

Principles of Nutritional Management

1. Every child with the diagnosis of ARFID will be unique in their nutritional requirements, due to their age, foods they will eat and concomitant diagnoses (i.e. food allergy). It is therefore important to seek individualised advice.
2. The primary nutritional priority is to ensure that requirements are met to support growth and development, in a way that is acceptable for the child. This may include:
 - a. Recipes for nutrient dense foods that fall within the food acceptance of the child.
 - b. Adjusting existing recipes to increase energy density.
 - c. Oral nutritional supplements-which need to be tailored towards taste acceptance and underlying diagnosis.
 - d. Modular additions (fat, protein and carbohydrates) that can be added to accepted foods.
 - e. Vitamin and mineral supplements (Please see guide to vitamins and minerals).
3. In children where growth faltering has been identified as a problem, it is important to note that catch up growth occurs not only with energy (i.e. addition of fat), but a combination of energy, protein and vitamins/minerals involved in growth (i.e. zinc, iron, vitamin D).
4. Children with ARFID will not eat a new food, even if they are very hungry. Advice on new food introductions should therefore not be based on waiting for the child to become hungry.

5. Even if a small variety of food is consumed, it is possible with supplements/oral nutritional supplements/food enrichment to achieve normal growth and development with appropriate advice.
6. Reduce the stress around mealtimes by:
 - a. Avoiding force feeding or coercion to trialling, new foods.
 - b. Avoiding extended mealtimes (ideal to reduce < 30 min).
 - c. Offer foods that the child will eat (even if this is the same food every day).
 - d. Provide guidance on what is an appropriate portion size for a child of that age and if portions are smaller then energy/protein enrichment may be indicated.
7. Consider how a child makes food choices to help with trialling new foods:
 - a. This is usually driven by a combination of texture, colour, temperature and smell of food.
 - b. New foods should ideally fall within the same identified sensory characteristics identified in point a.
 - c. The expectation should not be to consume a food the first time offered, but just for the child to tolerate the new food next to or on the plate and then allow further exploration at the rate acceptable for the child. It may take many many months before a child feels comfortable enough to take a bite of a new food.
 - d. Food chaining may be a useful method your dietitian may help you with.

Information For Schools

What are complex feeding disorders?

Some children develop complex feeding difficulties which cannot be explained having a swallowing or mechanical feeding problem.

Features of a feeding disorder can include some, but rarely all, of the following:

- A lack of interest in food.
- Rarely appearing to be hungry or asking for food.
- Avoiding / refusing to sit down for meals.
- Turing away, pushing the spoon away etc.
- An over-developed disgust response - gagging or vomiting at the sight/smell of food
- Eating very small amounts.
- Refusing to self-feed.
- Quickly complaining of being full/tired during meals.
- Spitting out food.
- Crying/screaming when being fed.
- Saying s/he does not like a particular food before trying it.
- **Eating a very restricted range of foods (selective eating). We usually refer to these foods as the child's 'safe foods'.**
- Eating a restricted range of food textures e.g. no lumps, dry crunchy only, smooth puree only etc. The refusal of fruit and vegetables is largely texture-related.
- Hyper-sensitive gag reflex - gagging and vomiting whilst being fed.

In the past children with these features were labelled as having a 'behavioural feeding disorder' – implying that they are being naughty or controlling. We prefer the term 'complex feeding disorder' or 'selective eating'. There is also a diagnosis of 'avoidant / restrictive food intake disorder' that is used when children show extreme anxiety/distress when asked to eat foods outside their "safe set".

Children with selective eating often eat only foods that are of a specific brand. This is because they crave predictability and sameness with regard to texture, smell and taste – something that is difficult to achieve in home cooking, even home-cooked versions of a child's safe foods. They may notice even small changes, particularly in 'new improved' recipes and a previously accepted food may be suddenly rejected.

What causes complex feeding disorders?

There is usually no one single cause. Instead, complex feeding difficulties usually involve a combination of factors. The following will increase the likelihood that a child may develop a complex feeding disorder: (not all children will have all factors).

- Prematurity.
- Complex medical problems in early life, requiring invasive procedures such as suctioning, ventilation, frequent blood tests or surgery.
- Complex medical conditions that affect appetite e.g. renal conditions.
- Early feeding difficulties e.g. problems latching on, falling asleep during feeds, small frequent feeds etc. Breathlessness on feeding, as seen in cardiac conditions may have long term effects, even after surgery.
- Poor sleeping and difficulties with self-calming.
- Vomiting or gastroesophageal reflux in infancy.
- Severe constipation.
- Eczema / food allergies.
- Late introduction of solid foods due to illness.
- Developmental difficulties – slow speech and language development, poor joint attention behaviours, preference for playing alone.

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- General dislike of change/new thing.
- Continued temper tantrums beyond the age when these are usually resolving.

Complex feeding difficulties, particularly selective eating patterns, are very common in children with autistic spectrum disorders, but not all children with complex feeding difficulties are autistic.

Parental mis-management of mealtimes is rarely the cause of feeding difficulties. However, anxiety over weight gain and nutrition has often resulted in stressful mealtimes. Selective diets are not what parents would choose for their children, but may be necessary in the early years to ensure a child grows and gains weight.

Many children with complex feeding difficulties also have other 'sensitivities' e.g. .

- Dislike of teeth cleaning.
- Dislike of the face being touched/washed.
- Irritated by collars / labels in clothing.
- Fear of hair-washing or cutting.
- Dislike of having messy hands.
- Dislike of bare feet.
- Unwilling to touch sand / paint / sticky substances.
- Other fears and strong reactions e.g. loud sounds, fluffy toys, animals, the dark etc.

How are complex feeding difficulties managed?

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Because feeding disorders arise from several factors, assessment and management often requires a multidisciplinary team:

- Doctors can advise on the management of any medical issues e.g. gastroesophageal reflux, allergies, respiratory health etc.
- Dietitians can advise on nutrition. Increasing the energy content of foods can mean that a child receives the maximum amount of energy for the minimum amount of food. Energy supplements (food or drinks) may also be available on prescription for children who are not showing expected weight gain and growth
- A speech and language therapist can advise on food textures e.g. suggestions for helping a child to move from puree to more chewable textures. She may also advise on strategies to improve communication at mealtimes, so children understand what is expected of them.
- Clinical psychologists advise on strategies for managing mealtimes, and helping children become more interested in eating. They can help parents to think about how to help their child at home to develop appropriate eating patterns.

Feeding difficulties have usually developed over months and years and can therefore be difficult to change. Some strategies which may have been suggested by well-meaning family members, friends or even professionals who are not expert in this area, such as force feeding, long gaps between meals or withholding preferred/safe foods in the hopes that a child will eat healthy foods, almost never work. Reward systems are often unhelpful (as they increase anxiety in the children) unless extremely carefully designed.

Progress may be very slow, often requiring several months before significant change is seen. Progress will be limited if medical problems (such as vomiting) are not resolved. Professionals with expertise in this area will work with families to set realistic targets, whilst monitoring a child's weight gain, growth and nutritional status.

What can schools do?

The ideas given below may be suggested by the feeding disorders team. Not all strategies are appropriate to all children, and should be discussed with the team supporting the child.

- Packed lunches – many children will eat a set of safe foods at school as part of a packed lunch. The safe foods rarely meet healthy mealtime guidelines as they are often carbohydrate-based, may contain sugar and rarely include vegetables. Exceptions may be required for children with complex feeding disorders as denying them access to safe foods may mean they eat nothing during the school day.
 - School lunches – some children may be able to eat one school meal per week, often on Friday when foods such as chips or pizza are available. If typical school practice is for children to have a little bit of everything on their plate this should not be enforced with children who have complex feeding disorders. Such children often have a strong 'contamination fear' – this is when safe foods are 'contaminated' by being on the same plate as unsafe foods e.g. chips can be eaten, but if a vegetable is put on the same plate, the chips will be rejected.
 - Avoiding offering new foods directly. It may sound counter-intuitive to not offer a child new foods, but our experience suggests that **the child needs to think that trying a food is his/her own idea**. Offering new foods simply provides the child with further practice of refusal – something they are already rather good at. Instead schools can make new foods available, often in the context of cookery sessions, but without asking the child to try them. When we feel they can cope we may suggest that 1 new food (a food eaten by the child's peers) is placed near the child or on his/her plate, alongside the safe foods.
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- Children are often more prepared to eat 'new foods' in the nursery/school context, where they have not already built-up routines and expectations.

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Such children clearly benefit from being included in school meals, eating alongside others, but they may need to have a smaller selection of food on their plate. Start with safe foods, and place one “new food” on a separate plate saying “here’s some ..., you eat it if you want to “.

- Desensitisation –sometimes we suggest a structured programme of desensitisation, to be undertaken in one-to-one sessions with a trusted person. There are several stages in the process of eating a new food and it may be necessary to work very slowly through a hierarchy. The next step is only introduced when a child is comfortable at the previous stage. Stages may include:

1. Looking at the food e.g. seeing on someone else’s plate, near the child’s own plate and finally on the plate (with no expectation it will be eaten, and no encouragement to do so).
2. Smelling the food.
3. Giving out the food to other members of the family e.g. by
4. passing the plate around.
5. Touching the food.
6. Bringing the food to the lips.
7. Licking the food.
8. Nibbling the food.
9. Eating small amounts – some children may need to spit out the food, preferably into a separate bowl or tissue.

Often children require pictures to support these stages – this can reduce anxiety and negotiation, whilst reminding the children of the target and then reward. We sometimes use a story book about Marvin the Food Scientist to help children work through these stages.

- Praise for desirable behaviour – many chronic food refusers receive most of their attention at mealtimes for undesirable behaviour (refusal) e.g. coaxing, bribery, threats etc. We would suggest only talking about

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desirable behaviours i.e. eating, however little. Comments such as 'nice eating', 'you're doing really well', 'you've had 3 spoonfuls of your potato – well done etc' will help to reinforce the good, rather than focusing on the negative. Maintaining this positive attention can be difficult, and is another reason for having shorter more frequent meals.

- Star charts are rarely helpful for introducing new foods. However, once a new food has entered the child's repertoire they may have a role in increasing the quantity a child will eat. They may also be helpful to encourage consistency e.g. if drinking sufficient quantity of fluid is a problem, a chart giving a realistic target (slightly less than on a good day, and slightly more than on a bad day) can be created. If the child achieves a certain number of ticks e.g. 3 cups a day on 5 out of 7 days, s/he can earn a reward. The reward should be set in advance (with a picture of it on the chart) so the child knows what s/he is working for.

Most children with complex eating disorders do get better. They gradually learn to recognise feelings of hunger and realise they need to eat.

It is common for children's eating patterns to be better in school where they may be prepared to try the foods they see other children eating – their desire to be like their friends can help them to overcome their strong disgust response, although this rarely happens before the age of 4 ½ years.

As children get older they can also learn about what foods they need to eat to be healthy and a more cognitive approach is possible.