

UK Standards of Care

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

Background

Standards were originally written by the Haemophilia Chartered Physiotherapists Association (HCPA) to assist physiotherapists with the management of patients with haemophilia & related bleeding disorders. They were first written in 1996 (1), reviewed and updated in 2002 (2) and again in 2012 (3). There is no uniform model for the provision of physiotherapy for children with haemophilia and this input currently varies between 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).

The Haemophilia Alliance National Service Specification recognises the importance of physiotherapy (5):

- *within the acute setting and the management of bleeds*
- *in ongoing monitoring joint health and function*
- *in helping improving joints and muscles on a long term basis*

The UKHCDO MSK guidelines go further in recognising the importance of physiotherapy (6):

- *in providing rehabilitation in the sub-acute phase to improve functional outcome*
- *in decreasing the risk of future recurrence of injury*

The World Federation of Haemophilia (WFH) guidelines for the management of haemophilia also support (7):

- *physiotherapy in the care and management of those with haemophilia from time of diagnosis, start of treatment and continuing through their lifespan*

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

STANDARD 1- Physiotherapy provision

- *Children should have access to a physiotherapist with specialist knowledge of haemophilia, paediatric musculoskeletal conditions, normal paediatric variants and child development (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 (4).*
- *The specialist physiotherapist should have dedicated/protected hours and flexibility within this to manage their haemophilia caseload/service.*

STANDARD 2- Referral and triage

Children 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 (9,10,11). This could be a telephone triage or face to face review.*

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 physiotherapist with effective communication between professionals.

STANDARD 3- Physiotherapy clinical management

Physiotherapists working with children 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 (12), and in line with the standards of conduct, performance and ethics, set out by the Health Care Professions Council (13).

Patient care and clinical management should be evidence based and informed by clinically suitable guidelines. A suggested resource is Physiotherapy Management in Haemophilia (14).

Each physiotherapy episode of care should:

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

STANDARD 4- Regular multidisciplinary review

As stated within the National Service Specification, all children with haemophilia should be offered a regular clinical multidisciplinary review (4).

- *At a minimum, patients with severe/ moderate haemophilia should be seen by a physiotherapist 6 monthly & those with mild haemophilia annually where clinically required (5).*
- *Children with frequent bleeding episodes, coagulation factor inhibitors, complications of bleeding episodes such as symptomatic arthropathies may require more frequent review (9,10,11).*
- *Patient review will include standardised & validated clinical examination scores such as the Haemophilia Joint Health Score (HJHS) (15), which should be incorporated into the prospective assessment of patients receiving prophylaxis (16,15,17).*
- *The use of validated functional and psychosocial outcome measures for children with haemophilia is endorsed as part of the regular review when relevant (17), considering the domains acknowledged in the World Health Organisation (WHO) ICF framework (18).*
- *A record of bleeding events, time off school and activity participation should also be noted (17).*
- *Those with a known history of intracranial haemorrhage should be monitored using appropriate standardised assessments to identify any sequale, if problems are identified, these will be discussed within the multidisciplinary team to facilitate management or onward referral as appropriate (21).*

The physiotherapy review should form part of a seamless multidisciplinary review of the patient, with relevant information being shared amongst team members.

- *Copies of the assessment 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 (6,14).

Education may include:

- *The role of physiotherapy within the medical team in the management of haemophilia.*
- *Identification and management of acute intracranial and musculoskeletal bleeding episodes.*
- *Long term implications of the impact of haemophilia on the musculoskeletal system.*
- *The importance of muscle power and proprioception in providing joint protection.*
- *Recognition of normal musculoskeletal variants and child development.*
- *Promoting the positive role of physical activity and sport on a child's health and offer support in choosing activities (19).*

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 (20).

This will 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

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7. Srivastava et al. WFH Guidelines for the management of haemophilia, Haemophilia 2013, Jan; 19(1):e1-47
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13. HCPC standards of conduct, performance and ethics, 2016
14. Physiotherapy Management in Haemophilia, Background and Practical guidelines Bayer Netherlands (online source of PDF)
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www.ipsg.ca to register and access the training tools and assessment paperwork for the Haemophilia Joint Health Score 2.1
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17. Clinical Outcome group, UKHCDO Annual Report 2011

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19. Gomis et al. Exercise and sport in the treatment of haemophilic patients: a systematic review. *Haemophilia* 2009, 15, 43-54
20. Transition from Children's to adult's services for young people using health or social services care. Feb 2016 nice.org.uk/guidance/ng43
21. Bladen et al. (2009) Long-term consequences of intracranial haemorrhage in children with haemophilia. *Haemophilia* 15, 1 184-192

Compendium of Assessment Tools can be found on World Federation of Haemophilia Website www.wfh.org and from the left hand menu, Publications/Videos then Assessment tools.