

PEGGY & FRIENDS

**THE IMMEDIATE AND SHORT-TERM IMPACT
OF LOWER LIMB LOSS**

NOTE: This advice sheet is based on our experience of our daughter, Laura's limb loss since 1998 and the experience of other families who have contacted the charity since 2000, together with our knowledge of the U.K. Limb Service. Therefore this advice sheet may not relate to your child's condition or your experience and is intended as a guide only. If you require specific advice about your child's condition, you should speak to your consultant at your limb centre.

1. INTRODUCTION

Having a child that has suffered limb loss, either as a result of birth defect or through elected or traumatic amputation is devastating for the whole family.

You as the child's parents, like us, will effectively go through a form of grieving, because you will have 'lost the normal child' that you expected or (in our case) previously had. Your family will probably feel helpless, unable to provide the answers that you require because it is unlikely that they have experienced this before. Your friends and family will probably try to offer what comfort and support that they are able, but many will feel awkward and embarrassed (do not be offended by this as it is a normal reaction). How well your child responds to the loss of a limb will depend a lot on their age (the younger they are the better they cope) but more importantly on how they see you cope.

Well-intentioned people will tell you to get back to normal as soon as possible, but you will struggle because 'normal' is not normal anymore and you will need to establish what your 'new normal' is. It is not, however, the end of the world although it may seem so at the time. We know because our daughter, Laura, lost her left leg below the knee in 1998 at the age of eight as the result of a terrorist bomb.

2. IMMEDIATELY AFTER AMPUTATION

If your child suffers limb loss as a result of amputation rather than birth defect, you should not consider it as 'destructive' surgery but rather as 'constructive' surgery in that it offers a new beginning.

Immediately after amputation your child's residual limb will be quite swollen due to the operation and the healing process, but it will shrink in time, because of muscle wastage.

It is also possible that your child may experience so called 'phantom limb pain' which occurs as a result of disconnected nerves continuing to send signals back to the brain. This is often seen in the form of strange sensations or the feeling that the amputated part of the limb is stuck in an awkward or uncomfortable position.

These pains should diminish over time, but if the problem persists, then you should speak to your consultant at the limb centre. They may be able provide pain relief or ask for your child to be referred to a pain management specialist, who can prescribe prescription medication to control this problem (see advice sheet AS30 – Phantom Limb Pain in Children and Adolescents).

3. EMOTIONAL REHABILITATION

We have already touched upon how you may be feeling about the loss and how each member of your family will react differently. You may have been told that it is best to talk openly about the situation and for many it is, but for some people, for example the grandparents this may be difficult. Mandy and I found it comforting to talk openly about Laura's limb loss and we found that it helped our children, but the children's grandparents did not and would not discuss it.

In the early stages you and your family will be suffering from shock and may well experience a full range of emotions including disbelief, anger, guilt, depression and bitterness. The extent that you and your family feel like this will vary from person to person. These feelings are normal and part of the human healing process but you may, like us, benefit from counselling to help you find emotional balance in your lives again.

In time, you will find that you think about it less often, however, you may find that some situations may make you think about it again. We avoid loud noises and fireworks which, act as a trigger for our memories of the bombing.

As we said earlier, it is very important that you accept what has happened and deal with it in a calm and rational manner, as your children will need you to set an example to them on how to deal with this situation. Mandy and I attempted to establish a routine that our children felt comfortable with and we talked openly about what had happened to us, and answered all questions that our children asked. For example, Jacob who was three years old at the time, wanted to know how the bomb blew Laura's leg off, so we answered it as best we could, and he has never asked again!

4. PROSTHETICS

The purpose of an artificial limb is to provide your child with the most natural movement and function possible. However, no matter how good the artificial limb is, it cannot replace a natural limb, and it is physically more demanding for a child to use than a natural limb.

All prostheses (artificial limbs) have the same basic design, in that your child's residual limb (we don't call it a stump, because we found that it upset Laura – as she told us, it was still her leg!) will be fitted for a socket. This in turn is fitted into the limb containing the components such as knee joint, shin pole and foot. A skin, called a cosmesis is then fitted over the skeletal frame to give it a more natural appearance.

5. PHYSICAL REHABILITATION

The need for, and intensity of, physical rehabilitation will vary depending upon age, physical maturity, levels of fitness prior to amputation, levels of limb loss, reason for limb loss and more importantly motivation of both the child and their family.

Physiotherapy will usually begin as soon as the child can tolerate it, which for children who have been amputated will be when the wound has healed and swelling reduced.

Physiotherapy can be very hard work, but in very general terms, the harder the child and their family is prepared to work at walk training and the exercises set by the physiotherapist, the greater the mobility they will achieve. In simple terms mobility provides independence and therefore it is important that you persevere.

6. THE LIMB CENTRE

Your GP or hospital (in the case of amputation) will arrange for you and your child to be referred to a limb centre*. The limb centre will provide your child's the prosthesis and on-going physical rehabilitation. Most limb centres will provide other support services such as counselling and may co-ordinate community care.

However, because centres vary in function and size we cannot say for sure what services are provided in your local centre and therefore you will need to check with them directly.

Tony and Mandy Giddings
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* Also known as Artificial Limb and Appliance Centre (ALAC), Disablement Service Centre (DSE), Enablement Centre or Rehabilitation Centre