Dealing with Avoidant Restrictive Food Intake Disorder (ARFID)

A Self Help Guide

SYEDA
SOUTH YORKSHIRE EATING DISORDERS ASSOCIATION

INTRODUCTION

Welcome to the ARFID Self-Help Guide.

Thank you for completing the ‘Getting Started’ questionnaire.

To help SYEDA continue providing valuable ARFID support, we’d really appreciate your feedback on how useful you’ve found our resources.

At the end, you’ll be invited to complete a short feedback form. Your feedback is important to us and will help us understand what’s working well and where we can make improvements.

By sharing your experience, you’ll help us make sure this resource continues to support as many people as possible.

This resource is for anyone having difficulty with certain types of foods or supporting someone who does.

It will take you through 4 steps that are helpful for dealing with these challenges, with exercises to help you learn and make changes as you go.

It is important to monitor your own response to trying new foods and only attempt things that feel safe for you.

What is ARFID?

ARFID is an eating disorder. People with ARFID avoid certain foods or food groups or restrict the amount they eat of certain foods. It is more than “picky eating”.

ARFID is different to other restrictive eating disorders:

Having ARFID doesn’t affect a person’s beliefs about the size and shape of their body.

Someone with ARFID doesn't restrict their food intake to lose weight.

ARFID doesn’t feature some of the behaviours that can be associated some other eating disorders, like over-exercising.

Taking 4 steps to dealing with ARFID

We'll use this 4 step approach to help you understand and deal with avoidant and restrictive eating.

Step 1: Discover

Learn about ARFID and think about how you relate to that information. Does it sound like you or a person you support?

Step 2: Plan

Think about what changes you might make and plan to make them. You might want to do this with someone who supports you.

Step 3: Experiment

Explore your fears and try different things. Find out how far you can go with new or different foods. Work out what works for you.

Step 4: Review

Look back at how far you've come and think about what's worked, what hasn't and what you might do differently.

Step 1: Discovering ARFID

In this section we will learn more about ARFID, considering what might cause avoidant and restrictive eating and the impacts these behaviours can have.

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ARFID is sometimes described as an ‘umbrella term’ as it includes a range of difficulties with food

ARFID can look quite different in one person compared to another

It's important to understand that someone with ARFID is not just being "picky" or "stubborn“. They are often fearful and unlike fussy eaters, they cannot be bribed or manipulated to try new foods.

Possible reasons for avoiding or restricting food

Sensory challenges

Food may have strange or intense tastes, textures, or smells, which can be very unpleasant to eat. People with sensory challenges may feel safer eating foods that they are comfortable with.

Bad experiences

Some people have had scary experiences with food, like throwing up, choking, or allergic reactions, so they may avoid the foods that made them sick or stop eating altogether.

Low interest

Some people generally have a poor appetite. Others may have given up trying new food because it is so stressful. Some may not notice they are hungry due to difficulty connecting with their body's signals (poor interoception, common in neurodivergent people).

The impact of ARFID

Eating a limited diet

Eating a very limited diet can:

- cause serious health problems like significant weight loss, osteoporosis, missed periods, muscle wasting and a decreased heart rate
- affect your mood – you might be depressed, irritable, anxious, suffer from exhaustion or find it difficult to concentrate
- make new foods taste even more different

Eating little or irregularly

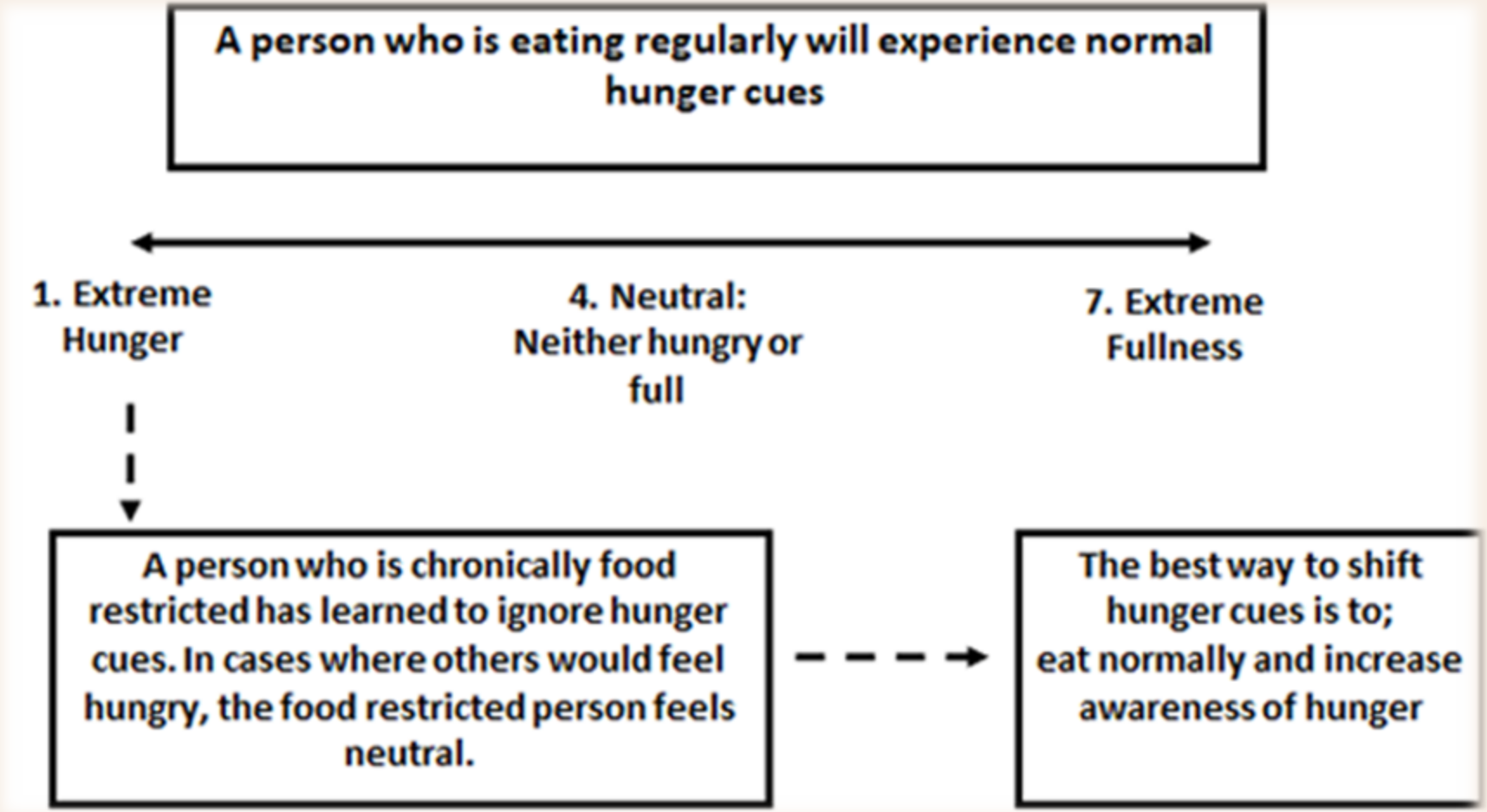
Eating very little or irregularly can:

- make you feel uncomfortably full when you do eat enough, because your stomach capacity decreases when you eat very little
- cause you to feel full quickly, even though you are not getting enough nutrients
- dull hunger cues, especially if you go long periods without eating, meaning you may forget to eat

You may also feel quite isolated if you find it difficult to eat around other people

You might also miss out on opportunities to learn about or try new foods if you always eat alone

Hunger Cues


A person who is eating regularly will experience normal hunger cues
1. Extreme Hunger
4. Neutral: Neither hungry or full
7. Extreme Fullness
A person who is chronically food restricted has learned to ignore hunger cues. In cases where others would feel hungry, the food restricted person feels neutral.
The best way to shift hunger cues is to; eat normally and increase awareness of hunger

Step 2: Planning changes

In this section we will think about what changes you might make and plan to make them. You might want to do this with someone who supports you.

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Activity 1: your challenges

What are your food and eating challenges? Make a note of which of these challenges concerns you the most from the list below and aim to focus on that first. Trying to change everything at once can be overwhelming.

A. Not eating enough for your energy needs?
B. Not eating a balance of nutrients so you are not getting the nutrients you need?
C. Not being able to eat socially?
D. Something else?

Activity 2: Understanding your sensory needs and preferences

Have a think about why you like / dislike certain food and record it on the workbook after activity one. To do this it maybe helpful to think about the effect food has on all your senses.

- **Texture, is it rough smooth, crunchy etc**
- **Taste, is it too sweet, sour, spicy etc**
- **Smell**
- **Feel of the food**
- **Look of the food, does it have to look the same, is it ok to be eating in a different format or situation**
- **Something else?**
- **Is your body using food to regulate itself?**

Is there anything about the environment that can help you? Such as lighting, temperature, noise, smell, cutlery etc? Where does it feel safe to eat and why?

Activity 3: pros and cons of changing what/how you eat

Consider the food or eating challenge you chose to focus on in Activity 1

PROS: What will you gain if you change how/what you eat?	CONS: What will you lose if you change how/what you eat?
Make a list of pros	Make a list of cons

Activity 4: your goals

The ARFID Intervention Monitoring Sheet (AIMS) on SYEDA webpage will help you to choose goals to aim for, to help you deal with your ARFID symptoms

YOUR GOALS

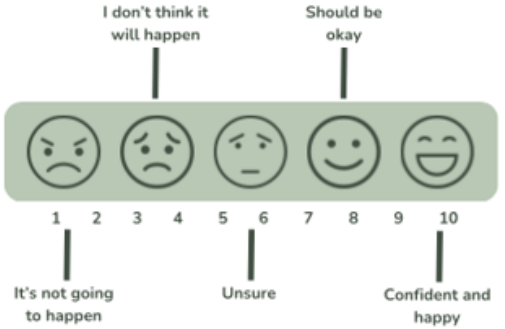
ARFID Intervention Monitoring Sheet (AIMS v1.2)

NAME:

DATE:

Since_____the following has happened

Things I am working towards	Please tick if an agreed goal	**If ticked:** How confident do you feel to be able to make these changes?	
		At beginning of course	At end of course
1. Being able to eat a bit more/ increase my intake (/fluid)			
2. Being able to eat three meals a day/spacing			
3. Introducing snacks			
4. Trying new things (foods/drinks/supplement)			
5. Having more of things I sometimes have, that I know are good for me			



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Step 3: Experimenting

In this section we will help you to explore your fears and try different things. You'll find out how far you can go with new or different foods and work out what works for you.

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Exposure and avoidance behaviors

Avoidance can increase anxiety

You've probably noticed that anxiety can increase when you think about trying a food you avoid and can decrease when you decide not to eat it.

But did you know that each time you consider trying a food you avoid, but don't try it, anxiety can *increase more?* You can get more scared and worried every time you avoid eating that food.

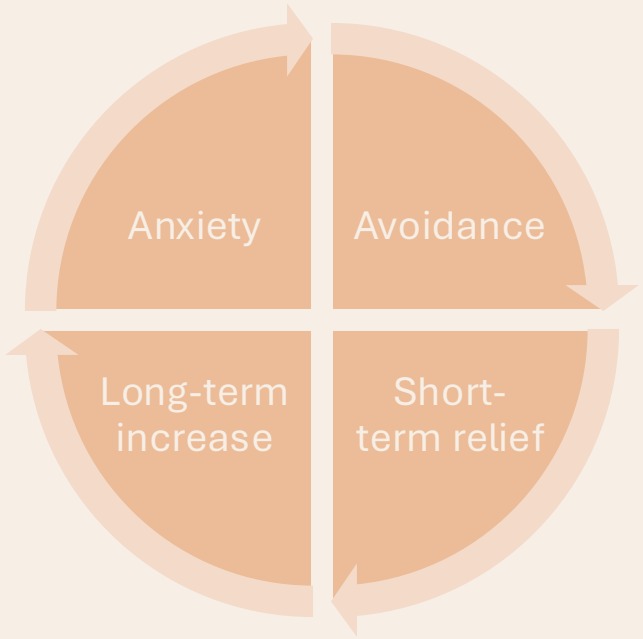
Trying food several times can decrease anxiety

If you try a food you usually avoid, your anxiety may increase at first but will likely decrease as you keep trying it.

It is important to be mindful of overwhelm and the effect this can have on your brain and response. Anything that you try must not leave you feeling traumatised and you need to feel in control of it.

If you have sensory issues with certain foods, they will likely ***not*** go away if you eat them **and this approach may not work for you**

Exposure & Avoidance Behaviours

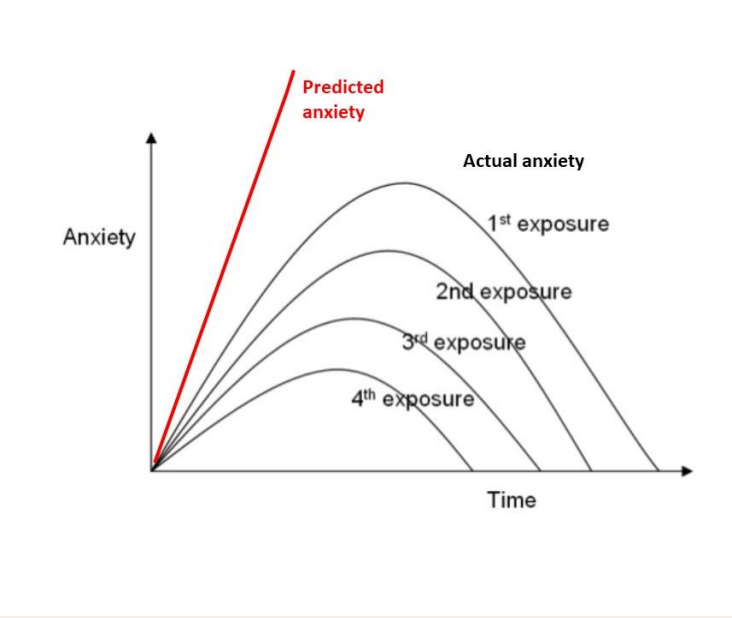


Avoidance <u>increases</u> anxiety:

- Anxiety can increase when you think about trying a food that you avoid and can decrease when you decide not to eat it.
- However, each time you consider trying a food that you avoid, but don't try it, anxiety can increase more. You can get more scared and worried every time that you avoid eating that food.

Exposure decreases anxiety:

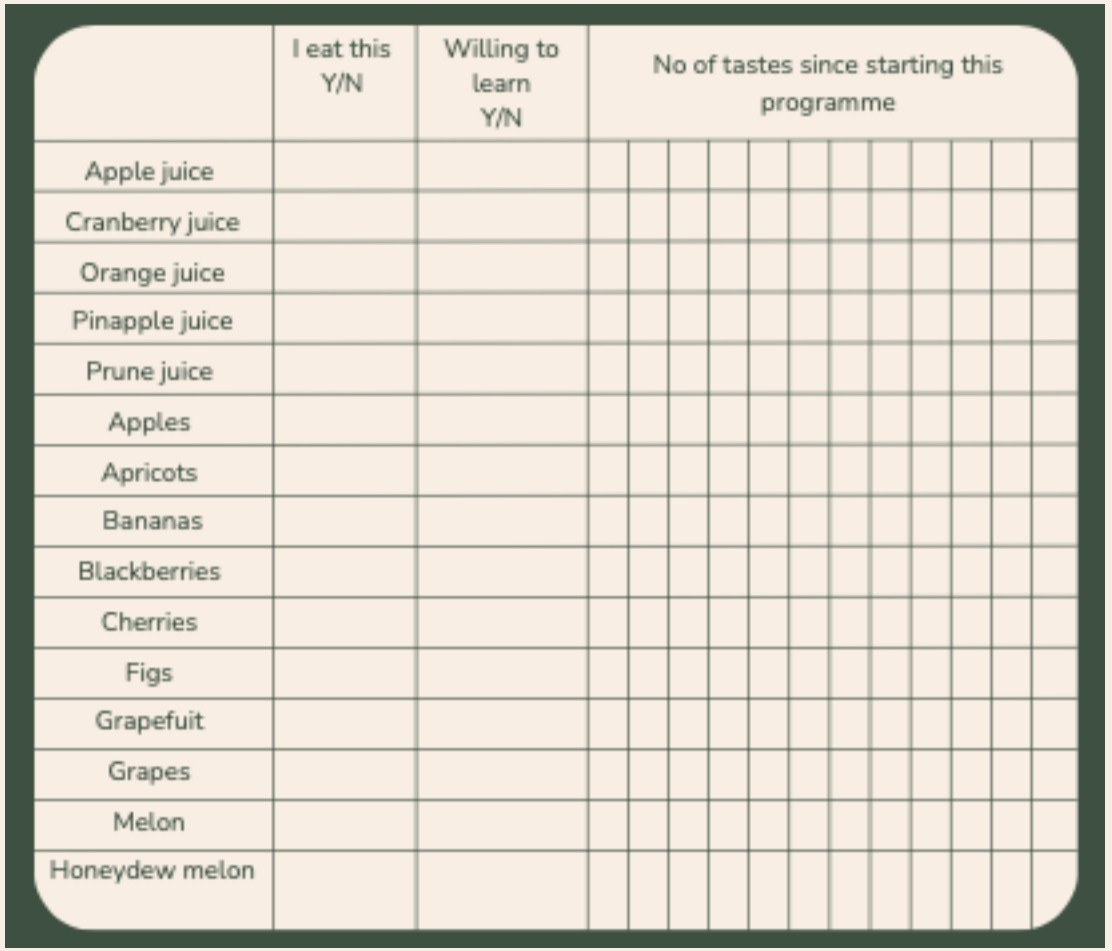
- If you try a food that you usually avoid, your anxiety may increase at first but will likely decrease as you keep trying it.
- *If you have sensory issues with certain foods, these will likely not go away but you can still use this to work on anxiety around foods you can tolerate.*



Activity 5: what do you eat and what will you try?

- It's useful to think about what you do eat consistently and what you might be willing to try so you can plan to experiment with food in the next section.

- The food list in **your handbook** can help you make a note of the food you eat often, choose the foods you want to try, and log the number of times you've tried foods during this course.
- Use the **food assessment** which lets you make notes about foods and discover how foods need to be adapted to explore. and **food hierarchy** (both available as a download on SYEDA website



	I eat this Y/N	Willing to learn Y/N	No of tastes since starting this programme
Apple juice			
Cranberry juice			
Orange juice			
Pinapple juice			
Prune juice			
Apples			
Apricots			
Bananas			
Blackberries			
Cherries			
Figs			
Grapefuit			
Grapes			
Melon			
Honeydew melon			

Exploring your fears

If your AFRID is related to a fear rather than sensory preferences then the following questions/ worksheet can be helpful.

Complete activity 7

Exposure scenario:

- What is my worst fear?
- Starting fear score (subjective rating of distress) rating(0–100)
- Starting certainty (%)
- Ending fear score rating (0–100)
- Ending certainty (%)
- Did my worst fear come true? What actually happened?
- What have I learnt from doing this?

- Scenario: **Eating salmon**
- What is my worst fear? **I will immediately be sick and not be able to stop being sick**
- Starting fear score (subjective rating of distress) rating(0–100) **80**
- Starting certainty (%) **85**
- Ending fear score rating (0–100) **65**
- Ending certainty (%) **30**
- Did my worst fear come true? What actually happened? **I managed to eat it, and did not feel overwhelmed as only ate one bite, I did not enjoy it but was not sick**
- What have I learnt from doing this? **Maybe salmon will not make me sick, it is ok to try a small mouthful**

Activity 8: exploring new foods

Spending time holding, looking at and smelling food can help you feel more comfortable with it and make you less anxious about eating it. If you are feeling quite comfortable around the food, give it a taste and see what the texture is like, this can take a while to gradually feel ok with a new food.

Focusing on your senses can also help you to reduce fear and anxiety by “grounding” you in your body, and taking you out of your head, where the anxious thoughts are. Use the **food map** resource available on the SYEDA website as a download.

LOOK	SMELL	FEEL	TASTE	TEXTURE
What does the food look like?	What does the food smell like?	What does the food feel like?	What does the food taste like?	What is the texture of the food like?

Introducing new foods at home

Fade it in

Start with a high portion of your preferred food & add a small portion of the new food. Gradually increase the portion of the new food while fading out the preferred food.

Change something

Try different presentations of new foods. Try cooked tomato instead of raw, try raw, grated carrot instead of cooked. Try cooking veg for more or less time.

Add something

Preferred condiments/spices can act as training wheels for trying new foods. E.g. add cheese to your broccoli, ketchup to meat.

Food chain

Use a preferred food to chain to a new food e.g., if you like potato crisps, try vegetable crisps. If you like ham, try turkey ham.

Take it apart

If you have never tried a new food before, start by trying one component of the food first and then layering on individual components one-by-one. E.g. pizza – try the crust alone, then crust with cheese, then crust with sauce and cheese.

Activity 11: food journal

Try keeping a food journal. Note down the day and time you tried new foods. Think about how you felt, what you were thinking, for instance:

- **How did you feel?**
- **What were you thinking when you tried it?**
- **Who was around? Were you on your own, or with others?**
- **What physical sensations did you notice when you tried the food?**

Distractions can sometimes change your experience of food so make sure you make a note of what was going on around you.

You might want to do this with a friend or carer. You can use the journal log page on page 11 of your handbook if you wish. Take your time, focus on your senses and how your body feels.

Step 4: Reviewing progress

In this section we will look back at how far you've come and think about what's worked, what hasn't and what you might do differently.

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Activity 12: looking back and moving forward

Take a moment to think about how far you have come and what changes you have noticed.

What has gone well & why?

What was a struggle & why?

What can I try next to keep making positive changes?

You might want to do this with a friend or carer. Sometimes, other people can be more honest with us about what has happened, including how well we have done, than we can with ourselves.

What does ‘recovery’ look like?

What does ‘recovery’ mean to you?

What does ‘recovery’ mean to your loved one?

‘Recovery’ and ARFID:

“To grow and live well, all people need a minimally safe food intake, or one which is ‘good enough’. It’s ok if this intake looks different to others, as long as it is enough for their body and still means they can engage in social activities with a few helpful adjustments”

- Managing expectations
- Wellbeing and ability to live life as they wish
- Small and slow changes
- Acknowledge and celebrate every victory

Useful techniques to reduce anxiety

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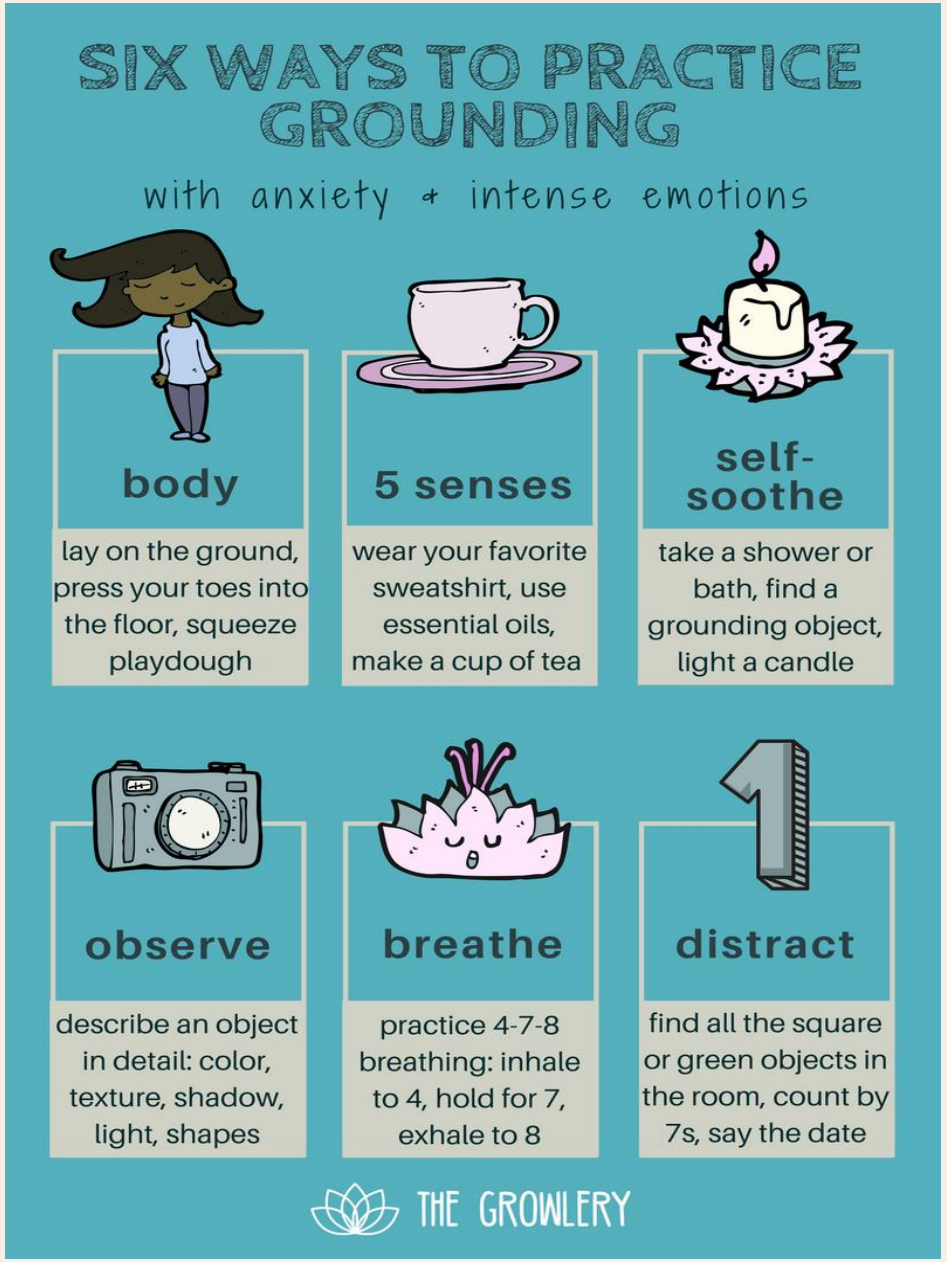
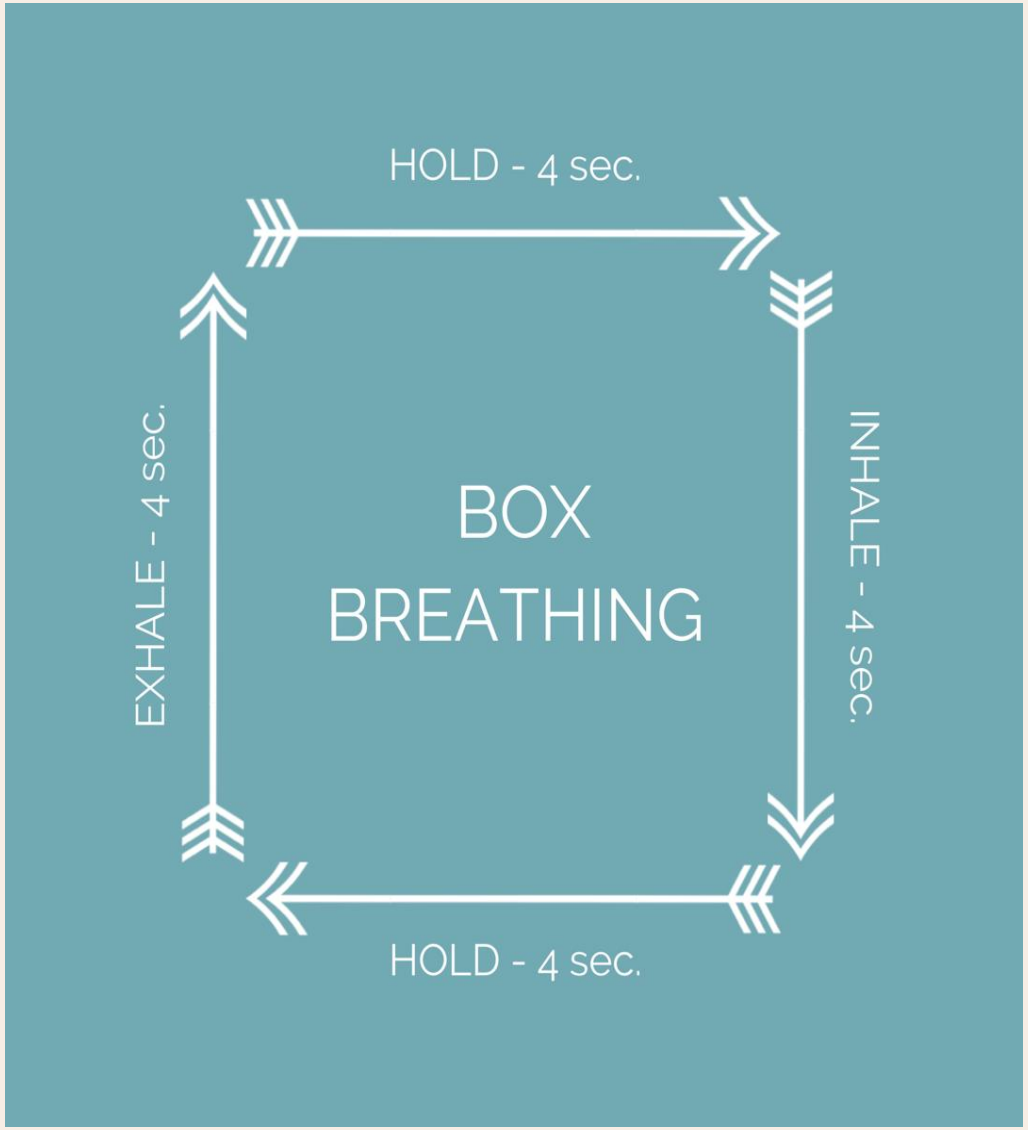
Grounding techniques can be great for helping you manage your anxiety and level out your emotions.

If you start to panic, or feel yourself getting more and more stressed, try these great techniques.

Not all of them will work for you, but one just might. Give them a try and see which suit you best





Breathing exercises can be particularly good for quickly calming you down and helping you focus.

Try breathing in for a count of 4,

then hold your breath and count to 4,

then breathe out for a count of 4,

then count 4 before breathing in again.

Repeat this until you feel calm and centred.

More info & further help

You can find more detailed information about aspects of ARFID in this section

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Experience of ARFID

"It's not easy for me to try new foods, so please don't pressure me to. Please don't draw attention to my eating habits; I know they are unusual, and it makes me self-conscious."

"It's not as simple as just forcing yourself to eat."

"We are not doing it for attention. We don't choose this. The anxiety we feel when confronted with food is all-consuming"

"For those with ARFID, I hope you know that you are never alone, there will always be someone out there who understands, never be afraid to reach out as help is always available. You are more than your eating disorder; never let it define you."

"It can slowly get better. People judge you less when you grow up, and slowly you might start trying new things over time. I have got a better diet than I did as a child, and I can even try new foods easier."

"Recovery is possible - it may take a long time, and the road is very frustrating, especially because many doctors don't know much about ARFID, but you can do it. Look for small ways to help yourself and they'll all add up to a happier and healthier picture."

"You are more than your eating disorder" – What do people affected by ARFID wish we knew? - Beat (beateatingdisorders.org.uk)

Top Tips

1. Be curious around food. Is there anything you can change about a food to make you want to explore it?
2. Start with the foods you have the least fear around.
3. Take things slow with small steps.
4. Celebrate each time you're able to explore.
5. It is okay to not like a food. Think about why you did not like it, so you can change things for when you next explore.
6. Multivitamins are a great way to supplement your diet and can come in many forms.
7. If you need to gain weight, eat according to a schedule, and prioritise nutritionally dense food. Examples: full fat foods, nuts, milk, cake, granola, yogurt.
8. It is okay for mealtimes to look different.
9. Find some places you can go to eat out in where food is always the same such as Nando's, McDonald's, Wetherspoons.
10. Always have safe foods to eat as your meal.

More info/ further help

WELL DONE! YOU'VE COME TO THE END OF THE COURSE.

Here are some useful resources that you might find help you keep going on your journey to dealing with ARFID

https://www.arfidawarenessuk.org/

https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/arfid/

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Nutritional deficiencies associated with ARFID

- Calcium: weak or broken bones
- Folate: weakness, fatigue, difficulty concentrating, irritability, headaches, shortness of breath, heart palpitations, soreness/ulcers in mouth
- Iron: difficulty thinking clearly, weakened immune system, low energy, feeling too hot/cold
- Protein: loss of lean body mass & decreased energy
- Vitamin A: night blindness/inability to see when it is dim/dark, decreased immunity, having severe illness or infections
- Vitamin B12: fatigue, weakness, weight loss, constipation, loss of appetite, numbness, tingling, confusion, depression, poor memory, soreness in mouth
- Vitamin C: severe deficiency can cause tiredness and weakness
- Vitamin D: bone pain, muscle weakness, low mood, skeletal deformities (in children)
- Vitamin K: bruising, bleeding in mouth, blood in stool, poor bone health
- Zinc: poor growth, loss of appetite, low immune function, taste changes, depression, hair loss, diarrhoea & eye and skin lesions

If you are concerned about any of these, please reach out to your GP as soon as possible, please also refer to ARFID restrictive eating tool (available as a download on SYEDA website)

Please complete the following survey

We value all feedback on this resource and make changes according to feedback. Please complete this short form:

ARFID Resource: Check-in & Reflection Questionnaires

https://forms.cloud.microsoft/e/0eA6CxdRNw