HCPA

Haemophilia
Chartered
Physiotherapist
Association

# UK Standards of Care

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

# 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), 2012 (3), 2017 (4) and again in 2020 (5). Given the advances in the current treatment landscape for many inherited bleeding disorders, alongside the recent review of the NHSE Service Specification for Haemophilia, the HCPA felt it appropriate to update the current standards of care. The HCPA Standards were endorsed by the UK Haemophilia Doctors Association (UKHCDO) in 2017. It remains important to publish standards of care as there remains no uniform model for the provision of physiotherapy for children with haemophilia, with levels of provision currently varying between haemophilia centres.

The NHSE Service Specification for Haemophilia requires services provide a model of care where patients have access to, and regular review by, experienced specialist physiotherapists trained in line with the HCPA (5-7). This perspective is endorsed by both the UKHCDO musculoskeletal guidelines (8) the WFH guidelines for the management of haemophilia (9) and the European Principles of Care for Physiotherapy in people with inherited bleeding disorders (10). The quality standards included in the UK wide peer review process of haemophilia centres recognise physiotherapy as a core component of the haemophilia comprehensive care team (6).

The aim of a physiotherapy service for people with inherited and acquired bleeding disorders is the provision of an evidence informed, fully integrated, person-centred programme of care delivered within a life-affirming and lifelong bio-psychosocially informed practice model.
The main tenets of this practice are to:

- *Undertake autonomous and highly specialist 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 in society amongst children with haemophilia and other inherited bleeding disorders.*

This document provides a framework for the standard of physiotherapy care provided to children with haemophilia and other inherited bleeding disorders and compliments the Service Provision of Physiotherapy for Adults with Haemophilia & other Inherited Bleeding Disorders - UK Standards of Care(11). It applies to all genders (hence the use of the term ‘child’ throughout this document) and all severities of inherited/acquired bleeding disorders that may benefit from expert physiotherapy intervention.

# STANDARD 1- Physiotherapy provision

- *Children should have access to a physiotherapist with specialist knowledge of haemostasis, haemophilia, paediatric musculoskeletal conditions, normal paediatric variants and child development (5).*

- *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 (5).*

- *The specialist physiotherapist should have dedicated / protected hours and flexibility within this to autonomously manage their patient caseload / service. This time must also reflect any professional and clinical network role they may have within the geographical location of their treatment centre.*

- *The specialist physiotherapist should be supported in continuing education activities that will ensure awareness of current best practice and development, leadership, education and research within haemophilia and inherited bleeding disorders. It should include knowledge and skills of physiotherapy practice unique to this area (i.e. emerging assessment techniques and relevant and appropriate outcomes measure) and medical advances (i.e. emerging new medical treatments) (12).*

# STANDARD 2- Triage and initiation of care

Children referred for physiotherapy should be seen within the appropriate time frame according to the clinical status (haematological and musculoskeletal) and have access to physiotherapy telephone or video conferencing triage and advice and in line with local trust policy.

- ***Acute condition referral****- a patient should be reviewed as soon as clinically possible, normally within 24 hours (12-15). This could be a telephone/video conferencing 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 paediatric physiotherapy setting as deemed clinically appropriate. The overall responsibility of physiotherapy management should remain with the specialist haemophilia physiotherapist with effective communication between professionals.

# STANDARD 3- Physiotherapy clinical management

Physiotherapists working with children with haemophilia and other inherited bleeding disorders should provide the highest standards of clinical care.

Clinical care should be consistent with the Code of Professional Values and Behaviour documented by the Chartered Society of Physiotherapy), and in line with the professional standards proficiency set out by the Health Care Professions Council (16-17).

Patient care and clinical management should be evidence based and informed by clinically suitable guidelines.  A suggested resource is Physiotherapy Management in Haemophilia (18).

Each physiotherapy episode of care should:

- *Include a thorough neuro-musculoskeletal assessment to review joint health & function, social well-being and participation.*

- *Show evidence of appropriate outcome measures used throughout the assessment, management and review process (5,14,18).*

- *Incorporate questioning specific to the bleeding disorder at hand-diagnosis and factor level, presence of inhibitor, treatment method, bleeding history, concordance with prescribed treatment.*

- *Undertake onwards referral to other specialties as appropriate such as radiology, rheumatology or orthopaedics when clinically appropriate.*

# STANDARD 4- Multidisciplinary review

As required in the National Service Specification and Quality Standards, all children with haemophilia and some other inherited bleeding disorders should be offered regular clinical multidisciplinary review (6-7). The review may be inclusive of annual or bi-annual reviews or for assessment and review of acute bleeding episodes secondary to trauma or injury. The physiotherapy review should form part of a seamless multidisciplinary review of the patient, with relevant information being shared amongst team members.

- *At minimum, children with severe/ moderate haemophilia should be reviewed by a physiotherapist 6 monthly & those with mild haemophilia annually where clinically required (6-7).*

- *Children with other inherited bleeding disorders will be reviewed as required*

- *Children with frequent bleeding episodes, coagulation factor inhibitors, or complications of bleeding episodes such as symptomatic arthropathies may require more frequent review (12-15).*

- *Review will include the use of standardised & validated clinical examination scores and assessment tools, e.g the Haemophilia Joint Health Score (HJHS) (19), which should be incorporated into the prospective assessment of children receiving prophylaxis (19-20).*

- *The use of validated functional and psychosocial outcome measures for children with haemophilia is endorsed as part of the regular review process when relevant (18), and should consider the domains of impairment, activity and participation and function acknowledged in the World Health Organisation (WHO) ICF framework (21-22).*

- *A record of bleeding events, time off school and activity participation should be noted (20).*

- *Those with a known history of intracranial haemorrhage should be monitored using appropriate standardised assessments to identify any sequelae, if problems are identified, these will be discussed within the multidisciplinary team to facilitate management or onward referral as appropriate (23).*

- *The review should involve identification and action (where necessary) on age-appropriate health related issues e.g development, obesity, bone health.*

- *Copies of the assessments, scores and physiotherapy recommendations should be shared within the multidisciplinary team, local therapy team and appropriate multiagency teams involved with the child and entered on required databases.*

# STANDARD 5- Education

Clear information should be provided related to how to manage all aspects of bleed risk, musculoskeletal health and well-being of the child. Information to the patient/carer and other relevant agencies should be provided based on the clinical assessment of the patient and most up to date evidence (7,17).

Education may include*:*

- *The role of physiotherapy within the comprehensive care team in the management of haemophilia and other inherited bleeding disorders*
- *Identification and management of acute intracranial and musculoskeletal bleeding episodes.*
- *Long term implications of the impact of haemophilia and other inherited bleeding disorders on the musculoskeletal system.*
- *The contribution of adequate joint and muscle health (strength, power, alignment, proprioception etc) alongside psychosocial wellbeing to best enable participation in physical activity and activities of daily living.*
- *Recognition of normal musculoskeletal variants and child development.*
- *Promoting the positive impact and role of physical activity, exercise and sport on a child's health and offer support in choosing activities (24-29)*
- *Educating the family on relevant aspects of being physically active including:*
- *-the benefits/risks of individual sports/activities*
- *-the importance of appropriate preparation*
- *-the appropriate use of recommended protective equipment*
- *Educating families regarding the negative impact of sedentary behaviour on a child's health and well-being (24-29)*

# STANDARD 6- Transition

The physiotherapist should assist in the seamless transfer of haemophilia care to the adult setting, with adult services taking joint responsibility with children's services for transition and be guided by national policy and paperwork (30).

This may include:

- *Planned attendance at joint clinic review with the adult team prior to transition to provide a complete and comprehensive handover of care.*
- *Providing relevant documentation with 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 given to the adult physiotherapy team.*

# 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. Haemophilia Chartered Physiotherapists Association Standards of Care 2017

5. Haemophilia Chartered Physiotherapists Association Standards of Care, 2020

6. NHS Service Specification for Haemophilia, 2013

7. Quality Standards – Care of people with inherited and acquired haemophilia and other bleeding disorders, UKHCDO 2018

8. Hanley J, McKernan A, Creagh MD, Classey S, McLaughlin P, Goddard N, Briggs PJ, Frostick S, Giangrande P, Wilde J, Thachil J, Chowdary P; Musculoskeletal Working Party of the UKHCDO. Guidelines for the management of acute joint bleeds and chronic synovitis in haemophilia: A United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) guideline. Haemophilia. 2017 Jul;23(4):511-520. doi: 10.1111/hae.13201. Epub 2017 Mar 30. PMID: 28370924.

9. Srivastava A, Santagostino E, Dougall A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. *Haemophilia*. 2020: 26(Suppl 6): 1-158. https://doi.org/10.1111/hae.14046

10. de Kleijn P, Duport G, Jansone K, et al. European principles of care for physiotherapy provision for persons with inherited bleeding disorders: Perspectives of physiotherapists and patients. *Haemophilia*. 2022; 28: 649655. https://doi.org/10.1111/hae.14566https://onlinelibrary.wiley.com/doi/full/10.1111/hae.14566

11. Service Provision of Physiotherapy for Adults with haemophilia & other inherited bleeding disorders

12. UK Standards of Care, May 2020

13. Stephensen D, Bladen M, McLaughlin P. Recent advances in musculoskeletal physiotherapy for haemophilia. Ther Adv Hematol. 2018 Jul 2;9(8):227-237. doi: 10.1177/2040620718784834. PMID: 30181843; PMCID: PMC6116756.

14. de Moerloose P, Fischer K, Lambert T, Windyga J, Batorova A, Lavigne-Lissalde G, Rocino A, Astermark J, Hermans C. Recommendations for assessment, monitoring and follow-up of patients with haemophilia. Haemophilia. 2012 May;18(3):319-25. doi: 10.1111/j.1365-2516.2011.02671.x. Epub 2011 Oct 13. PMID: 21992772.

15. Hermans C, De Moerloose P, Fischer K, Holstein K, Klamroth R, Lambert T, Lavigne-Lissalde G, Perez R, Richards M, Dolan G; European Haemophilia Therapy Standardisation Board. Management of acute haemarthrosis in haemophilia A without inhibitors: literature review, European survey and recommendations. Haemophilia. 2011 May;17(3):383-92. doi: 10.1111/j.1365-2516.2010.02449.x. Epub 2011 Feb 15. PMID: 21323794.

16. Sørensen B, Benson GM, Bladen M, Classey S, Keeling DM, McLaughlin P, Yee TT, Makris M. Management of muscle haematomas in patients with severe haemophilia in an evidence-poor world. Haemophilia. 2012 Jul;18(4):598-606. doi: 10.1111/j.1365-2516.2011.02720.x. Epub 2011 Dec 12. PMID: 22151135.

17. CSP Code of Members Professional Values and Behaviour 2020 https://www.csp.org.uk/publications/code-members-professional-values-behaviour

18. HCPC Standards of Proficiency September 2023 https://www.hcpc-uk.org/standards/standards-of-proficiency/

19. Physiotherapy Management in Haemophilia, Background and Practical guidelines. De Kleijn and Mauser-Bunschoten. Bayer Netherlands 2017

20. Hilliard et al. (2006) Haemophilia Joint Heath 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

21. 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

22. Clinical Outcome group, UKHCDO Annual Report 2011

23. WHO International classification of functioning, disability and health framework.

24. http://www.who.int/classifications/icf/en/

25. Bladen *et al*. (2009) Long-term consequences of intracranial haemorrhage in children with haemophilia. Haemophilia 15, 1 184-192

26. Overview | Physical activity for children and young people | Guidance | NICE

27. Physical activity guidelines for children (under 5 years) - NHS (www.nhs.uk)

28. Physical activity guidelines for children and young people - NHS (www.nhs.uk)

29. Physical activity (who.int)

30. Gomis M, Querol F, Gallach JE, González LM, Aznar JA. Exercise and sport in the treatment of haemophilic patients: a systematic review. Haemophilia. 2009 Jan;15(1):43-54. doi: 10.1111/j.1365-2516.2008.01867.x. Epub 2008 Aug 21. PMID: 18721151.

31. Strike K, Mulder K, Michael R. Exercise for haemophilia. Cochrane Database Syst Rev. 2016 Dec19;12(12):CD011180. doi: 10.1002/14651858.CD011180.pub2. PMID: 27992070; PMCID: PMC6463808.

32. Transition from Children's to adult's services for young people using health or social services care. Feb 2016 nice.org.uk/guidance/ng43

## Key individuals involved in the review of this document:

| Name | Designation | Date | Document Review Date: |
|---|---|---|---|
| Melanie Bladen | Clinical Specialist Physiotherapist in Haemophilia | 30/1/2024 | |
| Fionnuala Sayers | Clinical Specialist Physiotherapist in Haemophilia | 30/01/2024 | April 2029 version 5 |