

# AVOIDANT RESTRICTIVE FOOD INTAKE DISORDER

Review Draft for Comment

This **draft** resource is being prepared by specialist dietitians from the British Dietetic Association Mental Health Specialist Group. The content is **draft** only. Before being published, it will be updated based on feedback from professional peers and relevant patients, and then go through full graphic design, including the inclusion of relevant images/illustrations.

## **Aim**

To support children, young people and adults with ARFID and their parents/carers to understand their condition and the nutritional consequences, and help them to work towards improving their diet so that it is nutritionally complete.

## **Learning outcomes**

The Target Group (people with ARFID and their parents/carers) will:

- understand what ARFID is
- understand the nutritional consequences of ARFID and the impact on growth
- understand how to increase their food/energy intake if weight/growth is a concern
- know how to make small changes to food choices to increase their nutritional intake
- know that vitamin and mineral supplements may be required and that these come in different forms to suit individual preferences
- understand how to manage difficulties out of the home e.g. eating at school/work/restaurant.

## **Request for comments**

We welcome all feedback to help inform updates to the range, and we are seeking responses on clarity of key messages, suitability for purpose, length and amount of detail given. Please send feedback to [jenni.henderson@ndr-uk.org](mailto:jenni.henderson@ndr-uk.org) by **28/05/24** and/or by asking patients to respond via the questionnaire that can be accessed electronically via the QR code below.



## **Dietary Advice for Avoidant Restrictive Food Intake Disorder**

### **Avoidant Restrictive Food Intake Disorder (ARFID)**

When you have Avoidant Restrictive Food Intake Disorder, you might avoid certain foods, or food groups. You might also eat only small amounts and have little or no interest in food.

For a diagnosis of ARFID, your health professional will have noted that you experience one or more of the following:

- Not meeting nutrient needs e.g. vitamins, minerals, energy or protein.
- Significant weight loss, unable to gain enough weight or poor growth.
- Dependence on oral nutritional supplements or feeding via a tube.
- Problems doing everyday things which involve food e.g. going to school, eating with others, not being able to go on holidays or school trips.

There are many different reasons why people with ARFID may avoid food or eat less. Common reasons include:

- Fear of what might happen, for example a fear of vomiting, choking or gagging. This can happen at any age and without experiencing any adverse effects directly – seeing someone else vomiting, choking or gagging may trigger the fear. You may stop eating, or only have liquid foods such as juice, ice cream and yoghurt as they feel safer.
- A lack of interest in food – there is no pleasure in eating and it feels like a chore. You may feel “if I didn’t have to eat, I wouldn’t”. This may be related to an experience from the past such as an allergic reaction or reflux. However, sometimes there is no clear reason for it, just that food becomes not enjoyable. It usually leads to a lower weight and you may need prompted to eat every meal. Your appetite may be affected – you may feel full quickly or not feel hungry and this can lead to restricting your intake even more.
- Avoiding food based on sensory characteristics, for example how the food looks, it’s temperature, texture, taste and/or smell. You may have difficulties when eating out, have more rules around eating and a low tolerance to changes in how food is presented.

ARFID is different for different people, and you may have more than one reason for avoiding food. For example, you may:

- be sensitive to the way food looks or smells which may lead to long-term selective eating
- have no interest in eating caused by a lack of hunger
- have experienced an acute choking episode which has led to a fear of consequences.

The difference between ARFID and other eating disorders is that when you have ARFID, concerns about weight and body shape do not influence the foods you avoid or restrict.

Having ARFID can impact your growth and development, quality of life, energy levels, concentration and mental health. Therefore, it is important to try and increase the amount and type of food you eat. The guidance in this booklet will help you to do this gradually, at a pace you are comfortable with.

When you have ARFID, you may not be underweight.

ARFID has a huge overlap with autism and ADHD and may need adaptations in treatment.

## **Nutritional issues and ARFID**

When you have ARFID, your diet may be very limited. Foods that you can eat and manage are often referred to as 'preferred foods', 'accepted foods' or 'safe foods'.

Food groups include carbohydrate, protein, dairy and alternatives, fruit and vegetables, and fats. If you only accept food from one food group, this can lead to a lack of nutrients, for example:

- If you only eat refined carbohydrates e.g. white bread/pasta, you may have a low fibre intake and lack several vitamins and minerals. This can lead to constipation which can also affect your appetite.
- If you eat a lot of foods that are high in fat and sugar e.g. cakes, sweets and biscuits, this can impact your physical and dental health in the short and long term.
  - Children with ARFID may also struggle to clean their teeth due to sensory issues when using a toothbrush and toothpaste, and when dentists inspect their teeth.

However, it is necessary to continue eating your preferred foods to ensure you are getting enough energy each day, even if this does mean a high fat/sugar diet.

Not meeting your nutritional needs over time can affect your physical and mental health.

## Interoception

Our body communicates with us by sending messages to let us know when we are hungry and thirsty, when we need to go to the toilet, and if we are hot or cold. This is known as interoception. Along with sight, smell and touch, it is one of our senses.

For many people with ARFID, understanding these messages can be difficult. We all experience senses and our internal body signals differently, and all experiences are okay. However, if you are unable to tune in to how your body is feeling and what it needs, this can affect your ability to respond to your body's signals.

This all links to our mood, emotions, interest in social interaction, thinking and decision making. When you struggle to notice what your body is telling you, you can become more or less sensitive. You may display some of the following behaviours.

More sensitive	Less sensitive
<ul style="list-style-type: none"> <li>○ Increased sensitivity to your body's internal sensations</li> <li>○ Hunger may be extremely distracting and even painful</li> <li>○ Extreme emotional responses – fight, flight or freeze</li> <li>○ Difficulty maintaining attention to tasks</li> <li>○ Overactive food reward signals and more sensitive to hunger cues which can lead to overeating.</li> </ul>	<ul style="list-style-type: none"> <li>○ Less sensitivity to your body's internal sensations</li> <li>○ You may never feel full after eating or never feel hungry in the first place</li> <li>○ Crave more intense input e.g. needing intense flavours or noise</li> <li>○ Unable to recognise that you're full which can lead to overeating.</li> </ul>

If you struggle with interoception, there are things you can do which may help you notice your body's signals better, for example mindfulness, body scan, yoga, meditation and breathing exercises.

Using hunger and thirst charts can help you to understand your sensitivity around eating and drinking and identify ways to help. For example, setting meal plans for your preferred foods and meal, snack and drinking times.

## Diet and nutrition strategies for improving intake

### How can I increase my food intake?

If you are concerned about having low weight or delayed growth, you may need to increase your energy intake. Try increasing the amount of preferred foods you eat and how often you eat them by prioritising more time and opportunities to eat.

It can be helpful to develop a simple meal and snack plan. If you are anxious at mealtimes, planning meals and snacks in advance can reduce stress and help you to eat as you will know what you are having and when. It can also act as a prompt to eat if you often forget or lack structure when eating. Setting an alarm or electronic prompt may help too.

If you are a parent/carer making a meal and snack plan for your child with ARFID, try to involve them so that they have ownership of it. Try to include pictures, rather than words, for their preferred foods and drinks.

#### Top tips in putting together a meal and snack plan:

- Start by listing all preferred foods and foods that you have eaten in the past and are still acceptable.
- Put these foods in a daily plan and weekly timetable to ensure both food lists are included. This can help to keep all foods in the diet regularly and decrease food fatigue (when the same foods are eaten regularly and you get bored of them).

**It is not advisable to hide or sneak new foods into preferred foods as this can lead to mistrust and food refusal.**

### Daily meal and snack plan template

<b>Day:</b>	
<b>Breakfast</b>	
<b>Mid-morning snack</b>	
<b>Lunch</b>	
<b>Mid-afternoon snack</b>	
<b>Evening meal:</b>	
<b>Evening snack:</b>	

## **How can I introduce new foods?**

Food exposure can help introduce new foods to your diet in a safe way and help you increase the range of foods you can tolerate. There are different food exposure techniques that you can try. Discuss these with your health professional – they will provide guidance on the best options for you.

### **1. Initial food exposure/food therapy**

For very young children, start with getting to know a new food through play, for example drawing, colouring, picture books and playing with food models. There are also lots of food games you can try.

For young children, start with some interaction with food at home, but no pressure to eat. This is like ‘messy play’ – speak to your dietitian for more information. When ready, they can move on to more structured food exposure noted below.

For older children and adults, the first step is planned food exposure in clinic or at home. Here is some guidance to help you try this at home:

- Start by choosing the foods you are going to try. (If you are doing this with your child, they should choose the foods they are going to try).
- Choose three foods: a preferred food, a food that you are trying again or have not had in a while, and a new food.
- Start with the food you like best.
- Try to do this at least once a week. If this activity causes you a lot of anxiety, it may be best to do it less often.

Next, follow the six steps below with each food you have chosen. You can stop at any point if you are finding it tricky or it is making you feel very anxious.

1. Visual: what does the food look like?
  - a. What colour is it?
  - b. What size is it?
  - c. Describe it's appearance.
2. Touch: what does it feel like? Ideally, use your fingers but utensils can be used too.
  - a. Is it wet or dry?
  - b. Does it feel cold or hot?
  - c. Does it feel bumpy or rough?
3. Smell: what does it smell like?
  - a. Does it have a weak or strong smell?
  - b. Does it smell nice?
4. Taste: what does it taste like? You can use the tip of your tongue initially – this is sometimes called 'snake taste'.
  - a. Does it have a strong taste?
  - b. Is it sweet or salty?
  - c. Is it spicy?
5. Texture/sound: what is the texture like? What sound does it make in your mouth?
  - a. Does it sound loud when you chew it?
  - b. Is it crunchy?
  - c. Does it get soft quickly?
6. Swallow: do you experience any other sensations in your body?

Remember, you can stop at any step. You do not need to eat the food and it is okay to spit it out. If you do manage to eat it, a small nibble is fine, and you can increase the amount you eat over time.

Top tips for food exposure:

- Do this activity outside of mealtimes.
- Consider where you are – is it noisy, are there strong smells or bright lighting that may increase stress? Discuss this and make changes as needed.
- Involving others can be helpful, for example family or friends. Plan and discuss this with them in advance.
- Try to establish a routine, for example it can be helpful to stick to a specific day and time for food exposure. Establishing routines at the start and end of food exposure is also important. Try to follow the routine below every time.
  - Wash your hands.
  - Prepare the space.
  - Ensure plates, cups, utensils and a napkin are available.
  - Explore your chosen foods by following the six steps on page X.
  - Clean-up and wash your hands.

If you are doing this with your child, you could finish by playing a non-food game/activity or singing a song. For older children and adults, finish with something to lighten the mood or a small reward.

- If there are meals you want to explore that have several parts to them such as pizza, you may want to think about breaking these down into separate parts and starting with a plain pizza base first.

## 2. Food chaining

Food chaining is when you take a preferred food and change something about it in a small way. For example, by changing the brand of a preferred food, you can usually change its shape, texture, flavour or colour. These changes may be so small that they are difficult to detect but they are important. Choose a new food that is similar to a preferred food and that you are keen to explore. It can be helpful to introduce the new food using the steps for food exposure (page X).

Below are some examples of food chains using fries and bread. You may go part or all the way along the chain and this may take many months – some steps may happen more quickly than others.

1. McDonald's fries – 2. Fries to Go – 3. frozen fries – 4. skin on fries.

1. White bread – 2. a different brand of white bread – 3. another brand of white bread – 4. 50:50 (fortified) bread – 5. another brand of 50:50 (fortified) bread.

*The above will be shown in images.*

## 3. Fading in

Fading in is when you add a small amount of a food that isn't tolerated yet into a preferred food. For example, you could add a little spice, tomato sauce, curry sauce or sugar to your preferred food to change the taste slightly. This needs to be in full knowledge of the person with ARFID and they should choose what they want to add. If this change is not tolerated, you can try a different preferred food or try fading in a different food.



## Vitamins and minerals

Your health professional will check your daily nutrient intake to ensure you are getting enough energy, protein, vitamins and minerals. They may ask you to keep a food diary over 3-5 days – this is a record of everything you have had to eat and drink.

You may be advised to take vitamin and mineral supplements. These can be purchased from pharmacies, health food stores and supermarkets. Your GP may also be able to prescribe some. Most supplements have a flavour and smell, a few do not. You may need to be try a few to find one that is acceptable.

Vitamin and mineral supplements are available as a single vitamin or mineral, a few combined or one that provides all vitamins and minerals needed in one daily dose.

Supplements are available in different forms:

- Liquids – generally taken from a spoon and are available in many flavours and colours.
- Chewable – available in many flavours and colours.
- Powders – these are dissolvable in water or other liquids and are generally unflavoured.
- Coated granules – add to semi-solid foods such as yoghurt, jam or peanut butter.
- Sprays – these have a flavour and colour and are sprayed directly into the mouth.
- Tablets – these are unflavoured, but only suitable for 12 years upwards due to the risk of choking.
- Drops – available in unflavoured and flavoured varieties. They can be taken directly or added onto food such as biscuits or toast, or into drinks or sauces.

It is important that you don't exceed the recommended daily intake for any vitamin or mineral. This is particularly important for fat soluble vitamins such as A, D and E as the body stores these and high intakes can be dangerous. Speak to your dietitian or pharmacist about the suitability of supplements and whether it is safe to take more than one type daily.

### **Fortified foods**

Foods with added vitamins and minerals (fortified foods) such as breakfast cereals and yoghurts can also be useful sources.

It's a good idea to try to include more fortified foods in your diet. You can do this by looking at the ingredient labels of different brands or similar products and choosing products with added vitamins and minerals. Examples include:

- White bread has more calcium than wholemeal bread and some brands add extra calcium, iron and vitamin D.
- Yoghurts are a good source of calcium, and some have added vitamin D and omega-3.
- Instant oat cereal is an excellent source of many vitamins and minerals including calcium, iron and vitamin D. It can be eaten as cereal with milk or used to replace some of the flour in recipes for cakes and biscuits.
- Milk is a source of calcium. A few milk brands and products add iron and vitamin D. Plant-based milk alternatives also often have added vitamins and minerals. However, organic milk alternatives do not.

### **Nutritional support**

Sometimes it is not possible to meet your nutritional needs through food and drink alone. In this case, your dietitian may recommend nutritional supplements. These are prescribed by your GP and are available in the style of milkshakes, juices and desserts. Many products are available so you can find a flavour and texture that you can manage. Some supplements can provide all the nutrients required each day without eating any food, or they can be used in addition to food.

If you are not able to eat enough food and fluid for your body's needs, long- or short-term artificial feeding may need to be considered. This may involve a tube being placed in your stomach or through your nose. This will always be considered with your healthcare team and fully discussed with you. You can still eat and drink normally with a feeding tube in place.

## **Eating away from home**

Eating away from home can be difficult if you have ARFID. The eating environment is important – you may struggle to eat outside your home, in unfamiliar environments or with other people if there is too much noise, or strong or different food smells.

It can be helpful to explain ARFID to schools, colleagues, family and friends, giving a brief description of how it affects you and your coping strategies. It is important that you are not put into a situation where you feel judged or uncomfortable. Tools to support conversations are available – ask your health care professional for recommendations on how to access them.

### **Schools**

Children with ARFID may benefit from sitting in a quieter part of the dining area or a different room, away from too much noise and smells. It is important for children to feel included, but some may need to eat in a separate place as they may have strong reactions to the smell/sight of other people's food e.g. gagging or vomiting. If they need to eat in a separate area, they may benefit from taking a close friend with them.

- **Packed lunches**

Schools often focus on healthy eating. For children with ARFID, this is often not appropriate. They need to be able to have their preferred foods rather than complying with the school policy on the content of packed lunches. If their preferred foods are not allowed, they may not eat at all during the school day. Children with ARFID need to be able to bring foods to school that they can eat and manage to ensure that they have enough energy throughout the day. This may include foods that others would be discouraged from bringing to school. A letter from a health professional can be helpful in these circumstances.

- **School lunches**

Some children may feel comfortable with some school lunch food choices, for example pizza, chips, fish fingers. They may need their food cooked in a particular way. For example, they may reject slightly overcooked food, and often do not want the different foods to touch on the plate or even be on the same plate. Schools should try to accommodate this. A child with ARFID should never feel under pressure to eat or even 'try' a food as this can be overwhelming and upsetting. It can result in the child not feeling comfortable eating in that environment again. Schools can become involved in trying 'new foods' but this should be done as part of a structured programme (see page X).

### **Restaurants**

It is helpful to visit restaurants that are familiar, although even then, foods offered are not always the same each time. It can help to call ahead to check the menu and ask for a table in a quieter area, avoiding peak times where possible. You could also let the restaurant know if you need to bring your own food due to a medical condition (this may be something simple

such as breadsticks or crisps) or that you will not be eating and may attend to feel included. If you choose food from the menu, give clear instructions about portion size and if sauces and other garnishes need to be removed.

### **Workplace**

The advice above also applies to the workplace. It can be helpful explaining to colleagues that you have a medical condition that limits the foods you eat and how you eat them.

### **Important points to remember**

- It can be hard work and there is no quick fix to treat ARFID, so it is very important to practice the changes suggested in this booklet as much as you can. This will take time and will be different for everyone.
- Feeling under pressure (school/work) can affect your eating behaviours. Try to make sure that your basic needs are met, for example getting enough sleep, feeling safe.
- It is helpful to discuss expectations with your parents, carers, partners and/or health professionals – be clear and help them to understand your goals in treatment. Keep regular reviews with your healthcare team if possible. If you are doing this by yourself, remember to stop and look back on the progress you are making and celebrate the small steps.
- There are no right, wrong or specific steps. We all work at different paces.
- Each step can take days, months and sometimes years. You may change your mind during the process. The important thing is to be consistent.
- You are not expected to eat any new food straight away, sometimes it is just about exposure. It can take several attempts – try as many times as possible as most of the time you won't like the food straight away.
- You may feel anxious during food exposure as you are challenging a behaviour and doing something new – this is okay. Using distractions such as fidget toys, TV or breathing techniques can be helpful.
- Try to get support from your friends, family and health professionals. Remember, you are not alone.

## What does success look like?

Success is different for everyone, so it is important to think about what success looks like for you and your family. This could be:

- eating at school or sitting in the dining room with peers
- sitting in the same room as others who are eating
- sitting at the dining table with your family
- saying "I am hungry"
- trying something new, even if just once
- not reducing your preferred/safe/accepted foods
- managing to stay calm at the table even when different foods are around
- improvement in growth or weight
- fewer hospital appointments or admissions
- going out to eat.

Remember, every change is progress – very often we forget how the 'baby steps' lead to 'big steps' in the long journey.

DRAFT

## Further information and support

### Self-Help Programmes

An excellent source of self-help material:

- **Be Body Positive** provides support for young people with ARFID, their parents and carers: <https://bebodypositive.org.uk/>



### Sensory support

- **National Autistic Society** provides information on sensory difficulties. Visit [www.autism.org.uk](http://www.autism.org.uk) and search for 'sensory difficulties – a guide for all audiences'.



- **PEACE Pathway** provides information and support for people with an eating disorder and autism, and their carers. Visit: [www.peacepathway.org](http://www.peacepathway.org)



### Charity and Non-Profit Organisations

- **Beat** is the UK's eating disorder charity. They have a helpful support group for parents/carers of young people aged 5-15 years old with ARFID. Visit [www.beateatingdisorders.org.uk](http://www.beateatingdisorders.org.uk) and search for 'Endeavor ARFID carer support group'.

Helpline: 0808 801 0677. Available Monday-Friday 9am-8pm, and weekends 4pm-8pm.



- **ARFID Awareness UK** provides information and support for individuals, parents and carers as well as online virtual community support groups:  
[www.arfidawarenessuk.org](http://www.arfidawarenessuk.org)



- **Owl Blue** includes information and support for neurodivergence and ARFID. Visit:  
[www.owlblue.org](http://www.owlblue.org). They also have a helpful carers ARFID Facebook group.



**There are lots of helpful books available – speak to your dietitian for recommendations.**



**Notes**

