

## Access to Standards of Care for physiotherapy management of Spinal Muscular Atrophy in the UK

A Consensus document on SMA Standards of Care (SoC) was published in 2007 (1) and updated in 2017 (2,3). The aim of these publications was to benchmark diagnosis and management of SMA and they were based on the available evidence for diagnosis and interventions (4–10) but also to provide expert based recommendations and a consensus statement where new advances in care were not reflected in the existing literature.

According to the Standards of Care in SMA, all people with SMA should have access to a Specialist Neuromuscular Centre, where they should be seen for assessment and advice on physical management by trained examiners every 6 months. This includes recommendation and/or prescription of orthoses if required, advice on appropriate equipment, a physiotherapy programme including stretching, exercises, and activities liaison with community services.

Alongside the management stated above, it is vital individuals with SMA have access to a specialised respiratory team for on-going respiratory monitoring and management. This is an integral part of a multidisciplinary team approach. When clinically indicated, people with SMA should have individualised care plans which will involve a range of specific treatments, ranging from emergency care to secretion management based on individual need. This should be supported by the local hospitals and community teams.

Advice and recommendations are specific to each person and based on their individual assessment, using standardised assessments for range of movement, muscle strength, function, and posture which have been validated by the therapists and for which the therapists have received specific training. The advice should be age appropriate. It must be recognised that everyone is different, both regarding their starting point and in their progression, and the involvement of experienced professionals will ensure that these recommendations are tailored to each individual's needs. Comparison with peers and following recommendations from social media may not be appropriate and in some situations, could potentially be harmful.

Some families or individuals may choose to have additional private physiotherapy, which is their choice. It is important to check that the physiotherapist is state-registered (HCPC), but also genuinely experienced in the management of SMA. The Chartered Society of Physiotherapy (CSP) holds a list of private practitioners.

Despite the significant time since the publication of the standards of care, it is common knowledge within the community that its implementation has not been well established across the UK, and this has recently been reported (11). Significant differences were highlighted comparing access to different professionals for children and adults with SMA as well as limited access to orthoses, positioning equipment, and exercise.

As professionals we recognise these limitations, particularly in the light of the new disease-modifying treatments, and the consequent pressure on many services to optimise care provision. We also acknowledge the need of updating the current guidelines to adapt to the

current therapeutic scene. Our aim is to work collaboratively to increase awareness and ensure implementation of standards of care for people living with SMA in the UK.

The coordination between specialised centres and community services is important for an optimal outcome of management, but this requires training and increased awareness of this condition.

**As networks, we would like to provide reassurance that people living with SMA in the UK have access to specialist professionals that are competent within their fields of expertise. Our links to, and involvement with national and international networks and specialist working groups, and opportunities to engage in regular national meetings and collaborative workshops and training, aim to ensure that best practice of treatment and management for people with SMA in a rapidly changing landscape is shared. We will continue to provide support to professionals if and where individualised advice is required. Please do contact your reference team for specific advice, here are the list of reference centres in the UK:**

<https://smareachuk.org/>

**Paediatric centres:**

Addenbrooke's Hospital, Cambridge University Hospitals NHS Foundation Trust

Alder Hey Children's NHS Foundation Trust, Liverpool

Birmingham Children Hospital, Birmingham Women's and Children's NHS Foundation Trust

Bristol Royal Hospital for Children, University Hospitals Bristol NHS Foundation Trust

Evelina London Children's hospital, Guy's and St Thomas' NHS foundation Trust

Great Ormond Street Hospital for Children NHS Foundation Trust

Leeds Children Hospital, The Leeds Teaching Hospitals NHS Trust

Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust

Oxford Children's Hospital, Oxford University Hospitals NHS Foundation Trust

The Newcastle upon Tyne Hospitals NHS Foundation

The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust

Royal Aberdeen Children's Hospital, NHS Grampian

Royal Hospital for Children, NHS Greater Glasgow and Clyde

Royal Manchester Children's Hospital, Manchester University NHS foundation Trust

Royal Preston Hospital, Lancashire Teaching Hospitals NHS Foundation Trust

Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust

[Our Network – Adult SMA Reach](#)

**Adult centres:**

Cambridge University Hospitals NHS Foundation Trust

Cardiff and Vale University Health Board

NHS Greater Glasgow and Clyde

Guy's and St Thomas' NHS Foundation Trust

King's College Hospital NHS Foundation Trust

Leeds Teaching Hospitals NHS Trust

The Newcastle upon Tyne Hospitals NHS Foundation Trust

The Northern Care Alliance Foundation Trust

Nottingham University Hospitals Trust

North Bristol NHS Trust

Oxford University Hospitals Trust

The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust

South Eastern Health and Social Care Trust

Swansea Bay Local University Local Health Board

St George's University NHS Foundation Trust

Sheffield Teaching Hospitals NHS Foundation Trust

Univeristy Hospitals Birmingham HNS Foundation Trust

University Hospital Southampton NHS Foundation Trust

University College London Hospitals NHS Foundation Trust

The Walton Centre NHS Foundation Trus

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