

# PEGGY & FRIENDS

## LIVING WITH 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

In this advice sheet we try to provide some basic guidance about living with limb loss and using an artificial limb.

### 2. THE RESIDUAL LIMB

The most important part of wearing a prosthesis is taking good care of the skin of your child's residual limb. To ensure that it stays healthy you should:

- Wash it each day with a mild antibacterial or hypoallergenic soap and water.
- Inspect it each day for evidence of fitting problems such as sores, blisters or 'bruising' (redness) of the skin that does not go away when the prosthesis is taken off.

**Note: Many children, like Laura, who suffer limb loss as a result of amputation are often unaware that they may be having problems because the end of their residual limb remains 'numb' following surgery.**

- Change their prosthetic socks each day or more frequently in hot weather. Socks should also be changed after sport or other energetic activities.
- Remove the prosthesis often to give it a rest (a bit like taking your shoes off after doing a lot of walking).

**Tip: We use a product called PC 30V from Otto Bock that helps keep Laura's residual limb in good condition. It is applied each night prior to going to sleep.**

Even with these precautions, your child may still periodically develop the following problems:

#### 2.1 Eczema

Eczema can take the form of dry skin (often leading to cracks) or an itchy rash. If you suspect that your child suffers from eczema you should speak to your GP about:

- Preventing eczema with the daily application of an emolument. We use a prescription product called *Epaderm emolument* which, can also be used as a soap substitute.
- Treating eczema outbreaks with a short-term application of a steroid cream. We use another prescription product called *Elocon ointment*.

**TIP: When Laura is having problems with eczema, we try to avoid her skin drying out in bed at night by wrapping her residual limb in cling film and dressing that with a prosthetic sock and compression bandage (such as Tubigrip)!**

## 2.2 Spots

Germs or foreign substances like soap getting into the pores can cause spots on the residual limb. They can be very painful when pressure is put on them by applying the prosthesis. Using a non-prescription antiseptic cream can usually treat spots.

## 2.3 Inverted Hair Follicles

Inverted hair follicles look like small spots or red marks but do not respond to a non-prescription antiseptic cream and need to be treated with a prescription product from your GP. We use a product called *Fucidin cream*.

## 2.4 Fungal Growth

Fungal growth can develop because your child's residual limb is put into a hot, moist and dark environment (ideal for growing mushrooms!). That is why it is so important to wash it regularly and to use fresh, clean and dry prosthetic socks. If you suspect that your child has developed a fungal growth (similar to 'athlete's foot') speak to your GP.

## 2.5 Fluctuations

All residual limbs change in size during the day. In general terms, residual limbs are bigger in the morning than at night, because of fluid retention built-up from inactivity during sleep. This is why children often complain about their prosthesis being tight when they first put it on.

The combination of putting it in the socket and activity during the day, help to reduce this water retention, the residual limb shrinks and the prosthesis may become loose. For this reason, it is helpful for your child to have an additional prosthetic sock that can be put on to take-up the slack.

## 3. THE PROSTHESIS

### 3.1 General Care

Your rehabilitation team will provide you with the necessary training for looking after your child's prosthesis and this, together with a little common sense should keep it in good working condition. For example, if it's not designed for water use, don't put it in water and if it does get wet dry it off as soon as possible.

The socket should be washed with a mild antibacterial or hypoallergenic soap and water often and given a good rinse and dry before reuse. If this does not clear the smell, try a product containing ethyl alcohol, which will not dry out the skin.

If your child uses a removable liner this should be washed daily just like the residual limb, but you will need to ask the advice of your prosthetist as to suitable products. We wash Laura's Pelite liner in water with a touch of *Ace bleach*, rinse it and dry it overnight on a radiator.

### 3.2 Wear and tear

Your child's prosthesis is a fairly strong piece of equipment but it is not unbreakable so you should check it often for signs of excessive wear and tear. If you detect or even suspect a problem contact your limb centre immediately.

### 3.3 Fit

If your child has a unilateral limb loss (one side only) their prosthesis will be slightly longer than the sound side upon delivery to allow for growth (but should have minimal impact on their walking). However, because your child is constantly growing you should regularly measure their height to identify periodic growth spurts, which may signal the need for a change in, or modification to their prosthesis.

However, this monitoring only accounts for lateral growth (height) but does not help in monitoring changes in bulk. We have found through experience that a good indication of problems with fit from changes in bulk are signalled by Laura when she starts to complain that her prosthesis 'doesn't feel right'. At this point, we get her checked.

## 4. SCHOOL

It is very unlikely that your child's school will have any experience in dealing with the challenges that a child with limb loss brings, therefore it will be up to you to educate them.

### 4.1 Inclusion in school activities

The real challenge for the school will be balancing your child's inclusion in school activities with their safety. It is important that your child is included in as many activities as possible so as not to highlight their disability unnecessarily. To achieve this, it may be necessary for your prosthetist to modify the existing limb (for example Laura has a 'Vari-flex' from Flexfoot) or even to provide a dedicated sports leg.

### 4.2 Excellence and self-confidence

It is also extremely important that the school identifies a subject or a sport in which your child can excel and compete with able-bodied children on equal terms to build their self-confidence. For Laura, it is swimming in which she can compete on equal terms with able-bodied children.

### 4.3 Assistance at school

However, even though Laura excels at swimming she still requires assistance to enable her to compete. For a start, she swims without her prosthesis, which means that she needs to use crutches around the pool and therefore needs someone to carry her clothes etc. Furthermore, she has to do a modified speed dive from a kneeling position and therefore needs someone to 'steady' her on the wet diving platform.

The point that we are making is that with a little thought and a little bit of help your child can be included in many activities, which may at the out-set look unrealistic. Moreover, you can actually get state aid on behalf of your child's school to provide this assistance in the form of 'statementing' (to be covered in a future advice sheet).

#### 4.4 Guidance for your child's school

We took advice from Laura's prosthetist, physiotherapist and orthopaedic surgeon as well as using our own experience of living with her and put it on a factsheet with Laura's photo on it together with details of her condition and the guidance we had received for the benefit of her teachers.

We also asked that it be displayed in the staffroom so that anyone else who might come into contact with her had a good understanding of her needs. The factsheet is updated periodically as we discover what she can or cannot do (staff at the limb centre may be able to support this).

#### 4.5 Sport and activities

It is important that your child has the opportunity of taking part in some form of sport. You should however, be aware that the use of a prosthesis needs more effort to achieve the same level of activity as able-bodied children. For example, to use a single below knee prosthesis requires about 1.5 times the energy that is required for an able-bodied child to walk. For a single above knee prosthesis this rises to 2 times the energy required. Multiple limb loss increases the energy need even more.

Therefore, there are no simple rules by which we can guide you, except to say use your experience and knowledge of your child to set the ground rules for their school.

For example, we encouraged Laura to try netball, hockey, lacrosse and running. However, we had to take athletics one sport at a time and decided, that she could do long-jump but not high-jump or hurdles. We also decided that she could also do some gym work but definitely not the vault or rope-work (your physiotherapist may assist).

Laura was also very keen to take-up dancing and so we spent some time talking to her dance teacher about what she could or could not do. Following these discussions and with on-going consultation, her teacher was able to fully include her by changing some of the dance movements that she was unable to do with her inflexible ankle.

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