

Orthotics Guide

Introduction

This factsheet is for anyone who had polio or has Post-Polio Syndrome (PPS) and would like to learn more about different types of orthoses and how they function. This guide is focused on orthoses that you apply to the body and not wheelchair provision or walking aids.

Post-Polio symptoms

People who have contracted 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.

Due to these changes your orthotic prescription may need to be altered or changed as time progresses. What you used to find helpful may not be as helpful if your symptoms have changed.

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

Orthotics

What is an orthosis?

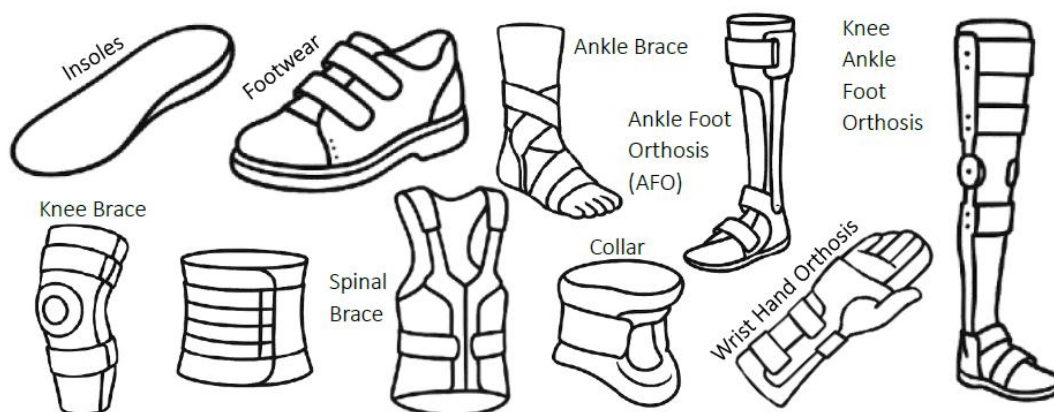
An orthosis is an externally applied device, designed to improve biomechanical function, encourage improved joint alignment, reduce pain, or protect a limb.

What is an orthotist?

Orthotists are independent healthcare professionals who assess how people walk and move. They use their knowledge of the body and engineering to design braces that support, or correct problems caused by nerve, muscle, or bone conditions.

What type of orthoses are there?

There are multiple different types of orthoses that may be prescribed for various reasons, made from a wide range of materials, both stock, modular and custom made.



- **Insoles:**

These can be made from multiple different materials depending on your clinical needs. They may be used to influence the biomechanics of the foot/ankle or spread pressure under the foot.

- **Footwear:**

These may be prescribed if there is a clinical need, and you are unable to fit within high street footwear. We can also provide advice regarding buying Highstreet footwear or adapting your own footwear where appropriate.

- **Ankle foot orthosis (AFO):**

These can be either stock devices or custom-made to fit individual needs. An AFO is usually prescribed to help with one or more of the following: improving stability around the foot and ankle, reducing pain, or supporting weakness.

- **Knee braces:**

These again can range from a stock device, which is most common, or a custom-made option. Knee braces come in a large variety of materials and designs depending on their intended functions.

- **Knee ankle foot orthosis (KAFO):**

These are most commonly a custom-made device that covers your knee, ankle, and foot, to help control movement around your knee and ankle to help accommodate for weakness and/or pain in these areas.

- **Spinal braces:**

These can be both stock or custom made, made from a variety of materials. It is important to understand the risks of using a spinal brace as in some cases it could encourage increased core weakness, leading to reliance on the brace. Make sure to discuss in depth with your orthotist prior to use.

- **Upper limb orthoses:**

These can vary from wrist hand orthosis, shoulder orthosis, collars or neck supports, which again come in both stock and custom-made options. You may also see an occupational therapist or physiotherapist within a Hand Therapy department instead.

Referral process

You will normally be referred to an orthotist via your GP (general practitioner) or on occasion a consultant within your local NHS trust, this depends on each service.

Most services will offer at least one episode of care, which would consist of an assessment, a fitting if required, and a review if needed. After you have met your allowance for your orthosis you may then require a further referral in future to access the service. Other services may operate multiple episodes of care and keep you on the system for a specified amount of time (usually between 2-5 years). In this time, you will be able to contact the service and request a review/reassessment if needed without the need for a new referral.

Establishing a strong ongoing working relationship with your orthotist is key to finding the most effective solution for your individual needs, as they change over time.

If you do not attend (DNA) an appointment some services may discharge you and you will require a new referral to access the service.

As each service operates differently it is always best to contact your local service to discuss their access policy.

Appointment length and description

Appointments should be of adequate length to ensure the orthotist has fully understood your requirements and can provide the correct prescription or recommendations. An initial consultation should be between 30-60 minutes; you may then be asked to return for a casting or measurement appointment if this was not possible to do within your appointment time. You may then need to attend a fitting appointment, which again should be between 30-60 minutes depending on the orthosis being fitted.

It is important to be honest about your needs and how you're managing day-to-day. Bring any previous orthoses, along with photos and notes, to help your orthotist understand what you've tried before, what worked and what didn't. This will also allow them to see if adjustments to your current device could improve comfort or function.

Be sure to bring any walking aids you use to take steps or stand to help your orthotist perform a full assessment. Additionally, you might want to consider taking a change of clothes, such as shorts to make the assessment easier and to allow better access for casting if needed.

Some orthoses such as footwear and KAFOs routinely require two fitting appointments. The time between each appointment will vary depending on multiple factors including the time it takes to manufacture the custom orthosis, or the delivery times for stock goods, as well as the waiting time within the clinic. On average most stock orthosis should arrive within 2-4 weeks, and custom orthosis can take 8+ weeks.

Most orthoses will require a period of adjustment, during this period you will be advised to gradually increase the duration that you wear your orthosis to allow your body to adjust to a new device and potentially a new position. During this time, it is common to have some minor aches and pains while your body adjusts, however this should settle down within a few weeks of consistent use. If this pain becomes severe and does not reduce, or there is any damage to your skin, you should stop using your orthosis and contact your orthotic department for an urgent review.

Once you have adjusted to your orthosis you will likely be offered a repeat, which in some cases such as footwear, will allow you to alter the style or colour for your second pair. It is likely that even with a repeat orthosis you may still have a preferred orthosis, as with custom made orthoses it is unlikely to have them exactly the same as they are often made by hand. A repeat orthosis may also feel different as it is newer and the materials have not had time to mould and shape to your body. It is important to have a spare orthosis to allow you to keep up with regular repairs, especially for items such as footwear and KAFOs.

It is important to always bring your orthosis and walking aids to your review appointment, even if there are issues and you are not using the device, as this allows the orthotist to review the fitting and see what adjustments may need to be done to improve the comfort/fit.

Prescription considerations

There are many elements that your Orthotist will take into consideration when deciding what is the most appropriate prescription for you. Below is highlighted just a few things they may want to consider:

- **Level of weakness and available range**

Your orthotist will carry out a full assessment of your muscle powers and range of motion at each joint.

- **Weight and activity level**

All orthoses will have specific weight limit for materials, so it is important for your orthotist to ask about your weight and activity levels as higher activity users will likely require a stronger, more durable orthosis.

- **Presence of swelling**

If swelling fluctuates this can impact which orthosis can be offered as accommodating a change in size with a custom device can be challenging.

- **Footwear choice**

If there is a specific design of footwear you choose to wear this can limit the orthotic options given. Most of the time a trainer style of shoe with an adjustable fastening is the most appropriate to work with an orthosis.

- **Living arrangements**

Your orthotist may discuss whether you need any additional support in your daily life and what form that support might take. This information will be considered when designing your orthosis to ensure you gain the greatest possible benefit from it. Factors such as when you need to wear the orthosis and whether you have assistance available to help you put it on will be taken into account. If the orthosis is applied with the help of a carer or family member, your ability to remove it independently may also be considered.

- **Hobbies**

There may be a specific hobby that you require your orthosis for which may require a slight alteration in design to help. Always be sure to mention these key hobbies to your Orthotist at the initial assessment.

Due to the changing nature of the effects of polio and PPS, it is possible that over time the most appropriate orthotic prescription for you may change to suit your needs. Due to this it is important to remain under an orthotic service for ongoing reviews to ensure your current prescription remains the most optimal treatment for you.

Repairs and safety risks

It's important to regularly check your orthosis for signs of wear and tear. Over time, parts can become loose, worn, or damaged, especially with frequent use. This is particularly important for larger, weight-bearing devices such as a KAFO.

A damaged KAFO may not provide the support it's designed for. If joints, straps, or structural components fail, there is a serious risk of the device giving way during walking or standing. This could lead to falls, injury, or loss of confidence in mobility.

If you notice any changes in how your orthosis feels, sounds (e.g. clicking or squeaking), or functions, or if it becomes uncomfortable, do not ignore it. Even small issues can quickly worsen.

Repairs should always be carried out by your orthotic service or a qualified professional. Attempting to fix it yourself can make the problem worse and potentially increase the risk of injury.

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 the most appropriate orthosis to assist with your daily mobility needs and dealing with the impact of polio or PPS. 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.
- Choice and information as to availability of products
- Prompt rectification of problems if they arise
- A spare orthosis, where appropriate, to allow for ongoing use during repairs, especially for items like KAFOs and specialist footwear
- An orthotist experienced in complex neurological and musculoskeletal problems of polio patients.

Alternatives to NHS provision

The National Health Service (NHS) is currently facing increasing financial pressures, along with a shortage of qualified orthotists across the UK. As a result, some areas may experience longer

waiting times and limited access to orthotic services. In these circumstances, you may wish to explore private orthotic services as an alternative.

Additionally, you may choose to have orthoses made privately if you require more devices than are available to you within your NHS allowance (i.e. the amount or type of orthotic care and devices you can receive through the NHS, based on your needs and local service guidelines – to understand your allowance speak to your orthotist).

Choosing to access a private orthotics service can come with some benefits. You may experience shorter waiting times between appointments, have more flexibility with appointment slots (including evenings and weekends), and in some cases, access orthotic options that your local NHS service might not be able to provide.

However, there are a few important things to consider. You won't have the same support network that comes with an NHS multi-disciplinary team, which may include physiotherapists, doctors, and other specialists. You'll also need to think about ongoing costs, such as repairs, adjustments, or follow-up appointments for your orthoses or footwear.

If you're thinking about private treatment, it can be helpful to ask others with polio or PPS for recommendations or read patient reviews online. Also, check whether the company is registered for VAT, as you may be eligible for VAT exemption.

NOTE: The British Polio Fellowship suggests that you seek advice from your GP, consultant, or appropriate health care professions before considering having your orthoses made privately.

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.

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