

PEGGY & FRIENDS

REHABILITATION FOR LOWER LIMB PROSTHETIC USERS

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 for families faced with the prospect of rehabilitation after limb loss. Whilst it focuses on limb loss as the result of amputation, much of the advice given here also applies to children with limb deficiencies being fitted with a prosthesis (artificial limb) for the first time.

2. **PRE-OPERATIVE MANAGEMENT**

If possible the child and their family should have the opportunity to discuss the consequences of the amputation, both physical and psychological prior to amputation with an appropriate member of the specialist team at the Limb Centre who will all be involved in post-operative management.

This session should include:

- A clear understanding of the child's and their family's expectations.
- A clear explanation of how these expectations can or cannot be met with a modern prosthesis (artificial limb).
- The short-term health implications that result from amputation.
- The psychological and social implications for life as an amputee.
- The long-term health implications that result from amputation.
- Any planning for further interventions, for example, counselling.

If it is not possible for this discussion to take place prior to amputation because of limb loss due to trauma, for example, it should take place as soon as practicable after surgery.

3. **INITIAL POST-OPERATIVE MANAGEMENT**

3.1 **Pain control**

Initial post-operative management will focus on pain control, as most children will experience post-operative pain for the first 48 to 72 hours. The use of pain control may well continue for several weeks after the operation but will usually have stopped by the time the first artificial limb is normally fitted. However, this will be looked at based on the needs of your child.

A further complication in amputation is 'phantom sensations' (feeling that the limb is still present) which occurs in 50% of children amputated after the age of six.

Some children also experience 'phantom pain' which can be very problematic to control because it tends to occur intermittently and no specific treatment appears to work for all patients. (See advice sheet AS30 – Phantom limb pain in children and young people).

3.2 Joint Movement

Another common problem experienced by many children is for them to unconsciously bend the residual limb at the remaining joint. For example, both we and our daughter Laura, who lost her leg below the knee, were unaware that she was curling-up her residual limb (the remaining portion of her leg) in a comfort response, resulting in a shortening of the tendons. Because it went unnoticed she needed extensive physiotherapy to regain knee movement, which was necessary for the fitting and use of her prosthesis.

4. CLINICAL CARE

For a stable, useful and pain free residual limb, an amputee needs the end of their residual limb to be well healed and non-sensitive and therefore early post-operative care is critical. Nursing staff, need to take special care to prevent infection and to monitor pressure areas on the residual limb.

5. POST-OPERATIVE COUNSELLING

The reassurance of an experienced counsellor is extremely useful because surgery of any kind is traumatic but particularly so in the case of amputation, which has a dramatic impact on both the lives of a child and their family. We found counselling very useful since it confirmed that what we were feeling was normal but also prepared us for the new life we were going to experience coping with Laura's condition.

6. THE REHABILITATION TEAM

6.1 Orthopaedic surgeon

The surgeon's role is to carry out the appropriate medical investigation, diagnose the condition, prescribe appropriate medical care including medication and advise on the necessity for amputation.

The surgeon will also select the level of amputation, if necessary, based on his assessment and the advice of other members of the rehabilitation team, in particular, the rehabilitation consultant and the prosthetist in difficult cases. The surgeon will also direct post-operative medical treatment.

6.2 Nursing Staff

Nursing staff, provide overall care including assessment on arrival and after surgery. They also provide on-going treatment such as pain relief, wound dressing, general hygiene and emotional support.

6.3 Physiotherapist

The hospital's physiotherapist's role is to get lower limb loss children mobile following amputation, by a combination of encouragement, exercise and walking training. They will also be involved in co-ordinating discharge planning and procedures together with the nursing staff, occupational therapist and social workers, if necessary.

After discharge, a specialist physiotherapist from the limb centre will be responsible for continuing physical rehabilitation.

6.4 Occupational Therapist

The hospital's occupational therapist will be involved in the assessment and management of the child for safe discharge. The aim is to assist the child to achieve the optimum level of independence after amputation.

After discharge, a specialist occupational therapist from the limb centre will assess all aspects of daily living including domestic environment, school and leisure activities with due consideration being given to physical, social, psychological and environmental factors and an evaluation of aids to daily living.

The occupational therapist will also provide training for upper limb users.

6.5 The Rehabilitation Consultant

The Rehabilitation Consultant at the Limb Centre provides for the long-term medical care needs of the child. At the first appointment at the Limb Centre following the amputation, the consultant will carry out an appraisal of the future rehabilitation needs of the child and family and may then prescribe a limb. In some limb centres this may happen prior to amputation.

During the rehabilitation stage the consultant and the other members of the rehabilitation team will organise the fitting of the limb, mobility training, and monitoring both the residual limb and the general progress that the child is making.

In the follow-up stage, the consultant and the rehabilitation team will reappraise the progress of the child and make any necessary refinement to the prescription of the artificial limb and will also identify and treat any skin complaints, phantom sensations or residual limb pain.

The consultant and the rehabilitation team will also establish links with community health workers including the family doctor, physiotherapist, occupational therapist etc.

The consultant and the rehabilitation team will usually carry out regular on-going assessment, of the child, including their leisure or sports needs and any other changes in lifestyle.

6.6 The Prosthetist

The prosthetist, in discussion with other members of the rehabilitation team, will design, fabricate and fit the artificial limb.

The prosthetist is responsible for specifying limb design, selecting materials and components, measuring and taking casts of the residual limb, and adjusting or modifying the limb supplied. The prosthetist will also evaluate the artificial limb once supplied; give instructions in its use and liaise with other members of the rehabilitation team.

They will remain the main contact point for the child, providing advice on new limbs and techniques and formulating prescription advice for the rehabilitation consultant.

6.7 The Counsellor

Most limb centres now have specialist counsellors who are available to provide support during the early days or other periods of difficulty.

6.8 Social Needs

Some limb centres also have other staff such as social workers or benefits officers who can make assessment of care needs arrangements for community services, as well as providing practical and emotional support to the whole family once the child has returned home. They will also provide advice on benefits and rights under disability discrimination legislation.

7. THE TREATMENT PLAN

At this stage all members of the multidisciplinary team will arrange an assessment of the needs of your child and agree a treatment plan in conjunction with you.

7.1 Clinical factors

The treatment plan will be based on an assessment of the following factors:

- The child's age
- The child's medical history.
- The outcome of the surgery.
- The motivation of the child and family to undergo rehabilitation.
- The child's and their family's awareness of the eventual outcome.
- The child's and their family's psychological condition.

7.2 Physical factors

Physical factors will also be taken into consideration:

- Muscle strength and joint range.
- Sensitivity of the residual limb.
- General condition of any sound limb.
- Sense of balance.
- Co-ordination.
- Exercise tolerance.

7.3 Physiotherapy

The aim of physiotherapy is to restore as much of the patient's physical independence as possible:

From the first post-operative day the child will re-learn to walk, using aids appropriate to their age to enable them to re-learn gait and balance. This will provide an objective assessment of the child's ability to use an artificial limb.

If the child is suitable for an artificial limb the first cast is taken as soon as the wound is healed and the swelling has gone down. If the child is not suitable for an artificial limb then rehabilitation is redirected towards wheelchair training.

The first fitting of the artificial limb or prosthesis should take place as soon as possible following cast. Training will continue with the child's own prosthesis usually for another couple of weeks, getting progressively more challenging, for example learning to climb stairs, until the team are sure that the child has achieved a functional level of independence.

The child's progress should be monitored on a regular basis.

7.4 Occupational therapy

The remit of this programme is to restore the child's functional independence and can be divided into five sections:

a. Wheelchair assessment and training

A self-propelling wheelchair is usually only issued on a permanent basis to bilateral amputees or to unilateral amputees where the use of a prosthesis is not an option.

b. Activities for daily living

This area covers such issues as access to and from toilets, beds, chairs, bath or showers and issues such as dressing. It also covers help needed at school and leisure activities.

c. 'Graded activities'

This activity training is intended to build upon the physiotherapy work to further increase the skills necessary for carrying out more complicated tasks such as sitting on a stool.

d. Environmental constraints and requirements

This section essentially deals with the home environment and looks at issues such as access to and from home, width of doors, floor coverings and so on.

e. Community Liaison and follow-up

At this stage the occupational therapist will contact support services in the community, if necessary to provide support after discharge. Regular reviews should also be arranged.

8. THE REHABILITATION PROCESS

The rehabilitation process is the toughest part of life as a prosthesis user, not only physically but also emotionally. However, in this advice sheet we will not discuss the emotional issues that you will face but concentrated on the physical process of rehabilitation. (See advice sheet AS20 – The psychological and social impact of limb loss).

The important thing to remember is that rehabilitation will take time, particularly if it has involved an amputation because the residual limb can continue to shrink for up to and sometimes beyond 12 months.

8.1 The Early Months

a. Post amputation

If your child has suffered limb loss as a result of an amputation, then the main goals during this period are:

- To ensure that your child's residual limb heals, without infection.
- To avoid them curling their limb up in a comfort response, since this will shorten their tendons requiring extensive physiotherapy to prepare them for their first limb fitting.
- For their residual limb swelling to reduce sufficiently for first fit.

b. First Fitting

First fitting will take place as soon as the wound has healed and the swelling has reduced and use of the prosthesis at this stage aims to:

- To strengthen the muscles in both the residual limb and the sound side, if any.
- To continue reducing the swelling of the residual limb (which is primarily achieved by walking).

8.2 The first year

Because of the continuing shrinkage of your child's residual limb they will need constant adjustments to the socket, both through the use of socks and in replacement sockets. This will be very frustrating, but you will need to endure it until the residual limb stabilises,

They will also need to learn to 'walk naturally' again by slowly improving their gait. Below knee users should be able to achieve a nearly natural gait with a good prosthesis and a lot of hard work. Above knee users will never achieve the same level of gait but must strive for the most natural movement since this will reduce the effort required to 'walk' and protect their other joints.

One very important point to remember is that they need not suffer pain. Don't let anyone tell you that constant pain is part of using a prosthesis. Yes, your child will suffer from soreness or tenderness at times particularly during the early days of learning to walk because of fluctuations in the volume of their residual limb. But, constant pain that does not get better indicates that their prosthesis does not fit and needs to be adjusted or replaced; or that the residual limb needs to be investigated.

Another point to remember, is that some users particularly those who have been amputated, do not always have normal feeling at the end of their residual limb and therefore will not always be aware that they are dropping down into the socket. Therefore, **it is important to check their residual limb daily for evidence of sores or blisters or redness that does not go away. If you detect these signs try altering the fit of the socket by adding or reducing the number of socks. If this still does not improve the situation, stop using the prosthesis and go back to your prosthetist.**

9. REGULAR REVIEWS

Your child will require regular reviews throughout the rest of their lives. These reviews will initially be very frequent because of shrinkage of their residual limb.

Once their limb has stabilised, they will need regular reviews because of growth, as often as every 3 months and certainly no longer than every 9 months.

If at any time you have any concerns it is important to return to the limb centre as soon as possible.

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