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of Ontario**

*Committed to improving  
the lives of people  
living with lymphedema*

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# Ask the Expert

## Children and Lymphedema

By Jacquelyne Todd

**As my child gets older and is exposed to more physical activities, I wonder about the precautions, if any, that need to be taken in case of sport injuries i.e. hockey? Is it safe for him to play contact sports?**



*Professor J. Todd is a Physiotherapist consultant of lymphoedema working for Leeds teaching Hospital's NHS Trust. She has been working with lymphoedema patients for over twenty years. She completed her doctorate around "exercise after breast cancer surgery" in 2008 and is now involved in research around issues of social and appearance concerns in people with lymphoedema. Another special interest is in developing lymphoedema services for children and young people. Since the completion of The Big Book of Lymphoedema, she has recently led work in the development of a website specifically for teenagers with lymphoedema. [www.lymteen.co.uk](http://www.lymteen.co.uk)*

I am always cautious to say a definitive 'no' to activities and exercise unless there is an established possibility of risk. Children have enough challenges in coming to terms with the restrictions imposed by lymphoedema without dealing with not being able to participate in activities with their friends.

They may need to take special precautions and the school will need to have these documented in writing so that it is entered onto the child's records. The child should be allowed to stop if they have had enough or are getting tired - which they may well do before the end of the lesson or game.

Care should be taken to wear as much protective clothing as possible - such as shin guards and long clothing to protect the swollen limb. The thicker custom made garments may also be more protective for young children and prevent them scraping the skin when they fall.

When the child starts a new activity, monitor them closely to check if there are signs of fatigue, swelling or pain. If it is a problem, try again another day but perhaps for less time. It may be possible to gradually increase stamina and strength so that the child is able to do more over time. If a particular activity remains a problem, try to get them interested in an alternative activity (i.e. horse back riding, swimming or golf). These activities do not put as much excess strain on the swollen limb and yet they still can be part

of a group activity and help to fulfil the child's natural sense of adventure.

**I have heard Dr. P. Mortimer mention that primary lymphedema is genetic but may or may not be hereditary. Could you explain?**

For most cases, we don't know what causes paediatric lymphoedema. Knowledge of heredity or genetic lymphoedema is extremely limited and in its infancy. So far researchers have only been able to identify a small number of genetic dispositions. However, we are starting to document different problems and symptoms in the various groups of patients so that we can start making links. This will strengthen the knowledge base in genetics and lymphoedema that is so desperately needed.

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## Ask the Expert

### **Are "strawberry marks" and lymphedema related?**

Strawberry marks are collections of cells made up of tiny blood vessels that usually fade away with time. Sometimes they may indicate an overgrowth of blood vessels when there are also changes in the way that the lymph system is developing. In these cases there may be a connection between the two. Your lymphoedema specialist will inspect the skin at assessment for any skin blemishes and will monitor them closely. They may also recommend some tests to look more closely at the structure and function of the blood and lymph vessels.

**My 8 year old boy has primary lymphedema bilateral in both legs. His legs are doing very well with his knee-high compression garments, and Reid sleeves at night, but his toes get no compression from either of these treatments. He will not keep bandages on his toes as they are very sensitive. We cannot get the compression garments over any type of bandaging. We are currently trying to get compression socks with individual toe compression, but are now on our third attempt to get the correct fit. Do you have any other suggestions? His toenails curl back from the swelling making them very tender. I would love to relieve this pressure!**

The very first thing to try would be made-to-measure compression toe caps to wear during the day. These are supplied by some of the hosiery companies. There is a choice of low compression, soft seamless garments that will cause less irritation. They should be open at the toes so that they do not irritate the toe nails. The toe caps are applied first and then an open toe stocking would be fitted on top.

**My child's lymphedema has extended to his penis. His pediatric urologist suggests a circumcision to remove much of the swollen tissue, and to remove the foreskin that does not retract. I have received advice from other sources suggesting that it would not be recommended. Do you have any experience with this type of surgery with the lymphedema complication?**

In many cases like this, circumcision is recommended for children with lymphoedema in their penis. It significantly reduces the risk of infection which can be a very difficult problem to treat for children when this happens.

**My child experiences nerve pain in the affected lymphedema area. I understand that this is a rare complication for primary lymphedema. What is your experience or awareness with regard to this type of clinical presentation?**

Pain can happen in some children and adults with

primary lymphoedema and can cause disturbing sensations. Certain positions of the limb or activities may trigger or increase problems with nerve pain. Try to pinpoint what time of day or what activity might have triggered the pain - it often seems to occur when the child is tired or has been doing a particular activity. Then try to reduce or modify that particular activity to help manage and control the pain. You could also time the MLD (massage) sessions at the end of the day to help relieve the pain, as well as the swelling. Bandaging or light weight support to the limb at night may also help.

**My child was diagnosed with lymphedema at age 4 and is now beginning adolescence. What type of changes can occur that affect lymphedema during adolescence?**

The main change to deal with is your teenager's attitude to treatment and acceptance of treatment. That will fundamentally affect how well they do in their management of lymphoedema. They don't do it at that age anymore because mom or dad tells them. They need enough motivation to do it for themselves and if they discontinue treatment they will experience physical changes that will have a serious impact and their lymphoedema will get worse.

As teenagers they may naturally not be as active as before due to longer periods of sitting down at a computer, not eating healthy foods etc. The onset of puberty will result in changes to the body shape and size and the young person will be experiencing both physical and emotional changes that will impact on how they feel about themselves. They often need considerable support and understanding during this time. Sometimes it is a period of weight gain which may make the swelling worse so vigilance with a healthy diet and exercise should be encouraged. Rapid physical growth means frequent review and changes of garments as required. Research the choice of garments available to find ones that the teenager is comfortable in and are prepared to wear. The key issue is promoting positive feelings about their lymphoedema treatment and encouraging them to persevere with their treatment.

**Does the swelling experienced with primary lymphedema in children (specifically Milroy's Disease) remain fairly constant throughout their lifetime, or worsen over time? What can be done to best prevent increased swelling or complications as children age?**

Lymphoedema can even get better over time. It really varies from patient to patient. In the case of Milroy's Disease, the lymphoedema will be confined to below the knees. Sometimes there is improvement over time and sometimes it does get worse, but continued treatment can stop the lymphoedema from getting too much worse.