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Early Childhood Lymphoedema

This information has been produced and verified by accepted experts in their field. It reflects current best practice and evidence-based research where appropriate. It has been designed to assist you in managing your child's condition and is not intended to replace advice you may receive from your healthcare practitioner. If you or your healthcare practitioner would like to ask any questions, provide us with feedback or require details of the research used to develop this information, please contact the Lymphoedema Support Network on 020 7351 4480.

Having a child diagnosed with lymphoedema can be a worrying time and whilst lymphoedema is a life-long condition, much can be done to manage and control the main symptoms. This fact sheet contains some general information that will help you make sense of the diagnosis and what might happen next. The LSN also provides FREE membership to all children and young people under the age of 18 living in the UK. We also produce age-specific packs that contain activity sheets, information for schools and clubs, answers to frequently asked questions and much more. If you would like to receive free membership and an age-appropriate pack for the child in your care then please contact the LSN office on 020 7351 4480.

What is lymphoedema?

Lymphoedema results from a failure of the lymphatic system. This can result in swelling, skin and tissue changes and a higher risk of infection in the swollen areas. It is most commonly seen in the arms or legs but may also affect the head and neck, trunk, breasts or genitalia. It is not painful but can ache if poorly controlled.

Primary lymphoedema may be present from birth or early childhood and is caused by the underdevelopment of the lymphatic system. Although the affected individual may be born with an underdevelopment or weakness in the lymphatic system, the swelling can develop at any age. It is not always present at birth.

Secondary lymphoedema is due to some cause that is external to the lymphatic system. This may be repeated skin infections, severe injury, burns or any other trauma. It can also occur in the treatment of cancer following surgery or radiotherapy.

What does the lymphatic system do?

The lymphatic system plays a very important part in the way that the body functions, for two reasons:

- It helps to drain away fluid, proteins and waste from the skin and tissues
- It is part of the body's immune defence against infection

Can lymphoedema be cured?

Lymphoedema cannot be cured, however, it can be controlled and many of the symptoms can be improved with treatment. Recent advances in research have already improved our understanding of the condition, which should lead to more effective treatments in the future.

Why has lymphoedema developed?

Lymphoedema that develops in childhood is quite rare and is not widely encountered by the general public or the medical profession. Diagnosis is often the first time parents will have even heard of the condition.

Most childhood lymphoedema is thought to be caused by genetic factors which may be inherited. For example, Milroy Disease is one type of hereditary lymphoedema that affects the legs and presents with swelling at birth. It is a dominant condition, which means that it can be inherited from an affected parent. If an adult has Milroy Disease, the offspring have a 50% chance of inheriting this condition.

Some of the genes linked with primary lymphoedema have been identified. For example, Milroy Disease is usually due to a mistake in a gene called VEGFR3, which is important in the development of the lymphatics while the baby is developing in the womb. There are now more than 20 genes identified which cause primary lymphoedema.

If a genetic cause can be found, it may be possible to predict the chance of having another child affected, and will also help to determine whether the children themselves are at risk of passing the condition on to their own offspring in the future. It is also helpful in identifying any associated problems. For example, mistakes in some of these genes may be associated with congenital heart disease, or a problem with the lymphatics in the bowel. Increased genetic knowledge may also help to guide the management of the condition both now and in the future.

In some cases, lymphoedema can occur in association with other problems. The paediatrician or geneticist will usually carry out several investigations in order to make an accurate diagnosis.

Many parents wonder if there was anything that they had done during the pregnancy to cause lymphoedema and the simple answer is no. **It is important not to blame yourselves – it is nothing you have done wrong!**

What can be done to help our child?

Before any treatment can be started, you need to find someone who can offer a thorough assessment, instigate the most appropriate investigations and give an accurate diagnosis. So if your child has been diagnosed with (or is suspected of having) lymphoedema, you should ideally be referred directly to one of the highly specialist lymphoedema clinics based in Derby or London (see addresses at the end of this fact sheet). These clinics have a team of experts (medics, researchers, geneticists, practitioners) who will be able to give you the best possible advice to successfully manage your child's condition according to the findings determined through thorough assessment, genetic testing and investigation. Once this is in place, your child can then be seen more locally at one of the clinics that treat children. These clinics have practitioners with a special interest in managing lymphoedema in children and they have great experience in this field.

Please note that this may involve you travelling some distance because although there may be an adult lymphoedema clinic closer to you, they may not (for a number of different reasons) be able to see children. Contact the LSN for a copy of the Children's Lymphoedema Specialist Interest Group (CLSIG) directory of children's services if you need information about the closest clinic that will be able to help your child.

As parents/guardians, you can play a vital role in helping to manage the condition, thereby enabling your child to live their life to the full. Treatment is a partnership between your lymphoedema practitioner, you, and your child. One of the most important things you can do is to gain as much information about lymphoedema as possible. There is much information available on the internet, but this often shows very extreme cases and can be quite frightening. Be assured that in most cases lymphoedema is not severe and can be managed very well and without disruption to your family. The condition will feel less frightening as you learn more and you will be able to guide and educate other members of your family, teachers and the people your child will encounter. Doing this in a positive way is helpful to your child, as it will increase understanding and help people to be aware of any special needs. If people know what to expect, they will feel more confident in helping you to look after your child.

What is the treatment?

There are four main elements to the treatment of lymphoedema – Skin Care, Compression, Exercise and a type of gentle massage called Manual Lymphatic Drainage.

Skin care

Looking after the skin is very important. Always keep the skin soft and supple – moisturise daily to prevent dryness. Try to avoid injury/trauma to the skin; prevention is always better than cure. For example, avoid sun damage by applying high factor sun creams and use mosquito repellent while on holiday to prevent bites.

With lymphoedema, the local immune system is not working as well as it should, and there is more of a risk of developing an infection such as cellulitis, verrucas or athlete's foot in the swollen limb. Cellulitis may increase the problems of lymphoedema. Signs to look out for are inflammation (redness), increased swelling, pain, fever or vomiting, 'flu'-like symptoms or a general feeling of being unwell. Seek medical help **immediately**; the earlier your child has antibiotics to treat the cellulitis the less severe the symptoms will be.

By carrying out a daily skin care routine for your child, you can reduce the risk of infection. Daily inspection for any skin damage is vital (especially between the toes if legs are affected), e.g. signs of redness, scratches, cuts or abrasions. Any breaks in the skin should be treated with an antiseptic such as Savlon or tea tree oil. If you notice frequent signs of athlete's foot, seek the advice of your lymphoedema practitioner or GP for an effective treatment. **Don't ignore skin problems.**

For more information see the LSN fact sheets 'Skin Care For People With Lymphoedema', 'What is Cellulitis?' and 'Management of Cellulitis in Lymphoedema'.

Compression

Compression treatment is provided using a garment e.g. knee-high socks or sleeves, depending on the site of swelling (or bandages on occasions). It works by reducing the build-up of fluid in the tissues and encouraging the fluid to move to an area that is draining well. Compression needs to be worn daily and most importantly when the child is exercising, as the compression helps the working muscles to drain the swelling. Sometimes it may be beneficial to wear day and night if swelling is particularly troublesome – the clinic will advise what is best for the child. The benefits of exercise are lost if compression is not worn and if not worn at the same time, can increase the swelling.

However, not all children require compression, particularly when they are very young. Your lymphoedema practitioner will discuss this in detail with you while liaising with the specialist clinic involved at diagnosis. Maintaining frequent contact with your clinic is in the best interests of your child. They are there to help you and advise, so do not be afraid to contact them for advice and support when needed.

Exercise

Keeping young children physically active is not usually a problem – more the reverse! Your lymphoedema practitioner (taking into account your child's individual needs) will encourage movement and exercise. Steady movement, such as walking and swimming, is particularly good but any physical activity that your child enjoys should be encouraged if it does not aggravate the swelling.

Elevation of the limbs is not necessary, but ideally, when the child is asleep, the legs should be horizontal rather than left dangling down.

Lymphatic drainage massage

A specialist massage technique called Manual Lymphatic Drainage (MLD) was developed to treat lymphoedema. MLD massage is very different from other types of massage in that it is very light and is performed in specific areas of the body. The aim is to stimulate lymph drainage by special massage strokes on the skin. This helps to move the lymphatic fluid away from the swollen, congested areas of the body. Specially trained therapists can perform MLD, however, you can be taught a simplified technique (SLD) that may help in the same way, especially if used regularly. Most clinics are only able to offer MLD as part of intensive decongestive treatment as there is currently no research to support that MLD alone will reduce swelling in the long term. However, many parents feel that learning SLD allows them to become really involved in helping with their child's treatment.

For more information see the LSN fact sheet 'Manual Lymphatic Drainage Therapy for People with Lymphoedema'.

Kinesio taping

Kinesio taping is another way of helping/improving lymphatic drainage. Originally used for sporting injuries, the tape has been widely adopted in lymphoedema clinics to address specific problems or to help improve the drainage capacity from the limb.

If suitable for the child's swelling, Kinesio tape can add 'fun' to treatment and as many famous sports people

use it, the child can often feel very special. It is available in bright colours as well as the traditional flesh colour, but unfortunately it is not yet available on prescription. However, if necessary (and suitable) the lymphoedema service may be able to provide it.

For more information on its use see the LSN fact sheet 'The use of Kinesio Tape in Lymphoedema Management'.

How will it affect our family life?

Having a child with any condition affects the entire family and, as such, it is important that all members, including brothers and sisters, understand the child's needs and feel that they can help. If siblings feel involved, they are less likely to feel ignored or to resent the extra attention given to the child. It is important that despite the special lymphoedema needs, you do not ignore the needs of others in the family. This can undermine the mutual support that is needed to ensure normality for the child and family.

There may be regular visits to doctors and clinics. These take time, including travelling time, although hopefully more local help will be available. There will also be daily time for exercise and application of creams, bandages and garments if appropriate.

It may be difficult to find suitable clothing and footwear for swollen limbs. Loose clothing is more comfortable. Hospitals may prescribe made to measure footwear if foot swelling is a problem and the CLSIG has other useful information about footwear if necessary (available from the LSN).

What about playgroup or school?

Childminders, playgroups, nursery schools and primary schools should all be able to deal with special needs of your child, but you will probably find that staff may not have met the condition before. It will be necessary to ensure that they are given sufficient and accurate information to enable them to plan a suitable programme, so that your child can lead a normal life but not aggravate their lymphoedema. If you need help with this, contact the LSN (who have useful information packs they can give to share with teachers, etc.) or your lymphoedema practitioner.

In a very few cases, it may be beneficial for children to enter primary school with an annually reviewed statement of special needs if, for instance, swollen fingers make self-care, dressing and undressing difficult. Some school activities may be unsuitable, e.g. doing PE barefoot; but if the school is aware and fully informed they are often able to help children to carry out normal everyday activities. There may be absences due to treatment or clinic visits, but again, if schools and parents work together, missed work can be covered.

The aim for children with lymphoedema is to live as normal a life as possible, and to enable them to gradually take more responsibility for their own self-care.

If you need help and information, contact the LSN or your lymphoedema practitioner.

What about the attitude of others?

Like anyone else who is seen as different, the child with lymphoedema is likely to experience both negative as well as positive reactions from others. Strangers may stare and children can ask hurtful questions. Most people will try to be helpful and supportive. Children usually accept a simple honest answer or explanation to questions. Do not hesitate to approach senior members of staff such as play leaders or head teachers if you are worried, so that any problems can be dealt with quickly.

Are we entitled to benefits for our child?

You may be, depending on the severity of the condition. It is worth seeking advice from your local Citizens Advice Bureau.

General do's and don'ts

- Always wash, dry and moisturise the skin carefully and thoroughly at least once a day.
- Try to avoid any injury to the skin such as sunburn, animal scratches, etc. and treat any breaks in the skin with an antiseptic such as Savlon or tea tree oil.

- Check the skin daily for any breaks or signs of infection.
- Treating skin problems quickly will help to prevent infection. Notify your GP of any persistent skin problems.
- Common signs of infection are – redness or rash around the area affected, pain and heat or generalised high temperature, headache, fever or 'flu'-like symptoms. **Seek medical help immediately as antibiotics may be needed. The LSN has information on the Management of Cellulitis in Lymphoedema patients.**
- If your child has had frequent infections, you may be advised by your doctor to keep your child on a small dose course of antibiotics or to keep a supply of antibiotics with you at all times. Antibiotics should be taken quickly in the event of attacks to prevent further damage to the lymphatic system. Antibiotics do have a use-by date, so it is important to make sure that you get a new supply when required.
- If the legs are affected, it is important to avoid injury – try not to allow your child to run around barefoot. If swimming, be alert for verrucae and treat promptly.
- Take great care when cutting toe and finger nails to avoid damage to the skin. If the toes or fingers are affected, always cut the nail straight across to avoid in-growing nails. If you can be referred to a chiropodist/podiatrist, he/she will be able to offer specialist foot care.

Maintaining a healthy weight is vital for anyone with lymphoedema – even children. Encouraging a normal, **healthy, well-balanced diet** (avoiding sugary drinks and sweets as much as possible) is recommended to prevent obesity. Exercise in conjunction with a healthy eating regimen will really help the lymphoedema and prevent it worsening.

Will my child lead a normal life?

If care is taken to look after the swollen limb, the condition can be well controlled and your child should be able to live a normal life without experiencing too many problems. It is, therefore, very important to try and get help and support as soon as possible – ideally getting referral to one of the specialist lymphoedema clinics in the UK.

As with other 'rare' conditions, it is always helpful to meet others suffering from the same condition. Children and their parents can often benefit from meeting others to exchange stories and tips about managing the situation. This is often helpful for parents whose child has recently been diagnosed – it can be very helpful to chat to other parents for support/help and advice. If this is something you would like to do then speak to your lymphoedema practitioner or contact the LSN to be put in contact with other parents of children with lymphoedema of a similar age.

The following comments have been made by parents of young children living with lymphoedema:

“The ‘not-knowing’ was the most difficult time I experienced as a mother”

“We are still unsure as to why or where this comes from but, after having the condition explained to us thoroughly, I threw myself into making sure I knew as much as I could to help my 4 year-old son adapt to his everyday life”

“With the help and encouragement from a lymphoedema practitioner we were soon able to see a huge difference in our son; his acceptance of lymphoedema; his lively spirit returned; a reduction in size of the swelling through treatment, MLD and compression stockings; and, most importantly, his life became very normal again and he is quite able to do most things children of his age should be able to do”

“It took a while to introduce a routine into our lives but now it is second nature and, as a family, and also at school, we just get on with it and we're thankful for the help and support we have had through our lymphoedema specialist”

“Lymphoedema has opened the door to allow more personal time with our daughter. While performing the daily massage techniques, we spend the time catching up, doing homework, or watching a movie. All in all it is a wonderful opportunity to bond and draw closer together”

“Our daughter wears compression stockings during the day that are stylish and unobtrusive. She does not have to be embarrassed by wearing these as they look like ordinary stockings. They are also comfortable so she can wear them for long periods of time”

“When we discovered our child had lymphoedema, no additional information was provided to us as there was not much known about the condition. Upon an additional ‘flare-up’, we were told about a clinic that demonstrated management techniques such as wrapping and bandaging, massaging, and other valuable resources. It was as if another world had opened up”

“It was comforting to know that others were managing and moving on with life just fine”

The following comments made by teenagers living with lymphoedema have been reproduced from a teenage newsletter produced by Dr Jacquelyne E. Todd:

“As I am studying for a Sports Science degree and my part time work is swimming instructor/lifeguard, I have learnt to cope with lymphoedema and am able to do most things”

“Not letting it rule your life – continuing with college as normal”

“Being confident and accepting my condition helped me feel happy with what I wore and who I am”

“Wind surfing and sailing are my two major sports. I tend to wear a short wet suit but I still wear a compression stocking”

“I have been able to play all types of sport especially football and basketball. I love swimming and lots of other sports too”

“My friends and family have helped me a lot, especially my mum, she has been a star, she’s always motivating me to put my stockings on”

“My friends have always been very supportive; once or twice I haven’t been included in parties because they were doing things I can’t join in with, but that stuff is rare. In fact they are as nice and as mean to me as they are to everyone else which is great”

“My mum has always been around to help me cope with lymphoedema. However, this year, I spent four months in Majorca working and this was a testing time for me with my lymphoedema. I feel I coped very well – having suffered a bout of cellulitis whilst there and had to visit hospital, it has made me a stronger person and I now know that I can cope with it on my own”

Useful links/Further reading

‘Big Book of Lymphoedema’ – a book specially designed for children with lymphoedema. Available from the Lymphoedema Department, Wharfedale Hospital, Leeds, or by emailing: sales@hadhealth.com or telephone 01844 208842.

The Children’s Lymphoedema Special Interest Group (CLSIG) is an independent group affiliated to the Lymphoedema Support Network (LSN). They have produced a Children’s Charter, to provide information and support for families affected by lymphoedema. They organise a bi-annual conference for children and their families called Lymphaletics. You may wish to look at their website for further information:

<https://lymphaletics.weebly.com>

The LSN also has information about lymphoedema in teenagers and young adults that will help your child as they grow. Please contact the LSN for a copy.

Specialist Lymphoedema Clinics

Royal Derby Hospital
Lymphoedema Clinic
Royal Derby Hospital
Level one, Main Hospital
Uttoxeter Road
Derby DE22 3NE

Lead contact: Sioban Knight
Tel: 01332 786378
Fax: 01332 787591

St George's University Hospitals NHS Foundation Trust

Lymphoedema Clinic B

St George's Hospital

Lanesborough Wing

Blackshaw Road

London SW17 0QT

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This information was revised in 06/2018. It will next be reviewed in 06/2020 or before, should the LSN become aware of significant changes in practice.