

Support

Factsheet



What you should know about your medication

A guide for people with polio or Post Polio Syndrome (PPS)

today's support and information network

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Introduction

There is no medication available that can cure Post Polio Syndrome (PPS). However, drugs may be used to treat some of the symptoms and therefore improve quality of life.

Medication, whether prescribed or over-the-counter, can produce side effects and not everyone responds to a particular drug in the same way. As people get older, they are more likely to be prescribed medication for a variety of conditions, such as arthritis and high blood pressure. If you are taking a mixture of drugs for different health conditions there is a greater chance of drug interaction.

This is a basic guide about medication, which has been written for people with polio/PPS. It is not a guide to all types of drug, but gives information about how some common drugs can affect post-polio symptoms and what you should be aware of.

For information about anaesthesia, see our Hospital Pack.

Post Polio Symptoms

People who had polio years ago and made a good recovery 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. Some drugs or combinations of drugs prescribed for other conditions may affect your symptoms or make them more noticeable.

Who is at greater risk?

You may be at greater risk of adverse side effects if you are experiencing the symptoms of Post Polio Syndrome, if you have reduced respiratory function, muscle weakness or paralysis, swallowing difficulties or if you are over 65 years of age.

Because of the lack of relevant clinical studies, much of the evidence of problems with certain drugs in people with polio/PPS is based on individuals' experiences and therefore may not apply to everyone. However, this evidence is still valuable and may be used as a general guide.

How you can help yourself

Understanding your medication is a good start. Always read the patient information leaflets that come with drugs - these will tell you about the side effects you might experience, including any that should reduce as your body gets used to the drug(s).

You should be aware of the best times to take your tablets, if they should be taken with meals or not, whether or not you can take over-the-counter medication such as paracetamol or antacids with your tablets and whether you should avoid alcohol.

Unless otherwise instructed (for example, some tablets should be chewed) always swallow your tablets with water. Some tablets may react with drinks other than water. Make sure you wash them down well; a sip may not be sufficient to wash a tablet out of your throat and into your stomach. Avoid taking tablets with a hot drink.

Always inform your doctor, dentist and pharmacist of the medication you are taking, whether over-the-counter or prescription.

Side effects

Most drugs are prescribed for their beneficial effects, but you should discuss potential side effects with your doctor, particularly those that may cause or increase the following symptoms:

- fatigue
- respiratory weakness
- muscle weakness
- dizziness and/or drowsiness, which may affect your balance and cause falls
- depression or anxiety. These can change your perception of pain, making it seem worse
- insomnia - this can increase fatigue
- constriction of blood vessels - this may increase cold intolerance

If you do have any new symptoms you can't explain, especially if you have started taking a new drug, speak to your doctor as soon as possible – it may be necessary to change your prescription. Of course, these symptoms may not be connected to your medication, but could be caused by something else.

Never stop taking prescribed medication without consulting your doctor. Some drugs must be gradually reduced before they can be stopped altogether or replaced by another drug and your doctor should monitor this process.

In short, be aware of your own body and its responses, be aware of the long-term effects of polio, understand your medication and always consult your doctor if you are at all concerned.

Things you may wish to consider

- Before requesting a prescription for a drug or buying it over the counter, ask yourself if it is absolutely necessary to take it. In some circumstances, it may be possible to change your lifestyle to reduce the need for further medication. Remember that the fewer drugs you are taking, the less likelihood of adverse reactions.
- If you are taking pain-relieving medication, you should still pace your activities to make sure you do not overuse your muscles and joints.
- When certain drugs are taken for a long time, an individual's requirements can change, needing more medication e.g. with progressive conditions.
- In some people, the long-term use of certain drugs can cause physical dependency and addiction, especially painkillers

Always consult your doctor before taking or changing any medication

Drugs and their effects

Alcohol

Alcohol is classed as a drug.

Alcohol may:

- inhibit swallowing
- affect balance and co-ordination, which could lead to falls
- decrease muscle strength

If you have breathing problems, you should avoid alcohol, especially before you go to bed.

Analgesics (painkillers)

Analgesics are a group of medicines used to relieve pain. Long-term use of analgesics can result in addiction in some people.

Analgesics can be split into three groups: opioids, non-opioids and combined analgesics.

Opioids

Opioids are powerful painkillers. They are used to ease moderate to severe pain and are often prescribed to patients recovering from operations, serious injuries or to ease the pain of terminal illnesses. Examples are codeine and morphine.

Opioids:

- produce central nervous system depression
- increase respiratory depression
- may require increasingly larger doses to gain the same effect
- may cause fainting or giddiness
- can produce physical dependency
- can cause constipation

If you have polio/PPS and have been prescribed opioids, you are strongly advised to discuss the possible side effects with your GP, particularly as opioids can depress breathing. Many people with polio do not realise that they have a breathing problem as these can progress very slowly.

Non-opioids

Non-opioids are mainly used to ease mild to moderate pain ranging from headaches, toothache, muscle and joint pains to period pains. Many non-opioid analgesics can be bought over the counter at chemists and supermarkets. Examples are fenoprofen and paracetamol. Paracetamol has relatively few side effects if taken correctly, but if taken in large quantities can cause liver damage or failure.

Some non-opioids also have anti-inflammatory as well as pain relieving properties; these are known as non-steroidal anti-inflammatory drugs (NSAIDs). Examples of these are aspirin and Ibuprofen.

NSAIDs are the most frequently used pain medications. They can control inflammation and pain with relatively mild side effects.

NSAIDs:

- may cause dizziness
- can cause muscle weakness
- may cause drowsiness
- can cause constipation
- long-term NSAIDs use can cause stomach irritation and ulcers.

Combined analgesics

Some analgesics combine both mild non-opioid drugs such as aspirin or paracetamol, with a small amount of opioid in a single tablet. These combination analgesics are often prescribed to people who are not benefiting from non-opioids, like paracetamol, alone. For example, people who experience migraines may use combination analgesics. Some combination

analgesics are aspirin with codeine and paracetamol with codeine.

If you are taking analgesics long term, you should inform your doctor, rather than self-medicate. You should also make sure that your current medication does not contain ingredients that may react badly to analgesics or already contain them.

Gabapentin (Neurontin)

Gabapentin is not an analgesic, but belongs to a group of medicines called antiepileptics or anticonvulsants.

However, as well as its use for controlling epileptic seizures, gabapentin can be used for controlling neuropathic pain. Some people with polio/PPS may wish to discuss with their GP whether they would benefit from gabapentin, if other pain medication has not helped.

Someone with polio/PPS may find it harder to tolerate some of the side effects associated with gabapentin, including fatigue, dizziness and balance problems. Starting at lower doses and increasing these over time may help to minimise side effects.

Gabapentin should not be taken at the same time as indigestion remedies. Some doctors prefer to prescribe Pregabalin as it is easier to establish doses.

Things you may wish to consider

Muscle and joint pain can be a daily reality for many people with polio/PPS, and you may be concerned about the heavy use of painkillers.

It is important to remember that even if pain is being controlled, more damage may be done to muscles and joints and the pain may increase if you do not pace your activities.

Joint pain can be minimised by looking after your joints. Use orthotics and assistive devices to help mobility and to reduce strain and wear and tear.

The application of hot and cold packs (not the latter if you experience cold intolerance), a warm bath or shower or a heated swimming pool can help to ease pain and provide comfort. Wheat bags (cloth bags full of wheat grains that are heated briefly in the microwave) are a good method of applying dry heat to aching muscles. They come in various shapes and sizes, may be draped over the body as needed and are available with soothing essential oils, such as lavender.

You may want to investigate complementary/alternative therapies to ease pain, such as acupuncture. Although there has been very little research into the benefits of individual complementary therapies in relation to PPS, anecdotal evidence has suggested that complementary therapies can be of assistance to some people with polio/PPS.

Another option is a TENS (Transcutaneous Electrical Nerve Stimulation) machine. 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.

You may want to ask your doctor to refer you to a pain clinic, where you would receive specialist treatment and advice on pain management.

Antidepressants

There are several types of antidepressants, including selective serotonin reuptake inhibitors (SSRIs) and tricyclic antidepressants (TCAs).

General side effects from antidepressants, which may be relevant to people with polio/PPS, include the following:

- urinary retention
- constipation
- sedation
- sleep disruption
- weight gain

- tremors
- agitation
- anxiety

Alternatives to taking antidepressants include talking therapies such as counselling and cognitive behavioural therapy. Keeping active and interested in life and finding some meaning to it by taking part in social, cultural, creative and spiritual pursuits may help to alleviate depression. Joining a support group or one of The British Polio Fellowship's Branches and Groups can provide support and social contacts.

Everyone feels unhappy at times and it is important to distinguish between feeling low and being genuinely depressed. Some of the symptoms of PPS can mistakenly be blamed on depression.

Antihistamines, allergy and travel/motion sickness drugs

These drugs are usually only for short-term use. Examples include loratadine (Clarityn), Piriton and Dramamine. This group of drugs can cause drowsiness and can increase fatigue.

Benzodiazepines

Benzodiazepines are a group of drugs also known as tranquillisers and sedatives. Two of the best known are diazepam (Valium) and temazepam. Mogadon is no longer prescribed but some people may still be taking it. Benzodiazepines are used for treating symptoms of anxiety and insomnia.

Benzodiazepines are prescribed for short periods of no more than 2-4 weeks. If you take them for longer, the body builds up a tolerance: they lose their effect and you will need a higher dosage for them to work.

Benzodiazepines are also muscle relaxants and may therefore increase fatigue and decrease muscle strength in people with polio/PPS. Even if you take them short-term, they can cause daytime drowsiness, which could increase the risk of falls and other accidents.

There is a good chance that you could become dependent on a benzodiazepine if you take it for more than four weeks. This means that withdrawal symptoms occur if the tablets are stopped suddenly.

Alternative ways to tackle anxiety include learning to relax, anxiety management courses and cognitive behavioural therapy. Simply talking things over with a friend, counsellor, or with members of a self-help group may also help. However, if symptoms become severe, you may be advised to take a benzodiazepine drug for a short time.

Beta-blockers

Beta-blockers are used to treat angina, heart failure, high blood pressure, some abnormal heart rhythms and other conditions. Evidence based on hearsay suggests that some people with polio/PPS encounter problems with beta-blockers. They are already likely to experience some of the side effects associated with these drugs.

These include:

- muscle aches
- fatigue
- dry eyes
- cold hands and feet
- sleep disturbances, including nightmares
- headaches
- breathing difficulties

Beta-blockers may also interfere with already weakened circulation.

There is some suggestion that lower dosages lead to less severe side effects. Therefore, if it is necessary to take a beta-blocker, use the lowest effective dose and your doctor should monitor its effects carefully.

Cough medicines and expectorants

These either suppress coughing or loosen secretions. They may contain alcohol or codeine. They can cause drowsiness, decreased co-ordination and may give a feeling of coldness.

Laxatives

One of the biggest problems with laxatives is that if taken long term, the body becomes used to their effects and normal bowel action becomes dependent on the laxative. Before resorting to using laxatives, increase the amount of fibre in your diet by eating more fresh fruit, vegetables and whole grains, drink more water and get more exercise if possible.

Remember that some painkillers and antidepressants can cause constipation.

Laxatives are available as the following:

- bulk-forming stool agents (eg Fybogel). These should always be taken with plenty of water
- stool softeners. Avoid long-term use of these
- stimulant laxatives. These are for occasional use only
- osmotic laxatives, eg Milk of Magnesia. These are also for occasional use only.

Statins

Statins are a group of drugs that are used to lower the level of cholesterol in the blood. This helps to prevent heart disease, stroke and related diseases in people at increased risk.

Statins work by blocking the action of a certain enzyme (chemical) in the liver, which increases levels of cholesterol.

Much has been written about statins, with some doctors and patients recommending that people with polio/PPS should not take them. The chief noted side effect is muscle pain, which is relevant to people with polio/PPS who may already have weakened muscles.

If you are taking a statin and have new or increased muscle pain, do discuss it with your doctor. A different brand of statin could be prescribed that will have fewer side effects. Like many other drugs, the balance between the benefits of the treatment (in this case, preventing serious illness) and the risk of side effects needs to be taken into account.

Things you may wish to consider

As well as taking statins, you are advised to reduce the amount of saturated fat in your diet and eat foods high in soluble fibre, such as grains, pulses, fruit and vegetables. Some people are able to lower their cholesterol this way without taking statins, but you should seek medical advice first. It is also recommended that you lose weight, exercise daily, treat high blood pressure, manage stress and stop smoking.

Swallowing difficulties

Many people with swallowing difficulties may be tempted to crush tablets or open capsules. Crushing certain pills can be dangerous. Slow-release pills, if crushed, can change the way the active ingredients are absorbed by the body. This can cause severe and sometimes fatal complications.

The table opposite provides a list of medication that should never be crushed or opened. It is based on lists published in the USA and Canada, and acts as a useful guide for healthcare practitioners here, as there is currently no official list in the UK. Additionally, before crushing any tablet or opening any capsule you should consider whether the person administering the medication may have a sensitivity to it. In which case contact, however minimal, could result in a serious reaction.

Medicines that should never be crushed or opened

Question	Notes and abbreviations	Reason for not crushing	Examples
Modified release	Frequently identifiable by two letters such as m/r, LA, SA, CR, XL or SR. Words such as “retard”, “slow” or “continus” in the title are sometimes used.	The medicine is designed to be released over a prolonged period. The mechanism for slowing release may be damaged. The patient receives the full dose quicker than expected and subsequently little or no dose at all for a period of time.	Verapamil (Securon SR) Propranolol (Inderal LA) Felodipine m/r (Plendil) Tramadol (Zydol SR) Morphine (MST Continus)
Enteric coated	Usually identifiable by the two letters EN or EC at the end of the name.	When the coating is added to protect the stomach, a suitable gastro-protective product should be taken in addition if the tablet is crushed or opened; but the potential for drug interactions needs to be considered. When the coating is designed to deliver the drug beyond the stomach, crushing may result in the medicine not reaching its intended target.	Aspirin (Nu-seals) Naproxen (Naprosyn EC) Sulphasalazine (Salazopyrin EN)
Hormonal, cytotoxic Or steroidal		The drug may be dispersed in the air if the tablet is crushed and the person giving the drug may be exposed to the drug.	Tamoxifen (Nolvadex) Methotrexate (Maxtrex) Dexamethasone Oral contraceptives Hormone replacement therapy
Film and sugar coated	Usually identifiable by the two letters f/c or s/c at the end of the name.	Disruption of the coating may result in rapid degradation of the drug, poor tasting medicine and may also cause skin irritation in the patient or carer.	Quinine sulphate Ibuprofen

If you are still considering crushing your tablets, you should first consult your GP to find out if crushing or opening is advisable. If the answer is no, you should consult an experienced pharmacist to check if a liquid alternative is available or if there is another method of taking the drug.

To conclude

This is a general guide only. You may be taking other types of medication not mentioned here. The ones included in this factsheet are some of those most likely to be taken by people with polio/PPS.

You are strongly advised to tell every medical practitioner you come into contact with that you have polio/PPS. It would be helpful if you told them about your symptoms and how you manage them. Let them know which medications you are already taking. Do not forget to tell them about any other health conditions you may have, which could affect the suitability of the medication.

Familiarise yourself with the medication(s) you are taking, be aware of potential side effects and discuss these with your doctor.

When buying over-the-counter medicines, such as cold or indigestion remedies, do tell your pharmacist about any prescribed medication you are taking, in case of any potential interactions.

If you are experiencing side effects, don't suffer in silence - talk to your doctor immediately. Do not stop taking your medication or change it without consulting your doctor first.

Take care of your general health and review your lifestyle. Look after your muscles and joints, pace yourself and conserve your energy.

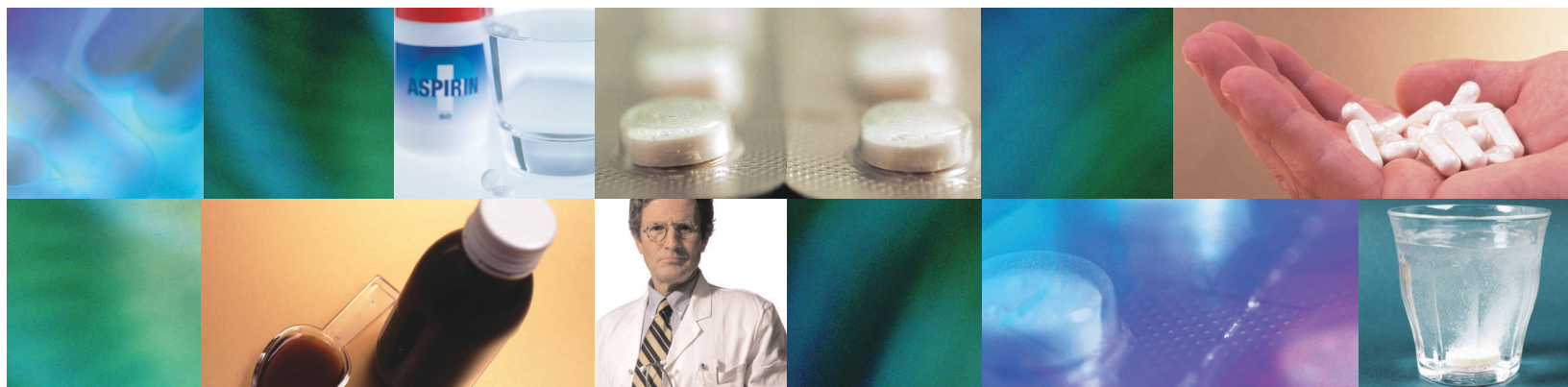
Remember that drugs do save and prolong lives. You should balance the possible side effects of a particular drug against the risks of not using it or using an alternative treatment for the problem.

Lastly, listen to your body and remember that no one can know it better than you.

Medical Disclaimer

The information given in this factsheet is not medical advice and by providing it The British Polio Fellowship and our medical advisors do not undertake any responsibility for your medical care. Before acting on any of the information contained in this factsheet, you should discuss the matter with your GP or any other medical professional who is treating you.

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