UK Standards of Care

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

Haemophilia Chartered Physiotherapists Association (HCPA)
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Approved by HCPA: May 2017 *To be reviewed: May 2019*

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 adults 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 adults with haemophilia, and to compliment the Service Provision of Physiotherapy for Children with Haemophilia & other Inherited Bleeding Disorders - UK Standards of Care (8).

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 (4).*

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

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 (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 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 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 (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 used 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 adults with haemophilia should be offered a regular clinical multidisciplinary review (4).

- *At a minimum, patients with a symptomatic diagnosis of haemophilia or on prophylaxis should be seen by a physiotherapist at least annually (5).*

- *Adults with frequent bleeding episodes, coagulation factor inhibitors, complications of bleeding episodes such as symptomatic arthropathies will 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 adults 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, functional difficulties and time off work should also be noted (17).*

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 adult and entered on required databases.*

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 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 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 issues related to the aging process.*
- *Promoting the positive role of physical activity, exercise and sport and offer support in choosing activities (19).*

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 (20).

This will 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.*

References

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4. NHS Service Specification for Haemophilia, 2013

5. The Haemophilia Alliance (2006) A National Service Specification for Haemophilia and Other Inherited Bleeding Disorders

6. 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 2013, Jan; 19(1):e1-47

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12. Quality Assurance Standards for Physiotherapy Service Delivery, The Chartered Society of Physiotherapy, 2012

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

16. 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

17. Clinical Outcome group, UKHCDO Annual Report 2011

18. WHO International classification of functioning, disability and health framework. http://www.who.int/classifications/icf/en/

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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

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.