Limb reconstruction: Living with external fixation

Introduction
Coping with a child in an external fixator can seem like a daunting task. The aim of this booklet is to provide parents and carers with information and ideas about ways to cope at home. Please share the information in this booklet with grandparents, babysitters and schoolteachers, or anyone who assists you in caring for your child.

Preparation for surgery
There are a number of ways that your family and child can prepare for treatment.

Diet
As it is common for children to lose their appetite whilst undergoing treatment, overall fitness and good eating habits prior to surgery will assist in a more rapid recovery. During treatment it is important that your child receives a healthy diet to assist with tissue repair, growth and bone healing. If eating or weight loss become a problem, a dietician’s help may be required.

Physical
You will meet with the physiotherapist who will give you some simple stretching and muscle strengthening exercises to do before surgery.

Smoking
The Limb Reconstruction service adopts a NON-SMOKING policy. Active and passive smoking is known to have a delaying effect on bone formation, which will prolong healing time (and therefore treatment time).

Drugs
It is important that we know about every medication your child is taking. This includes ‘over the counter’ drugs, such as Nurofen and aspirin, as well as any vitamins or ‘natural remedies’. Some of these drugs affect bone healing and may lead to serious problems.

Psychological
Open discussion about the treatment amongst family is encouraged, as it helps the child come to terms with the treatment plan. If you think that your child is not coping with the idea of the fixator, please let us know so that we can address these issues prior to the fixator going on.

Home environment
If your child is going to be wheelchair bound post operatively, the home environment may need to be modified. The limb reconstruction nurse will discuss with you ways in which you can manage the stairs, toilet and bathroom, and bedroom. Equipment required can be hired from the hospital.

School
Let your child’s school know of the planned surgery. If your child is to be wheelchair bound post operatively, the school may need to install ramps for easy access. The limb reconstruction team will liaise with the school to advocate for your child if you wish. Children returning to school need to be able to toilet themselves unassisted. If your child is not able to do this, the hospital will support your school in the application for an aide for your child.

Clothing
Clothes may need to be modified to fit over the fixator. The external fixator can be bulky and can catch on clothing (it can also damage bedding, soft furnishings and car seats). Clothing needs to be bigger than usual. Suggestions include:

• Pull away track suit pants with Velcro or press-studs down the outside seam.
• Underwear or boxer shorts can be worn with press-studs or velcro down the seam.
• Girls often find wearing a long skirt a comfortable alternative to pants.
• Do not buy new or expensive clothing as the fixator often damages clothing.
• It is simple to make a “sleeve” to go over the external fixator, using a tube of material with elastic at each end.
• Children with a fixator on the thigh are able to wear their usual flat shoes, however those with lower leg fixators may need modification of their footwear. This can be addressed whilst you are in hospital. For lower leg external fixator short ankle socks are also needed.

The hospital stay
Admission to hospital is the day of surgery. The length of stay is usually 3–6 days. We recommend no visitors other than immediate family for the first two days to allow your child time to recuperate and rest. During your hospital stay,
you will be encouraged to participate in your child’s care. This is to ensure that you gain confidence and ease with handling the external fixator. Ward nursing staff and the limb reconstruction nurse are available to answer any queries you may have, and discuss ways in which you can manage at home. The time spent in the operating suite is generally between 3–4 hours. One parent is allowed to accompany the child to the induction room, where the anaesthetic is started, and both parents will be invited to the recovery room as your child wakes up. Once the operation has finished, a member of the surgical team will come and speak to the family.

Return to the ward
Nursing staff will closely monitor your child throughout the hospital stay. They will be assessing vital signs, (heart rate, breathing rate, temperature and blood pressure) and the operated limb.

Pain relief
Treatment with an external fixator will involve some pain and discomfort. For the first days following surgery, pain relief will be provided intravenously by either a patient or nurse controlled system (these methods will be explained to you fully by the nursing staff and anaesthetist). This is then followed by tablets or medicine, which the child will continue to take at home. Pain medication is required regularly during the early part of the treatment time, however once this is past, many children only require occasional medication.

Pin site care
The pin sites are dressed throughout treatment. Dressings will be changed daily for the first three days and then approximately every 7 days. Pin sites on the thigh are often dressed twice a week. All families are offered a 4–6 week package of care to attend to pin site care at home. Nurses from the hospital or Royal District Nursing Service will visit the home to attend to dressings. Some children find the cleaning of the pin sites uncomfortable to begin with, but this usually settles. All parents (and older children) are given the opportunity to learn to perform the dressings. Children are regularly reviewed as an outpatient and any troublesome pin sites will be reviewed at these visits. All families are given the opportunity to learn the dressing procedure. Be sure that your child does not poke things around the pin sites, or play with them. This can become a focus for infection and may lead to treatment time being delayed. The only time that pin sites are to be touched is during the dressing procedure.

Physiotherapy
This is a vital part of successful limb reconstruction. The amount of physiotherapy required will be determined on an individual basis. Your child will be seen on the ward the day after surgery, and gentle stretches will be started. The physiotherapist will need the help and support of the parents from the beginning. This may involve encouragement in the initial phase, and then supervision of exercises as they are carried out at home. A lot of children with a fixator are able to walk with assistance, and are encouraged to do so. Putting weight through the treated leg influences bone healing in a positive way. Walking also helps with independence of the child.

Follow up appointments
You will be seen in orthopaedic out-patients the week after your discharge. After this, you will be seen fortnightly whilst you are correcting your frame, and monthly after this time. X-rays will often be done at these appointments.

Discharge needs
Certain equipment may need to be hired from the hospital. This may include:
- Wheelchair.
- Legboard.
- Walking frame/rollator.
- Crutches.
- Portable ramps.
- Commode chair.
- Shower chair.

You will also need to purchase dressing products, so that the pin site dressings can be done at home. The approximate costs of these are $40. The limb reconstruction nurse or ward nurses will give you instructions on what to purchase.

Managing at home
Most children will spend some time in a wheelchair but eventually, we like all children to be up walking. It is important that walking is encouraged once allowed, as this helps the child gain independence, which in turn helps with acceptance of treatment. Once your child can safely use the crutches/frame then the wheelchair should be used only for long distances. In the early stages, the use of interactive toys and frequent scenery changes can help to alleviate boredom. Put some thought into activities that your child can participate in to help pass the time. When visiting new places, it is often useful to do some ‘research’ into the place you intend to visit. Check that there are facilities for the disabled; wheelchair access is vital if your child is using one.

Transport
Most children are able to travel in the car with some minor adjustments. Many children travel in the front seat of the car with the affected leg elevated on pillows or a small
beanbag. A seat belt or other approved safety restraint must be used at all times. To travel without your child being safely restrained is illegal. If your child uses a booster seat, the nurses may ask you to bring it up to the ward to ensure that your child will still fit into it safely.

Positioning and lifting
Correct positioning will be taught by the physiotherapist. This is to prevent the complication of contracture. A contracture is an abnormal shortening of the soft tissues and muscles around the joint. It results in stiffness and deformity. Common sites of contracture are hip, knee, foot and toes. Careful positioning, splinting and following your physiotherapy regime can prevent contractures developing. To prevent a foot deformity, always use the splint or sandal provided, particularly when resting in bed. To prevent knee contractures, it is vital that the child does not have a pillow placed under the knee. The use of pillows or a rolled up towel under the ankle will ensure that the knee remains straight. Older children with fixators can be very heavy, particularly if both legs are treated. The occupational therapist (OT) may be of assistance with providing equipment (eg. hoists). Likewise if you have any concerns about lifting your child or about the amount of support you have at home please discuss them with the limb reconstruction nurse, or the nurses on the ward.

Other handy information

Disabled parking permits
Ask the ward nurses/care manager or limb reconstruction nurse for an application form for a temporary Disability Sticker for your car. It can be very difficult getting your child in and out of a car in a small car space. The medical section of the form will be completed, then you must complete the rest and take the form to your local council to have the sticker issued.

VPTAS forms
If you have to travel more than 100 kms or 500 kms for five weeks or more to the nearest medical or dental specialist from home you may be eligible for travel assistance through the Victorian Patient Transport Assistance scheme. Forms are available from the limb reconstruction nurse, the care manager on the ward or from the Social Work Department on the 5th floor of the South East Building. Forms are also available at Department of Human services Regional offices. Your GP and surgeon will need to complete some sections of the form before you can claim

Internet sites
There are a number of sites that have information about external fixation devices. Please note that these sites will have some information and practices that vary from ours. This is not to say that some are right and others are wrong, rather, all are different.

When to call us
- If there is an increase in pain of the affected limb.
- If there is any redness, swelling or tenderness around any of the pin sites.
- If there is any discharge from the pin sites.
- If there is a fever that can’t be explained by a cold, ear infection or other illness.
- If there are problems with the fixator, such as broken wires or pressure areas on the skin under the rings.

Contact names and numbers

Limb Reconstruction Service: Cheryl Dingey, Mondays and Wednesday to Friday on 9345 7027 or via switchboard on 9345 5522 (Note if there is no answer, please refer to the ward or leave a message)
4 North: 9345 5303
Orthopaedic Outpatients: 9345 5311
Limb Reconstruction Fellow: 9345 5522 and ask for him/her to be paged
The Fellow is:  
Orthopaedic Registrar: 9345 5522 and ask for him/her to be paged
Physiotherapist: Greg Cull 9345 5411 or via switchboard on 9345 5522
Occupational Therapist: Anna Loughnan 9345 5402, Zoe Strang 9345 5402
Education Advisor: Barbara Emblin 9322 5121

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