Support Services

Post-Polio Syndrome (PPS)

An Introduction

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today's support and information network

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Introduction

It is estimated that there are as many as 120,000[1] people in the UK who survived polio, very often encouraged to get on with their lives[2], forget polio, and adopt a "flair for denial" as there was a belief that polio was something in the past, which would not change.

Since 1875 there have been descriptions of people experiencing new weakness and fatigue years after having polio, but it wasn't really until the 1980s that numbers of people began coming forward with new symptoms.

We now know that people who had polio may develop new polio-related symptoms years later. These symptoms may result from the original weakness and orthopaedic problems, or can be caused by Post-Polio Syndrome (PPS).

What is Post-Polio Syndrome?

Post-Polio Syndrome (PPS) is a neurological condition, which can occur in people who have had polio. After an interval of several years of stability, people may then develop increasing weakness, stamina problems, fatigue and pain. PPS may respond to a range of therapies, which might prevent further deterioration[3].

Symptoms include the onset of new weakness or abnormal fatigue in previously affected or unaffected muscles, a general reduction in stamina, muscle and/or joint pain, muscle atrophy, breathing, sleeping and/or swallowing problems or cold intolerance. Symptoms may lead to loss of endurance or function[3].

A diagnosis of PPS assumes the absence of any other conditions that could explain the above symptoms. Such conditions should be considered and excluded by appropriate investigations[3].

PPS usually begins very slowly, although it can appear suddenly and events like falls, surgery or immobility can seem to be trigger factors. PPS occurs irrespective of age, and in people who had paralytic or non-paralytic polio.

References:
1 The National Service Framework for Long-term Conditions, 2005
2 Post-Polio Syndrome: A Guide for Polio Survivors and Their Families, Silver, 2001
3 British Polio Fellowship Expert Panel Definition of Post Polio Syndrome

How is PPS Managed?

There is no specific cure for PPS, but properly managed it may stabilise or progress only slowly. Much can be done to retain independence, including appropriate treatment for symptoms, use of self-management strategies and referral for assessment from health care professionals, ideally with knowledge of polio/PPS, as described below.

Energy Management

Balancing rest and activity or “pacing”. Over-activity or under-activity can lead to fatigue, increased weakness and pain. However important it may be to keep mobile, activity levels may need to be balanced. It is not about stopping everything, but finding the right balance of activity e.g. do a little gardening at a time with breaks. Each person is an individual and professional guidance is recommended.

There is more information in our guide, “Pacing for Activity and Exercise”.

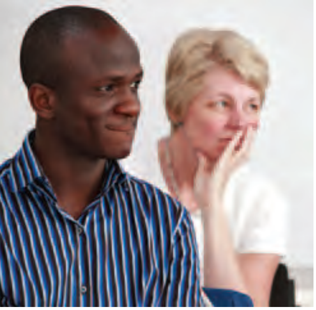
Review use of aids and equipment

Equipment and adaptive strategies can enable people to be as active as possible whilst managing energy levels. Some may need advice or referral e.g. for use of a walking stick, callipers, scooter, wheelchair, or orthopaedic footwear. Advice from an occupational therapist or physiotherapist may be useful.

Appropriate referral

Delay in diagnosis can lead to more deterioration than is necessary. People may be referred to a range of health professionals, including neurologist, orthopaedic surgeon, respiratory consultant or specialist respiratory unit, rehabilitation consultant, orthotist, physiotherapist, occupational therapist, chiropodist or podiatrist, or pain clinic. Many find self-management courses or Expert Patient Programmes useful.

The Fellowship maintains a list of interested health care professionals.



Care with certain medications

Extra care and appropriate advice may be needed when prescribing and monitoring the side-effects or dosage of certain medications, anaesthesia or sedation. The Fellowship may provide more detailed information.

Social and emotional support

Support from friends, family, professionals or the British Polio Fellowship may help people come to terms with changing health or increasing disability. Many will have been adapting strategies to manage their polio over the years - and will need to adapt again which may take time. Information and peer support is often invaluable.

Look after general health

Eat a healthy balanced diet, keep warm, maintain a healthy weight and do not smoke.

About The British Polio Fellowship

The British Polio Fellowship was founded, by and for people with polio, in 1939. The Fellowship continues to offer support, information and social contacts to people with polio or Post-Polio Syndrome. Our services are especially relevant today, as people with polio may now be experiencing declining health, including the symptoms of Post-Polio Syndrome.

Contact us for information about:

- Polio or Post-Polio Syndrome
- Membership of The British Polio Fellowship
- Our quarterly magazine, *The Bulletin*
- Information and advice services
- Social contacts & support through our network of local branches
- Our small grants schemes
- Holiday Programme
- Campaigning and outreach
- Making a donation or fundraising

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