Supporting Children with Multiple Limb Deficiency

An Information Booklet for Families, Teachers and Therapists
This booklet is designed to help families, teachers and therapists to understand how to enable and support children with MLD to maximise their independence and potential. We highlight practical ideas that can be used at home and school, particularly geared to those 0–11 years of age.

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Supporting Children with Multiple Limb Deficiency

All children are unique and often find their own ways of working things out. Children are adaptive and imaginative, and should be encouraged to be as independent as possible in everyday activities. Even if a child is unable to achieve complete independence, it is vital to encourage them to achieve maximum potential with appropriate support and adaptations. It is important for the child and family to be referred to a prosthetic centre at the earliest possible stage.

This will ensure that the child and family are supported at all stages of development, with expert advice and help. There are designated prosthetic centres, details of which can be found from Reach, Steps or the Limbless Association.

Causes of MLD:
MLD in children is very rare and may be the result of congenital (present at birth) defects of unknown or genetic origins. Children may also have amputations as a result of trauma or infection for example, meningococcal septicaemia.

This can be very distressing for the family so early referral, ongoing support, advice and encouragement from an appropriate service, is essential.

Team involved in caring for your child:
You and your child may meet the following people at the prosthetic centre:

Consultant in Rehabilitation Medicine – usually leads the multidisciplinary team in providing specialist care and attending to the medical needs of your child.
Counsellor – provides a safe, supportive, confidential environment to explore worries or concerns.
Nurse – attends to any dressings and give general nursing advice about the care of your child.
Occupational Therapist – assists you and your child to achieve maximum independence skills, with or without a prosthesis, both at home and at school.
Physiotherapist – assists your child to gain independence with mobility. Also they will assist your child to maintain good strength and range of movement of their remaining joints.
Prosthetist – is responsible for the manufacture and maintenance of your child’s prosthesis (artificial limb) or device.
Rehabilitation Engineer – may advise/design specialist equipment.

The following associations are also useful sources of information and support:
- REACH
- STEPS
- Meningitis Trust
- Limbless Association

More details available at the end of this booklet.
Medical Issues related to MLD:

Posture: MLD can affect a child’s posture; when your child has learnt to sit or stand, attention should be paid to good posture.

Body Temperature: People sweat through all of their skin, therefore absence of the hands and feet can result in different body temperature regulation. Children with MLD may feel very warm in summer and want to wear fewer clothes than expected in the winter.

Overuse of Remaining Limbs: Children will use all parts of their body, so it is important to be aware that repetitive activities can cause overuse of remaining limbs with long term wear and tear on joints and muscles.

Energy Requirements: Children with MLD may use more energy when performing everyday activities. They therefore may tire easily and attention should be paid to energy saving strategies where possible. Being over weight will make all tasks harder, therefore maintaining an optimum weight is advised.

Further considerations following amputation:

Scarring: Effective scar management is important to maximise the child’s potential for successfully using a prosthesis (artificial limb). Keeping the skin protected, supple and clean is essential and massaging is helpful. Joints moving freely to their full range can also be affected if scarring is around a joint area eg. a knee or elbow. These areas may require further surgery at a later date.

Oedema: Swelling of residual limb. Keeping the limb elevated and wearing compression socks helps reduce oedema.

Sensation/Pain: Following amputation some children may have the sensation of the amputated limb – phantom sensation and occasionally this may be painful. Discuss these different pain sensations with the team, there are treatment options available.

Bone Overgrowth: This is rare and occurs in a small percentage of children, mostly affecting children with amputations or limb deficiency below knee and above elbow due to the way children’s bones grow. When this occurs it can cause localised pain, problems with prosthetic fitting and occasionally skin breakdown. The problem may be solved by adapting the socket or may require surgery.

Prosthetics

A prosthesis (artificial limb) replaces the part of the body which is missing (plural = prostheses). A prosthesis will be considered when the child is at the appropriate developmental stage e.g. when wanting to sit, or pull to standing. If the child has an amputation, the fitting will be done when the wounds are sufficiently healed.

If the child has no lower limbs (with or without arms) cushions can be placed to assist balance in the early stages but a ‘sitting socket’ may be helpful to enable them to reach to play and engage with others. This socket can then be attached to wheels so they can be pulled along, like a ride on toy. As older children they may have prostheses, use crutches and many choose to use a wheelchair.

If the child has no legs from below the knee they will be able to sit and may pull themselves up to standing (as if kneeling). They will benefit from ‘stubbies’ (socks to protect their limbs) especially for outdoor use. They will learn to walk with these and may well progress to suitable prostheses at an appropriate time.

Children born without arms will probably not want to use prostheses in the early years but will learn to be independent with their feet and they should be encouraged to use their feet at all times. They may be interested in prostheses for cosmetic reasons when they are older but these may or may not add to function.

Children without arms at or above the elbow may find prostheses helpful at some stage in life. Consideration will need to be given as to what kind of prosthesis, elbow, hand or other device is beneficial.

Children without arms below the elbow are more likely to find prostheses useful but many prefer to have the sensation of their residual limb than the advantage that the prosthesis gives them. It is beneficial for children to be aware and if possible, try the different prosthetic options, so that they are fully informed and can be involved in decision making when they are old enough.

Often these children find specially designed tools and devices more useful than standard prostheses. Discussion with the Occupational Therapist or Prosthetist will be helpful and it may be helpful to be referred to one of the charities who make special equipment e.g. REMAP.

“When she was first born I found it difficult to come to terms with her disability. However I soon realised she is just like any other little girl who needs her Mummy to feed her, care for her, protect her, and love her unconditionally. The rest seemed to fall into place with time.”
Early Years

Whether the MLD is revealed before or after birth, how that information is given to, or discovered by the parents, can make an enormous difference to the family’s ability to come to terms with it. Counselling and support should be available for as long as it is needed, and can be accessed via the G.P. The Health Visitor will provide support, and a Paediatric Community Occupational Therapist and Physiotherapist should be involved if available in the area.

Some families find it helpful to be introduced to other families of children with limb absence. A very good way to meet people and share mutual support is to join one of the relevant support groups linked to organisations or prosthetic centres (see end of booklet).

Baby: A child with MLD may roll sooner than most children, and parents should be aware of this when placing their child on a raised surface, or in the vicinity of a hazard. Children will learn to use the sensation present in the end of their remaining limbs, so ideally these should be kept uncovered.

Use of standard nappies for children without lower limbs can be problematic. It is advisable to put a terry nappy over the disposable one folded in a way to cover the whole area to prevent leakage.

Posture and Mobility: A child who is having difficulty in developing sitting balance or trunk stability may benefit from support from a cushion, sitting socket, or a specialist seat e.g. for the car or the highchair.

Sometimes a child without arms may have difficulty learning to walk. This may be due to reduced balance. A push-along-toy may help your child to walk. Some may require the toy to have extra weight and an extended handle. A suitable bicycle or tricycle may need to be adapted by the prosthetic service, bicycle shop or REMAP. See www.reach.org.uk.

Discuss with your Occupational Therapist regarding specialist car seats and buggies.

Play: Children learn vital skills through play. If the child is without hands, they should be encouraged to use their feet to play and develop early co-ordination and grasp skills. Whenever appropriate, socks can be removed to give the child maximum sensation.

Self Care: The child’s Occupational Therapist can offer support and advice on the development of the following:

Self-Feeding: This should be started at the usual time using finger foods. If they are able to use a spoon it may be useful to use a longer one than usual, or a curved one. Availability and suitability can be discussed with your Occupational Therapist. Children who are learning to feed themselves using their feet, should start by sitting on the floor with the plate at the same level. They lift the finger food, spoon or cup to their mouth supporting it with the other knee. Non-slip matting may be useful to prevent crockery moving and a plate with a raised edge on one side is helpful for scooping up food.

Dressing/undressing: The following tips may be useful:

- Getting undressed is easier than getting dressed, so start with this skill.
- Always take your cue from the child. They will probably be able to work out the best way of doing things for themselves. Give them sufficient time and opportunity to practice.

- Choose clothing thoughtfully. Loose clothing is easier to manage initially. Elastic waists are best for skirts and trousers. Slip-on shoes or velcro fastenings may be helpful.

Discuss with your Occupational Therapist if your child is having any difficulties and to investigate whether any aids/adaptations may be of use.

Toileting: It is easier to practise at home initially when wearing pyjamas or nothing at all. Different types of potties are available to suit your child’s needs, and this can be discussed with your Occupational Therapist.

Later the child may need a secure inner toilet seat. Children with short or without limbs may find a small set of portable steps with a rail helpful. Alternatively a low stool and a handrail attached to the wall may be suitable. Once the child feels securely balanced, wiping can be attempted.

Children without upper limbs wiping themselves will be the greatest difficulty. Ideally the child should not be dependent on equipment only available at home.

The following are possible methods:

- Paper over the toilet seat or pan. A long length of soft toilet paper is pulled and placed over the toilet seat/pan so that it dangling into the water to prevent it slipping. The body is then moved on the paper and the soiled paper kicked into the toilet.
- Paper on the heel of one foot, which is positioned on the toilet seat. Move the body on the paper over the heel, and then shift the soiled paper into the toilet.
- It may be worth considering installing a wash and dry toilet at home, your Occupational Therapist can help organise this i.e Closomat.

Bathing: Children without lower limbs may be able to use steps to climb into the bath. The following equipment may be helpful:

- Non-slip mat
- Lever taps
- Long handled sponge or a wash mitt
- A towel with loops at either end
- Over-bath shower

For drying, try wearing a towelling dressing gown, lie on a large towel on the bed, or use an electric body dryer.
Getting about and the environment:
Ideally an Occupational Therapist or Physiotherapist will assess a child’s mobility around the school, including the risk of falling and teach the child how to get up if they do fall. When the class change rooms it may be worth considering allowing the child to leave class a few minutes early to minimise the risks. Children without upper limbs may have problems with balance when running around and they have no arms to protect themselves if they fall. Opening doors and climbing stairs may also be difficult.
For children without lower limbs, mobility may be with prostheses and/or wheelchair. Those walking may use walking aids and may need supervision.
For example, some children may require an adapted toilet, (including possible wash and dry facility) rails or steps. If they are taking their prostheses on and off, they may require a private changing area and assistance. A child with lower limb deficiency will require a wheelchair friendly environment and provision of appropriate equipment, however it is useful to remember that walking on ramps is more difficult than climbing up a step. School staff may also need to be trained in safe transfer techniques if using manual handling equipment.
Self care: By the time the child starts school they are likely to have developed their own methods of managing some tasks for themselves, however some children may still require a significant amount of support and time. Refer to earlier sections for more information.

Issues may arise around the school environment and the type of adaptations required will very much depend on the child.

Writing:
Positioning and posture will need to be considered, including chair and desk height, and possible use of an angled writing slope.
For a child without upper limbs they will be encouraged to use their feet and early introduction of computer can be considered alongside voice activated software or use of a scribe in lessons.
For a child without upper limbs use of prosthesis or device can be considered to help with writing. Other useful equipment could include: writing slope, slip resistant matting, adapted ruler, desk clamp, book holders, and adapted scissors.

Technology: IT knowledge is rapidly developing, such as the use of touch screen and voice activated technology that can be useful for a child to gain computer access. There are also many types of hardware available and this may require more formal assessment. For further details please refer to end of booklet.

Music:
It is helpful to encourage a child to participate in whatever way possible, such as through the use of feet and/or mouth for a child without upper limbs. A one handed instruments are available through Reach (further details at end of booklet).
Percussion or brass instruments can often be used although it may be necessary to adapt the method. Encourage singing too! It’s about being creative and inclusive.

School years
This section assumes a positive partnership between the family, school and health professionals. In order to help a child integrate into a new nursery or school, contacting the school and meeting teachers early helps to resolve any concerns before the child starts. If the child requires support or additional equipment this needs to be addressed before they start school. Emotionally this is an important step in easing the transition into the new environment and also ensuring that all those who are working with the child are confident in their role and how to help and indeed, to recognise when help is not required.
Most children will attend a mainstream school. Some will need a statement of special educational needs and appropriate support. It is vital to involve an Occupational Therapist at transition from nursery or pre-school to primary school and then on to senior school, with regular reviews.

Sport/PE:
For a child without lower limbs it may be possible to participate using a wheelchair or prostheses/walking aids, or floor level activities for example, sit down volleyball.
It is helpful for a child without upper limbs to participate in sporting activity where possible to help maintain mobility, strength in the upper spine and trunk, and balance.
Swimming is an excellent activity although access to pool will need to be considered and buoyancy aids for a child without upper limbs.
Practical lessons: Children can join in all class activities, adapting the activity and using equipment as necessary, for example food preparation devices.

Transition to secondary school:
It is highly recommended that before you start secondary school you involve an Occupational Therapist in moving onto a new school.
In particular, assessing the environment and offering support.
Psychological Considerations
It is important that the whole family receives information and reassurance from the professionals involved in their child’s care and that practical advice and counselling are available when needed.
Parents may need the opportunity to discuss their feelings and the time to adjust to the situation. When making decisions there is not one “right” decision. The opportunity to meet another families who have gone through a similar experience can be helpful.

Babies and very young children are unlikely to have awareness that they are different from other children. Parents may however, have difficulties adjusting to their child’s physical difference. It is important to offer and seek support in coming to terms with this.

In the early years social interaction with other children is important and attending a parent and toddler group can help both the child and the parent gain confidence. Meeting new people can help develop strategies for describing and talking about the limb absence.

Being matter of fact and using simple terms will assist the child to answer questions about their condition when they are older and seeing how their parents do this will be of great help to them.

Teasing can be very hurtful and most school children experience it at some time for anything that may appear “different”. Some children may benefit from assistance in dealing with this. Nurturing school and home relationships are important to resolve issues quickly and positively.

The opportunity for children to be part of the decision making process when deciding on their clothes and the opportunity to express themselves is important in creating a confident attitude. If they wear a prosthesis, being able to have some choice in style is important. The prosthesis may be viewed by the child as an integral part of their body, or it may be viewed as a device that is worn when carrying out a certain activity.

If you have any queries not covered in this leaflet, please contact your prosthetic Occupational Therapist or GP for further discussion.

“...amazed at what he can do. We could learn a lot watching him tackle any task head on. We are so very proud of our lad.” Dad

Useful support groups and contacts

**Reach:** The Association for Children with Upper Limb Deficiency  
Tel: 0845 1306 225  
Mobile: 07721 929 583  
E-mail: reach@reach.org.uk  
www.reach.org.uk

**Steps:** National charity supporting children and adults affected by a lower limb condition  
Helpline: 01925 750 271  
E-mail: info@steps-charity.org.uk  
www.steps-charity.org.uk

**Limbless Association**  
Tel: 01277 725182 or 725184 or 725186  
Out of hours tel: 07795 410 800  
www.limbless-association.org  
E-mail: enquiries@limbless-association.org

**The Meningitis Trust**  
Tel: 01453 768000  
UK: Freephone 0800 0281 828  
Children’s Helpline (UK only): Freephone 0800 801 0388  
E-mail: info@meningitis-trust.org

**The Douglas Bader Foundation**  
Tel: 07831 596 015  
E-mail: douglasbaderfdn@btinternet.com  
douglasbaderfoundation.com

**For IT and educational support:**  
**AbilityNet**  
Freephone 0800 269 545  
E-mail: enquiries@abilitynet.org.uk  
www.abilitynet.org.uk

**CENMAC (London only)**  
Tel: 02088 541 019  
Email: mail@cennmac.com  
www.cennmac.com/index.htm

**OHMI Trust** – One handed musical instrument trust  
www.ohmi.org.uk

**Adapt-IT:** Enabling through IT  
Tel: 0844 414 1325  
Email: info@adapt-it.co.uk  
www.adapt-it.org.uk

**ACE (Aiding Communication in Education)**  
Centre Advisory Trust. Based: Oxford & Oldam  
Tel: 01865 759 800  
Email: info@ace-centre.org.uk  
www.ace-centre.org.uk

**Keytools (Making IT Easier)**  
Tel: 0844 879 2282  
Email: keytools@hypertec.co.uk  
www.keytools.co.uk

**For custom-made equipment:**  
**MERU – Medical Engineering Resource Unit**  
Tel: 01372 725 203  
E-mail: info@meru.org.uk  
www.meru.org.uk

**DEMAND – Design & Manufacture for Disability**  
Tel: 01923 681 800 or 01484 666 261  
www.demand.org.uk  
Email: info@demand.org.uk

**REMAP – Custom made equipment for people with disabilities**  
Tel: 0845 130 0456  
www.remap.org.uk  
Email: data@remap.org.uk

**For Sports:**  
**English Federation of Disability Sport**  
Tel: 01509 227 750  
www.efds.co.uk

**Disability Sport England Online**  
Tel: 01619 532 499  
Email: info@disabilitysport.org.uk  
www.disabilitysport.org.uk

**Swimfriends – Specialist buoyancy products**  
Tel: 01332 842685  
www.swimfriends.co.uk

**Limb Power**  
Tel: 07502 276 858  
E-mail: kiera@limbpower.com  
www.limbpower.com

**Music / instruments:**  
**Living My Song:** Making music accessible for all  
www.livingmysong.org.uk
Acknowledgements:

This booklet was written by members of the South East Prosthetic Occupational Therapy Group (SEPOT), a subgroup of the Upper and Lower Limb Prosthetic Occupational Therapy Group (UL/LLPOT).

With special thanks to members of Reach, Meningitis Now and Steps for their feedback and contributions.

And to the children and families who consented to use of their quotes and photographs in this booklet.

Glossary:

Prosthesis – artificial limb
Prostheses – (plural of prosthesis)
Oedema – swelling from excessive accumulation of fluid
Residual limb – remaining part of absent limb/stump
Genetic – inherited
Congenital – present at birth
Paediatrician – a specialist in the care of babies and young children.

Reach:
The association for children with Upper Limb Deficiency.
Tel: 0845 1306 225
Mobile: 07721 929 583
E-mail: reach@reach.org.uk
www.reach.org.uk

Steps:
National charity supporting children and adults affected by a Lower Limb Condition.
Helpline: 01925 750 271
E-mail: info@steps-charity.org.uk
www.steps-charity.org.uk

Meningitis Now:
The first Meningitis patient group in the world, founders of the Meningitis movement and the only charity dedicated to fighting Meningitis in the UK.
Helpline: 0808 8010 388
E-mail: info@meningitisnow.org
www.meningitisnow.org