

Myotubular Trust Family Day: Finding strength in eating and feeding

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Finding strength

- Sharing concerns and solutions
- Individual stories and solutions are unique
- Normalising and dissolving blame
- Understanding challenges
- Mourning and accepting losses
- Noticing exceptions, possibilities and strengths
- Building strength through playful and collaborative approaches

Mealtime dance

- Who's responsible for what?
- Parent
- Child

- **Parent** provides structure, what's on offer, expectations of social behaviour in your culture
- Aim for setting that allows child enough independence and exploration
- Respect child's caution and encourage step by step learning

The child's role

- Experiences control over own body
- Builds self-esteem through developing skills in a safe context
- Regulates own appetite as much as possible
- Learns to fit in with social rules of family mealtimes
- Learns from watching others
- Enjoys social conversation
- Develops own eating preferences within family cultural context
- Gains energy to live life to the full

General facts and principles

- Feeding is emotional, social and physical
- Feeding oneself and playing with food are important aspects of development
- An area for children to develop autonomy
- Feeding good nutritious food = commitment of loving parent
- Child who does not/cannot eat may = parent feels bad/inadequate
- Tension understandable: 1/3 of under fives parents report problems with eating, up to 40-70% in children with chronic illness

Can I trust my child to eat enough?

- General feeding advice based on fact that even young babies good at self regulating amount of food they eat
- BUT ability to self-regulate affected by
 1. Physical and medical factors
 2. Supplementary feeds
 3. Unpleasant experiences

How come we like what we do?

- We learn to eat from range of food we're given in early childhood
- Liking and disliking tastes are both natural and helpful
- Children are most open to new tastes and textures in early months and years
- 18 months – 5years: fear of new foods appears and strengthens but can be overcome by imitation and trying slightly different but similar foods
- Strong unpleasant experiences can be very off putting e.g. vomiting, GOR, tube discomfort, force-feeding
- The more you come across a food, the more likely you are to 'like' it (up to 20x tastes to like)
- Step by step approach helps e.g. looking, smelling, mixing, touching, to lips, tasting, chewing

How children learn skills for eating

- Play, exploration, experimenting, games
- Socially – models in family, peers
 - from how others respond to them e.g. positive attention for behaviour you want to see more of, ignore what you want to see less of
- Regular setting – cues, routine, few distractions
- Step by step e.g. build up child's confidence and self-esteem in trying new food
- Cognitively – understanding nutrition and social value e.g. stories when younger, educational resources for older ages e.g. www.fooddudes.co.uk, may wish to change restricted pattern in later childhood to be like peers

Ingredients for change

- Don't blame yourself or your child – join forces
- We battle for things we value – what are the values that are worth 'fighting' for in your family?
- Where are those values coming through in other activities you and your child do ?
- Use your own and your child's strengths and imagination to reassure yourself about where they're doing well, how mealtimes are ok and to learn new skills if medically safe

Be clear about your family aims

- Relieve pressure of weight management
- Increase oral intake
- Making eating more bearable/achievable
- Create a relaxed context for mealtimes
- Broaden food choices
- Give child/young person increased control
- Identify and build on strength and positives
- Expect behaviour your child can do e.g. social rules
- Help your child learn new skills and confidence

Looking for strengths

- If you are seeing a 'problem' look around for its partner 'solution' in your child and family e.g.
- Battle working together
- Helplessness Ability
- Laziness tries hard
- Slow fast
- Fear bravery
- Guilt values
- Disinterest interests
- Weakness strength

Building solutions

- Look for exceptions – where you and child enjoy mealtimes or show strengths needed to improve mealtimes.
- Be curious – how come? What's different? They may be much smaller than 'the problem' but can be built on
- Look to the future – how would you like things to be, what other changes might change this too, what would be a little step in right direction, how to cope in the meantime.

Who can help?

- You as a resourceful parent who knows your family values and child best
- Your child with his/her unique strengths and dreams
- Your family if you can discuss differences, agree shared goals, assign roles according to strengths and needs
- Friends who will listen, help you identify strengths in you and your child, share possibilities
- Health professionals, parenting resources.