

Children with Exceptional Healthcare Needs

National Managed Clinical Network

The emotional impact of tube feeding.

How does it feel?

"To feed your child is such a natural part of parenting it can feel really hard to lose this role....."



Introduction

This is an information leaflet for parents/carers whose children need help with feeding. The impact of tube feeding is different for everyone. Parents' experiences of tube feeding and their feelings have informed the content of this leaflet.

Your child may already have a nasogastric (NG) tube or the doctors may have asked you to think about tube feeding or your child having a gastrostomy. The practical aspects of tube feeding will impact on your day to day life and it's natural that you may also be feeling emotional about this change.

Why is oral feeding important to us?

"...it's what you do as a mother for your baby"

Feeding and eating is very much part of everyday life:

- it helps parents to bond with their child
- it's a way of showing love and care
- it's about choice and control
- most cultures celebrate with food.

Losing that ability and choice to feed orally, even when parents understand the reasons, can feel challenging and distressing.



The emotional impact

Your feelings may be complicated, confusing and distressing and this is completely natural. However necessary, many parents experience the move to tube feeding as a loss. This may be for the reasons opposite but also because you are on a continuing journey of acknowledging and adjusting to your child's difficulties that are ever changing and probably not at all what you expected as parents. In addition, a lot of what you consider 'ordinary life' may be feeling medicalised.

"I can't decide what he eats or really how he feeds.....you lose so many choices that other parents can have..."

Deciding to change to a gastrostomy

The decision to feed your child through a nasogastric tube may have been something that was necessary and even life saving. However, this may not mean that you are able to easily accept the need for a change to a gastrostomy. It is important that the people around you acknowledge this. Often people need time to think about this decision and have the opportunity to talk through all the implications for your child and your family.

Your child with feeding difficulties

Children have varying degrees of awareness and you will know what your child can understand and how best to communicate with them. Your child may never have had a chance to feed orally, but if they have been fed orally then losing that sensation may make them sad too. If feeding was always a struggle, starting tube feeding may feel a relief. Acknowledging how your child is feeling can be helpful for you both.

Each family will deal with things in their own way. Some parents try not to expose their child to food once tube feeding has started. Others are keen to include their child in every meal time and in the preparation of food. Parents say it helps to talk about what you want to do and what will work best for your family.

Other children

Understandably your child with feeding difficulties will take up much of your time and attention. You may well feel guilty and anxious about this if you have other children. Your other children may be worried about their brother or sister or may be jealous and angry with them. They could feel guilty and confused by their feelings or want to be involved in their care. Eating and food takes on a new meaning for everyone and it's fine to talk about all of these feelings.



Brothers and sisters may like to be involved in the care of their sibling and prepare food together.

Who to talk to about how you are feeling:

If you are affected by the issues mentioned in this leaflet you can talk to the people involved in the care of your child, such as your:

- children's community nurse
- nurse specialist
- dietician
- paediatrician
- health visitor.

Many parents find speaking to other parents very helpful. Voluntary and parent organisations can also offer emotional support and a chance to talk about how you are feeling.

Useful Contacts

Childrens Health Scotland
enquiries@childrenshealthscotland.org
Tel: 0131-553-6553

Contact a Family
<http://www.cafamily.org.uk/scotland>
Tel: 0131-659-2930

PINNT UK
COMMS@pinnt.com
Tel: 020-3004-6193

PAMIS
<http://pamis.org.uk/>

This leaflet was developed by the National Managed Clinical Network for Children with Exceptional Healthcare Needs. More information about the work of the network and other useful support organisations can be found on our website.

www.cen.scot.nhs.uk

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