injury to soft tissues, especially in the shoulders, hands and wrists.

Your instinct may be to protect your body by moving it as little as possible or holding it in a stiff way. This can lead to a loss of strength, flexibility and range of movement. It is therefore important to keep as active and mobile as you can.

#### **Post-polio neuromuscular pain**

Post-polio neuromuscular pain is commonly described as a burning or aching pain often associated with muscular fatigue. People may also experience cramping and twitching (fasciculations), often described as a crawling sensation. It is associated with overuse and usually relieved by rest. This type of pain often occurs at night-time or the end of the day and is worsened by physical activity, stress and cold temperatures.

This type of pain may be useful in that it can help people begin to recognise PPS symptoms and also when they may be overdoing activities, in order to apply energy management techniques.

#### **Overuse injury**

This type of pain includes injuries to soft tissue, muscles, tendons, ligaments and bursa (small fluid-filled sacs that help to reduce friction, such as around joints). The site of pain is at the structure that has been overused.

A common example is tendonitis from overuse of the shoulders. People who had polio usually have stronger arms than legs and may use their upper body to compensate for their weaker legs, for movements such as getting up from a chair, climbing out of the bath, walking with crutches or using manual wheelchairs. Over time, this can cause inflammation and the pain increases the more often the movement is carried out.

### **Biomechanical pain**

People who had polio often have different muscle strength on each side of the body, leading to an imbalanced posture and inefficient body movements (biomechanics). Weak muscles across joints can lead to joint instability leading to pain.

Many also have different leg lengths and/or curvature of the spine (scoliosis).

The long-term strain that this places on the joints can make them more susceptible to painful degenerative joint disease (DJD).

For example, sacroiliac joint dysfunction can be caused by legs of unequal length, an imbalance or weakness of muscle in the legs/trunk and trauma or injury from a fall resulting in lower back pain. The sacroiliac (SI) joints are on each side of the lower back, at the top of the buttocks. They connect the base of the spine (sacrum) with the hips/pelvis (ilium). Sacroiliac pain can be caused by too much movement freedom (hypermobility or instability) or too little movement freedom (hypomobility or fixation) around a joint. It is usually described as sharp and stabbing, or a dull ache and can be worsened by twisting, sitting or standing for long periods with poor posture.

Those who use manual wheelchairs or devices such as callipers, walking sticks and crutches are prone to DJD, or overuse syndromes in their upper limbs, especially the wrists (carpal-tunnel syndrome) and shoulders.

### **Neuropathic pain**

This type of pain is caused by a problem with one or more nerves themselves. This is often when nerves are compressed or pinched due to the biomechanical problems discussed above. Sometimes there is no "injury" or tissue damage that triggers the pain. However, the function of the nerve is affected in a way that sends pain messages to the brain.

Neuropathic pain is often described as burning, stabbing, shooting, aching, or like an electric

shock. Other symptoms are pins and needles, numbness and weakness.

### **Pain and other PPS symptoms**

Fatigue is already a problem for many people who had polio and pain can often worsen this. People can become caught up in cycles of pain, fatigue, negative thinking, depression and stress, which can make the pain seem worse and therefore much more difficult to deal with. Learning to manage pain can help to break this cycle.

## **4. Pain management - first steps**

### **Acknowledging that you have pain**

The first, most important and often the most challenging step towards successful pain management is acknowledging that you have pain. Once you are able to do this, you can begin to move forward. Acknowledging that you have pain does not mean that nothing can be done. It means arriving at a place where you are aware of the reality of your pain and are open to trying more ways in which to help yourself. This comes more easily to some people than others. Don't be hard on yourself if you find it difficult, or if your feelings vary from day to day - talk about your feelings or write them down. Be kind to yourself.

### **Understanding your own pain**

You may think that this is a rather strange idea. Really getting to know your pain, however difficult this may be, can help to remind you that it is not you, but something separate from you, with its own characteristics, which ebb and flow during the day. Listening to your body and knowing when to rest overused muscles or injured soft tissues is probably the most important lesson in controlling pain.

You might like to try keeping a detailed "pain diary" for a few days. Be creative: describe it in your own words, give your pain a colour, a form. Note the things that make it worse, or that reduce it.

Do you notice any patterns emerging? This can identify activities that trigger your pain and be a starting point for lifestyle changes that may help. When you have done any of these exercises, consider if your thoughts about your pain have changed in any way.

### **Getting your pain assessed**

A pain diary can also be very helpful when talking to your doctor or other health care professionals. It can be hard to remember details when in a

a doctor's surgery, so bringing a written list can really help. The words you use to describe your pain along with any triggers you identify can help them diagnose the causes and develop a suitable management plan.

It is important to talk to your GP about any pain you are experiencing. They can assess your symptoms and determine if any other conditions are causing the pain, and also see if a diagnosis of PPS is appropriate. As there is no single diagnostic test for PPS, a number of tests may need to be carried out to rule out other conditions.

They can also refer you to specialists for further investigations. A rehabilitation consultant can evaluate the cause of your pain and make treatment recommendations. A neurologist can carry out nerve and muscle tests and an orthopaedic consultant or rheumatologist can assess the health of your joints. Your GP may decide to refer you to a physiotherapist or to attend a pain management course.

It would be best to see healthcare practitioners who have knowledge of polio and PPS and experience of dealing with people who had polio. If these are not available easily, then ask for referral to professionals with experience in neurological conditions.

### 5. Pain management methods

Methods used to manage pain in people who had polio may include the following:

1. Energy management techniques to reduce the causes of overuse and injury; for example, pacing, mobility aids, assistive devices, good orthotics and lifestyle modification
2. Medication
3. Physical therapies such as hydrotherapy, heat, TENS
4. Using the mind - such as relaxation or talking therapy

These techniques can be thought of as a toolbox.

Your pain is affected by your polio history and your lifestyle and is personal to you. It can also change from day to day. Some of these techniques will be more useful than others and some you may only use occasionally. Taking control of your life, deciding what changes best minimise your pain is both effective and empowering and will enhance any professional treatment you are receiving.

### 6. Reducing the causes of pain

Some methods aim to reduce how often pain is

triggered or to reduce the number of injuries due to overuse. The goal is to change how we prioritise and carry out activities so that we can keep on doing the things we enjoy.

### Pacing and energy conservation

Pacing and energy conservation are probably the most important strategies for managing post-polio symptoms and avoiding the 'Boom and Bust' cycle, where over-activity one day (boom) leads to fatigue or pain and enforced underactivity during the following days (bust) with a possible decrease in fitness.

Pacing is a way of recognising your individual baseline of activity, so instead of continuing an activity to the point of exhaustion or pain, you stop before that point, resting both the muscles being used and the body, which is expending abnormal effort because of the polio damaged nervous system. After resting, which may involve anything from minutes to hours to days, you can start your activity again. For example, for a walk or some gardening, divide it up into several short stints with rests in between. Pacing your day-to-day activities is essential when managing pain, not only to avoid causing long-term damage and more pain, but also to allow you to keep doing the things you need and want to do.

Energy conservation involves simplifying tasks: using aids to make tasks easier; doing some jobs less often or for a shorter time; or getting someone else to do certain jobs.

On the other hand, some people have reduced their activity levels to very low levels because of the pain. They may only be doing basic daily tasks, but the pain is still present most of the time regardless of activity level. For them, the goal might be to actually slowly increase a range of varied activities over time, and if this increases pain and muscle fatigue, then more energy conservation should be tried. If the pain is in the legs, more activities might be needed to be done sitting down or possibly a wheelchair could be tried. This can also be considered a type of pacing. If you think this applies to you, it is best to get advice from a physiotherapist or a pain management team to guide you through this process.

A physiotherapist or an occupational therapist with experience in managing neurological conditions can be a great help with learning how to pace and conserve energy. Physiotherapists can

offer a tailored programme to help people manage chronic pain. This may include specialist exercises, posture management and hydrotherapy.

Our factsheet, *Pacing for Activity and Exercise*, gives more information about pacing, conserving energy and how to work out a baseline of activity.

### Equipment, aids and adaptations

Mobility aids and other assistive devices can take the strain from muscles and joints, reduce pain, and create new independence. With new mobility aids you may be able to visit places or do things you have had to stop doing because of pain or fatigue, for example, by using an electric scooter.

If you already use mobility aids, you may want to think about how you can adapt or change them in order to make them better or more comfortable. For example, if you use crutches, consider changing to lightweight ones or those with foam covered handles or hand grips shaped to evenly distribute weight across your palms. If the long-term use of crutches has caused wrist and shoulder problems, you might want to think about switching to a wheelchair or scooter. This may be a very challenging step for some people, so you might want to try alternating between the two methods, at least at first.

If you use a manual wheelchair, you might want to switch to a powered wheelchair or scooter.

Some daily activities or equipment could be making your pain worse, so it may be a good idea to think about what could be changed, modified or done less frequently. For example, cooking utensils can strain weak hands, low seating and beds can be hard to rise up from. Bathrooms or steps in and out of your house could be improved to make using them easier and less dangerous.

Getting professional advice and support - an assessment from an occupational therapist from social services or visiting a mobility or disability resource centre to try out equipment - can be very useful as new equipment is being developed all the time. Some adaptations may qualify for grant aid.

### Orthotics

If you use orthotics, talk to your orthotist about any problems you are having - do not suffer ill-fitting callipers or orthopaedic footwear in silence. If you feel that your stronger limb is experiencing muscle fatigue and contributing to falls, it may also need extra support. Correct, well-fitting orthotics

can relieve muscle fatigue and reduce the pressure on joints, helping to relieve pain.

A wider range of orthoses is available privately than on the NHS, including lightweight callipers.

### Exercise

Taking regular exercise can help you manage your pain **as long as it is pain-free and non-fatiguing**. It may be tempting to avoid exercise or physical activity altogether, for fear of injuring yourself and making the pain worse but keeping moving will maintain fitness and help your body cope with pain better. Exercise can also release endorphins and increase self-esteem and wellbeing, which also helps minimise the impact of pain.

However, for some people, daily activities already use muscles to their maximum and trying to do more is not possible without pain. As with pacing, exercise needs to be tailored to the individual, so you are advised to ask for help from a registered physiotherapist with **experience in neurological conditions**. The key is to find the correct balance of activity and rest for each person. This can be difficult, as people with polio are all unique and so everyone's correct balance is different.

Varying your activities will help you stick to a physical activity/exercise regime. Little and often is key. Build up slowly and regularly over a few weeks monitoring your pain and fatigue levels. Gentle stretching exercises such as yoga or Pilates can help maintain flexibility, while non-fatiguing aerobic exercise can improve the stamina of the heart and lungs, improve blood circulation, lower blood pressure and aid relaxation and sleep - all of which may improve pain management.

**Remember: It is important that exercise should be non-fatiguing and pain-free.**

For further information about exercise, see our factsheet *Pacing for Activity and Exercise*.

### Medication

Painkilling drugs can make a dramatic improvement to the quality of life of many people living with chronic pain. A reduction in pain can improve sleep, fatigue levels and your ability to function on a day-to-day basis. This can have a very positive effect on your physical and emotional wellbeing, as well as your general quality of life and personal relationships. Even if taking medication is not your first approach to pain relief, it is useful to know what the options are. You may wish to talk to your GP about what is available.

Some people may be reluctant to take painkillers. This may be because of concerns about side effects. All drugs unfortunately have potential side effects and you may have to weigh up the possibility of these against the obvious benefits of reduced pain. Some people may worry about becoming dependent upon painkillers. If you have any concerns, talk them through with your GP as it is important to fully understand what side effects may be experienced and how to manage them. You should always seek medical advice before taking painkilling drugs and always inform your doctor and pharmacist of all the medication you are taking.

Masking pain with painkillers may lead people to overuse their muscles and in the end cause damage to muscles or soft tissue and possibly worse pain. It is recommended to first try to relieve pain through energy conservation and rest.

Further information about painkillers is contained in our Medication Guide factsheet: *What you should know about your medication*.

## 7. Physical Therapies

Other management methods reduce the severity of pain that we feel.

### Hydrotherapy

Hydrotherapy is the use of water-based movement to treat a variety of conditions, such as arthritis or back pain. Doing special exercises in a warm water pool, usually within a hospital physiotherapy department, allows muscles to relax, eases pain and increases the range of movement of joints and can help improve muscle strength. A physiotherapist will decide if you would benefit from hydrotherapy. You do not have to be able to swim to have hydrotherapy and a physiotherapist should always be in the pool with you. The physiotherapist will help you develop a programme of exercise that you would continue on your own to maintain any benefits gained.

### TENS

Some people who had polio or have PPS find TENS machines helpful as part of a pain management programme. TENS stands for Transcutaneous Electrical Nerve Stimulation. TENS machines deliver small electrical pulses to the body via electrodes placed on the skin. It is thought that pulses from the TENS machine “block” pain signals from the source of the pain to the brain. If the brain receives fewer signals, we may then feel less pain.

### Sleep

Chronic pain can disrupt sleep, leading to a cycle of increased fatigue, stress, and inability to cope resulting in more pain and even less sleep. Improving the quality of sleep may help in pain management.

It is a good idea to get into a routine of winding down before you go to bed, to calm your mind and body. A warm bath is very helpful, as are doing specific relaxation exercises, creative visualisation (using your imagination to create clear “images” of a desired scenario in your mind) or listening to relaxing music. Try not to eat your evening meal too late - allow at least a couple of hours before you go to bed. It also helps to avoid caffeine, nicotine and alcohol. Some people find that avoiding the television helps them to literally “switch off” at the end of the day - others find that reading a book that is not too taxing works wonders.

### Heat

Everyone will appreciate how comforting a hot compress or hot water bottle can be, but heat can also temporarily shut down the pain response. Research has found that if heat of more than 40C (104F) is applied to the skin near where pain is felt, it activates heat receptors, which block the body's ability to detect pain. There is a wide range of heat products available on the market, including microwaveable wheat bags, pads and pillows, battery heated socks, hand warmers and, of course, hot water bottles.

### Cooling

Not all pain is eased by heat, some pain may respond better to local cooling, particularly where the pain is caused by inflammation. These areas may feel hot to touch. Those who are intolerant to cold may over-respond and need to use cooling with caution.

### Healthy eating and weight control

Eating a healthy, balanced diet will improve your general health and wellbeing, helping you to deal better with your pain. Good nutrition can also help you maintain a healthy weight, which can reduce strain on muscles and joints, and therefore reduce pain.

### Complementary therapies

Although there is insufficient clinical research in this area, some complementary therapies, such as acupuncture, osteopathy, Alexander Technique and hypnosis, have been found to be effective in

helping some people manage their pain. Gentle massage may help relieve tight muscles.

## 8. Using the mind

### Talking therapies

Many people who had polio have responded to the challenge by pushing themselves very hard. Often, many do not want to ask for help. In the 1950's and 60's following the polio epidemics, the message was to 'use it or lose it' and to do as much as possible for themselves. This can make it hard for polio survivors to change behaviour, to modify activities, use aids, or ask for help. Talking to an qualified therapist can be very helpful in making positive changes to manage pain.

According to a survey carried out by the British Pain Society, 49% of people with chronic pain become depressed. Talking therapies can help people come to terms with their pain and explore the way it is affecting them and their daily life. Talking to a counsellor, psychotherapist or psychologist allows people to work through their feelings about their pain and to find ways of making changes to help them cope with it better.

Cognitive behavioural therapy (CBT) is a talking therapy that was originally developed to help treat depression, but the techniques it uses have been found to be highly effective for treating a range of problems, including compulsive behaviour and drug and alcohol addiction. The basic idea behind CBT is that the ways we think, feel and behave are very closely linked. Changing the way we think about ourselves, our experiences and the world around us, changes the way we feel and what we can do. During CBT, the therapist helps the person to identify and challenge their negative thoughts, which can help them escape the cycle of negative thoughts and feelings. The therapist also shows the person different ways to cope with unhelpful thinking and behaviour patterns. CBT has been found to be very helpful for people living with chronic pain, particularly where anxiety appears to be a strong component; for example, the person frequently seeks reassurance, worries persistently and avoids specific movements or situations.

There is an increasing range of pain management self-help manuals available, many of which use CBT principles and techniques. While these can certainly be very helpful, they are no substitute for a suitably qualified therapist.

### Relaxation

Muscle tension and stress and anxiety can worsen

pain, so learning to relax is a very important part of the pain management process. Relaxing activities, such as listening to soothing music, reading and gardening can be helpful. You may also want to try relaxation exercises, guided relaxation CDs, deep breathing or meditation. Try and make time to relax every day.

### Distraction and visualisation

The sensation of pain may be reduced if the mind is focussed on other things, such as a challenging game or a favourite hobby. There are some other distraction techniques that can be learned such as counting down from 100, or reciting lists of names. These all divert the attention from the pain so that it is less noticeable.

Visualisation techniques can also help - for example these may involve visualising yourself in a special place or locking your pain away where it cannot be felt.

Both of these may be taught on a pain management course.

## 9. Other help

### Pain management programmes

Pain management programmes are usually run in hospital pain clinics by pain rehabilitation teams. They often involve working in a group with other people experiencing chronic pain and programme lengths and numbers of sessions will vary. A typical pain management programme is rather like a part-time course, helping people learn more about pain and offering practical strategies and coping skills.

Many people with chronic pain have found these programmes very helpful, particularly as they can receive support from others going through similar experiences and learn about others' coping methods.

**However, pain as a result of living with the long-term effects of polio first needs assessing by a specialist with experience in neurological conditions before trying a pain management programme.**

### Expert Patients Programmes

Expert Patients Programmes are free self-management courses delivered by trained tutors who have experience of living with a long-term condition. Your GP or pain specialist should be able to advise you of Expert Patients Programmes for pain management in your area.

## 10. To summarise

1. Acknowledge that the pain is there and that you can take action to manage it. After making changes in your life your pain might be greatly reduced or you may be pain-free, depending on the cause of your pain.
2. Understand your pain - keep a pain diary to find out what makes it worse or better
3. Get your pain assessed - discuss your pain with your doctor, a diary may help the conversation
4. Seek help and support. With your doctor, physiotherapist or occupational therapist review your pain management methods. Discuss other help such as expert referral, a pain management course or support group. Don't suffer in silence; talk about how you are feeling.
5. Pace your activities to prevent further pain - know when to stop and rest. Learn what can be simplified or stopped.
6. Look at any equipment and aids you use to see if they can be improved or whether new aids would make life easier.
7. Get an orthotics review
8. Be positive every day and make time for fun and relaxation.
9. Keep your mind active - socialising, a hobby or interest, learning something new
10. Look after your general health - eat a healthy diet, make sure you get enough sleep and try to maintain a healthy weight.
11. Keep a diary to record your progress. Learn from experiences that didn't work for you and celebrate the successes you have achieved.

## 11. Useful organisations

The British Pain Society is the largest multidisciplinary professional organisation in the field of pain within the UK. It aims to promote education, training, research and development in all fields of pain and to increase both professional and public awareness of the prevalence of pain and the facilities available for its management.

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