

UK Standards of Care

Service Provision of Physiotherapy For Adults with Haemophilia & other Inherited Bleeding Disorders

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

Background

The Physiotherapy Standards for Haemophilia Care were originally written by the Haemophilia Chartered Physiotherapists Association (HCPA) to assist physiotherapists with the management of patients with haemophilia & related bleeding disorders in 1996 (1). These were reviewed and updated in 2002 (2) and again in 2012 (3). Regular review of the standards of care since has been carried out. The current Standards were endorsed by the UK Haemophilia Doctors Association (UKHCDO) in 2017. There is no uniform model for the provision of physiotherapy for adults with haemophilia and levels of provision currently vary between haemophilia centres.

The NHS Service Specification for Haemophilia suggests a model of care where patients have access to, and regular review by, experienced specialist physiotherapists trained in line with the HCPA (4). This perspective is endorsed by both the UKHCDO musculoskeletal guidelines (6) and the WFH guidelines for the management of haemophilia (7). More recently, a set of quality standards have been established for the care of people with inherited and acquired haemophilia and other bleeding disorders by the UKHCDO Peer Review working party in partnership with the West Midlands Quality Review Service. These standards recognise physiotherapy as a core component of the haemophilia comprehensive care team (5).

The main tenants of practice are to

- *Undertake assessments and initiate interventions to prevent or minimise the risk of musculoskeletal injury/recurrence of a previous injury*
- *Ensure ongoing monitoring of joint health*
- *Facilitate good physical function and participation in activities*
- *Provide rehabilitation of acute, subacute and chronic manifestations of musculoskeletal disease*
- *Provide activity and health education and to promote participation amongst patients with haemophilia*

This document aims to provide a 'framework' for the establishment of standards for provision of physiotherapy to adults with haemophilia, and to compliment the Service Provision of Physiotherapy for Children with Haemophilia & other Inherited Bleeding Disorders - UK Standards of Care (8).

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

STANDARD 1- Physiotherapy provision

- *Adults should have access to a physiotherapist with specialist knowledge of haemophilia and musculoskeletal conditions (4).*

- *The physiotherapist should be a member of the Haemophilia Chartered Physiotherapists Association (HCPA) and be able to attend / undertake training to ensure the continuation of best practice and provision of quality care in this specialist area (4).*

- *The specialist physiotherapist should have dedicated / protected hours and flexibility within this to manage their haemophilia caseload / service.*

- *The specialist physiotherapist should be supported in continuing education activities that will ensure awareness of current best practice, and current research and developments within haemophilia. Including knowledge and skills of physiotherapy practice unique to this area (i.e. up to date assessment techniques and relevant outcomes) and medical advances (i.e. emerging new medical treatments) (9)*

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

STANDARD 2- Referral and triage

Adults referred for physiotherapy should be seen within the appropriate time frame according to the clinical status and have access to physiotherapy telephone triage and advice.

- **Acute condition referral-** *a patient should be reviewed as soon as is clinically possible, normally within 24 hours (10,11,12). This could be a telephone triage or face to face review as an outpatient or inpatient.*

It is acknowledged that when a referral occurs prior to a bank holiday / weekend, review should be the next available and clinically appropriate appointment.

- **Chronic condition referral-** *a patient should be offered an appointment which will be within 2 weeks.*

Physiotherapy management may take place within the local physiotherapy setting as deemed clinically appropriate. The overall responsibility of physiotherapy management should remain with the specialist physiotherapist with effective communication between professionals.

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

STANDARD 3- Physiotherapy clinical management

Physiotherapists working with adults with haemophilia should provide the highest standards of clinical care.

Clinical care should be consistent with the Quality Assurance Standards for Physiotherapy Service Delivery documented by the Chartered Society of Physiotherapy (13), and in line with the standards of conduct, performance and ethics, set out by the Health Care Professions Council (14).

Patient care and clinical management should be evidence based and informed by clinically suitable guidelines. A suggested resource is Physiotherapy Management in Haemophilia (15).

Each physiotherapy episode of care should:

- *Include a thorough neuro-musculoskeletal assessment to review joint health & function and participation.*
- *Show evidence of appropriate outcome measures used throughout the assessment, management and review process (9, 10, 11, 12).*
- *Incorporate medical specific haemophilia questioning - diagnosis and factor level, presence of inhibitor, treatment method, bleeding history, compliance.*
- *Undertake onwards referral to other specialties such as radiology, rheumatology or orthopaedics when clinically appropriate.*

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

STANDARD 4- Regular multidisciplinary review

As stated within the National Service Specification and Quality Standards, all adults with haemophilia should be offered regular clinical multidisciplinary review (4, 5). The physiotherapy review should form part of a seamless multidisciplinary review of the patient, with relevant information being shared amongst team members.

- *At a minimum, patients with a symptomatic diagnosis of haemophilia or on prophylaxis should be reviewed by a physiotherapist at least twice yearly (5)*
- *Adults with frequent bleeding episodes, coagulation factor inhibitors, complications of bleeding episodes such as symptomatic arthropathies may require more frequent review (10, 11, 12).*
- *Patient review will include the use of standardised & validated clinical examination scores and assessment tools, e.g. the Haemophilia Joint Health Score (HJHS) (16), which should be incorporated into the prospective assessment of patients receiving prophylaxis (16,17,18).*
- *The use of validated functional and psychosocial outcome measures for adults with haemophilia is endorsed as part of the regular review when relevant (18), and should consider the domains of impairment, activity, participation and function acknowledged in the World health organisation (WHO) ICF framework (19).*
- *A record of bleeding events, functional difficulties and time off work should also be noted (18).*
- *Identifying and addressing other age appropriate health related issues e.g falls risk, obesity, bone health.*
- *Copies of the assessment, scores and physiotherapy recommendations should be shared within the multidisciplinary team, local therapy team and appropriate multiagency teams involved with the adult and entered on required databases.*

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

STANDARD 5- Education

Clear information should be provided relating to how to manage all aspects of bleed risk and musculoskeletal health. Information to the patient and other relevant agencies should be provided based on the clinical assessment of the patient and the most up to date evidence (6,15).

Education may include:

- *The role of physiotherapy within the comprehensive care team in the management of haemophilia.*
- *Identification and management of acute musculoskeletal bleeding episodes.*
- *Long term implications of the impact of haemophilia on the musculoskeletal system.*
- *The contribution of muscle power and proprioception in providing joint protection.*
- *Recognition of normal musculoskeletal issues related to the aging process.*
- *Promoting the impact and role of physical activity, exercise and sport on adult health and offer support in activity selection (20).*

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

STANDARD 6- Transition

The physiotherapist should assist in the seamless transfer of haemophilia care from the paediatric setting, with adult services taking joint responsibility with paediatric services for transition and be guided by national policy and paperwork (21).

This may include:

- *Planned attendance from the paediatric physiotherapist at joint clinic review with the adult team prior to transition to provide a complete and comprehensive handover of care.*
- *Liaising with the paediatric team to acquire relevant documentation including any standardised assessments, previous history and management.*
- *Promotion of independent management of the individual's condition, within school, further education and career.*
- *Ensuring contact details are received from the paediatric physiotherapy team.*

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

References

1. Standards for Haemophilia, Chartered Society of Physiotherapy, 1996
2. Haemophilia Chartered Physiotherapists Association Standards of Care, Chartered Society of Physiotherapy, revised 2002
3. Haemophilia Chartered Physiotherapists Association Standards of Care, 2012
4. NHS Service Specification for Haemophilia, 2013
5. Quality Standards – Care of people with inherited and acquired haemophilia and other bleeding disorders, UKHCDO 2018
6. Hanley *et al.* Guidelines for the management of acute Joint Bleeds and Chronic Synovitis in Haemophilia, UKHCDO guideline. 2017
7. Srivastava *et al.* WFH Guidelines for the management of haemophilia, Haemophilia 2012,
8. Service Provision of Physiotherapy for Children with haemophilia & other inherited bleeding disorders – UK Standards of Care, May 2017
9. Stephensen *et al.* Recent advances in musculoskeletal physiotherapy for haemophilia, *Ther Adv Hematol* 2018, Vol 9(8) 227-237
10. De Moerloose *et al.* Recommendations for assessment, monitoring and follow-up of patients with haemophilia. *Haemophilia* 2011, 1-7
11. Hermans *et al.* Management of acute haemarthrosis in haemophilia A without inhibitors: literature review, European survey and recommendations. *Haemophilia* 2011, 17, 383-392
12. Sorensen *et al.* Management of muscle haematomas in patients with severe haemophilia in an evidence-poor world. *Haemophilia* 2011, 1-9
13. Quality Assurance Standards for Physiotherapy Service Delivery, The Chartered Society of Physiotherapy, 2012
14. HCPC standards of conduct, performance and ethics, 2016
15. Physiotherapy Management in Haemophilia, Background and Practical guidelines. De Kleijn and Mauser-Bunschoten. Bayer Netherlands 2017
16. Hilliard *et al.* (2006) Haemophilia Joint Health Score reliability study. *Haemophilia* 12, 5, 518-525 (www.ipsg.ca to register and access the training tools and assessment paperwork for the Haemophilia Joint Health Score 2.1)
17. Richards *et al.* (2010) A United Kingdom Haemophilia Centre Doctors' Organization guideline approved by the British Committee for Standards in Haematology: guideline on the use of prophylactic factor VIII concentrate in children and adults with severe haemophilia A. *British Journal of Haematology*, 149, 498-507

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025

18. Clinical Outcome group, UKHCDO Annual Report 2011
19. WHO International classification of functioning, disability and health framework.
<http://www.who.int/classifications/icf/en/>
20. Gomis et al. Exercise and sport in the treatment of haemophiliac patients: a systematic review.
Haemophilia 2009, 15, 43-54
21. Transition from Children's to adult's services for young people using health or social services care.
Feb 2016 nice.org.uk/guidance/ng43

Service Provision of Physiotherapy for Adults with Haemophilia

Authors: Stephen Classey & Nicola Hubert

Approved by HCPA: March 2020

Next review: March 2025