

Charter of Care for Children and Young People with Lymphoedema

This Charter has been developed by the Children's Lymphoedema Special Interest Group (CLSIG), a group comprised of health care professionals directly involved in the provision of care for children with lymphoedema and their families. The Charter represents the minimum requirements that a child or young person with lymphoedema should have access to. The aim is to inform clinicians, commissioners and lymphoedema services of what a child, young person and their family should expect when lymphoedema is suspected or diagnosed. It offers direction to the co-ordination of care and support with the school and community services. This will enable the child or young person to receive thorough investigation and diagnosis as early as possible, optimal care provided at high quality and in accordance with best practice (safe, effective, and caring),^{13,17} and that this care is provided close to home (right care, right time, and right place)¹⁷.

As is stated in BLS (2013) Standards of lymphoedema care¹, "lymphoedema arises when the lymphatic system inadequately fulfils its function of regulating fluid balance in tissue spaces. This results in oedema or swelling, which may occur anywhere in the body, but most commonly affects the limbs. It also causes changes in the skin and body tissues, which do not occur in other chronic oedemas" (pg 1). Where the lymphatics of the small intestine are involved, metabolism may be affected and lymph or chyle reflux may occur. Some genetic and syndromic causes of lymphoedema have been identified.

Lymphoedema treatment for children and young people follows the same principles as that for adults, but planning and provision is adapted in consideration of the maturing lymphatic system, growth and development of the child or young person, the acceptability of the treatment to the child or young person and the family unit, and the psychosocial impact of lymphoedema for the child or young person.

The *United Nations Convention on the Rights of the Child*¹⁹ states that all children have 'the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health'. This Charter provides guidance on how this can be achieved for children and young people with suspected or previously diagnosed lymphoedema.

The Charter focusses on several themes

Diagnosis and Treatment addresses the pathway to diagnosis and the requirements of the lymphoedema treatment service for specialist care suitable for the physical and psychological needs of a child or young person

Communication, Involvement and Collaboration addresses the need for close medical and social multiagency care with direct involvement of the child, young person and their parent/guardian

Environment recognises the need for appropriate environment of the lymphoedema service

School Nurse – Transition addresses the collaboration and support required for the child and school once they reach school age and as the young person then progresses through it

Transition to Adulthood recognises the need to support the transition from child to adult services

Evaluation recognises the need for continued service improvement through comment and evaluation

Support recognises the child, young person, and parent/guardian's need for support and where this can be sought

The Charter

Diagnosis and Treatment

- 1) Once other causes of swelling have been excluded and lymphoedema is suspected, the child or young person should be referred to a Lymphoedema service. To ensure correct investigations are conducted for the establishment of the correct diagnosis, the lymphoedema service must be able to follow the CLSIG Childhood Lymphoedema Diagnostic and Assessment pathways and the St Georges paediatric Investigation Tool for patients with primary lymphoedema, which is to be followed alongside the Classification and Diagnostic Algorithm for Primary Lymphatic Dysplasia^{3,4}. These three documents are in constant progression, the latest versions are available on the LSN and BLS websites; <http://www.lymphoedema.org/> and <http://www.thebls.com/the-bls/>.
If the pathways, tool and algorithm cannot be followed locally, then the child or young adult needs to be referred to a Specialist Lymphoedema Centre for formal assessment and diagnosis. Currently there are two main Specialist Centres, St Georges University NHS Trust in London and the Royal Derby Hospital in Derbyshire. These services can also provide treatment, but if the child or young person lives distant from these centres then referral for lymphoedema treatment will also need to be made. The service needs to offer specialist lymphoedema treatment and should be accessible and within reasonable proximity to the child or young person⁷ (see point 3). If referral to one of the specialist lymphoedema centres, for diagnosis and investigation, is not agreed locally the child can be referred to their local genetics department instead; a list of UK Genetics Services can be found on <http://www.geneticalliance.org.uk/services.htm>, subsequent referral to a local lymphoedema service for provision of treatment will be required
- 2) Information regarding lymphoedema services can be sought through the local Clinical Commissioning Group (CCG), the British Lymphology Society directory <http://www.thebls.com/directory/index.php>, or the Lymphoedema Support network <http://www.lymphoedema.org> ph: 0207 351 4480. Additionally, the LSN and BLS websites contain the CLSIG Register of Paediatric Clinics in the UK, which is a directory of lymphoedema services providing treatment of children and young people with lymphoedema.
- 3) The lymphoedema service should provide specialist assessment conducted by a Health Care Professional who is an experienced lymphoedema practitioner with a specialist lymphoedema qualification. The service must provide co-ordinated multi-agency care for investigations or medical treatment associated with the lymphoedema if required¹²
- 4) All health care professionals involved with a child or young person with lymphoedema must have completed Level 3 Child Safeguarding Training with consideration to additional training regarding consent, parental responsibility, Fraser Guidelines, confidentiality and, if providing treatment for children with communication or learning difficulties, communication skills training. Health care professionals who are experienced lymphoedema practitioners need not have a specific Paediatric professional qualification but must work within the limits of their knowledge, skills and competence. It is recommended that regular contact is maintained with a local Paediatric Nurse Consultant to be kept informed of changes to paediatric legislation, local policy and practice. Legislation changes will be specific to each country in the UK (Wales, Scotland, England and Northern Ireland). Furthermore, involvement of a Senior Children's Nurse who can be contacted on a day to day basis is advised
- 5) The lymphoedema service should work to high standards, providing evidenced-based or consensual treatment (where evidence-base has not been established) and packages of care^{1,13}. Several resources and documents are suggested in Appendix 1
- 6) Lymphoedema treatment should include access to regular specialist lymphoedema assessment and review

- 7) Children can be seen in an Adult Lymphoedema service that has provision for children. The service should offer the child or young person and their families an opportunity to meet others with lymphoedema and should provide access to other services such as paediatrics, genetics and play therapists²⁰. The delivery of treatment should be conducted in a setting that meets their physical and psychological needs and the environment should be conducive to their developmental stage of learning and comprehension²⁰

Communication, Involvement and Collaboration

- 8) Where a genetic cause is suspected, the child or young person should have access to genetic counselling
- 9) The child or young person and their parents/guardians must be involved when planning and providing treatment and care, their views must govern decision making^{7,18,15}
- 10) The child and young person must be consulted and be part of decision making about their treatment options. This must be discussed in an age appropriate manner and considerate of their ability to understand and comprehend^{15,18,9}
- 11) The child and young person should be able to discuss their concerns privately if they wish^{18,9}. Involvement and collaboration with psychological support or counselling may be required.
- 12) Good communication and collaboration must be maintained between the lymphoedema service, GP, health care professionals, the school, community agencies, parents/guardians and the child or young person^{18,9}
- 13) Consideration must be made to minimise disruption to schooling when planning courses of treatment and clinic appointments^{20,9}
- 14) Consideration must be made with regards to family life, family commitments and family economics when planning courses of treatment and clinic appointments so that the child or young person can attend the appointments^{10,17,18}
- 15) Information regarding sources of financial support should be provided if necessary

Environment

- 16) The environment of the lymphoedema service should be suitable for children and young people in accordance with the national guidelines for Children's services. Ideally it should be facilitated by a practitioner who is knowledgeable about child development and the framework of national child-related policies⁹

Transitions – early learning, childcare, pre-school and school

- 17) Where lymphoedema has been present from birth or infancy, collaboration with the lymphoedema service, health visitor and nursery, or other providers involved in the care of the child, may be required so the needs of the child can be supported by their care agents.
- 18) When the child reaches school age, the lymphoedema service should be involved in the transition between the Health Visitor and School Nurse to ensure the health and support needs of the child are maintained. If required, this should occur in collaboration with relevant local authorities' Specialist Paediatric Community Nurse⁸
- 19) During school years the School Nurse should be closely involved with the wider supportive team involved with the child in order that lymphoedema and its treatment is understood by the school and the teachers, and that the needs of the child or young person can be supported⁷

- 20) Involvement of the School Nurse is necessary to help prevent and reduce avoidable school absence due to their lymphoedema, and support the child or young person if school absence is necessary^{10,11}
- 21) Involvement of the School Nurse is critical when the child approaches transition from primary to secondary school in order to ensure care pathways are maintained, provide staff training and ensure continuation of collaboration between health and education agencies^{10,11}

Transition to adulthood

- 22) When the young person approaches adulthood discussion of their care and treatment must take place with the young person and the wider health and social agencies involved, particularly regarding any changes to their ongoing health needs and provision of their health care. Referral should be made to adult services for continuation of care⁹

Evaluation

- 23) The child, young person, parent/guardian and associated services should have the opportunity to comment or evaluate on the service, treatment and care, to allow for continued service improvement⁹

Support

- 24) The child and parents/guardians should be advised of lymphoedema support fora¹⁷, such as:
Lymphoedema Support Network,
St Luke's Crypt, Sydney Street, London, SW3 6NH.
Ph 020 7351 0990. www.lymphoedema.org
Free for children and young people to join

This Charter, written by the Children's Lymphoedema Special Interest Group, is not intended to provide all the details required for the assessment, diagnosis and care of a child or young person with lymphoedema, but rather provides a guide to the minimum requirements expected.

The Charter is available from the Lymphoedema Support Network website <http://www.lymphoedema.org/> and the British Lymphology Society website <http://www.thebls.com/the-bls/>

Contact for the Children's Lymphoedema Special Interest Group (CLSIG) can be made via the lymphoedema support network or British Lymphology Society

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Appendix 1

Suggested resources describing evidenced-based or consensual treatment, packages of care and considerations when treating children and young people with lymphoedema.

Some documents listed, regarding lymphoedema treatment, are not specifically written for the management of children and young people but an experienced lymphoedema practitioner will adapt the treatment for the child or young person:

- **CREST Guidelines**
Clinical Resource Efficiency Support Team(2008). Guidelines for the diagnosis, assessment and management of Lymphoedema; available from: <http://www.gain-ni.org/index.php/audits/guidelines>
 - **International Lymphoedema Framework (ILF):**
Care of Children with Lymphoedema, (ILF 2010); available from: www.lympho.org
Best Practice for the Management of Lymphoedema. International Consensus. London: MEP Ltd, 2006; available from www.lympho.org
 - **The British Lymphology Society** is focused on increasing education and knowledge of lymphology and improving the provision of services and management of chronic oedema and lymphoedema. Website: <http://www.thebls.com/>
 - **A number of documents are available from the UK Department of Health, concerning children and young people with particular needs in specific settings and with long term conditions.**
 - Department of Health (2004). Getting the right start. The National service framework for children, young people and Maternity services. Hospital Standard DH London
 - Department of Health (2004). National Service Framework for Children, Young People and Maternity Services: Children and Young People who are Ill
 - Department of Health (2004). National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health NeedsThese 3 documents are available on the following link:
<https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services>
 - Department of Health (2005) The National Service Framework for Long-term Conditions; available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pdf
 - NHS England (2016) NHS Outcomes Framework: Domain 2 – Enhancing Quality of Life for People with Long Term Conditions <https://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/>
- **Strategy for Children and Young People’s Health:**
 - Department of Health, Department for children, schools & families (2009). Healthier lives, brighter futures: The Strategy for children and young people’s health. DCSF, London; available from http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_094400
Or <http://www.chimat.org.uk/%5Cdefault.aspx?QN=CHMCHS>
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