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This leaflet has been produced in a multi-disciplinary working project between Speech & Language Therapy, Occupational Therapy & Psychology at Ryegate Children's Centre.

Parent/carer information leaflet

Children With Neurodevelopmental Difficulties Who Avoid or Refuse Food

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Our young patients are at the centre of everything we do and all our work is focused on providing them with the best facilities, equipment and experience possible, helping to provide a world-class facility that is positioned at the very forefront of paediatric care.

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Introduction

Children with developmental difficulties (e.g. Autism Spectrum Disorder) often have problems with eating. Research has shown that 40-80% will have problems with food at some point. This can range from children who over eat to children who have restricted diets.

As parents/carers, it may feel really difficult if you are worried about your child's eating patterns. Food can be a really emotional issue, and mealtimes can end up being stressful and frustrating for families.

We hope this leaflet will give you more information about eating problems in children with developmental difficulties who avoid or refuse food. It also contains advice about strategies to try and how different professionals at The Ryegate Children's Centre might be able to help.

It is important to remember that we all have a "limited diet" and our own food likes and dislikes. Think about the meals you eat each week, or what you have for lunch each day. It's probably fairly similar.

Restricted eating only becomes a problem when:

- A child isn't growing properly or is not getting enough of the right nutrients they need.
- It has a significant impact on family life.
- It interferes with the child or young person's social life, or makes it difficult for them to fit in.

Key Points

- We all have a limited diet, but there are specific times when this becomes a problem, especially for children with developmental difficulties.
- Understanding your child's experience of food and eating will help you find the cause of their restricted eating.
- Over-sensitive children may need preparation for eating, a good sitting position, distraction from the appearance of food and a lower sensory environment for mealtimes.
- Children who have had stressful feeding experiences may need help to develop their feeding skills and make more positive associations with eating and food.
- Children with restricted diets may need change in their diet to happen gradually and slowly and at times in their life when they feel safe and free from other stresses.
- Never hide food you want your child to eat, in food you know they will eat. You may "contaminate" the safe food.

Who else can help?

There are a number of professionals at The Ryegate Children's Centre who might be able to help you think about your child's eating and give you advice.

- **Parent Workshops:** If your child has an Autism Spectrum Disorder (ASD), you will have been invited to a workshop which aims to help parents increase their overall understanding of ASD. As part of this workshop, eating difficulties are discussed and some general strategies are provided.
- **Sensory Service:** If your child has ASD and sensory issues that are affecting them in a number of ways, including eating, you could be invited to a Parent Sensory Workshop run by the Occupational Therapists and Physiotherapists.
- **Speech and Language Therapy:** If your child will only accept a limited range or texture of food, the Speech and Language Therapist will assess your child's chewing and swallowing. You will then have the opportunity to attend a workshop with the Speech and Language Therapist, to explore strategies that you can try at home.
- **Psychologists:** If your child's eating difficulties are a symptom of more general difficulties with managing anxiety, you might be invited to a workshop aimed at helping your child manage difficult feelings.
- **Doctors:** If you or someone else is really worried that your child's eating difficulties are affecting their health, they may be reviewed by a paediatrician or referred to a dietician to make sure they are growing and have all the nutrients they need. The dietitians are based at Sheffield Children's Hospital and your GP or paediatrician will be able to refer your child to them.



If your child is experiencing any of the above, then hopefully this leaflet will help.

Why are children with neurodevelopmental disorders more likely to have problems with eating?

Some children may have sensory difficulties affecting their experience of how food looks, smells or feels.

Social interaction difficulties may mean the social aspect of eating is challenging, for example, sitting in a school dining room. They also mean children are less likely to observe and pick up good eating behaviours from other people.

Children with neurodevelopmental disorders find change is difficult, and tend to prefer things around them to stay the same. This may be because their brains process information differently, or because they tend to have higher anxiety levels than other children. This can make it difficult for children to try different foods or eat in new places.

How can I help my child?

All the above reasons mean children with neurodevelopmental disorders are more likely to have had difficult experiences of food or eating and to feel anxious or 'unsafe' around certain foods.

The important part of knowing how to help is understanding your own child's experience of food and eating. This can help find the cause of the problem. A **food diary** can be a really useful place to begin. Start to take note of what is eaten and when.

{ WEEKLY FOOD DIARY }							
	monday	tuesday	wednesday	thursday	friday	saturday	sunday
breakfast							
lunch							
dinner							
snacks							

Sometimes keeping a food diary can also be reassuring because you might discover that your child eats a greater amount and wider range of foods than you originally thought.

The following information and advice might also be helpful in thinking about your child’s relationship with food.

Is it sensory?

Lots of children with neurodevelopmental disorders also have sensory processing difficulties.

Taste and **smell** are two of our senses which influence our eating behaviours.

Children can be **over sensitive** to certain tastes and smells. These children often present with a dislike of **strong tastes** and restrict their diet to bland foods. They may dislike the **textures** of certain foods, such as wet, runny, mushy or lumpy foods, and restrict themselves to dry foods such as toast or crackers. The **smells** of food cooking can be over-whelming for very sensitive children.

Some children are **not sensitive enough** to tastes and smells. These children tend to **crave strong tastes** and **smells** (e.g. hot curry), and hard, crunchy textures. They may try to eat non-foods.

Manage your stress. Children learn very quickly that *what*, and *how much* they eat is important to their parents.

If you are anxious, your child will probably sense this. It may make them more anxious, or they may see an opportunity for exerting their own control and bargaining with you. If your child is healthy and growing, avoid getting into a debate with them. Let them eat what they want without making a fuss.

Remember eating a new food is challenging for everyone! We will all only try a small taste of something new, don’t put the amount of food you want your child to eat on the plate and then have to throw it away, give them the amount you know they might eat.

Remember that your child will probably be feeling **really scared** about trying a new food. Give them lots of **praise** every time they make a step towards trying anything new.

Remember that what is ‘normal’ eating for a child with developmental difficulties might not be the same as ‘normal’ eating for a child who doesn’t have developmental difficulties. Think about what should be normal for your family, and try to stick to that.



Strategies that might help with behaviour and eating

Involve your child if possible. Talk to them about a goal. Is there a particular food they want to be able to eat? Is there a situation where they want to be able to eat? Make this manageable by only choosing one thing to work on at a time.

Your child will need to go through different stages to accept new foods.

First let your child just **look** at the food, then **touch** it, then invite them to put the **food on their plate**, then **smell** it, **lick** it, put it into their **mouth**, **bite** it, **chew** it, and **swallow** it.



Try not to react negatively to food being spat out. This is helping your child to become comfortable with different foods being in and around their mouth.

Each of these steps could take months to complete. Try to see the goal as learning about and being comfortable around different foods, rather than getting them to eat all of the different foods presented.

Manage your expectations: Don't expect big changes to happen quickly. It will take time for a child to accept new foods (research has found that children need to try food at least 8-15 times before they accept it into their diet).

Strategies that might help **over-sensitive** children:

Is your child ready to eat?

Warn your child that a meal is nearly ready (5 minutes is enough), so that they have time to prepare their sensory system.



Desensitise their mouth. Some children benefit from some massage around the face and mouth before eating, using their own hands or the handle of a vibrating electric tooth brush held against the cheeks and lips for a few minutes.

Is the smell of cooking too much?

If possible, avoid cooking and eating in the same room, as some children will be overwhelmed by the smells of cooking and then unable to eat.

Are they sitting comfortably?

Make sure your child is comfortable where they are eating. If they are sitting at a dining table, make sure their feet can touch the floor, or rest on a stool/box under the table. If they prefer to eat with their feet tucked underneath them on the chair, or kneeling up, allow this. The extra sensory feedback to their body may calm the over-sensitivity in their mouth.

Do they need distracting?

As well as the smells and tastes, some children find the sight of food off-putting because they are visually over-sensitive. If this is a problem for your child, accept that they may eat better when distracted by watching a TV programme or the iPad. You may have to lower your expectations for conventional table manners if you want your child to eat!

Do they need a calmer environment?

Busy school canteens and noisy restaurants can be overwhelming for an over-sensitive child. If they won't eat at school, ask if there is a quieter, calmer space for them to eat their lunch.

Is it about anxiety?

When we are anxious, our senses will be heightened. This means that smells, tastes and textures become more over-whelming. We also experience lots of physical sensations, including feeling sick or a '**butterflies in the stomach**' sensation when we're anxious. If we feel like this, we may only feel like eating certain things.



We also know that when children are anxious, they become more **rigid** and **inflexible**. This will make it more challenging to try new foods or change their behaviour around eating.

Sticking to **routine** around food and mealtimes can help children feel more comfortable, but try to avoid going to extremes to get your child to eat, such as presenting the food in a certain rigid pattern.

Is it about behaviour?

The answer to this question is probably YES!

Something is described as a behaviour when we have learned to do it or not to do it. Learning happens very quickly when we have had a 'bad experience' because our brains are programmed to keep us safe and avoid danger.

Most people will be able to think of foods they don't eat because of one **bad experience**, such as being ill. For children with neurodevelopmental disorders, most eating difficulties will start as a sensory issue or a difficult experience with food (e.g. reflux as a baby, being sick), but your child will learn very quickly to avoid certain foods or eating in particular times or places.

When we have learned that something isn't safe, we have to **retrain our brains** to realise that it's OK really. This is called '**desensitisation**'. Desensitisation involves a gradual exposure to new foods and can lower anxiety and eventually lead to the food being accepted into the child's diet. However, just like learning anything new, it can take lots of time and practice to feel comfortable.

Strategies that might help:

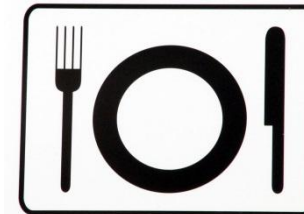
- Never hide food you want your child to eat inside food you know they will eat. This may contaminate their **safe food** and they may refuse to eat it again.
- Listen when your child tells you a food they have previously eaten (or you would like them to eat) is different or 'wrong'. They are probably right! Understanding why they have a problem with something will help you work out a solution.
- Try to think about introducing foods that are **similar** in some way to something your child already eats, e.g. colour, texture, food group. You could try talking to your child about how a food might be similar or different to other food they already like.
- Presenting the same food over a few days or weeks can be helpful, rather than changing frequently between new foods, e.g. have a '**food of the week**'.
- A new food on the same plate as a safe food may contaminate the safe food for your child. Think about **putting new food on a separate plate**.
- Make sure your **child sees you** eating the food you would like them to try.
- For some children, writing a **social story** might help you work out together what is OK and not OK about differences in foods.



Prompt your child to try things but **never put pressure on them** to eat something. This will increase their anxiety and have the opposite effect.

Strategies that might help highly anxious children:

Think about when to make changes. If your child has a lot of difficult things going on in their life, it might not be a good time to start trying to introduce new foods.



Reduce stress in other areas of their life.

If you think your child's anxiety is affecting their eating behaviour, it might help to reduce other demands in their life. For example, make sure their **daily routine is predictable and consistent**, introduce **visual reminders**, ensure they have plenty of **calming activities** planned into their day and reduce **unnecessary social interaction**.

Is it about food?

Has your child had experiences with food and eating that have caused them stress?

Past feeding experiences can have a big impact on how children eat, even from as far back as from when they were born. If your child was born prematurely and fed by a tube or vomited a lot when feeding this can cause difficulties with eating later on.

If mealtimes at school or at home are stressful this can affect appetite and reduce the amount a child will eat.

Has your child missed out on eating different textures so they are unsure what to do with foods in their mouth?

The Speech and Language Therapist can advise you how to help your child develop the different skills needed to chew different foods. This might involve some messy food play.

Messy food play can help children explore food without the pressure to eat. In time this will help lessen their anxiety around food. It will also help them explore how foods feel, smell and change. This will help them know how food will feel and behave in their mouth and may desensitise them to the feel and smell of food.

How do you and your child communicate about food and mealtimes?

It is important that you communicate with your child in a clear, consistent and calm way.

Presenting information visually can also help. This could be a visual timetable to show when meals are, what foods are on offer at school or pictures of emotions to help your child express how they feel about food.



Try not to categorise foods into healthy and unhealthy, or good and bad. This can sometimes be taken too literally and can cause further problems. Instead look at the different categories of foods and what physical characteristics the foods share. All crisps are hard, beige and crispy but vegetables come in all different colours shapes and sizes! This is one reason why fruit and vegetables are so challenging for children

Is it to do with the social aspect of eating?

The social nature of mealtimes can be stressful. Your child might be more relaxed, and eat more volume or variety, if they are allowed to eat in a **smaller group** or room at school.



If a meal is not going to be at home, **prepare your child in advance** by telling them who will be there, who will they be sitting with or next to, what people might talk about, and what they could say to start a conversation.

A **social story** could help someone to understand why we eat and the function of food.

Is it because change is difficult?

Most children with neurodevelopmental disorders find change difficult and prefer things around them to stay the same. One reason for this is that their brains process information differently. Children with neurodevelopmental disorders often have a brilliant attention to detail, but can find generalising and categorising objects more difficult.

This means children might:

- Notice tiny 'imperfections' in foods.
- Refuse a food they have previously eaten if the packaging or recipe changes slightly?
- Struggle to recognise that two foods may be similar to each other, like strawberries and raspberries; pasta shapes and spaghetti.
- Notice how food is presented or positioned on a plate.

It also means that children feel like they are constantly experiencing new things. This makes the world feel quite overwhelming and scary. Sticking to the same foods can help them to feel safe.