

Living with a bleeding disorder: Are you getting the physiotherapy service you need?

A specialist haemophilia physiotherapist is a core member of the multidisciplinary team (MDT) which provides care for all persons with a bleeding disorder (PwBD) living in the UK.¹⁻² This allows the PwBD direct access to assessment and treatment of acute bleeds & injuries in addition to regular reviews; at least twice a year for severe to moderate conditions and annually for milder disorders.¹⁻² The NHS specification for haemophilia services states that PwBD should have access to musculoskeletal and specialist physiotherapy services.³ A recent national peer review looked at the availability of physiotherapy in UK centres and found that a substantial number of centres are not providing an adequate service.⁴

Responsibility to provide a specialist haemophilia physiotherapy service lies with the NHS Hospital Trust where the haemophilia care centres are located.³ This should be available to all adults and children with an inherited bleeding disorder and be of a standard to meet their needs from the point of diagnosis throughout a lifetime of care, as recommended in the World Federation of Haemophilia (WFH) guidelines.⁵

What specialist haemophilia physiotherapy is:

Physiotherapy provides a wide range of physical techniques including strength & balance training, sports therapy, and hydrotherapy, often started after a bleeding episode.¹⁻² However, specialist physiotherapy goes beyond rehabilitation following an injury or acute bleed. It supports lifestyle changes, encourages early and safe adoption of activities & sports which can in turn reduce the risk of injury, pain, and minimise joint damage.⁶⁻⁸ Your centre's physiotherapist will have developed a long-term relationship with their PwBD, and their families, and so be able to support them in improving function, selecting beneficial activities and sports leading to greater participation in everyday life which in turn is linked to improved quality of life.⁶⁻⁹ Haemophilia physiotherapy is also a cost effective resource.⁹

Current position: Variable access to specialist physiotherapy for UK patients

A recent audit of all haemophilia centres in the UK⁴ and an All-Party Parliamentary Group (APPG)¹⁰ report on bleeding disorders care, and a recent patient experience survey by the Haemophilia Society¹¹ showed:

- The responsibility to provide physiotherapy was not met in a significant number of centres.⁴
- **Inadequate** physiotherapy provision was identified in 59% centres reviewed.⁴
- There was a general deficit in access to specialist haemophilia physiotherapist services^{4, 10}
- Support and access to specialist physiotherapy was highly rated by patients however it was not always offered even when patients wanted it at their centre.¹¹

What is the Haemophilia Chartered Physiotherapists Association (HCPA)

The HCPA is an organisation for specialist physiotherapists working with PwBD who are registered at a haemophilia or comprehensive care centre in the UK. They provide bespoke training & education, mentoring and an extensive research network all aimed at enhancing the care and capabilities of all PwBD. ([Haemophilia Chartered Physiotherapists Association \(HCPA\) – UKHCDO](#))

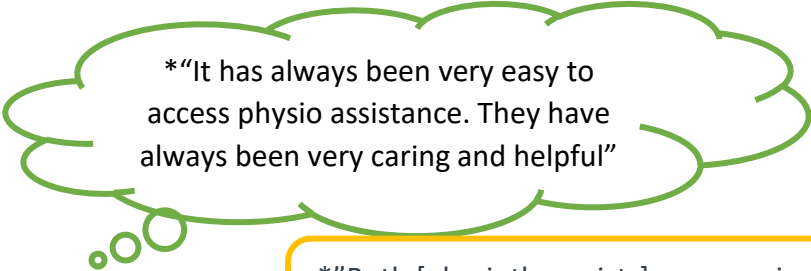
What should a good specialist haemophilia service provide?

All PwBD, no matter where they are in the UK, should have access to a physiotherapy service which can provide the following:

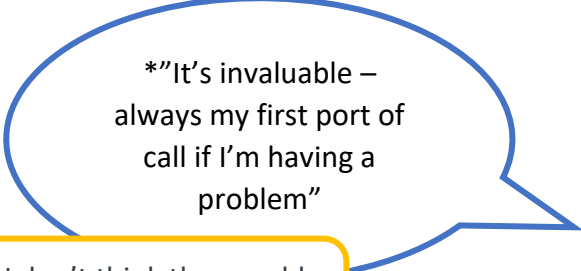
- Specialist physiotherapists registered with the HCPA, with experience in musculoskeletal care and work in the haemophilia MDT ¹⁻²
- Adherence to all aspects of the HCPA Standards of Care for Adults and Children¹⁻²
Ability to deal with chronic referrals within two weeks and be available to review acute conditions within 24 hours where practicable ¹⁻²
- Dedicated hours to provide continuing care to PwBD registered at their haemophilia centre including an assessment of the Haemophilia Joint Health Score (HJHS), partnering with individuals and families to optimise musculoskeletal health, participation, and health equity ^{4, 6-9}
- Agreed time for physiotherapists to access continuing professional development and training supported by the HCPA. ¹⁻²

What does a good specialist haemophilia physiotherapy service feel like?

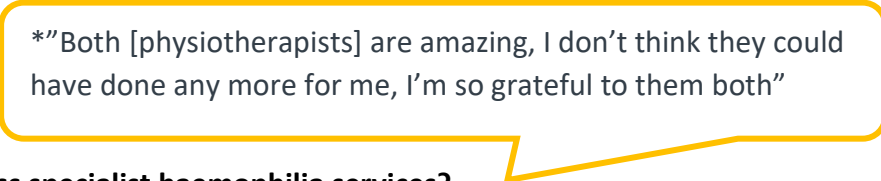
(*From recent survey of access to haemophilia physiotherapy during pandemic March 2020 to November 2021)



*"It has always been very easy to access physio assistance. They have always been very caring and helpful"



*"It's invaluable – always my first port of call if I'm having a problem"



*"Both [physiotherapists] are amazing, I don't think they could have done any more for me, I'm so grateful to them both"

How do I access specialist haemophilia services?

- Ask at your centre or next clinic appointment
- Contact the Physiotherapy Service at your local NHS Trust
- Get in touch with The Haemophilia Society

References available at haemophilia.org.uk/access-to-physio