

# Understanding Fatigue for Post Polio Syndrome (PPS) and Late Effects of Polio (LEOP) Patients

## What is Fatigue?

Many people who have had polio will be living with fatigue. You may be aware of it or you may have got so used to it that it just feels “normal” for you. You may also find it has got worse with time, particularly if you are living with post polio syndrome. Fatigue following polio is different from other people’s ‘tiredness’. It can come on after very little activity and isn’t a satisfying “earned” tiredness that you might get from physical work. People’s fatigue patterns vary greatly. Some people may wake up feeling fatigued and others may start feeling it by mid morning, or not until later in the day. Some people may have better days than others.

## The Different Types of Fatigue:

### Physical (Neuromuscular) Fatigue

This fatigue comes from polio affected muscles with limited endurance. As the muscles are used they can suddenly fatigue leading to weakness and sometimes an aching pain. This can be worse in the cold. This feeling will usually improve when you stop and rest, although it may take longer to recover over time, or in the cold.

### General Fatigue

This fatigue refers to a feeling of whole body exhaustion or being totally drained. It can occur with physical fatigue.

### Mental Fatigue

This refers to problems with concentration, memory or a general lack of motivation.

## What are the Consequences of Fatigue?

Fatigue can have a profound effect on people’s lives. It can affect their ability to work, garden, cook, take care of themselves, affect how they spend time with their children or grandchildren. It can mean missing out on social events and hurt relationships. It can affect people’s quality and enjoyment of life and cause depression and feelings of guilt. It can stop people living their life to the full and be very distressing. People experiencing fatigue may find it harder to perform tasks such as lifting and carry out activities such as walking. They may experience more falls.

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**Can Fatigue be fixed? Improving fatigue levels to some extent is possible for most people. It involves two key steps.**

## Step One: is to understand what is contributing to your fatigue. There are often multiple factors that can make fatigue worse such as:

- Boom and bust behaviour - continuing activity beyond capacity without resting or pacing.
- Not getting quality sleep. This could be due to breathing difficulties at night (that you may not be aware of), having to wake frequently for the toilet, restless legs, pain, not being able to roll over easily in your sleep. It may be due to habits such as watching TV too late at night or drinking coffee in the evenings.
- Being depressed. Depression often causes feelings of fatigue (and feeling fatigued all the time can cause depression!).
- The side effects of some medication.
- Being in pain.
- Physically struggling to manage walking and day to day activities – therefore using all your energy just to do basic things and having nothing left.

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- Damage to parts of the brain responsible for wakefulness, concentration and memory during your initial polio disease.
- Low physical activity.
- Stress.
- Medical conditions such as heart disease, diabetes.

Considering each factor and dealing with it, usually with help from a health professional, can significantly help overall fatigue. It is worth discussing your fatigue with your GP and asking them to check if you could have any other conditions or be on any medications that can cause fatigue. Your GP can also help with depression, pain, breathing issues, restless legs, bladder issues. A physiotherapist or occupational therapist can help with physical activity, strength, aids to help you manage your daily tasks and mobility, and also with planning for effective energy use. It is highly recommended you have a physiotherapist or occupational therapist come to your home and offer advice and suggestions as there may be things you have never considered or known could help.

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### **Step Two: is to understand your own daily life and how it is affected by fatigue. Then making small (or big!) changes to help keep fatigue levels under control.**

This is a big step and it is often easier to do with support. In order to make changes it is important that you can understand your own fatigue and this is best done by recording activity and fatigue levels for a week in a fatigue diary. Once you have a good overview of your fatigue ask yourself the following questions.

- Are there any patterns to my fatigue? Are there days when it is obviously better or worse?
- Are there times of day when I feel better and should plan to do my most important tasks?
- Am I doing things I don't need to do such as showering every single day?
- Are there things that important to me that I could stop?
- Are there things I could do on different days so that my week's tasks are more evenly spread?
- Are there things that someone else could do instead of me?
- Could I make things easier by sitting down instead of standing?
- Could I plan more rest periods into my week, especially before an event that is likely to cause fatigue?
- Can I do big jobs in smaller chunks so that I can get to the end without feeling exhausted?
- Do I get warning signs that fatigue is setting in and could I be better at listening to my body and having a rest before my fatigue gets too bad.

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**Managing fatigue well often involves changing life long habits and learning new strategies, techniques and skills. Contact Polio New Zealand to find out if there is a fatigue management course or a fatigue management expert in your area.**