HCPA

Haemophilia
Chartered
Physiotherapist
Association

UK Standards of Care

Service Provision of Physiotherapy For Adults with Haemophilia & other Inherited and Acquired 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 is important to publish standards of care as there remains no uniform model for the provision of physiotherapy for adults with haemophilia, with levels of provision currently varying between haemophilia centres.

The NHSE Service Specification for Haemophilia requires services to 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 World Federation of Haemophilia (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 (7).

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 biopsychosocially 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 people with haemophilia and other inherited and acquired bleeding disorders.*
- To support and work with people to live as full a life as possible and support healthy aging using person centred approaches. This would include minimising condition impacts whilst optimising health and social outcomes.

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

STANDARD 1- Physiotherapy Provision

Adults should have access to a physiotherapist with specialist knowledge of haemostasis, haemophilia and musculoskeletal conditions (6).

- *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 (6).*

- *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

Adults 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 videoconferencing triage and advice.

- ***Acute condition referral****- a patient should be reviewed as soon as is clinically possible, normally within 24 hours (12-15). This could be a telephone/video triage or face to face review as an outpatient or inpatient.*
  It is acknowledged that when a referral occurs over 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 haemophilia physiotherapist with effective communication between professionals.

STANDARD 3 - Physiotherapy Clinical Management

Physiotherapists working with adults 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. Examples include but are not limited to Physiotherapy Management in Haemophilia (18), National Institute for Health and Care Excellence (NICE) Guidance for Management of Chronic Primary and Secondary Pain (19), NICE Guidelines for Joint Replacement (20)

Each physiotherapy episode of care should:

- *Include a thorough neuro-musculoskeletal assessment to review joint health & function, social wellbeing, and participation.*
- *Show evidence of appropriate outcome measures used throughout the assessment, management, and review process (12-15).*
- *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, Frailty Clinics, Pain Management, Care of the Elderly, or Orthopaedics when clinically appropriate.*

STANDARD 4 - Multidisciplinary Review

As required in the National Service Specification, all adults with haemophilia and some other inherited bleeding disorders should be offered regular clinical multidisciplinary review including Physiotherapy (6-7). The physiotherapy review may be inclusive of annual or bi-annual reviews, or, for assessment and review of acute bleeding episodes secondary to trauma, injury or chronic conditions. 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, people with a symptomatic diagnosis of haemophilia or on prophylaxis should be reviewed by a physiotherapist at least twice yearly (6-7)*

- *Adults with frequent bleeding episodes, coagulation factor inhibitors, complications of bleeding episodes such as symptomatic arthropathies may require more frequent review (13-15).*

- *Adults with non-severe haemophilia and other bleeding disorders should have equitable access to physiotherapy as and when this is needed. This may range from ad hoc reviews of musculoskeletal bleeding to longer term engagement with physiotherapy if chronic musculoskeletal complications are associated with their bleeding disorder.*

- *Review will include the use of standardised, validated clinical examination scores and assessment tools, e.g., the Haemophilia Joint Health Score (HJHS) (21), which should be incorporated into the prospective assessment of people receiving prophylaxis (21-23).*

- *The use of validated functional and psychosocial outcome measures for adults with haemophilia is endorsed as part of the regular review when relevant (21), and should consider the domains of impairment, activity, participation and function as acknowledged in the World Health Organisation (WHO) ICF framework (24).*

- *A record of bleeding events, functional difficulties and time off education/ work should also be noted (23).*

- *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.*

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 person and the most up to date evidence (8,15).

Education may include:

- *The role of physiotherapy within the comprehensive care team in the management of haemophilia and other inherited and acquired bleeding disorders.*
- *Identification and management of acute 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) alongside psychosocial well-being to best enable participation in physical activity and activities of daily living.*
- *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 (25-26).*

STANDARD 6 - Transition

The physiotherapist should assist in the seamless transfer of bleeding disorders care from the paediatric setting, with adult services taking joint responsibility with paediatric services for transition and be guided by national policy and paperwork (27).

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.*

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