

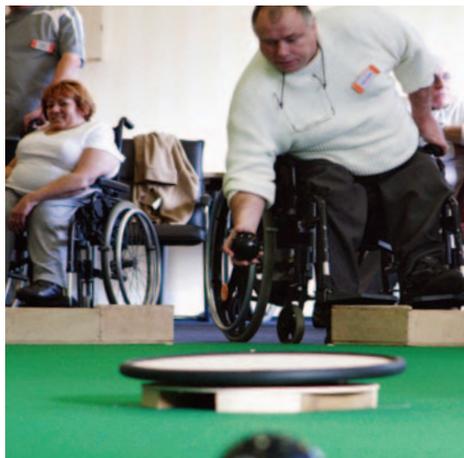
Pacing for Activity and Exercise



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Lifestyle adjustment tips for
everyday life to ease symptoms
and maintain independence

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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. These symptoms may be associated with Post Polio Syndrome (PPS) and can lead to a decline in function. However, there is much people can do to manage symptoms, including pacing. Specialist assessment may also be recommended.

When people recovered from the original polio they often took part in intensive exercise and may now believe this can, as before, help them to regain muscle strength and function. But instead of regaining power, many describe the opposite. The Lane Fox Unit at St Thomas' Hospital in London recommends a holistic approach, taking the whole person into account, when designing a programme of rehabilitation or exercise. Although there may be benefits from some form of exercise, PPS requires a broader management.

This factsheet discusses a number of lifestyle adjustments such as pacing and energy conservation, which when used in everyday life and when doing exercise can help to ease symptoms and maintain independence. It is based largely on information provided by the Lane Fox Unit and we are grateful for its permission to use this.

Physical activity

Physical activity is generally thought to be an essential part of a healthy lifestyle. Some evidence suggests that appropriate exercise can improve the ability of people with polio to take part in ongoing daily physical activity and people should “be aware of inactivity!” However, it is thought that too much activity can lead to an increase in weakness and fatigue in people with polio. There is a theory that overuse can lead to a further decrease in function. This causes a dilemma for many people with PPS – how much activity or exercise should they be doing?

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.

It is important to tailor the activity or exercise plans to suit each person – ideally with advice from a reputable and knowledgeable healthcare professional.



Boom and Bust activity cycle

The Boom and Bust cycle can be described as starting with an episode of overactivity – the Boom phase. For example, on a day that you have more energy it is tempting to do jobs or exercise you have put off before. Willpower and a sense of achievement encourage you to continue. It is easy to do more than the body and muscles are used to, which then causes an increase in symptoms.



You start to feel better, and increase activities to catch up

You decrease activities because your pain, for example, has increased

The resulting fatigue means you are forced to rest and are unable to do much for several days – the Bust phase. This period of underactivity results in a drop in fitness, meaning it becomes easier to overdo activities. This behaviour becomes a vicious cycle and can have long-term damaging effects.

This pattern can be applied to many daily activities. The following example of mowing the lawn shows how easy it is to slip into the cycle.

You start to mow the lawn, and halfway through you begin to feel tired but it is tempting to continue and anyway, the forecast is for rain later. You finish the job, causing you to become 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 due to the enforced rest, and so you tire more easily, and the cycle goes on.

What is “pacing”?

Pacing is the opposite of “Boom and Bust”. It is a method of learning to recognise your own individual and manageable baseline of activity, so instead of continuing an activity to the point of exhaustion, you stop before that point.

Continuing on the theme of mowing the lawn, before you start to feel tired, you stop and rest. After your rest, you return to mowing, stop and rest again and so on.

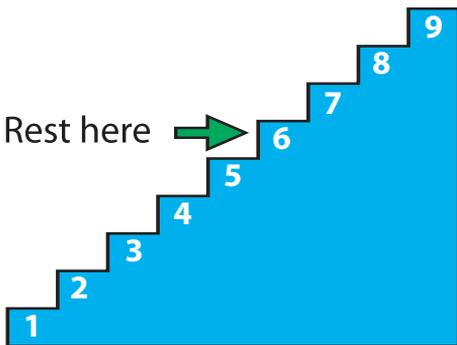
By always stopping before you become tired, you can continue for longer. Pacing smoothes out the peaks and troughs of activity caused by the Boom and Bust cycle.



How to work out a baseline of activity

You can work out and set your own baseline for the activity by monitoring how long you can carry out the task on several different occasions, before you start to fatigue. The Lane Fox Unit generally suggests setting your baseline 50% below this level (this may need to be lowered for some people – so take advice). Instead of continuing the activity to the point of exhaustion (which is 100% of your potential), you stop at the 50% mark, aiming to avoid the Boom and Bust cycle.

For example, when you are climbing stairs; if you have to stop after 10 steps because you are tired, try next time taking a break before you get tired, at the fifth step (10 steps minus 50% = five steps) then carry on for another five steps and rest again, so avoiding physical exhaustion. Remember, each person is different.



The same principle can be applied to other activities i.e. gardening, washing etc. You could set a timer, or put stickers around the house to remind you to pace. The practice of resting before you become tired or exhausted, or before an increase in symptoms, is so effective that it should be your number one priority in energy conservation.

Energy conservation

Energy conservation means using energy efficiently to do the things you need to do so you still have the energy to do the things you want to do. It is about making the most of the energy you have. It can be helpful to think through how you go about everyday activities, modifying and adapting each task as necessary.

1. Prioritising

Ask yourself the following questions:

- Does it all need to be done today?
- Does it need to be done at all or is there any part of the task that could be avoided?
- Can I get someone to help me with all or part of the task?
- Which jobs are necessary and perhaps need to be done first?

2. Planning

Ask yourself the following questions:

- Is there a time of the day or the week when I feel my best?
- Is there too much to do on any one day?
- Can I break the job down into smaller and more achievable stages?
- What basic activities does each stage involve? e.g. are easier / lighter tasks alternated with more difficult/heavier tasks?
- Can tasks be balanced across the week?
- Have I scheduled enough rest periods or enough time for the task?

- Can I change positions to use different sets of muscles and avoid fatigue?
- Can I minimise reaching or bending?
- What do I need to carry out the job? Are there any assistive devices or equipment that could make the job easier?
Is everything I need within easy reach?

You may wish to assess your work areas, to see if any changes to design, organisation and the use of equipment can minimise effort needed to do tasks.

For example, in the kitchen:

- Have most frequently used items within easy reach.
- Sit for as many activities as possible, as standing uses 25% more energy.
- Use energy-saving devices like an electric can opener, blender, built-up or long-handled utensils.
- Consider having heavier groceries delivered.
- Avoid ironing items that really don't need it.

Remember:

- A little and often is a good starting point.
- Try using a daily or weekly schedule.
- Avoid doing “five minutes more” – rest before you feel tired and pace.
- Relaxation techniques can also be useful.

Physical fitness

Now that you have read about the principles of energy conservation and pacing, you may ask, “how can I safely exercise, as surely this will use too much energy?”

The link between these principles and safe exercise is determined by how much energy each person uses on a daily basis. This can best be explained in relation to an athlete. In order to improve their personal best they need to train and in doing so they will increase their fitness and energy levels, leading to an improvement in performance.

The principles of training can often be combined with those of pacing and the 50% baseline, in people with PPS, to gradually improve daily energy levels. Physical activity, exercise and fitness mean different things to different people. They do not necessarily mean hard physical activity or monotonous workouts, but are entirely dependent on the individual's needs and physical capabilities.



Health related physical fitness

Health related physical fitness refers to the ability of your heart, lungs and muscles to carry out daily tasks with minimal fatigue and discomfort. In other words, it's having the reserve to do what you want to do. There are four aspects of physical fitness that are "health related", because an improvement in any or all of them will generally lead to improvements in health and well-being:

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.
4. **Body composition** – the amount of fat compared to other tissue in the body.

Exercise regimes

As discussed already, exercise can be beneficial for most people, but unbalanced levels of activity could be harmful for people with PPS. We look here at what types of exercise are generally safe to do, as well as how to develop a non-fatiguing exercise programme. However, as with pacing, exercise needs to be specifically tailored to the individual and monitored. For this we suggest you seek help from a registered physiotherapist.

Exercise can be used for different goals:

- To reverse the effects of deconditioning in the body.

- To increase general activity levels and endurance.
- To work on improving areas with physical difficulties.
- To help return to previous activities or start new ones.
- To help feel better and more confident about yourself.

There is general agreement that the main focus of a new exercise programme should be on stretching and general aerobic or cardiovascular (heart and blood vessels) conditioning exercises to improve endurance.

Strengthening exercise needs to be approached much more cautiously. Exercise can improve muscle strength, especially in the case of disuse and muscle groups that are only moderately affected by polio. Intensive strengthening exercises are not generally recommended.

The exercise programme may include one or more of these forms of exercise:

1. Stretching exercises

These can help stiff muscles and joints to loosen and become supple. Stiffness may create discomfort due to muscle pain and spasm and poor posture, and can restrict activities.

Greater flexibility can improve posture and make everyday activities easier to perform. Care should be taken not to stretch unstable joints, or to over-stretch and strain.

Gentle stretches for the whole body may be carried out every day by moving the limbs, head and neck and trunk systematically through their comfortable range of movement, holding each movement at a firm comfortable stretch for about 15 seconds. Always avoid pain.

Muscle tightness may sometimes be the body's way of compensating for muscle weakness. Stretching can undo this benefit and could result in less function, which is why it is advisable to consult with a healthcare professional before beginning any new exercise programme, including stretching exercises. Some people have found yoga a gentle way to stretch muscles and practise deep breathing.

2. Postural exercises

With improved flexibility from stretching, better posture can be achieved. Trying to achieve your best posture, despite altered skeletal systems from polio, can be beneficial.

Posture can be practised in front of a full-length mirror. Try to achieve the best alignment of your head on your neck and your upper body on your lower body by pulling in your muscles to support your skeleton, especially the deep abdominal muscles and the muscles of the neck. These exercises can help you to have better body awareness.

3. Aerobic exercises

These exercises help to build up the stamina of the heart and lungs, improve circulation and lower blood pressure, improve weight control and aid sleep and relaxation. Examples include walking, swimming, cycling, and climbing stairs or any activity that raises your heart rate and makes you breathe more deeply.

Aerobic exercise can be practiced in people with PPS, providing that firstly they have addressed their lifestyle balance, and secondly, that they undertake aerobic exercise in a non-fatiguing manner.

Non-fatiguing aerobic exercise

As mentioned before, new exercise regimes should be developed with the help of a registered physiotherapist. As few physiotherapists today will have experience of treating people with polio, the following gives some general guidelines.

Physiotherapy rehabilitation for people with polio or PPS has changed from that originally advised after the polio epidemics. High resistance work such as pumping iron and repetitively pushing heavy weights is not advisable.

Exercise for people with PPS should be non-fatiguing, using the principles of interval training and pacing. The main focus of any exercise programme should be on building endurance, not strength.

For some people this may include returning to leisure activities; others might prefer a simple series of exercises that can be carried out at home. The exercise needs to be realistic, achievable, enjoyable and fit into your lifestyle balance.

Some people prefer to exercise in the hydrotherapy or swimming pool where buoyancy can be used to assist or resist movement but remember it can be easy to overdo it in the pool as it can be easier to move.

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

Non-fatiguing exercise can be achieved by applying the following principles:

- Setting baselines, as in pacing.
- Interval training; alternating exercises with equal amounts of rest.
- Never carry out aerobic exercise on two or more days in a row; always allow the body to rest fully following exercise.
- Exercise muscles in turn. Focus on least affected limbs or muscles that seem to be completely unaffected by polio rather than those that are.

The first step in carrying out non-fatiguing aerobic exercise is to develop a baseline of activity by deciding how much of that activity you can do without developing symptoms. For example, the length of time you can exercise, the number of repetitions you can do, or the distance you can walk or swim.

The Lane Fox Unit suggests you then reduce this figure by half to set your 50% baseline. Exercise at your 50% baseline followed by an equal amount of rest, and so on. You should tailor this to meet your own abilities and needs.

Exercise, but always make sure that you do not worsen your PPS symptoms.

Always monitor your symptoms during and after your exercise or activity sessions and for up to 48 hours afterwards. Stop if you become fatigued during the exercise programme, or if you experience sharp or new aches or pains in your muscles. A brief period of fatigue and minor muscle pain after exercise may be normal.

Conditioning exercises or any repetitive activity, including walking, which causes pain or a sense of excessive muscle fatigue and increased weakness should be stopped.

Symptoms that last longer may mean muscle overwork and possible injury. If this occurs, the exercise or activity should be reduced or stopped. Do not push to perform the extreme of the motion or exercise.

Symptoms of overuse that may show a need to stop or decrease the amount of exercise or the frequency of activity include: muscle cramps and spasms, muscle twitching, muscle pain and extreme fatigue. Any exercise that causes additional weakness, unusual muscle twitching, or inability to perform a task that you can normally do without help should be stopped.

It is important to respect these symptoms in order to avoid doing permanent harm to your muscles.

If you have no increase in symptoms over a period of time then you can gradually start increasing the amount of exercise you are doing, always monitoring symptoms. If you feel your symptoms have increased after exercise perhaps even the 50% baseline is too much and you need to reduce this to, for example, 25% of your baseline before resting. Some suggest starting with an even lower baseline and even this may be too much for some people with polio where the activities of daily living are enough, so seek advice from a physiotherapist.

Having a two-month start-up period in which your response to exercise is monitored by the professional you are working with has been suggested.

Exercise guidelines:

- Start slowly (even three to five minutes may be enough if muscles haven't been exercised for a period of time).
- Exercise slowly, progress slowly and build in rest breaks.
- Intensity should be low to moderate.
- Wear comfortable clothing and suitable footwear.
- Always warm up and cool down.
- Never reach dangerous fatigue levels – you could do irreversible harm to your muscles.
- Never exercise if you are unwell, injured or fatigued. Aim to restart exercising when you are better, and gradually build up to previously achieved levels.
- Keep a log of your exercise and activity routines and how you feel.



To round up

Remember the key to achieving lifestyle balance is to avoid pushing yourself beyond your abilities, relax, conserve energy, and pace where necessary. Consider doing regular stretches, paying attention to your posture, gently and gradually building up activities, eventually allowing you to undertake non-fatiguing exercise as appropriate.

There is no one formula for what will work for everyone, as people with polio are all unique. It is important to find out how each individual feels and what works for them, but this is best done with appropriate advice from healthcare professionals like physiotherapists.

Slow and steady wins the race! – one report suggests that people who took rest breaks, paced themselves and conserved energy had up to 22% less pain, weakness and fatigue.

Further references:

“After the iron lung – post polio syndrome”, Joan Stuart, The British Polio Fellowship Bulletin, July 2001.

“EFNS guideline on diagnosis and management of post-polio syndrome – report of an EFNS task force”, European Journal of Neurology, 2006. 13: 795-801.

“Energy Conservation & Work Simplification”, Griffith Rehabilitation Hospital, Occupational Therapy Department.

“To reap the rewards of Post-Polio exercise”, Roller S & Maynard F, 2002.

“The TEN Commandments for Polio Survivors”, Bruno R, Frick N.

“Exercise, Part 2: What steps to take – exercise and Post-Polio Syndrome”, Klein M, 2005, Courtesy of Post-Polio Health International website.

“Solutions for overuse and disuse weakness: overuse”, Nollet, F – 2005, Strategies for Living Well.

“Options when a Post-Polio clinic is not an option”, Vandenakker C, 2005, Strategies for Living Well.

“Shoulder concerns for people experiencing post polio”, 2006, Polio/Post Polio Awareness, 21, no 2. Handbook on the Late Effects of Poliomyelitis for physicians and survivors.
See www.post-polio.org

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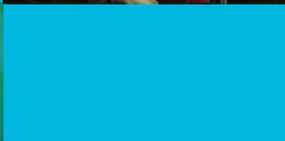
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Please note: only generalised information can be discussed with people who have not been seen or assessed at the Lane Fox Unit.

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