

LYMPHOEDEMA SERVICES FOR CHILDREN AND YOUNG PEOPLE

Jacquelyne Todd

Lymphoedema can have a profound effect on children's development during their formative years. The implications of having a young child or teenager with lymphoedema can also have a major impact on family life. This paper examines the requirements that have been set out in national guidance for the treatment of childhood lymphoedema and how they can be integrated into the provision of children's services. The author proposes that children's services are offered through a network of regional centres sharing the same standards in terms of access to professionals and child-centred facilities.

Key words

Childhood lymphoedema
Children's services
National guidance
Standardised care

Recent evidence-based clinical guidelines have had a national and world-wide impact on lymphoedema treatment (International Society of Lymphology [ISL], 2003; Lymphoedema Framework, 2006; Clinical Resource Efficiency Support Team [CREST], 2008). They have helped to promote clinical excellence and standardise high quality services. While the clinical guidelines are relevant to all people with lymphoedema, irrespective of age, children and young people with lymphoedema have additional needs, as defined in recent UK Department of Health (DH) guidance on the provision of children's services (DH, 2003, 2004; Department for Children, Schools and Families [DCSF], 2009).

Dedicated services for children with lymphoedema are rare both nationally and internationally, with no clear standards or guidelines for the provision of such services. Lymphoedema is likely to have a profound effect on the child's development during important, formative years as they grow into young adults. The implications of having a young child or teenager with lymphoedema can have a major impact on family life and is likely to place an additional burden on parents or carers, as they take on the responsibility of incorporating a treatment routine into daily life. Children's services in England are expected to conform with national guidelines (DH, 2003, 2004; DCSF, 2009). This means that there is an explicit focus on the needs of the child, not just their illness. In line with the NHS Plan (DH, 2000), lymphoedema services for children and young people will be expected to address the spectrum of needs that arise from their condition.

This paper will summarise the requirements set out in national guidance and discuss how they can be integrated into the standardised provision of children's services. This approach is used to provide a framework for the delivery of children's lymphoedema services.

The Change for Children programme (DH, 2003) sets out a vision

of the outcomes to be achieved. Each child is to be supported to:

- » Be healthy
- » Stay safe
- » Enjoy and achieve
- » Make a positive contribution
- » Achieve economic well-being.

The proposed framework for lymphoedema treatment services will dovetail into these overarching outcomes.

Standards for the delivery of children's services

There are recurring central principles underpinning national standards set out in the DH guidance National Service Framework for Children, Young People and Maternity Services *Getting the right start: National Service Framework for Children, Standard for Hospital Services* (2004) [hereafter described as the NSF]. These are summarised in Table 1.

The treatment of childhood lymphoedema is based on the same clinical standards as defined in existing guidance (ISL, 2003; Lymphoedema Framework, 2006; CREST, 2008). Principles for assessment and treatment are adapted from approaches used in the management of adults (Mansour and Sharland, 2000). An overarching difference is the context of care, with treatment complying with the more broad-reaching standards for the delivery of children's services.

Jacquelyne Todd is a Physiotherapist Consultant in Lymphoedema, Lymphoedema Department, Leeds Teaching Hospitals NHS Trust

Table 1

Central principles outlines in the National Service Framework for Children, Young People and Maternity Services (2004)

Description	NSF Standard number
Coordinated multi-agency care	1
Empowering children and young people to take responsibility for their actions and make informed choices about their health	1
Provision of support, education and information	2 and 3
Accessible services that are responsive to the needs of children and families	3 and 4
Staff share a common core of skills, knowledge and competencies	3
Services are age-appropriate and address needs associated with the condition in other aspects of life	4
Adherence to policies and guidelines on consent and confidentiality	3 and 4
Child and young peoples' protection is everyone's responsibility	5
Access to high quality treatment that addresses all aspects of the child's welfare	6
Care delivered within a framework of clinical governance	7
Care delivered in appropriate settings	7
Children with disabilities, complex health needs or mental health problems are provided with care from a family-centred service that comprehensively addresses their needs	8 and 9
Decisions regarding the use of medicines are based on the best available evidence and careful analysis of potential risk and benefit	10

Setting the scene: key issues underpinning children's services

Who is the service for?

There is very little evidence about the number of children affected with this condition, however, it is considered to be rare in childhood and adolescence (Mansour and Sharland, 2000). The majority of referrals are for children with primary lymphoedema which occurs in approximately one in 100,000 persons aged less than 20 years (Smeltzer et al, 1985). The congenital nature of primary lymphoedema means that some children will be referred for treatment from birth, with

late onset cases presenting at puberty or late childhood. Within this spectrum of age ranges, there are varying levels of needs in terms of multidisciplinary input, with an underlying and fundamental requirement to support and inform parents and carers. Within our own service, children attend one of two groups; 'Little stars' (babies, toddlers, young children) and 'Comets' (older children and teenagers). Transition into the older group is mainly determined by the emotional maturity of the child, rather than simply depending on the age of the child.

Another key question is up to what age do children's services apply? In the NSF Hospital Services (DH, 2004), children and young people are defined as under 19 years. However, there is an acknowledgement that age ranges will vary according to the different agencies statutory obligations. As lymphoedema services are small, cohesive units, the transition into adult services is usually straightforward as the same therapist, or team of therapists, will continue to provide their care.

Some approaches that may facilitate the young person's transition to being treated as an adult include the following strategies:

- ▶ The same clinician continues to take the lead role in care provision for the individual
- ▶ Clinics are available specifically for the use of young adults (19–25 years). This strategy provides the opportunity for social interaction, education and information-giving between the individuals attending the clinic. It reduces the feeling of isolation that many young people experience because they do not know anyone else with the same condition.

Roles and responsibilities

In contrast to the guidance around the delivery of adult services, there is little existing information on a healthcare model to address the needs of children and young people with lymphoedema.

It is likely that only one or two lymphoedema practitioners in each clinic will take responsibility for this part of the service. There is a strong argument that treatment is provided by advanced and consultant practitioners (Career Frameworks levels 7 and 8) (Skills for Health, 2005). Specialists at this level will have the experience and clinical skills to address the potential complexity of physical, functional and psychosocial needs of both the child and their family, as well as to coordinate care and communicate with different agencies such as the child's school (Sneddon, 2007). In addition to their treatment-specific expertise, practitioners will need a broader set

of skills, knowledge and competencies around the provision of child-centred services (standard 3). This will involve specific training in child protection and safeguarding children's welfare, including procedures that have been established by the local safeguarding children board (LSCB) (standards 5, 6, 7). Local trusts will have their own local protocols which are likely to include the following:

- » Extended police check
- » Training in child protection
- » Training in basic life support.

Multidisciplinary approach to child-centred services

A team-based approach is needed to address the needs of the child, both from a clinical and psychological perspective. Such an approach may prevent some of the difficulties that families have described in terms of limited information and support (Todd et al, 2002; Murray and Moffatt, 2009). From a clinical perspective, joint clinical sessions with a paediatrician and geneticist provide the necessary medical expertise. Although our understanding of genetic abnormalities is, as yet, incomplete — a geneticist plays an important role in identifying inherited forms of lymphoedema and counselling families regarding what to expect as their child grows. They will also discuss the relative probability of passing on a genetic abnormality to future generations.

A paediatrician with a special interest in lymphoedema will be able to assess and offer medical advice with specific reference to the problems associated with lymphoedema, such as cellulitis or syndromes with a lymphoedema component, such as Turner's or Klippel-Trenauney Webber syndrome. In certain situations he/she may refer children on for a further surgical or dermatological opinion. Additional sessions may be needed when the family can see other professionals such as a clinical psychologist or dietitian for specific support and advice.

Referrals are made to the surgical appliance department for footwear. Practitioners often need to make a special case for an ample supply of shoes and boots as children grow out of

shoes quickly and need alternative pairs for school use. One way of coordinating the input of a number of professionals attending clinics is to plan the clinic diary well in advance, so that clinics involving other members of the multidisciplinary team can be organised in advance. In addition to designated clinical sessions, another crucially important member of the team is a play therapist. This role will be discussed in the following section.

Child-centred facilities

Children require special facilities for treatment, in which they feel happy, safe and secure. Lymphoedema services will be expected to comply with both national guidelines and local protocols which will determine where and how treatment for children can be provided. Certain measures need to be put in place to safeguard children and ensure their protection. For example, when the service is delivered as an out-patient service, practitioners treat the child only in the presence of a parent or responsible caring adult.

The provision of a child-orientated clinical environment can be planned in a number of ways, including:

- » Arranging to use the space and resources of an existing children's unit for specific lymphoedema sessions if there is no suitable space within the department
- » If there is adequate space available within the department, a separate waiting area and treatment room is set aside for children and families. Baby changing facilities, toys and suitable printed information should be available for these sessions
- » Planning special sessions exclusively for the treatment of children and young children, during which sessions, appropriate facilities and resources are made available.

The provision of such an environment opens up opportunities to support the family as well as the child. The child and other siblings can be occupied in an activity with the play specialist while the parents can talk to a professional without concern about the child hearing or distracting their conversation. There is a perceived unmet

parental need for information and advice from professionals with an unacceptable delay in being referred for treatment (Murray and Moffatt, 2009). This may mean that parents have a number of concerns and queries by the time they attend clinic and require dedicated time to discuss these issues.

In terms of providing a suitable environment — the sort of toys, books and resources will vary according to the age of the child and therefore a wide selection is needed. Play is an essential part of services provided for children when they visit the service, irrespective of where they are seen (standard 7). Computer and electronic games are useful resources for teenagers and older children. Trusts will have a toy policy that offers guidance on the sort of toys and resources that should be made available to children attending treatment. In essence, toys and play materials should offer enjoyable and safe play and not expose the child to potential harm or the risk of acquiring infections.

Lymphoedema can be an isolating condition to many children and young people. Despite striving to lead a normal life, they are likely to be the only one with this problem in their school or social network. Attendance at the clinic provides an opportunity for children and families to meet and share experiences. It may be possible to coordinate group activities in which children and their families can interact. A play specialist has the requisite skills and knowledge to facilitate play and enhance the clinical services (Walker, 2006; Murray and Moffatt, 2009). Play minimises the negative reactions that are generated by the unfamiliar hospital setting. The extended team involved in the care of the child is outlined in Table 2.

Children are likely to make up a small proportion of the total clinical caseload and in many clinics it will not be possible to offer the clinical support described in this paper. Furthermore, it is not easy to offer opportunities for children and families to meet if there are only one or two children on the caseload. One way to address

Table 2
Extended team involved in the child’s lymphoedema care

Core team working within the department	Others involved in care	Sources of external support
Lymphoedema therapist/nurse	Dermatologist	Patient support group (Lymphoedema Support Network [LSN])
Paediatrician	Physiotherapist	
Geneticist Clinical psychologist	Occupational therapist Surgical fitter (footwear)	Hosiery company (advice on compression garments)
Play specialist	Dietitian	
	Surgeon	

these problems is the development of regional children’s units for lymphoedema services. Such a network would be able to offer standardised high quality care to a larger number of children, thus offering more opportunity for social networking.

Communicating with children, parents and professionals

In some cases, children will be referred back to a local service for ongoing care. If this is planned, it is important to ensure that the family feel confident about the ongoing daily management programme and that they have the contact details of the professionals who are taking on their future care. In our clinic, families have a choice to receive a copy of letters sent on to other professionals and this means that they are aware of all the information and contacts. Email communication between appointments has proved popular with parents and also teenagers, as it offers them a quick and effective method of seeking advice.

Another strategy which helps in improving communication and awareness is to provide child-specific information. This is some indication that parents are not aware of what treatment and services their child is entitled to, such as hosiery and footwear (Murray and Moffatt, 2009). We provide individualised books for each child that

provide guidance on treatment such as skin care, modified manual lymphatic drainage (MLD) and bandaging techniques. There is a growing resource of web-based material that has been produced for children and teenagers.

An annual newsletter is produced by the author’s service for teenagers with features on fashion and aspects of self management. This is available to read on the following website (www.lymphoedemaleeds.co.uk).

A new initiative is the development of an activity book on lymphoedema. This is designed to be fun to use, offering the child an opportunity to express themselves through their creative skills. The book introduces topics associated with lymphoedema in a non-threatening way and there is space for recording key aspects of progress and treatment such as weight, height and a list of compression garments supplied, together with the date.

Common Assessment Framework (CAF) for children and young people

In most cases, children attending clinic have no identified needs other than the problems associated with their lymphoedema. Some children may have additional needs and require targeted support from other services because of their risk of a poor outcome. Some examples of cases of additional need

are outlined in Table 3. In these cases, targeted support may be required that extends beyond the remit of the single practitioner.

The CAF provides a standardised approach of conducting an assessment of a child’s additional needs. It facilitates information sharing between professionals and enables the identification of a lead professional to coordinate the care of a child if this is required. There are a small number of children with complex additional needs, which meet the threshold for statutory involvement (Table 4).

Comprehensive details on the CAF can be accessed in the document *Common Assessment Framework for children and young people: practitioners’ guide* (Children’s Workforce Development Council, 2007) (www.cwdcouncil.org.uk). This document provides guidance on when a CAF should be carried out. It is unlikely that lymphoedema practitioners will be qualified to undertake the assessment themselves, but they should know who is available within their agency and how they can be accessed.

Information for children, young people and their families

Lymphoedema-specific information

Standards 2 and 3 of the NSF Hospital Services refer to the provision of information for children and their families. In relation to lymphoedema service delivery, there are two perspectives to the provision of information.

Firstly, there is a need for information on lymphoedema and its treatment which will address a number of requirements. As well as information for the family, the child will benefit from literature that explains the condition and its treatment at the appropriate level. Furthermore, the family may request specific information to share with other agencies, such as the child’s school or care providers. Although child and family-specific literature on lymphoedema is quite rare, there are a number of resources that may be made available, including:

- » Child and teenager factsheets available from the LSN (www.lymphoedema.org/lsn/)
- » There are small sections on the treatment of lymphoedema in children in some publications aimed at people with lymphoedema and their families (Casley Smith and Casley Smith, 1997; Mortimer and Todd, 2007)
- » Tailor-made information can be assembled for each child and their family by their practitioner.

Promoting health and well-being

In addition to the necessary clinical perspective of information, there are more general long-term health outcomes. Standard 1 of the children and young people's NSF recommends that information should be offered to prevent risk-taking and to promote healthy lifestyles in children and young people. This advice is targeted at helping them reaching their maximum potential and living healthy and active

lives. Suggested key areas include healthy eating, use of recreational time, good mental and oral health. Other subjects appropriate to teenagers and young adults include the promotion of good sexual health and awareness of the effects of tobacco, alcohol and drugs.

Best practice for the management of lymphoedema in children

Agreed standards of practice (Lymphoedema Framework, 2006) also apply to the management of lymphoedema in children. In addition to the considerations already discussed in previous sections, there are other lymphoedema-specific objectives that can be added to each of the standards set out in the Best Practice document.

Standard 1: Identification of people at risk of or with lymphoedema

The identification of children at risk of or with lymphoedema may be compromised by the lack of public and professional awareness of the condition. The provision of tailored information may help to raise the profile of this condition and what can be done to help. However, any attempts to raise awareness should be preceded by an organised campaign to ensure that children can access high quality treatment and support.

Standard 2: Empowerment of people at risk of or with lymphoedema

Individual plans of care, while implicit to lymphoedema services at all ages, require special attention in the treatment of children. The needs of the children and their families may change rapidly, and, for this reason, it is likely that more regular appointments may be needed. These may be structured around school holidays to minimise the disruption to the child's education. In addition to these contacts, it is likely that families will require access to timely advice, support and information via the telephone and internet.

Standard 3: Provision of lymphoedema services that deliver high quality clinical care that is subject to continuous improvement and integrates community, hospital and hospice-based services

High quality clinical care is needed to ensure that the child achieves their maximum physical and functional potential and to minimise psychological distress. A creative and flexible approach is needed so that treatment can be integrated into the family lifestyle and does not disrupt the pattern of normal life for the child. The benefits of treatment should not outweigh its burden. If the burden of treatment is perceived to be too great, the child may develop a negative attitude to their treatment. It is important that the child, as well as the family, are aware of the long-term benefits of the treatment and of all the methods that can be used to improve the condition.

Standard 4: Provision of high quality clinical care for people with cellulitis/erysipelas

Protocols for the rapid and effective treatment of cellulitis apply to the treatment of children and young people. Vigilant skin hygiene and care is of crucial importance and should be reinforced in verbal as well as printed form. Special guidance on the use of emollients and antibiotics could be included within this.

Standard 5: Provision of compression garments for people with lymphoedema

Compression garments for children and young people, while fulfilling the same aims and objectives as in the treatment of adults, require special consideration. Provision for this age group brings with

Table 3	
Examples of children with additional needs (DH, 2003)	
Category	Examples
Health	Physical disabilities Poor nutrition Ill-health Anxiety and depression
Education	Poor attendance or exclusion from school Experiencing bullying Special educational needs
Social	Disruptive or antisocial behaviour Overt parental conflict Lack of parental support or boundaries Involvement in or risk of offending Substance misuse Housing issues Pregnancy and parenthood

Table 4	
Children with complex needs	
»	Children who are subject of a child protection plan
»	Children in care
»	Children who have left care
»	Children for whom adoption is planned
»	Children with severe/complex special educational needs
»	Children with complex disabilities or health needs
»	Children diagnosed with significant mental health problems
»	Young offenders involved with youth justice service (community or custodial)

it additional functional and cosmetic requirements. Active lifestyles may mean that the child needs more than two sets of garments every six months. More frequent replacements are also needed at some ages as the child or young adult grows and changes shape. Regular monitoring is needed to ensure that the garment fits well and is comfortable. Hosiery is likely to be less acceptable if it is perceived as unsightly and unattractive, and every measure should be taken to ensure that the hosiery is acceptable to the child and the family. Despite the marked advances in the provision of compression garments for adult patients, there are few options in choice and style that are designed around the needs of children and young adults.

Standard 6: Provision of multi-agency healthy and social care

The provision of a comprehensive assessment and multi-agency support is central to national guidance on children's services. While practitioners may not be in a position to deliver this service themselves, they can provide information about services that are available in the region and facilitate the referral process. They can also provide initial information and advice to children and their families as they await an appointment with the children's service.

Conclusion

Children with lymphoedema require high quality clinical care that is delivered in a child-centred environment. It is the intention that services focus on the child's needs and not just their condition. Standards for the provision of such services are shaped by local and national guidance, specifically the recommendations set out in the Children's NSF, Hospital Services. In terms of lymphoedema treatment, this means a broader focus on how and where services are provided and working within a team-based approach.

This paper proposes that children's services are offered through a network of regional centres sharing the same quality of expertise and standards of care in terms of access to professionals and child-centred facilities. Standards are based on existing clinical guidelines

for lymphoedema treatment and also comply with recommendations for children's services as defined in national policy. Regionalised units will be in a better position to draw on a wide network of professionals to enhance the quality of care for the child and will open up a wider network of support and information for the family. Although lymphoedema in childhood is relatively rare, this small group require specific care to address their complex and life-long needs. This can only be achieved by adding new perspectives and ways of working into the way we deliver children's lymphoedema services. JL

This article was originally produced on behalf of the International Lymphoedema Framework. The full version can be found at www.lympho.org, and an abridged version in the ILF Focus Document Care of Children with Lymphoedema (2010), ILF, London. JOL would like to thank the ILF for permission to reproduce it.

References

- Casley Smith JR, Casley Smith Judith R (1997) *Modern Treatment for Lymphoedema*. Terrace Printing, Adelaide
- Children's Workforce Development Council (2007) *Common Assessment Framework for children and young people: practitioners' guide*. Department for Education and Skills, Nottingham
- Clinical Resource Efficiency Support Team (CREST) (2008) *Guidelines for the diagnosis, assessment and management of lymphoedema*. CREST, Belfast
- DH (2000) *The NHS Plan: a plan for investment, a plan for reform*. DH, London
- DH (2003) *Every child matters: change for children*. DH, London
- DH (2004) *Getting the Right Start: The National Service Framework for Children, Young People and Maternity Services. Hospital Standard*. DH, London
- DCSF (2009) *Healthy lives, brighter futures: The strategy for children and young people's health*. DCSF, London
- International Society of Lymphology (2003) *The diagnosis and treatment of peripheral lymphedema. Consensus document of the International Society of Lymphology*. *Lymphology* 36(2): 84–91
- Lymphoedema Framework (2006) *Best Practice for the Management of Lymphoedema*. International Consensus. London: MEP Ltd
- Mansour S, Sharland M (2000) Lymphoedema in childhood. In: Twycross R, Jenns K, Todd J, eds. *Lymphoedema*. Radcliffe Medical Press, Oxford
- Mortimer P, Todd J (2007) *Lymphoedema Advice on Self-management and Treatment*. 3rd edn. Beaconsfield Publishers Ltd, Buckinghamshire
- Murray S, Moffatt C (2009) The experience of children and families with lymphoedema. In: *Focus Document: Care of Children with Lymphoedema*. ILF, London. Available online at: www.lympho.org
- Skills for Health (2005) *A career framework for health*. Skills for Health, Bristol
- Smeltzer DM, Gunnar B, Stickler MD, Schirger A (1985) Primary lymphedema in children and adolescents: a follow-up study and review. *Pediatrics* 76: 206–18
- Sneddon M (2007) Education: building on the past and preparing for the future. *J Lymphoedema* 2(1): 66–72
- Todd M, Welsh J, Moriarty D (2002) The experience of parents of children with primary lymphoedema. *Int J Palliative Nurs* 8(9): 444–51
- Walker J (2007) *Delivering and Auditing Quality in Hospital Play Services*. National Association of Hospital Play Staff, London

Key points

- ▶ Lymphoedema can be an isolating condition for many children and young people.
- ▶ Children with lymphoedema require high quality clinical care that is delivered in a child-centred environment.
- ▶ The author proposes that children's services are offered through a network of regional centres sharing the same standards of care in terms of access to professionals and child-centred facilities
- ▶ Regionalised units can draw on a wide network of professionals to enhance the quality of care for the child and open up a wider network of support and information for the family.