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Mealtimes

A guide to eating issues for people with cerebral palsy and those that care for them

Introduction

Some people with cerebral palsy may experience difficulty eating. This factsheet examines some of the issues that may relate to such difficulties.

Sometimes babies with cerebral palsy will have difficulties with feeding, from the breast or bottle, that are apparent soon after birth. Such difficulties may continue throughout life. Others may experience an onset of difficulties later in life, occasionally in adulthood.

There may be a number of reasons why someone with cerebral palsy may be having difficulty eating. Possible causes include structural abnormalities, psychological or behavioural conditions, motor or sensory impairments, or something else that isn't related to their cerebral palsy. Because of the diverse nature of such difficulties it is necessary to take a multidisciplinary team approach to investigating and working on them. The team should include a speech and language therapist (who is likely to be the team leader), a physiotherapist, an occupational therapist, a dietician, a doctor, a health visitor (in the case of children), district nurse (in the case of adults), the person's carers and the person with cerebral palsy themselves (if appropriate).

If you are a person with cerebral palsy who has concerns about eating or you are a carer concerned about someone you know, then it is important that you seek advice and support. The first step is getting an assessment. You may already be having contact with health professionals, who will form part of the multidisciplinary team. If so, you can express your concerns to them. Alternatively, contact your local speech and language department, they will have access to a therapist specialising in such matters. If you are finding it difficult to access assistance or are uncertain who to talk to, you may find your

GP a good starting point for getting specialist help.

It is important to remember that mealtimes are not just about eating but can also provide a valuable opportunity for communication and social interaction. They should be enjoyable occasions and as stress-free as possible.

The early years

Sucking. Some babies with cerebral palsy may experience difficulties with sucking, either from the breast or bottle. It is important to remember that many new babies experience initial problems latching onto the nipple or teat and that it does not necessarily imply that a baby has cerebral palsy. Seeking early advice on any feeding difficulty is recommended. The nursing staff on the maternity ward are often able to assist. There may even be a specialist nurse advisor available. Once the baby is home, the Health Visitor should be able to advise if the problem persists.

Weaning. Unless there is a good medical reason not to, babies with cerebral palsy should start to be weaned at the same age as babies without the condition, often at about four months. The baby's health visitor should be able to advise on issues to do with weaning. The speech and language therapist is also a very useful person to seek advice. Weaning may take longer than it would for a child who doesn't have cerebral palsy and considerable persistence may be needed. It can be a frustrating process and so the person responsible for helping the baby to progress from milk, to semi-solids and then chewable food, may need a lot of support. Many babies with cerebral palsy actually find eating semi-solid food easier than sucking and so may thrive better once they have begun to be weaned. Prolonged use of bottle-feeding should be avoided but not at the expense of nutritional or fluid intake.

Growing up and gaining more independence

Many people with cerebral palsy would prefer to be able to sit at the table and feed themselves, even if it takes longer or is messier than being assisted to eat by someone else. Being able to choose what one eats and when one eats it is one of life's pleasures for many people. Most children with cerebral palsy will learn to feed themselves to some degree eventually. Taking the time and effort to help a person to develop these skills can sometimes also help them in other ways, such as language development, greater awareness of

position and movements and hand-eye co-ordination.

An A to Z guide to eating issues

The following is a brief introduction to some of the issues that might be relevant to mealtimes, for either children or adults with cerebral palsy. It is not intended to be comprehensive or to be used for diagnostic purposes. If in doubt always seek professional guidance.

Bite Reflex. This is when the person being fed immediately 'locks' their mouth onto anything that is introduced into it. They have no control of this and it may only happen occasionally. Sometimes a speech and language therapist can advise on techniques that may help with this and demonstrate how to 'unlock' the jaw if the reflex occurs. The use of a plastic spoon will lessen the chance of injury to the mouth or damage to the teeth.

Choking. This is often caused by poor positioning of the head and trunk. Regular choking can cause considerable anxiety at mealtimes for both the enabler and the person with cerebral palsy. In the worse case scenario it may even result in death. Receiving advice about how to react to choking may help lessen any anxiety and make those concerned more confident that they know how to react in an emergency. A doctor, physiotherapist or speech and language therapist should be able to advise. Persistent choking should always be investigated by the doctor.

Constipation. This is common in people with cerebral palsy, especially if they have reduced mobility. An underlying medical problem, poor diet and/or inadequate fluid intake may be the cause. Often the situation can be improved by adding more fruit, vegetables and whole grains to the person's diet. If the problem is happening frequently, the advice of the general practitioner should be sought.

Dental Care. Sometimes difficulty in feeding can result from the way the teeth close together or as a result of pain caused by a dental problem. No one should neglect their dental care but for some people with cerebral palsy it is especially important because they may take certain medicines that may increase the risk of gum problems. Good oral hygiene can be more difficult for those that have limited control in opening their mouth, bite reflex or are reliant on others to clean their teeth for them. Frequent and regular check-ups at the dentist are therefore recommended. It is also possible to seek assistance from specialist dentists.

Diet. A nourishing and balanced diet is an important factor in maintaining health and well-being. This can sometimes be difficult to do for some people who experience difficulty eating, especially if they can only eat certain types of food or can only manage small amounts. Some people with cerebral palsy experience a lot of involuntary movements. These movements burn up energy, which needs to be taken into account when the person's diet is being planned. A person with cerebral palsy may need to consume extra calories to compensate for the additional movement.

Sometimes a food supplement is suggested or prescribed to help ensure that a person's nutritional needs are being met.

Health Visitors can advise on food consistencies and suitable diets to wean babies onto. The advice of a dietician may be helpful, both for children and adults. Speech and language therapists can also advise especially in relation to the food texture and consistency an individual will find most manageable.

Dysphagia. This is a technical term for swallowing difficulties.

Equipment and Utensils. Most babies can normally 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 be helpful. Special plates, bowls, cups, adapted cutlery and non-slip mats to help keep the dish in place are all available. Also there are specialist bibs and other things to help keep food off clothing. The occupational therapist should be able to advise what would be most appropriate and how it can be obtained.

When items are being obtained for adults it is important to consider whether the appearance of them makes them suitable for someone of that age. Equipment and utensils should enhance a person's sense of self-reliance and independence. This is unlikely to be the case if the items serve further to single the person out from their peer group e.g. bibs with pictures of teddies or bunnies are not appropriate for adults!

For those who experience poor trunk control or are unable to support their own heads, specialist supportive furniture may be recommended by the professionals working with the person. Sometimes it is necessary for the person assisting with eating to help support the head with their hand. A person should never be fed with their head falling backwards as this causes a possible risk of choking

or vomiting.

There is also 'high-tech' equipment available to assist adults in having a greater degree of independence at mealtimes. These take various forms, such as a robotic arm that moves food from the bowl to the mouth. Such things are not necessary or suitable for the majority of people with cerebral palsy and often have to be independently funded.

Excessive Drooling. This difficulty can be particularly troublesome for a person who has no awareness that they are dribbling or is unable to wipe their mouth themselves. In addition to making mealtimes messier it has potential social implications and can sometimes result in the chin becoming sore. Scope produces a factsheet on this topic that may be of interest, details of which are listed at the end of this factsheet.

Feeding and Swallowing Advisory Clinics. There are a small number of specialist clinics in the United Kingdom. They may be able to assist, should the advice received from the multi-disciplinary team prove not to be sufficient. In order to attend a specialist clinic it is normally necessary to obtain a referral from a health professional.

High Palate. This is not uncommon in people with cerebral palsy. Should food gather in this space, it is likely to stick there. If this occurs it needs to be removed during the meal to avoid the possibility that it may later drop down and cause choking.

Hypersensitivity. Some people with cerebral palsy will experience additional difficulty with eating because they are unusually sensitive to being touched on their face or in their mouth. Similarly, they may have a strong reaction to the temperature or texture of their food or drink. A speech therapist or occupational therapist may be able to advise on ways of working on this. Often a programme of activities to gradually get the person used to such sensations and build up their tolerance to them may be recommended.

Non-Oral Feeding. This may be necessary for some people who are not able to suck or swallow adequately to get proper nutrition or to avoid food passing into the lungs rather than the stomach.

The most common type is naso-gastric, where a tube is inserted up the nose in order to pass food into the stomach.

Some people with cerebral palsy are fitted with a gastrostomy tube (often naso-gastric tube feeding will have been tried first). A tube is

surgically inserted directly into the stomach through a small incision made into the abdomen.

Both naso-gastric and gastrostomy tube feeding have been shown to be helpful in assisting some people with cerebral palsy. Tube feeding may be a short-term procedure but occasionally it needs to be permanent. Sometimes a combination of tube and conventional feeding is recommended.

If you are responsible for the care of someone who is being tube fed, it is important to ensure that you are confident and comfortable with what needs to be done. Support and advice should be available from the doctors, nurses and therapists at the hospital. There are also specialist support organisations (see resources list). Remember that those being tube fed should still be included in the social interaction of mealtimes.

Positioning. It is important for the person with cerebral palsy to be in the best possible position for eating. This will vary from person to person depending on their medical condition. The physiotherapist or occupational therapist, together with the speech and language therapist, are the best people to advise on positioning.

Reflux. This is a problem resulting in discomfort during or after eating. On occasions it may cause vomiting. There are several reasons for reflux such as medical or anatomical problems, allergy, or limited movement patterns. Investigation by the GP is suggested in the first instance.

Supplements. see Diet.

Tongue Thrust. This occurs when there is a strong, inappropriate and unconscious forward movement of the tongue that pushes food out of the mouth. This should not be confused with behaviour that looks similar but is really a conscious attempt by the person to communicate that they do not wish to eat what is in their mouth. It is worth seeking professional advice, normally from a speech and language therapist, on techniques that may help with tongue thrust.

Tube Feeding. See Non-oral Feeding.

Vomiting. Frequent vomiting maybe distressing for all concerned and should always be investigated. Sometimes the problem can be helped by improved positioning and avoiding laying down too soon after eating. If this doesn't help, seek the advice of your GP, as the

causes of the vomiting may need to be investigated.

Recommended reading

Feeding the Disabled Child. 1996. Edited by Peter B Sullivan and Lewis Rosenbloom. Published by MacKeith Press. ISBN 0069 4835.

Feeding Problems in Children. 2000. Edited by Angela Southall and Anthony Schmartz. Published by Radcliffe Medical Press. ISBN 1 85775 218 2

Scope factsheets

Scope's Drooling and Cerebral Palsy factsheet gives further information on the unintentional loss of saliva from the mouth. It can be viewed and printed off from www.scope.org.uk or alternatively the Cerebral Palsy Helpline can post out a copy on request.

Further information

ARCOS (Association for Rehabilitation of Communication and Oral Skills)

Whitbourne Lodge, 137 Church Street, Malvern, Worcestershire, WR14 2AN

Telephone/fax: 01684 576795

Email: arcos@globalnet.co.uk

Website: www.arcos.org.uk

A national charity working for improved services for people with communication and feeding difficulties. Services include nationwide assessment, advice, information and equipment loan.

BSDH (British Society for Disability and Oral Health)

Dept. Of Special Care Dentistry, Chorley and District General Hospital, Preston Road, Chorley, Lancs, PR7 1PD

Telephone: 01257 245664

Website: www.bsdh.org.uk

Aims to improve, preserve and protect the oral health of disabled people.

Disabled Living Foundation

380/384 Harrow Road, London, W9 2HU

Telephone: 0845 130 9177 (local rate)

Textphone: 020 7432 8009

Fax: 020 7266 2922

Email: dlfinfo@dlf.org.uk

Website: www.dlf.org.uk

Gives practical, unbiased information and advice on disability equipment

Gut Motility Disorders Support Network

Westcott Farm, Oakford, Tiverton, Devon, EX16 9EZ

Telephone: 01398 351173 (weekday mornings only)

Email: help@gmdnet.org.uk

Group offering telephone support to parents of children with a range of conditions that result in the regular movements of the digestive tract being disrupted.

Half PINNT

3 St Martins Close, Harpenden, Herts, AL5 5JG

Telephone: 01582 765238

Offers advice to parents of children on tube, naso-gastric or intravenous feeding.

PINNT (Patients on Intravenous and Naso-gastric Nutrition Therapy)

PO Box 3126, Christchurch, Dorset, BH23 2XS

Telephone: 01202 481625

Email: pinnt@dial.pipex.com

Website: www.pinnt.com

Voluntary organisation supporting people requiring nutrition therapy. Sub-committee called LITRE that deals with equipment problems and a children's group called Half PINNT (see above).

This document is for information purposes only.

For more information about cerebral palsy and Scope services

Contact Scope's Cerebral Palsy Helpline for information, advice and support. Copies of all Scope's information sheets can be downloaded from the website or obtained from the Helpline. Referrals to Scope's Community Teams and services can be made through the Helpline.

The Helpline hours are:

Monday - Friday 9 am to 9 pm. Weekends 2 pm to 6 pm

Cerebral Palsy Helpline

PO Box 833

Milton Keynes

MK12 5NY

Tel: 0808 800 3333

Fax: 01908 321051

Email: cphelpline@scope.org.uk

Scope's website address is www.scope.org.uk

Scope acknowledges the help and support of everyone who has been involved in the production of this information.

This information can be made available in other formats if required eg. large print or tape. We also have information about Scope and cerebral palsy available in 13 languages on audiotape and can offer a telephone interpreting service to people whose preferred language is not English.

Please contact Scope's Cerebral Palsy Helpline for more details of these services.

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