

Orthotics Guide

Introduction

This factsheet is for anyone who had polio or has post polio syndrome (PPS) who would like to learn more about orthoses and specialist footwear, but not wheelchair provision or walking aids.

Post-polio symptoms

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.

There is more information on PPS in other British Polio Fellowship factsheets.

Orthotics

As a person who had polio or has Post Polio Syndrome you may have requirements for orthoses or specialist footwear to assist with your mobility needs. This factsheet aims to provide guidance as to services currently provided by the NHS and private providers and services you should expect as a user. It offers practical suggestions to enable you to achieve the most suitable orthoses or footwear for your individual needs.

An orthosis is a support, brace or splint used to support, protect, align, prevent or correct the function of moveable parts of the body. These can range from shoe inserts to more complicated knee ankle foot orthoses (KAFO) or braces to support the spine.

Shoe inserts are orthotics that are intended to correct an abnormal or irregular walking pattern by altering the angles at which the foot strikes the ground or takes weight.

An orthotist is the primary medical practitioner who may be assisted by a specialist technician or manufacturing company. The orthotics department may previously have been known as the appliance department and the orthotist may have been referred to as a fitter.

Footwear

Specialist footwear is normally provided when there is a significant leg length discrepancy, an unusual shaped foot that cannot fit within standard footwear or more support and protection of your foot is required than can be achieved within standard footwear. There are often different ways to achieve the same result and the orthotist will discuss with you, which most suits your needs.

He/she may provide insoles that will fit within standard footwear that can be adapted to accommodate height differences or provide more support where required. If this is not possible stock or modular orthopaedic shoes may be ordered to allow the insoles and adaptations to be accommodated – these normally come in different width and depths and the orthotist will work with you to find a suitable style and the best comfort for you. You may have to try different sizes before you achieve the perfect fit for you. They should normally be provided within 2-4 weeks of ordering.

Bespoke footwear will be provided if your needs are more complex and cannot be accommodated within modular footwear. This type of footwear is made individually for you and will be made to measures and plaster casts, scans or foot impressions. The orthotist will use measurement techniques that best suits the clinical environment, manufacturing methods and your feet. You will require a trial fitting before the footwear is completed. Due to the individual handmade nature of the footwear it can take between 6-12 weeks to complete.

Referral Process

Initially you have to be referred to an orthotist by your GP (general practitioner). If your needs are deemed to be simple, some services will take direct referrals from a GP, but often your GP needs to refer to an orthopaedic specialist, rehabilitation or other consultant who will then refer to the orthotic service.

After an initial consultation, you should be able to refer yourself back into the system for a quick and timely appointment to resolve any issues. Each area has their own system and you should find out directly from them how you should access their services. Sometimes you have to see the consultant in charge of your care on a regular basis (yearly or 5 yearly) so that you can continue to have direct access to orthotic services.

Appointment Length

Appointments should be of adequate length to ensure the orthotist has fully understood your requirements and can provide the correct prescription. An initial consultation should be at least 20 minutes and then a further appointment will be given to take the appropriate measurements and casts if necessary. If your needs are complex more time should be given. You should then be given an appointment to fit the orthosis or footwear when the device is incomplete and changes can be made. There may be two fittings before the orthoses or footwear are then supplied to you.

When the orthoses or footwear are ready for supply you will be asked to attend the department to try these out. If you have any concerns at this point please discuss them with the orthotist. The orthotist may be able to make adjustments on site or may have to return them back to the manufacturer. If you are happy with what has been made you can then take them home to try.

A period of adjustment when receiving new orthoses or footwear is usual as your body has to adjust to the changes that have been made. Many people who had polio have been wearing orthotics for decades and adapting to a new style can be very challenging. It is advisable to try the orthoses or footwear for shorter periods then gradually increase the length of wear. Your orthotist is the best person to advise you on this process. Sessions with a physiotherapist with neurological experience can also be useful.

You should be given a further appointment to review the orthoses or footwear. This is often approximately 6 weeks after supply, which should have given you plenty of time to adjust and discover if anything needs changing with your prescription.

If the orthosis or footwear is successful, a second orthosis or footwear may be supplied but this will vary from region to region and may depend on your usage. If you are active and rely on your orthoses or footwear then a second pair is desirable so that you can wear one pair of footwear or orthoses when the other is being repaired or altered.

If you are supplied with two pairs of footwear or orthoses it is important that you wear them alternately so that you ensure both are fully functional. It is normal to have a preference of footwear but you should try to ensure you alternate use.

It is not unusual to find that a second orthoses or pair of footwear is not exactly the same as the previous pair. This may be due to the period of adaption which is necessary, or it may be due to a change in manufacturer, prescription or work practices. Discuss this with the orthotist in charge – it may be possible to send a sample orthosis or footwear to the manufacturer. Sometimes due to changes in body alignment or musculature a change in prescription is necessary and an exact repeat prescription may not be suitable any longer,

The waiting time between appointments should be kept to a minimum, especially if an orthosis needs to be returned for adjustment or repair. Without the orthosis, it could be very difficult for you to get around.

The waiting time will depend on the actual prescription of the orthosis. Footwear can take approximately three weeks to fitting stage and five weeks before being delivered. If your case is complex this may be longer. You should expect an appointment to have your orthosis fitted up to 21 or less than 30 days, after your assessment.

You should be given the option to book appointments in advance or in blocks, rather than waiting for the orthosis to be returned from the manufacturer. Your

orthotist and the administration staff should be aware of supplier lead times and minimise delays and repeat visits

Your orthotist should include other teams and departments, technicians and/or manufacturers, as required. This should result in the prescription meeting your needs and fewer adjustments being required. Sometimes physiotherapy will be needed after supply of an orthosis to assist you with your new pattern of walking.

Where a made to measure orthosis is required, you should expect your orthotist to be communicating with the technician and manufacturer to ensure your orthosis is being made to your individual prescription.

Your orthotist should prescribe the most appropriate orthosis for your needs and then review its suitability with you on a regular basis. You should notify your orthotist if you are to have any surgery (e.g. joint replacement) that might affect your orthotic needs. As your condition may change over time and newer products may become available, your orthotist should make you aware of other products that may be more suitable. As well as taking into account the functional requirements of the orthosis, your orthotist should also consider your personal and social needs, depending upon your age, activity, gender and lifestyle.

Older orthoses are not always better and may have encouraged “bad habits”. A more modern orthosis may help to correct any problems and enable you to maintain a better level of health. However, you may need to “unlearn” existing patterns of usage, which could require effort to make the best of a more supportive orthosis. Your orthotist should work with your occupational therapist, physiotherapist or relevant health professional to ensure you can use your new orthosis correctly and understand why it feels different.

If your orthotist follows good prescribing practice, this should reduce the risk of poorly designed or fitted orthoses and ongoing problems. If, for any reason, an orthosis has to be returned for more than 3 adjustments, your orthotist should (without you needing to ask) arrange a collective meeting with the technician and/or manufacturer to assist with fitting. If you are not offered this automatically, you should request it.

You can help the orthotist to achieve the best result for you by taking with you the orthosis or footwear that is causing difficulty and discussing with the orthotist what you feel may be wrong or what can be done to help you. Communication with the orthotist is important. Sometimes it can help to write down your concerns before the appointment so that important information is not missed.

If you need to complain about your treatment or any aspect of the service:

The first step is to raise your concerns directly with the orthotist, relevant team member or the manager of the service concerned. Hopefully this will result in a quick and effective local resolution of the problem.

If you don't get a satisfactory response from the person or department providing the service, you should speak to the Patient Advice and Liaison Service (PALS) staff or complaints manager at the NHS Trust Hospital or Primary Care Trust involved. They may be able to resolve the problem without the need to make a formal complaint. If not, they will provide help and support to take your complaint further.

Information on how to make a complaint about the NHS can be found on the NHS website: www.nhs.uk. (Just type in the word "complaints" in the search box). You can direct your complaint to either the service provider or the Clinical Commissioning Group. (You should not approach both over a single complaint). In the event of difficulty in making a complaint, the NHS Complaints Advocacy Service, which is independent of the NHS, should be approached via the local authority.

To summarise

You should expect to be provided with orthoses or footwear to assist with your daily mobility needs and dealing with the impact of polio or post polio syndrome.

You should expect:

- Ease of referral
- Your local Orthotics provider to be easily accessible
- Adequate length of time for appointments
- Timely appointments and notification of delays
- Appropriate and accurate prescribing to meet your individual needs, including the involvement of technicians in complex cases
- Choice and information as to availability of products
- Prompt rectification of problems the involvement of technicians and/or manufacturers onsite
- an orthotist experienced in complex neurological and musculoskeletal problems of polio patients

Alternatives to NHS provision

The National Health service is under increasing financial pressures and you may prefer to pay for the service you require, or you may feel you have no alternative but to seek private orthotic provision. The British Polio Fellowship suggests that you seek advice from your GP, consultant or appropriate health care professions before considering having your orthoses or footwear made privately.

You may consider having orthoses made privately because you wish to have more orthoses than those available to you on the NHS. You may wish to research more advanced or higher specified orthoses such as carbon fibre orthoses, which are lighter than more traditional materials or electronically controlled knee joints for your orthoses. You may have more choice over the orthotist who you see and you may see a more experienced orthotist. However, you should consider that orthoses and footwear are expensive. You will not have the support network provided by qualified healthcare professionals within the NHS. You may have to travel further. You should also consider the maintenance and repair costs and costs of further appointments to have adjustments made to your orthoses or footwear.

If you are considering private treatment it is worth looking for recommendations from another person who has had polio or has PPS. You should check to see if the company is registered for VAT as you may be exempt.

Medical disclaimer

The purpose of this publication is for information only. The British Polio Fellowship disclaims all liability for any claims, losses, damages, costs and expenses incurred as a result of reliance on this information. It is not a substitute for advice from your doctor, physiotherapist or other health care professional

Author

This factsheet was produced by the British Polio Fellowship Expert Panel.

This replaces previous factsheets on 'Callipers and insoles', 'Orthotic services' and 'Orthotics, private' Lead author Laura Skorupa

Version 1. Lead author Jane Hunter, BSc Hons Prosthetics and Orthotics. With thanks to members of the expert panel for their help and advice with the writing of this factsheet.

Date: 14/July/2020

The British Polio Fellowship Contact Details

The British Polio Fellowship
CP House, Otterspool Way,
Watford Bypass, Watford, WD258HR
Freephone: 0800 043 1935/ 01923 889 501
Website: www.britishpolio.org.uk
Email: info@britishpolio.org.uk
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