FEEDING & EATING

INFORMATION FOR PARENTS OF DISABLED CHILDREN

contact

INTRODUCTION

It is the natural instinct of a mother to feed her child from birth to infancy and onwards. If a child refuses food or has difficulty with eating, it can leave parents feeling very anxious, helpless and frustrated. A disabled child can have difficulty feeding for several reasons. The child may:

- ***find it difficult to chew, swallow or digest certain food.***
- ***have limited mobility, making it more difficult to feed themselves on their own.***
- ***have a learning disability, making it more difficult for them to learn or understand appropriate behaviour when eating and at mealtimes.***
- ***be reluctant to eat, or only eat a few types of food. This type of behaviour can be associated with certain medical conditions.***
- ***be prevented from feeding/sucking as babies, because of medical problems and then find it harder to develop these skills later on.***

If your child is having problems eating it is important you seek help from a health professional who can check for possible medical causes as well as provide advice on how to deal with the problem.

Perseverance and patience can often be needed so mealtimes do not become a battle ground, leaving both child and parent frustrated with each other. Parents often find it helpful to talk to others who have faced similar problems. We can help you find groups who provide support around a child's specific medical condition and may also be able to direct you to parents living in your area.

This booklet lists some of the physical problems that can cause difficulties with feeding, provides a few tips and ideas around managing meal times, and gives details of other organisations that may be able to help.

PHYSICAL PROBLEMS THAT AFFECT EATING/FEEDING

- **Difficulty sucking** – many new babies experience initial problems and this does not imply they have a long-term medical condition. Problems with sucking can occur with certain conditions such as cleft palate and cerebral palsy. This problem will be apparent very early on and staff on the maternity ward, the midwife or a health visitor should all be able to offer suggestions.
- **Weaning** – this is the process when a young child moves on from drinking to eating solid food. Some children find it harder to chew solid foods so moving from milk to semi-solids to solids is harder for them. However some babies who find sucking difficult find eating semi-solid food easier so may thrive better when weaned. A health visitor can advise on this.

- **Bite reflex** – this occurs during feeding when the child immediately 'locks' the mouth onto anything that is introduced into it. The child is not doing this deliberately. A speech and language therapist can advise on techniques that may help and a plastic spoon will lessen the chance of injury to the mouth or damage to the teeth.
- **Choking** – regular choking can cause considerable anxiety for both the child and the carer. A doctor, health visitor, physiotherapist or speech and language therapist should be able to advise how to prevent choking and what actions to take if it does occur.
- **Constipation** – this is when a child is unable to open his/her bowels. It can be caused by an underlying medical problem, not eating enough of certain types of food, not drinking enough liquids or the consequence of reduced mobility. A health visitor, a paediatrician or the child's GP should be able to help.
- **Dental care** – difficulties in feeding can be because of the way teeth close together or as a result of pain caused by a dental problem. It can be more difficult to keep a disabled child's teeth clean. Frequent check-ups at the dentist are recommended and it may be necessary to go to a community dentist who has experience of dealing with disabled children.
- **Reflux** – is when food that has been swallowed comes back up into the oesophagus tube that goes into the stomach. This can cause discomfort both during and after eating and may cause vomiting. It should always be investigated by a doctor who can advise on treatment options.
- **Vomiting** – frequent vomiting may be distressing for all concerned. Where the child is physically disabled this may be improved by changing the child's position and avoiding lying down too soon after eating. If it persists seek advice from your health visitor or GP.

EATING INDEPENDENTLY

It can take longer for a disabled child to learn to feed themselves, however, as they get older most children prefer to be able to do this and find depending on others frustrating. It may take time and effort to help a disabled child to develop these skills but it will help them in other areas such as language development, mobility and hand-eye coordination.

EQUIPMENT AND UTENSILS

Most babies can be fed with the ordinary spoons designed for young children and readily available in high street stores. As children mature and begin to attempt to feed themselves there are a number of utensils that may help. Special plates, bowls, cups, adapted cutlery and non-slip mats that help to keep the dish in place are all available, as are specialist bibs to help keep food off clothing. An occupational therapist can advise what would be most appropriate.

DIET

A nourishing and well balanced diet is important for staying healthy. Health visitors and dieticians can advise on suitable diets. If there is a problem in chewing and swallowing then a speech and language therapist can advise on suitable food textures and consistency. This should help increase the range of food the child will take.

For general advice on what to feed your baby or toddler go to the NHS Choices website and search for 'what to feed young children'. There you'll also find Start4Life, their mini-site which has information on feeding and weaning very young babies **www.nhs.uk**

TUBE FEEDING

Sometimes babies and children aren't able to suck or swallow adequately, meaning they can't take in the nutrition they need. If this happens they can be fed by tube.

A nasogastric tube (NG tube) is passed up the nose and into a tube leading to the stomach

A gastrostomy tube is placed through a small incision in the abdomen directly into the stomach. This involves surgery.

Both have been shown to be helpful in assisting some people. Tube feeding may be a short term procedure but occasionally needs to be permanent. Sometimes a combination of tube and conventional feeding is recommended. Details of PINNT, a support group who offer advice to parents of children being tube fed is provided at the end of this guide.

HINTS/TIPS AROUND MEALTIMES

EATING TOGETHER AS A FAMILY

Sitting down as a family to eat a meal together helps children learn appropriate eating behaviour. It is particularly helpful to children who have problems learning or listening as they find out about appropriate behaviour by watching others. Parents can find it difficult to organise regular family meals, especially if other members of the family are coming and going at various times. Always make sure at least one person sits with the child while they eat and try to organise family meals whenever possible.

DECIDE A PLACE FOR THE CHILD TO SIT AT MEAL TIMES

Regular routine at mealtimes helps the child understand what is being asked of them. Try to choose a table and chair in proportion to the child's size. Some parents choose to sit their child in front of the television or video, so they can be distracted whilst eating. This may be a difficult habit to break and cause problems if eating out. It may be better to use a more mobile distraction, which can be more easily moved to the main table, for example a favourite toy or book.

GET THE CHILD INTO THE RIGHT POSITION

If your child is physically disabled they may need supporting so they are sitting in the right position. It is very difficult to eat or drink with the head tilted back. Seek advice from a physiotherapist/occupational therapist.

WARN YOUR CHILD WHEN THE MEAL IS NEARLY READY

If a child is engrossed in an activity they might have temper tantrums if suddenly told to stop what they are doing and come to eat. Warn the child the meal will soon be ready by talking to them, giving signs such as laying the table or showing them pictures of food.

RELUCTANT EATERS

When introducing new food, intersperse it with food you know your child likes. Don't force them to eat food they dislike. If your child has sat at the table for a short time and eaten a little food, then praise and reward them. If they find it difficult to sit for long periods you might try timing your child sitting down by using a large egg timer, and allow them to move once time is up. This will give them a visual link for 'sitting down time'. Over time you can gradually build up the sitting down period. Again don't rush things and don't expect instant change.

POSSIBLE CAUSES OF PROBLEMS

Try to identify what might be causing problems. Here are some possible ones:

- **Not in the right position** to eat comfortably, not able to see what they are eating or feeling insecure sitting in a big chair.
- **Not liking certain foods.** Children can sometimes dislike certain textures, tastes or smells. Keep a note of foods accepted or rejected to see if there is a pattern. This may simply be a 'food fad' which can affect all children.
- **Not liking the feel of cutlery in their mouth.** Metal utensils and forks are more likely to be troublesome.
- **Some children like to see the food presented on the plates in a certain order** and don't like their food being mashed together.
- **Being overwhelmed with the amount of food on the plate.** It can be better to only offer a little food at first, and add more if wanted.
- **Some babies prefer to feed themselves with finger food** rather than being spoon fed.
- **Having to sit close to one particular person.**
- **Lots of noise or distractions** from other members of the family.

UNSOCIAL BEHAVIOUR

If your child really plays up at the table and even resorts to spitting food on the floor, try not to give them a reaction as this will only reinforce their behaviour and may encourage them to do it again. This is not an easy thing to do. Never try to force food as this will create even more of a problem.

REMEMBER

Try not to let your child sense if you are feeling stressed about his/her eating habits as this may create further anxiety and make the problem worse.

IS YOUR CHILD EATING ENOUGH?

It may sometimes feel that your child has hardly eaten anything all day, so it is sometimes worth writing down what they have eaten. It might surprise you that it is quite a lot even if this is chocolate, sweets and crisps! Take this with you when you go to discuss their diet with a health professional.

GETTING SPECIALIST HELP

There are times when parents need specialist help and support. Don't struggle alone but talk to your child's doctor, health visitor or nurse. Try to get a referral for help from an appropriate professional. The dietician, community nurse, speech and language therapist and occupational therapist all have particular skills which can help you and your child.

Our guide ***Concerned about your child*** lists all the people who may be able to help. It's free from our helpline **0808 808 3555** or to download at **www.contact.org.uk/parent-guide-concerned**

USEFUL CONTACTS

Contact

We provide support to families of disabled children, whatever their condition. We offer a telephone interpreting service in over 200 different languages. We can also put parents in touch with each other and with support groups for their child's condition.

Helpline: 0808 808 3555
www.contact.org.uk

National Autistic Society

Advice and information on feeding and eating for parents of children with an autism spectrum disorder. Search for 'eating' on their website. They also have information on PICA – eating or mouthing non-edible items, such as stones, dirt, metal and so on.

Helpline: 0808 800 4104
www.autism.org.uk

PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy)

Advice on tube, nasogastric or intravenous feeding. They have a linking scheme for parents to get in touch with each other to share problems and experiences. Search for 'Halfpinnt' in the website.

020 3004 6193
www.pinnt.com

Scope

Have an A-Z of eating difficulties on their website, plus tips on feeding children with under or over-sensitive mouths. Search for 'eating difficulties'.

0808 800 3333
www.scope.org.uk

GET IN CONTACT

Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

0808 808 3555

info@contact.org.uk

www.contact.org.uk

twitter.com/contactfamilies

facebook.com/contactfamilies

youtube.com/contactfamilies

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We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

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