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1. Introduction

People who had Polio years ago may now be experiencing new or increased 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 that symptoms get worse. 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 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.

1. 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 who have had Polio to take part in ongoing daily physical activity, and people should avoid being completely inactive.

However, it is thought that too much activity can lead to an increase in symptoms, particularly fatigue in people living with PPS. There is a theory that overuse can contribute to a further decrease in function. This causes a dilemma for many people living with PPS – how much activity or exercise should they be doing?

The key is to find a manageable balance of activity and rest for each person. This can be difficult, as people who have had Polio are all unique, so everyone's balance is different.

2. 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.

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.

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You start to mow the lawn, and halfway through you begin to feel tired but it is tempting to continue, but you want to complete the task and 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 a few days later, your fitness levels have dropped due to the enforced rest, and so you tire more easily, and the cycle goes on.

3. What is “pacing”?

Pacing is the opposite of “Boom and Bust”. It starts with learning to recognise your own individual and manageable baseline of activity. Instead of continuing an activity to the point and beyond, 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 planning to stop before you become tired, overall you can continue for longer. Pacing smooths out the peaks and troughs of activity caused by the Boom and Bust cycle.

4. How to work out a baseline of activity

You can work out and set your own baseline for an activity by monitoring how long you can carry out the task over 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 halfway, at the fifth step (10 steps minus 50% = five steps) then carry on for another five steps and rest again, aiming to avoid the physical exhaustion. Remember, each person is different.

The same principle can be applied to other activities i.e. gardening, washing etc. It does take some pre-planning and practice.

Suggestion for prompts include setting a timer or putting stickers around the house to remind you to take breaks and 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.

5. 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 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 productivity 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, ideally on the counter.
- 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 grips, 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.

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

7. 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 physical reserve to do what you want to do. There are four aspects of physical fitness that are health-related in people who have had Polio, because an improvement in any or all of them will generally lead to improvements in health and well-being:

- Aerobic fitness – the body’s ability to take in and use oxygen to produce energy.
- Muscular fitness – the strength and endurance of muscles.
- Flexibility – the ability to bend joints and move through a full range of motion.
- Body composition – the amount of fat or muscle compared to other tissue in the body.

8. Exercise routines

Exercise can be beneficial for most people, but pushing yourself

to do more exercise or activity without considering how well your body is managing could make symptoms worse for people living with PPS. 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 manage 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 flexibility and general aerobic or cardiovascular (heart and blood vessels) conditioning exercises to improve endurance. Strengthening exercises can also be included with some considerations. The exercise programme may include one or more of these forms of exercise:

1. **Exercise** can improve muscle strength, especially in the case of disuse and muscle groups that are only moderately affected by Polio. Don't forget about your back and stomach (often called the core muscles). Intensive strengthening exercises are not generally recommended.
2. **Flexibility exercises** These can help tight muscles and joints to loosen and become supple. Tighter joints and soft tissues are less able to produce the movement you want. Tight areas may create discomfort and restrict activities. More flexible joints are generally more comfortable, strong and healthy. Greater flexibility can also improve posture and make everyday activities easier to perform.
 - 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 up to 15 seconds. Always avoid pain. Some people have found yoga or other stretching routines found online useful to guide them through a programme, to stretch muscle and joints.

- Care should be taken not to stretch joints that already bend in the wrong direction, or joints surrounded by very weak muscles that appear quite floppy. Also, if joints are surgically fixed in one position, you don't want to stretch these areas.
- It is advisable to consult with a healthcare professional before beginning any new exercise programme, including stretching exercises.

3. **Aerobic exercises**

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

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

As with all adults, the recommend amount is 30 minutes, five times a week of moderate activity. However, this may be out of

reach for some people. Research shows that some activity is better than none.

4. Non-fatiguing aerobic exercise

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

Physiotherapy rehabilitation for people who have had Polio or are living with PPS has changed from that originally advised after the Polio epidemics. High-resistance work such as repetitively moving heavy weights is not advisable.

Exercise for people living 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 whereas others might prefer a simple series of exercises that can be carried out at home. The exercise needs to be realistic, achievable, enjoyable - or at least seem worthwhile - and fit into your lifestyle balance.

Some people prefer to exercise in the swimming pool where buoyancy can be used to assist or resist movement.

Whatever exercise is chosen, it is important to start with an amount that feels comfortable and build up the amount of time you exercise slowly.

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 limbs or muscles that seem to be 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, considering 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.

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. If you experience ongoing pain or a sense of excessive muscle fatigue, especially more weakness for a longer period afterwards, then reduce the level of 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 increasing 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. Even this may be too much for some people who have had Polio where completing activities of daily living is enough activity, so seek advice from a physiotherapist.

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, whilst always monitoring symptoms.

9. Exercise guidelines

- Start slowly (even a few minutes might be your baseline that you can manage, 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.
- Never push through fatigue levels.
- 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.
- Keeping a log of your exercise and activity routines, and how you feel, can help monitor progress over time, or decide if what you are doing is about right for you.

10. To round up

Remember the key to achieving lifestyle balance is to avoid pushing yourself beyond your abilities, conserve energy, and pace where necessary, but still maintain some physical activity within your capabilities. Consider doing regular stretches, gently and gradually build up activities, strengthen the areas with less Polio-weakness and PPS symptoms such as fatigue, and if you can manage it, include some exercise that raise your heart rate.

There is no one formula for what will work for everyone, as people who have had Polio are all unique. Appropriate advice from healthcare professionals, like physiotherapists, can help you work out what an exercise programme might consist of.

Ref: <https://www.who.int/news-room/factsheets/detail/physical-activity>

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