

# Wheelchairs for children

Some thoughts from parents



This booklet has been written by parents for parents. We hope that it might give other parents a better understanding when it comes to making choices for their children, helping to avoid some of the misunderstandings that we've experienced and the mistakes that we've made.

## **Extra support for sitting**

If your child is having problems sitting up, a buggy or wheelchair with postural support might be recommended. It is really important to get the right type of corrective and supportive seating at an early stage. This is not just for your child's comfort but also to help them to learn how to sit and may reduce the possibility of your child developing posture problems as they get bigger.

A good sitting position can make all the difference to how your child sees the world and interacts with everyone around them.

**Quote: " Our daughter is a teenager now and she has a curved spine – I wish we had accepted the seating system that we were offered when she was young"**

## **Going along to appointments**

Most wheelchair services have somebody who specialises in children's buggies and wheelchairs, and you will be seeing them many times as your child grows and their needs change.

There will be an initial assessment and although it isn't easy for any of us to know what to expect, it is really important for you to be actively involved at all stages.

**Quote: "Unfortunately because I work, I was unable to attend the appointment which was organised at school. A chair was delivered for my son that I knew nothing about":**

We have found that it works well when your own Therapist goes with you to appointments. They are the people who have valuable information to share about your child's physical needs.

**Quote: "Our daughter was quite anxious about going to the appointment, it affected her muscle tone and we were really glad that her physiotherapist came with us. She was able to give the best description on how Katie usually sits at home".**

## During the assessment

You might meet one or more of the following people when you go along: an Occupational Therapist, Physiotherapist, Bioengineer, Technician and in some cases, a Rehabilitation Consultant, Orthopaedic surgeon, Paediatrician and Orthotist.

They form the Assessment Team and will be responsible for assessing your child's physical, mobility and postural needs.

This will involve:

- Looking at your child's muscle tone and how much movement they have in their joints
- Looking at how your child sits and what seating support they might need, if any
- Taking measurements

You will also be asked some questions at the assessment and it is good to have a think about these beforehand.

- Where will your child be using the wheelchair or buggy – what is the physical environment of your home, their school, your neighbourhood like?
- What type of support does your child need to sit and does this change during the course of the day?
- What kind of transport will you be using? Will the wheelchair or buggy be suitable for public transport, will the wheelchair or buggy fit into your car?
- Are there other items of medical equipment that you need to carry all the time?

All this information is needed to be able to prescribe the correct size and type of equipment for your child.

Children generally want to be able to join in with their friends at school and in other activities – so a wheelchair that will fit in under a school desk if possible or an easily removable tray to allow access to a big craft table can make all the difference. Think about all the places you would like your child to go with their wheelchair (not just the places you go to now). Think about what is important to allow your child to go to these places. It might be that the chair is slightly too wide for some places. If you point this out sometimes a

slight adjustment can be made or an alternative may be found. It may not be possible to achieve everything with one piece of equipment and sometimes compromises will have to be made.

## **Buying your own wheelchair or buggy**

It is our belief as parents that no-one should have to spend their own money on buying a wheelchair, but you may find there are circumstances where it might be helpful to have, for example, a powered chair or a second wheelchair (such as a very basic one for quick shopping trips).

You can buy wheelchairs privately and it is good to think about the pros and cons:

- Will the chair be well suited to your child? It is vital to seek the opinion of an independent, informed professional – preferably someone who knows your child well and who can be involved with you when company reps come to try out equipment with your child.
- Look at the alternatives and, if possible, choose a supplier that offers more than one make of equipment. Looking at the choices can help you decide what the important features are for you and your child.
- Sometimes (but not always) privately purchased equipment can offer additional features that you would like.
- Wheelchairs bought privately can be available more quickly than through the NHS.
- There may be more choice of style, colour, etc.
- You will be responsible for all the repairs and maintenance needed – this can be expensive, find out about what extended warranties and maintenance contracts are available.
- You will need to ensure that you are insured in case of accidents to your child, to others and to the equipment itself.

# Mobility Aids and Lifestyle

We have all been involved in frustrating situations that could have been avoided by planning ahead, such as:

- Difficulties in getting in and out of the house
- Coping with narrow doorways
- Not having the right sort of vehicle to make transporting your child in their wheelchair as easy as possible.

## Access to your home

Your child is entitled to an assessment under Section 23 of the 1995 Children (Scotland) Act. The home assessment will look at the kinds of adaptations you might need. The kind of adaptations you might need to enable your child to move around the house may include:

- Fitting a ramp to your front door
- Widening doorways
- Putting in handrails
- Putting in a stair-lift
- Adapting other rooms
- Putting in a level-access shower
- Adapting the toilet
- Making part of the garden accessible so that your child can play outdoors

Ask your child's Therapist to refer you to your local Social Service Department for an assessment by a Community Occupational Therapist. You do not need to be in receipt of benefits to obtain financial help with building adaptations.

**Quote: "I had always thought that you only went to Social Services if you were a bad parent. I didn't realise that they could help a family like ours, parents both working, reasonably well-off, but not well-off enough to do all the building alterations that we needed to make the house accessible for our daughter. They came and had a look at the house and we got a grant to build a ramp and put in a level access shower. It took a while but it makes all the difference and they also told me we were entitled to a reduction in Council Tax into the bargain!"**

If your child has to use a wheelchair within the house, or requires an additional bathroom (not a toilet) to meet their needs, then in most cases you are entitled to a reduction in your council tax bill. Contact your local council tax office.

## **Getting Around**

You might want to think about an adapted vehicle which can transport your child in their wheelchair safely. It can be tricky to get from a wheelchair into a car seat, especially in a wet supermarket car park. There are lots of suitable vehicles on the market. You can get demonstrations of a range of these at exhibitions such as the Independent Living Exhibition or Kidz to Adultz Scotland which are usually held in Glasgow or Edinburgh every couple of years. Many companies also advertise in the specialist disability magazines for example "**Disability Now**" or "**Able**". Check with your wheelchair service that the wheelchair is suitable for use as a vehicle seat and look in the instruction book for instructions on fitting it safely into the vehicle.

It is important to get advice from your child's Occupational Therapist or Physiotherapist if you are thinking of buying a vehicle. It might also be an idea to speak to other parents who can describe the benefits and pitfalls of the different types, as well as the pros and cons of different methods of purchasing or hiring.

**Whatever you do, do not rely only on the company reps – their aim is to sell you their vehicle and it might not be the best option for your circumstances.**

**Quote: "we bought this car with a ramp at the back. The ramp was really heavy and I couldn't lift it out by myself. Then, once the luggage was in, we couldn't even stop at a service station. We had to take all the luggage out first before getting the wheelchair out. It was hopeless."**

## Concluding Comments

As parents we have all had to try to develop a positive approach so that our children can also be positive as possible about their wheelchairs and to see them as enabling pieces of equipment.

**Quote: “ When my eleven year old daughter told me “I hate being in a wheelchair, I wish I could walk like everyone else” it nearly broke my heart. But as a mum you can’t afford to become despondent, nor can you waste your life hoping for some kind of miracle cure. The fact is, for my daughter, a wheelchair is her way of getting from A to B. I told her “none of your friends dream about being able to walk – walking is only a means to an end. You should have bigger dreams than that”. Having a good life is not about being able to walk. For children who need wheelchairs it’s about getting one that works well, keeps you safe and enables you to live your life as well as possible”.**

## Glossary

### Adapted Vehicles

As your child grows, you may find that it becomes difficult to manage the transfer from a wheelchair into the car seat. One solution to this problem is a vehicle which has been modified so that the wheelchair can roll up a ramp into the car and be clamped in position. Other modifications include fitting lifts and rotating seats to the car. You may be able to get assistance from the Motability Scheme to purchase a modified vehicle.

### Bioengineer (Rehabilitation Engineer)

The NHS in Scotland employs Engineers who specialise in designing, modifying and fitting equipment that assists people with disabilities. The wheelchair service will have a Bioengineer who may be involved in adapting the equipment for your child so that it meets their individual needs.

## **Buggies**

Some young children have difficulty sitting up in a standard baby buggy. Other older children may find that they are too large for conventional buggies but they are not yet ready to move onto a wheelchair. In some cases, the NHS may supply specialised buggies to assist with mobility and seating problems.

## **Eligibility**

NHS Scotland has a set of rules or criteria that the wheelchair services follow to determine who can be supplied with wheelchairs and other equipment by the service. Copies of these are available through the wheelchair services and can be accessed via their web site

<https://www.nhsggc.org.uk/your-health/health-services/west-marc/info-centre/resources/>

A wheelchair which is propelled by pushing on the rims of the wheels or by an attendant pushing the handles.

## **Powered wheelchair**

A wheelchair that uses electric motors and batteries to provide the power, usually controlled through a joystick or by switches. Powered wheelchairs are a lot heavier than manual chairs and can be difficult to manage but can also give more independence.

## **Repair Service**

All wheelchair services provide a repair service to keep your child's wheelchair in good working order. If you have a problem, call the repair number which you will have been given by the service and the repair will normally be carried out at your home or at your child's school.



## **Special seating (postural support, supporting seating)**

Many children who have difficulty walking also find it difficult to sit upright for long periods. The wheelchair service may recommend that the wheelchair have a seating system built into it, this will give more support and improve the comfort of the chair. Whilst this will add to the weight of the chair, it should make it easier for your child to use and may help prevent orthopaedic problems from developing in the long term.

## **Wheelchair Services**

NHS Scotland has a responsibility to provide wheelchairs and other mobility equipment for people who have a permanent disability that affects their mobility. This service is provided by five centres whose addresses are at the back of this booklet.

## **Wheelchair Technician**

The wheelchair services employ Technicians who will carry out repairs and adjustments to your wheelchair. These are not the same as the Engineers (see above) who are involved in prescribing wheelchairs and seats.

## Contact Details

Should you require further information on wheelchair services you may wish to consider contacting the following organisations.

### **Rehabilitation Technology Information Service (ReTIS)**

ReTIS is jointly funded by all NHS Boards to provide a national information service in the field of rehabilitation technology. The service provides information and support in the areas of wheelchairs and seating, prosthetics, orthotics and electronic assistive technology:

**[www.retis.scot.nhs.uk](http://www.retis.scot.nhs.uk)**

### **Whizz-Kidz (The movement for non-mobile children)**

4th floor

Portland House

Bressenden Place

London SW1E 5BH

Tel. 020 7233 6600

**[Email. info@whizz-kidz.org.uk](mailto:info@whizz-kidz.org.uk)**

### **Communication Aids for Language and Learning (CALL) Centre**

The University of Edinburgh

Moray House

Paterson's Land

Holyrood Road

Edinburgh EH8 8AQ

Tel: 0131 651 6235

Fax: 0131 651 6234

**[www.callcentre.education.ed.ac.uk](http://www.callcentre.education.ed.ac.uk)**

The CALL Centre developed the Smart Wheelchair for children with severe and multiple disabilities who cannot use ordinary mobility aids.

## Addresses of the five wheelchair centres in Scotland:

<b>Aberdeen</b>	<b>Mobility and Rehabilitation Service MARS</b> Woodend Hospital Eday Road Aberdeen AB15 6LS
<b>Dundee</b>	<b>Tayside Orthopaedic and Rehabilitation Technology (TORT) Centre</b> Ninewells Hospital Dundee DD1 9SY
<b>Edinburgh</b>	<b>South East Mobility and Rehabilitation Technology (SMART) Services</b> Astley Ainslie Hospital 133 Grange Loan Edinburgh EH9 2HL
<b>Glasgow</b>	<b>West of Scotland Mobility and Rehabilitation Centre (WestMARC)</b> Queen Elizabeth University Hospital 1345 Govan Road Glasgow G51 4TF
<b>Inverness</b>	<b>Rehabilitation Services</b> Raigmore Hospital Inverness IV2 4UG

If you would like to talk to any of the parents involved in writing this leaflet, please contact your local wheelchair centre.

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Further printed copies of this booklet are available from:

**West of Scotland Mobility and Rehabilitation Centre (WestMARC)**

Queen Elizabeth University Hospital

1345 Govan Road

Glasgow

G51 4TF

Tel: 0300 790 0129

An electronic copy can be downloaded from the website

<http://library.nhsggc.org.uk/mediaAssets/Westmarc/Wheelchairs%20for%20children-%20Some%20thoughts%20from%20parents-270173.pdf>

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