Category: Behavior, Medical/Genetics

Friday
Breakout Session #3:17: 2:15-3:15
Palomino 6 & 7

The Challenge of Mealtimes for Children with CHARGE

Steve Rose
Head of Children's Specialist Services / Specialist Speech and Language Therapist
Sense

Presenter Information:

Steve Rose is a Health Professions Council registered speech and language therapist specialising in working with people with deafblindness. He has previously worked as an intervenor and for Sense working with family support groups until returning to study to train as an SLT. Graduating from UCL in 2003 he subsequently worked in special schools in North London with children with physical disabilities, sensory impairments, autistic spectrum disorders and learning difficulties. Steve has particular interest in the development of eating and drinking skills and early interventions, including parent-child interaction therapy. He has recently completed his MEd in deafblindness at Birmingham University and currently heads Sense Children's Specialist Services.

Presentation Abstract:

It is well documented that individuals with CHARGE syndrome may face difficulties with eating and drinking. There is emerging literature that documents the prevalence of these issues and support intervention for such difficulties.

This presentation explores literature of the prevalence, nature and range of difficulties and the subsequent challenges presented. The features of CHARGE that relate to difficulties with mealtimes are also identified. It will outline some observations on the nature of the challenges facing children with CHARGE seen at our centre in North London. These challenges will be discussed in the context of case studies to illustrate individual challenges and possible management strategies.

It is recognised that the early oral experiences of children who experience challenges eating and drinking have an impact on later development and prognosis. The involvement of cranial nerve dysfunction in CHARGE leads to a high percentage of children having eating, drinking and swallowing disorders – up to an estimate of 80% of all cases (Sanlaville and Verloes 2007). In addition there are numerous other factors and co-occurring features that impact on these difficulties, combined these present significant challenges for the child that are often seen as 'behavioural feeding issues'.

Case studies will identify some of the 'mealtime behaviour' of children seen at our centre and begin to develop some understanding of the challenges facing this group of children and the sort of support that could help to overcome them. This is an area where there is less specific literature and it is hoped that this paper will begin to contribute to a greater understanding of these issues for this group of children.

The challenge of mealtimes for children with CHARGE syndrome

Steve Rose
Speech and Language Therapist / Head of Children's Specialist Services
11th International CHARGE Syndrome Conference
July 25-28 2013

The plan for this session is to

- explore the nature of eating and drinking difficulties in it's broadest context.
- look at the neurological control required to eat and drink, including to trigger the swallow (a pattern elicited response).
- look at which aspects of CHARGE impact on eating and drinking, exploring themes which have emerged from the evidence base in this area.
- identify other issues based on observations made within our service paying particular attention to sensory-based feeding disorders illustrated with case studies.

"For most of us, food and drink are sources of pleasure; they satisfy hunger and thirst, help to structure our day and provide opportunities for social interaction"

(Winstock 2007 p.1)

"The primary goal in managing eating and drinking difficulties should address the child's safety [of swallow], nutrition and hydration needs along with emotional well-being of the whole family."

(Winstock 2007 p 128)

Challenges

1) children who present with some sort of oral / motor problem (dysphagia)

2) children who present with a sensory based feeding difficulty

3) children who have difficulty organising the transfer of food to their mouth.

Risks

Dysphagia:

- Dehydration and malnutrition (leading to organic failure to thrive)
- Aspiration
- Choking
- Faltered development of eating and drinking skills
- Infection (secondary to previous risks)

Sensory based feeding difficulties:

- Dehydration and malnutrition (leading to non-organic failure to thrive)
- Faltered development of eating and drinking skills

Neurology and swallowing

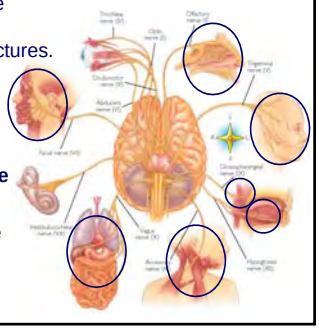
The normal swallow is a four stage process

- Oral preparatory stage – food is manipulated in the mouth.
- Oral stage – tongue pushes food back.
- Pharyngeal stage – swallow reflex triggered, food moves down through pharynx.
- Oesophageal stage – food moves down to the stomach.

Neurology and swallowing

Cranial Nerves involved in the Innervation of the oral and pharyngeal muscles and structures.

I Olfactory Nerve
V Trigeminal Nerve
VII Facial Nerve
IX Glossopharyngeal Nerve
X Vagus Nerve
XI Spinal Accessory Nerve
XII Hypoglossal Nerve



CHARGE

79 - 90%
of children with CHARGE have feeding difficulties

(Blake et al 1998, Harvey et al 1991, White et al 2005, Hartsthorne et al 2005, Dobbelsteyn et al 2008)

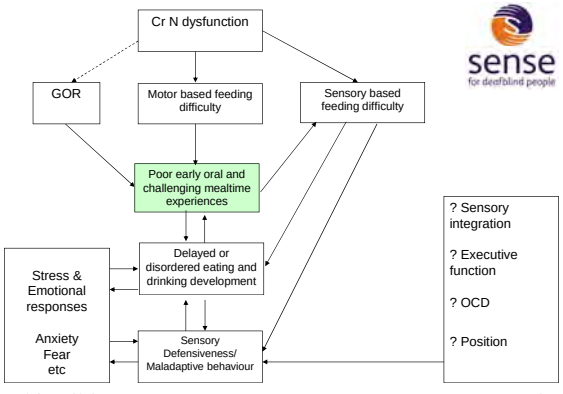
Characteristics of CHARGE associated with eating and drinking difficulty.

Motor related

- Cranial Nerve dysfunction
  - Smell (Cr N I)
  - Weak suck / poor chew (Cr N V VII XII)
  - Swallowing difficulty (Cr N V IX X XI)
  - GOR (Cr N X)
- Respiratory problems
- Cleft (lip, palate or both)
- Choanal Atresia

Sensory related

- Cranial Nerve dysfunction
- GOR
- Long term NG tube
- Discomfort (related to GOR?)
- Numerous medical interventions



Our Assessment Centre

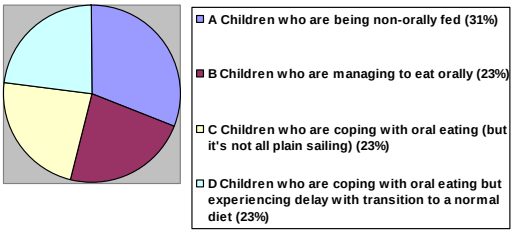
A: Children who are being non-orally fed

B: Children who are managing to eat orally

C: Children who are coping with oral eating (but it's not all plain sailing)

D: Children who are coping with oral eating and experiencing delay with the transition to a normal diet

Our Assessment Centre



Case studies

Preparing for mealtimes

- Take time
- Involve the child in preparation
- Set up the environment
- Sit in a good seating postion
- Prepare the face / hands (massage?)
- Use the right cues (more, enough, stop!)
- Establish sensory equilibrium – Sensory diet activities before the mealtime
- Think about starting, continuing and finishing
- Prepare the right texture foods (and separate tastes)

During mealtimes

- Use the right utensils
- Relax!
- Don't have a battle
- Take a break – consider little and often?
- Think about the social elements
- Consider use of distractors and motivators

Food Play Texture Hierarchy

Easy			Challenging
Firm and dry: ▪Dry textures fall away and the child can control contact with the texture. ▪No brushing or wiping is required	**Soft and Dry:** ▪Dry textures that mostly fall away, some particles or bits may stick to the hand, ▪Brushing residue required to break contact	**Wet:** ▪Wet textures that maintain contact with the hand but the child can easily break contact with the texture ▪Requires wiping to break contact with texture.	**Wet and sticky:** ▪Wet textures that stick to the hand and the child has least control when breaking contact with the texture, ▪Requires repeated wiping to break residue away.
▪Marzipan ▪Ready roll icing ▪Broken pancakes ▪Cereals – cornflakes, rice krispies, cocoa pops etc. ▪Uncooked noodles (hard) ▪raw vegetables (either whole or in chunks – but dry!) ▪liquorice ▪snack foods – skips wotsits,	▪Icing sugar ▪Cocoa powder ▪Dry angel delight mix ▪Dry porridge oats ▪Granulated sugar ▪Sherbert ▪cake decorations – hundreds and thousands, strands etc	▪Water ▪Cooked noodles ▪Cooked lentils ▪Cooked pasta / spaghetti ▪Cooked rice ▪Jelly ▪Mashed potato ▪Ice cubes ▪piping icing ▪Custard ▪Yoghurt ▪Baked beans ▪puréed fruit and vegetables	▪Melted chocolate ▪Mashed banana ▪Angel delight ▪Porridge ▪Ice cream ▪Tinned Spaghetti ▪chocolate spread ▪jam, lemon curd etc. ▪ketchup ▪sweet and sour sauce
			Items may also include additional properties at this end of the scale (e.g. ice cream is wet, sticky and cold)

Oral motor / awareness programmes

Conclusions for management

- Proactive management promoting positive mealtime experiences
- Whilst anatomical and medical aspects are being managed the introduction of a positive oral stimulation program is considered and where possible implemented
- Mealtime assessment should be undertaken between SLT and /OT colleagues and within the context of a sensory integration approach.

"need for sensory integrative approach to management of eating and drinking. Feeding is a highly integrated multisystem skill and many contemporary clinicians support the approach that it is not helpful to focus solely on the child's mouth but to consider the whole child, including the environment, the child's sensori-motor profile and the context of mealtimes when developing a treatment plan" (Maune 2007 p.4)

Conclusions for management

- Multi-professional, trans-disciplinary management .
- Transitions are planned and reviewed frequently, with a a duty to promote transition to oral feeding.
- Investigations should be undertaken for GOR and aspiration for all individuals with CHARGE syndrome
- Intervention is ongoing, multidisciplinary and multi-sensory system

"All children with CHARGE syndrome to be followed proactively by a multidisciplinary team consisting of gastroenterologist, ENT surgeon, nutritionist and other feeding specialists (occupational therapist and/or speech and language pathologist) to ensure appropriate management of feeding issues"

Dobbelsteyn et al 2008 p 132

"The presence of gastro oesophageal reflux and aspiration early in life will increase the probability of ongoing feeding problems……
Dobbelsteyn et al 2008 p 132

"follow up should involve multi disciplinary feeding team and parents should be made aware of the potential long term feeding issues"

Dobbelsteyn et al 2005 p. 99

Contact Details

Thank you to all the children and families who supported this presentation.

Steve Rose
Head of Children's Specialist Services
Specialist Speech and Language Therapist - Deafblindness

Children's Specialist Services
Sense, Novellus Court
61 South Street
Epsom
Surrey
KT18 7PX
tel: 0845 127 0076
email: steve.rose@sense.org.uk