

# Post-polio syndrome - advice on the management of your symptoms

Information from the Lane Fox  
Unit

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## Introduction

The aim of this booklet is to help people with post-polio syndrome relieve their symptoms and stay independent.

Post-polio syndrome affects people who had acute poliomyelitis 15 to 50 years ago. They are now experiencing new symptoms, such as:

- **fatigue** – this is not the same as tiredness. The main difference is that fatigue is not always related to how active you have been. For example, you can avoid physical activity, but still feel tired. You may also have tired and heavy limbs, ‘twitchy muscles’ (fasciculation) and struggle to do everyday tasks
- **pain in muscles or joints**
- **new muscle weakness**
- **shortness of breath or disturbed sleep.**

Many people with post-polio syndrome find daily activities difficult and painful. As a result, they struggle to maintain their muscle strength and function. Because of this, some people are doing intense exercise programmes, featuring high-resistance work such as lifting weights, to rebuild their muscle strength.

However, many people are finding that intense activity and exercise do not rebuild muscle strength. Instead, they make their post-polio symptoms worse.

Our experience on the Lane Fox Unit shows that although everyone can benefit from some form of exercise, it needs to be combined with other techniques to conserve energy and manage post-polio. **High-resistance work such as lifting heavy weights is not advisable.**

## Physical activity

Physical activity is an essential part of a healthy lifestyle. Inactivity leads to the 'de-conditioning' of your body. This, in turn, leads to weakness and fatigue.

This statement is problematic for many post-polio survivors. They need to exercise, but many find that too much exercise makes their symptoms worse.

The key is to find the correct balance of activity and rest. This can prove difficult as everyone's correct balance is different.

## The 'boom and bust' activity cycle

Many people with post-polio experience the 'boom and bust' activity cycle. This is a cycle of over-activity and fatigue:

- **The boom phase** – this is a period of over-activity. For example, on a day that you have more energy, you do jobs or exercise you have put off. Will power and a sense of achievement keep you going, so it is easy to do more than your body and muscles are used to.

- **The bust phase** – following the boom phase, you experience fatigue and/or pain. You are forced to rest, and recovery sometimes takes several days. This period of under-activity can result in a drop in fitness, which means it is easier to overdo activities when you get better. This behaviour of ‘boom and bust’ becomes a vicious cycle.

It is often easy to see this type of pattern in your lifestyle. For example, you start to mow the lawn and half-way through you begin to feel tired. It is tempting to continue and finish the job. However, finishing the whole job makes you totally exhausted and you are forced to rest.

The next morning, you wake with stiff joints and aching muscles and have to rest again. When you start to feel better, maybe days later, your fitness levels have dropped because of the enforced rest. It is likely that you will tire more easily when you recover, and so the cycle continues.

## What can I do to avoid the ‘boom and bust’ activity cycle?

### Pacing

Pacing is the opposite of ‘**boom and bust**’. You learn to understand your body and manage your activity levels. Instead of continuing an activity to the point of exhaustion you stop before you reach that point.

For example, when mowing the lawn, stop and rest before you begin to feel tired. After your rest, you can

return to mowing. When you feel tired, you stop and rest again.

The same principle can be applied to other activities, for example, gardening or washing. You could use a timer to help work out when you are getting tired. You could also put stickers around the house to remind you to pace yourself.

By pacing the job in this way, you can stop before you become exhausted. It means you can maintain a certain level of activity day after day. You can finish a job without triggering the boom and bust cycle.

### **Your activity baseline**

The difficult part when 'pacing' is to work out when you should rest. You can do this by setting yourself an 'activity baseline' for each activity.

You can set your baseline by timing how long you can do a task before you begin to tire. Do this a few times and then set your own level at half of the average time. For example, the next time you climb the stairs count the number of steps it takes you to get tired. If you get tired after ten steps you can work out your activity baseline – half of ten steps = five steps.

So, stop and take a rest at the fifth step. After a few seconds you can carry on for another five steps and rest again. Your activity baseline will help you avoid physical exhaustion.

**The practice of resting before you become tired or exhausted is so effective that it should be your number one priority in energy conservation.**

## **Energy conservation**

Everyone has a different amount of energy to use in a day. If you over-use your energy allowance for one day, you will have to pay it back the next day.

Energy conservation means making the most of your body's available energy. In other words, getting the most amount of work done using the least amount of energy.

If you can conserve some of your energy during routine daily tasks, you might be able to take part in more enjoyable activities at other times.

Following these principles will help you to conserve as much energy as possible:

### **1. Prioritising**

Ask yourself the following questions:

- Does it all need to be done today?
- Can I get someone to help me?
- Does it need to be done at all?

### **2. Planning**

Ask yourself the following questions:

- Can I break the job down into different stages?
- What do I need to carry out the job?
- What basic activities does each stage involve, e.g. walking/sitting/standing?
- Is there too much to do on any one day?

- Could easier/lighter tasks be alternated with more difficult/heavier tasks?
- Have I scheduled enough rest periods?

An important part of planning is to make sure work areas are arranged in the most effective way. If you have the correct equipment in the right place you can do a job using as little energy as possible.

For example, in the kitchen:

- have the most frequently used items in the most easy to reach places
- sit down when preparing a meal as this uses 25% less energy
- use energy saving devices such as electric can openers, blenders, built-up or long-handled utensils.

### **Remember:**

- 'little and often' is a good starting point
- try using a daily or weekly schedule to plan heavy tasks
- avoid doing a task for 'just five minutes more'. If you are getting tired you need to rest – do not keep on going.

**The 'no pain – no gain' philosophy most polio survivors learnt when initially recovering from polio has been replaced by one of 'energy conservation' and 'pacing' of activity.**



## Physical fitness

The question you may ask now, having read the principles of energy conservation and pacing, is “Can I exercise safely without using too much energy?”

Athletes improve their performance by training to increase their fitness and energy levels. If you have post-polio syndrome, you need to train your body too. And you can do this safely by using the principles of pacing and activity baselines when you exercise. By doing this you will be able to gradually improve your daily energy levels.

## Health-related physical fitness

Health-related physical fitness relates to the ability of your heart, lungs and muscles to carry out daily tasks with as little fatigue and discomfort as possible.

There are three areas of health related fitness:

1. **aerobic fitness** – the body’s ability to take in and use oxygen to produce energy
2. **muscular fitness** – the strength and endurance of muscles
3. **flexibility** – the ability to bend joints and stretch muscles through a full range of motion.

These three areas are ‘health-related’ because if you improve any or all of them, you will begin to improve your health and well-being.

## Exercise programmes

If you have post-polio syndrome, unbalanced levels of activity can be bad for your body. Because of this you need to do exercises that are safe and follow a programme that does not tire you out.

There are three types of exercise that are suitable for you:

- 1. Aerobic exercise** – these exercises help to build up the endurance of your heart and lungs. They can improve circulation and lower blood pressure. They also aid sleep and relaxation. Examples include walking, swimming, cycling – in fact any activity that raises your heart rate and makes you breathe more deeply. If you have post-polio syndrome, you can do aerobic exercise if you have addressed your lifestyle balance and applied the principles of energy conservation and pacing. Remember, your aerobic exercise must not tire you out.
- 2. Muscular fitness** – you can work on strengthening your muscles but you should aim for low resistance and to repeat the exercise frequently. You should not attempt to strengthen muscles that can no longer move against gravity. As with all exercise, you should start with a small amount of muscle strengthening work and gradually try to increase it.

3. **Flexibility** – stretching exercises can help your muscles and joints work better. Stiffness can be very uncomfortable. It can lead to poor posture and stop you from doing certain activities. Improved flexibility can improve your posture and make it easier to move into different positions. You can reduce discomfort around your joints and muscles by reducing tension.

You should not stretch joints which are weak and floppy and move further than expected already. All other joints can be gently stretched. You can do stretches for your whole body every day. Move your limbs, head and neck, and trunk systematically through their comfortable range of movement. Hold each stretch – making sure it is firm but comfortable – for about fifteen seconds.

You can use a programme of these exercises to achieve different goals. You can use it to:

- reverse the effects of de-conditioning on your body
- increase your energy levels and endurance
- improve areas of physical difficulty
- help feel better and more confident about yourself.

## Non-fatiguing exercises

Your exercise programme should be built on the principles of interval training (alternating exercise with an equal amount of rest) and pacing.

Some people may choose to return to leisure activities. Other people might prefer a simple programme of exercises that can be carried out at home.

The exercise programme needs to be realistic, achievable, enjoyable, and fit into your lifestyle.

For some people, developing an exercise programme in the swimming pool is the answer – the water can assist or resist your movement. Hydrotherapy in warm water may be even better but it may need referral from your doctor.

Whatever exercise you choose, it is important to prepare your body beforehand with a gentle warm-up, and to slow down gradually at the end with a gentle cool-down.

You can make sure your exercise does not tire you out by following these guidelines:

- **Pacing** – do half of what your body can manage to prevent fatigue. You can set your baseline at length of time or number of repetitions, depending on the activity. (For more information on finding your activity baseline see pages 5 & 6).
- **Never do aerobic exercise two days in a row** – this means your body can rest fully following exercise.
- **Interval training** – this helps you to avoid fatigue when exercising.

Always monitor your symptoms during and after your exercise session. If you have no increase in symptoms the day after an exercise session, then you can gradually start increasing the amount of exercise that you are doing.

Always review symptoms on a day-to-day basis.

## Exercise guidelines

- **Wear comfortable clothing and suitable footwear.**
- **Always warm-up and cool down when you exercise** – Begin with stretches and then very gentle exercises so that your muscles can warm up. End your exercise session with gentle exercise and then stretches so that your muscles can cool down.
- **Never over-exercise** – If you become too tired this may be dangerous, for example you may become unsteady on your feet.
- **Never exercise if you are unwell or injured** – Aim to restart exercising when you are better, and build up to previous levels slowly.

## Appointments at King's

We have teamed up with King's College Hospital in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at King's. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

### Contact details

If you have any questions about information in this booklet, please contact the **physiotherapy or the occupational therapy department** of the Lane Fox Unit on **020 7188 3442**.

**Lane Fox Respiratory Unit – St Thomas' Hospital**  
**t:** 020 7188 8832

**British Polio Fellowship**  
**t:** 0800 0180 586 **w:** [www.britishpolio.org.uk](http://www.britishpolio.org.uk)

**Lincolnshire Post-Polio Network**  
**t:** 01522 888601 **fax:** 0870 1600840  
**w:** [www.ott.zynet.co.uk/polio/lincolnshire/index.html](http://www.ott.zynet.co.uk/polio/lincolnshire/index.html)

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

## Notes

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## Contact us

### **Pharmacy Medicines Helpline**

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

**Patient Advice and Liaison Service (PALS)** – To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

**t:** 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**Language support services** – If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

**t:** 020 7188 8815 **fax:** 020 7188 5953

**NHS Choices** – Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

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