

Sussex Eating Disorder Services (SEDS)

Thank you to our colleagues at the Eating Disorders Service, South London and Maudsley NHS Foundation Trust, London who inspired us with the idea of “starter packs” and special thanks to Georgie Jones, Trainee Clinical Psychologist, who adapted this pack for individuals presenting with ARFID.

With thanks to, and for further information: Thomas, J.J. and Eddy, K.T. (2019). Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder: Children, Adolescents, & Adults. Cambridge: Cambridge University Press.

Getting started with treatment for Avoidant and Restrictive Food Intake Disorder

We know that seeking help for an eating disorder can be a big step. Once you have reached out, it can be hard to wait for treatment.

This pack is our attempt to bridge the gap between assessment and face-to-face therapy. It includes a mix of information and exercises for you to complete. The material will pave the way for future therapy sessions and your therapist will review it with you when you start working together.

Other people with eating disorders have told us that self-help material has benefited them and allowed them to start to make changes.

We recommend setting aside some time each week to work through the modules. You may want to schedule this into your diary as if you were attending a therapy appointment.

Each section ends with a summary of ‘top tips’ and includes space for you to write what you learnt from the module and to set any goals for the next week.

If you want more support, you may like to use the resources provided by Beat, the UK eating disorder charity. These include online information, online chat support, and telephone support – see <https://www.beateatingdisorders.org.uk/types/arfid>

In addition, there are self-help cognitive-behavioural workbooks for eating disorders on the Centre for Clinical Interventions (CCI) website – see <http://www.cci.health.wa.gov.au/>.

Contents

Module one: Understanding eating disorders

What are eating disorders?

What do we mean by ARFID?

“Picky eating” and ARFID.

Module two: Nutrition and the Impact of ARFID

Nutritional advice

Minnesota semi-starvation study

Effects on the body and brain

Effects on social and emotional functioning

Module three: Thinking about change

My pros and cons of change

My values

Initial goals and steps for change

Making a start

Module four: Managing my anxiety around novel foods

How to approach novel foods?

Ways to incorporate novel foods into my diet?

Module one: Understanding eating disorders

As you read through the material, we recommend highlighting information that seems relevant to you or which fits with your experiences. If there is anything that doesn't make sense, or which you disagree with, mark this too and you can discuss it with your therapist when you meet them.

What are eating disorders?

Eating disorders are serious mental illnesses that involve extreme concern about eating, weight or shape plus disordered eating. They are not a lifestyle choice or "phase" and they aren't all about food. People with eating disorders often feel a lot of pain, sadness and worry. The eating disorder can be a way to cope.

'Disordered eating' can include limiting food intake, binge eating (eating a very large amount of food at once and feeling out of control of eating) and/or purging (making yourself sick or misusing laxatives). People may also exercise a lot, or exercise in rigid ways.

Anyone can develop an eating disorder. They occur in boys and girls, men and women, young and old, rich and poor, and people of all cultures. It is generally accepted that eating disorders have a genetic component (in other words, there is an inherited risk and some people will have a higher risk than others) with multiple social and environmental risk factors also playing a role in their development.

There are four main categories of eating disorder: anorexia nervosa, bulimia nervosa, binge eating disorder, and "other specified feeding or eating disorder" (OSFED). OSFED is no less serious than the other categories and just means that symptoms don't exactly match those for anorexia nervosa, bulimia nervosa or binge eating disorder. It is very common for people to move between different eating disorder diagnoses over time.

Avoidant restrictive food intake disorder, more commonly known as ARFID, is another eating disorder that is much less known about. It is characterised by a person avoiding certain foods or types of food, having restricted intake in terms of overall amount eaten, or both. ARFID is a new diagnosis that was introduced with the publication of the Diagnostic and Statistical Manual, 5th edition (DSM-5) in 2013.



“Picky Eating” and ARFID

ARFID may be seen as “just being a picky eater”, you might even describe yourself a picky eater or might have friends and family who describe you as such. However, ARFID is more than just picky eating. Those with ARFID may present with an extreme avoidance of food, may not be interested in food and miss meals because they do not think about food, and can cause significant weight loss. For instance, ARFID may be a result of sensory sensitivities and/or aversions to food (most often caused by an adverse event or effect of eating that could include vomiting, choking or a real or feared allergic reaction) that cause restrictive eating.

Symptoms of ARFID

Some of the symptoms associated with ARFID are listed below. You may wish to tick the ones that are relevant to you, and add any other symptoms you have noticed in yourself.

- Eating a reasonable range of foods but overall having much less food than is needed to stay healthy.
- Finding it difficult to recognise when hungry.
- Feeling full after only a few mouthfuls and struggling to eat more.
- Taking a long time over mealtimes/finding eating a ‘chore’.
- Missing meals completely, especially when busy with something else.
- Sensitivity to aspects of some foods, such as the texture, smell, or temperature.
- Appearing to be a “picky eater”.
- Always having the same meals.
- Always eating something different to everyone else.
- Only eating food of a similar colour (e.g. beige).
- Attempting to avoid social events where food would be present.
- Being very anxious at mealtimes, chewing food very carefully, taking small sips and bites, etc.
- Weight loss (or in children, not gaining weight as expected).

Is ARFID different to Anorexia or Bulimia?

ARFID is different from anorexia nervosa, bulimia nervosa and other related eating disorders. Often individuals who suffer with ARFID may have a low weight and restrict food intake and this may be confused with anorexia. However, in ARFID, beliefs about weight and shape **do not** contribute to the avoidance or restriction of food intake. A diagnosis of ARFID would not

be given at the same time as one of these other eating disorders, although it could precede or follow.

Anyone of any age can have ARFID, but it is commonly picked up in children. People with ARFID can lose weight and become very underweight, or their weight may be in a “normal” range, or they may even gain weight. ARFID can be present on its own, or it can co-occur with other conditions; those most commonly co-occurring with ARFID are anxiety disorders, autism, ADHD.

How does avoiding food and eating keep the problem going?

You may be using "safety behaviours" to try and prevent another traumatic experience (like choking, gagging or vomiting) from happening. These commonly look like

- Taking very small bites
- Chewing for much longer than needed
- Only eating safe and familiar foods, only eating at home or only eating in familiar restaurants
- Not eating at all

Safety behaviours prevent you from testing negative predictions about eating. The more you avoid eating, the scarier it becomes!

How does eating very little keep the problem going?

Even if you are born with a smaller appetite than others, eating very little may further reduce your appetite. Furthermore, eating a limited variety can decrease your ability to eat a sufficient volume of food because you get bored of eating the same things and then eat less of them. In the next section, we go into detail about the physical, emotional and social impacts of eating very little.

Top tips:

- Think about which ARFID symptoms you relate to. Have they changed over time? Are there any symptoms you would like to change?
- Remember that ARFID is an eating disorder, and is a severe mental illness and they can affect anyone. No one is to blame for having an eating disorder.

What is the most important thing I learnt from this section?

Is there anything I will try to do this week as a result?

Module two: The effects of eating disorders on the body, brain and relationships

Minnesota Semi-Starvation Study

One of the earliest insights into the effects of eating disorders is from a study in World War II, sometimes referred to as the Minnesota Study or Semi-Starvation Study. This was conducted by Ancel Keys and his colleagues at the University of Minnesota. It involved 36 young men who were physically and psychologically healthy. The men agreed to participate in the experiment as an alternative to military service.

For the first three months, the men ate normally. For the next six months, they were restricted to approximately half of their former food intake. Over this time they lost, on average, 25% of their original body weight. They then had three months when they were gradually re-fed.

During all three phases the men were observed closely and their behaviour, personality and eating patterns were studied in detail. The researchers observed dramatic physical, psychological, and social changes as a result of the semi-starvation. These persisted during the refeeding phase of the study but did, in time, reverse. It was notable that many of the experiences of the semi-starved men parallel those of individuals with anorexia nervosa, bulimia nervosa and OSFED.

The main changes noticed by the men are listed below. You may wish to tick any that you have noticed since developing your eating disorder.

Attitudes and behaviours related to eating

- Increased preoccupation with food
- Planning meals
- Tendency to hoard
- Change in speed of eating
- Increased hunger

Emotional changes

- Depression
- Anxiety
- Irritability
- Apathy (lack of motivation)
- Neglected personal hygiene

Cognitive changes

- Impaired concentration & alertness

Physical activity

- Tiredness
- Weakness
- Listlessness
- Apathy

Social and sexual changes

- Withdrawal
- Reduced sense of humour
- Feelings of social inadequacy
- Isolation
- Strained relationships
- Reduced sexual interest

Physical changes

- Gastrointestinal discomfort
- Reduced need for sleep
- Dizziness

NHS Foundation Trust

- Headaches
- Hypersensitivity to noise & light
- Reduced strength
- Oedema (build up of fluid)
- Hair loss
- Impaired comprehension & judgment
- Reduced tolerance for cold temperatures
- Abnormal tingling / pricking in hands & feet

The study taught us that all of these symptoms can be brought on by severely restricting food intake, and that improving eating again can lead to the symptoms improving.

Other physical effects on the body

Since the Minnesota Study, much more research has been conducted to examine the consequences of eating disorders. The following physical effects are associated with anorexia nervosa, bulimia nervosa and related eating disorders. Again, you may wish to tick those that you have experienced (although not all of these symptoms will be evident without medical testing).

- Gastrointestinal problems.** Restricted eating, irregular eating and purging (vomiting or misusing laxatives) can result in delayed gastric emptying (delays in the stomach emptying). This means that individuals with eating disorders may feel full more quickly than normal, and feel full after eating for longer than normal. They may also experience difficulties with constipation, stomach pain and bloating.
- Electrolyte disturbances.** Electrolytes are salts in the body that carry electrical charges. They include potassium, sodium and chloride. These electrolytes are essential for the functioning of the heart, brain, kidneys, nerves and muscles cells. Electrolyte imbalance may cause weakness, tiredness, constipation, depression, and cardiac problems. This usually occurs with purging (vomiting or misusing laxatives) but can also be associated with excessive exercise and drinking too much fluid.
- Cardiac problems.** In addition to the cardiac problems that can result from electrolyte disturbances, many individuals with eating disorders have slowed heart rates, low blood pressure and poor circulation. Blood pressure may drop when standing up from sitting or lying, which can result in dizziness and fainting. Cardiac irregularities may cause swelling of the feet and ankles, and blueness in the hands and feet.
- Oedema (water retention).** Oedema can happen as a result of dehydration from purging (vomiting or misusing laxatives) and/or strict dieting, which then leads to “rebound” water retention. Water retention can be very distressing as it may result in temporary weight gain (“water weight”). Excessive water retention may also be related to low protein intake.

NHS Foundation Trust

- **Endocrine / hormone problems.** These problems include a loss of menstrual periods in women (amenorrhea), reduced body temperature, and reduced interest in sex. When amenorrhea occurs, bone density is also being lost and so over time, individuals with eating disorders can develop osteoporosis or osteopenia (low bone density) and be more at risk of fractures.
- **Dental Problems.** Dental problems are mostly linked to self-induced vomiting, which can discolour and erode teeth due to the acid present in vomit. To reduce damage, avoid brushing your teeth immediately after vomiting and instead rinse your mouth with water or (ideally) a mix of water and bicarbonate of soda.

Most of the above problems improve with regular eating and nutrition and stopping binge eating and purging

Effects on the brain

Pictures of the brain (brain scans) show that when someone is unwell with anorexia nervosa some areas of the brain shrink. They also show that once someone with anorexia has recovered, there is an increase in their brain size again. The longer someone is recovered, the more improvement in brain size there is. If people recover quickly and fully, they will not usually have any long lasting effects.



Shrinkage of the brain is mostly associated with anorexia nervosa, but other eating disorders also impact brain functioning. Up to one quarter of our calorie intake each day goes to the brain. If someone is struggling to eat, either eating too little or binge eating and purging, the brain may not get enough energy.

The brain is made up of white and grey matter. White matter connects different parts of the brain with one another. It also sends messages between the parts. Grey matter is responsible for all the brain's most important jobs like memory and planning.

Studies have collected brain images from people with anorexia nervosa and compared them to those of people who have never had anorexia. These studies have shown that adults with anorexia have less white and grey matter in the brain than people who have never had anorexia. This means that their brains are smaller in size. In fact, the brain of someone with anorexia can look similar to the brain of someone with dementia, a very serious disease of the brain.

We do not know exactly why the brain shrinks in anorexia. It may be due to damage caused by starvation. As the brains of young people are still developing up until the mid-20's, their brains may be particularly affected by anorexia symptoms. In fact, we may see even more brain shrinkage in these younger people.

Importantly, a review of studies showed that once people with anorexia nervosa returned to a healthy weight, there was an increase in the amount of white matter in the brain. Moreover, after staying at a healthy weight for a few years there were also improvements to grey matter. In fact, there was so much improvement that there were no longer any differences in brain size between those with anorexia and those without.

Although these findings are positive and encouraging, we still have a lot to learn. We still don't exactly know how eating disorders affect brain shrinkage. We also don't know if there are areas of the brain that are more affected than others, or if some damage cannot be reversed.

One thing we can be certain of is that the earlier we can provide help the better. The sooner you combat an eating disorder the better the outcome for the brain is likely to be.

Effects on social relationships

Research tells us that people with eating disorders have difficulty with social interactions. They also seem to have trouble reading and expressing emotions.



Research suggests that these difficulties are made worse by starvation and improve in recovery.

Social situations are full of information. For example, a person uses words to share their point of view. They also use the rest of their body to send messages about what they are thinking and feeling. When we interact with others our brains try to use all the information available to help us understand and respond.

Research shows that even short-term dietary restriction messes with our ability to make sense of all this information. So what happens if you have an eating disorder?

Studies have shown that people with eating disorders have trouble making sense of social and emotional information. They also have trouble making judgments about what other people are thinking and feeling, and so struggle to predict what action another person might take. This is most true for people with anorexia nervosa. When we compare people with anorexia to people who have never had an eating disorder we see a number of differences. For example, people with anorexia have difficulty recognising facial emotion. They also have

trouble reading the emotions people express using their voice or body. People with anorexia also show less emotion in their face when looking at emotional images.

The longer an eating disorder goes on, the greater the difficulties. This may be because eating disorders are very isolating. This means that people don't get enough practice reading and interacting with others.

Fortunately, things seem to get better with recovery. Once someone with an eating disorder has recovered, their ability to interpret social and emotional information improves. People also report more positive social relationships.

Top tips:

- Eating disorders like ARFID, anorexia nervosa and alike cause disturbances in physical, psychological, social and brain functioning. These disturbances can be reversed with improved nutrition.
- The sooner you improve nutrition, the better. It doesn't matter how long you have had an eating disorder for, making changes as soon as possible will increase your chances of recovery.

Module three: Thinking about change

My pros and cons of change

Often, an eating disorder like ARFID may have been in place for many years and the thought of trying to tackle it can feel very overwhelming and daunting. In some ways, our ARFID can feel like a friend, like a safe, familiar place, but in other ways, your ARFID may feel like an enemy, keeping you stuck, scared and isolated.

Thinking about engaging in psychological therapy to overcome ARFID may feel really scary, so before going any further it is important to get in touch with the positives and negatives of change, and also the positives and negatives of staying the same.

<p>List the negative consequences of experiencing your current problem</p> <p><i>Think about the difficulties that you are currently experiencing because of your eating disorder. For example, perhaps you stay home a lot, think about food all the time, or have difficulty in your interpersonal relationships.</i></p>	<p>List the positive aspects of experiencing your current problem</p> <p><i>There are positives and negatives about almost every situation. For example, perhaps you have been using eating disorder to manage painful feelings, or avoid anxiety and fear about trying new foods?</i></p>
Empty space for user input	Empty space for user input
<p>List the personal benefits that you expect if you overcome your current problem</p> <p><i>Think about the general goal that you have set and how your life will change in a positive way if you achieve it. For example, perhaps you will be able to enjoy eating out with friends, or experience improved health?</i></p>	<p>List the personal costs that you expect if you change</p> <p><i>What do you think you'll need to dedicate or give up in order to change? There are costs and benefits to most types of change. For example, perhaps you'll be expected to do things differently and get out of your comfort zone; this means you might need to tolerate distress or discomfort.</i></p>
Empty space for user input	Empty space for user input

My values

Sometimes, eating disorders like ARFID seem to consume all our lives. We want to encourage you to put ARFID to the side for a moment and to allow your non-eating disorder self to speak, to tell us about your underlying values and principles.

As part of thinking about your life, your bulimia, and where you are currently at, as well as where you want to be, the kind of person you'd like to be, and how you'd like to live your life, it can be very helpful to map out the guiding principles and core values in your life. You can take these everywhere you go and even though your eating disorder may have overshadowed them...they are still in there, we promise. Now, let's do some work digging them out!

- Look at the whole list of principles/values over the page and pick out the **5 values** that are **least important** for you and never have been. Mark these in yellow. Rank these in order with least important as number 1.
- Now pick out the **5 values** that are **most important** to you as **guiding principles** in your life and mark them in green. Rank them in order of their importance to you, 1 being the most important.
- Now cast your mind back to the time before your bulimia began, what were the values that seemed most important then?

Least Important	Most Important
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.

Initial goals and steps for change

You may not feel 100% ready to give up your eating disorder. However, after completing the exercises above, we hope that you might feel able to summon up the courage to make some small steps towards change.

Initial steps could include eating more regularly across the day, increasing the amount you eat, reducing purging, or reducing exercise. Alternatively, your initial goal might be to tell someone close to you about your difficulties, or to act more in accordance with your values (as identified above). If you have skipped any of the earlier sections, an initial goal might be to complete them.

My initial goals for change:

Try to write down three initial goals, and then pick one to start this week.

1. _____
2. _____
3. _____

This week I will start by focusing on goal number: _____

To do this I will need to: _____

An example is included below.

Elly's initial goals:

1. I will eat lunch every day
2. I will try to eat a couple of meals with my flatmates this week
3. I will tell my flatmate that I am having trouble with eating

This week I will start by focusing on goal number: 1 - eating lunch each day

To do this I will need to: Set an alarm on my phone to remind me it is lunch time. Make a plan in advance of meals I feel comfortable eating. Do something to calm myself down if I feel anxious about mealtimes, like listening to music or having a shower or talking to my sister.

We recommend planning some time in a week to review how you got on with your first goal. If you weren't able to make changes, try to trouble-shoot what went wrong or adjust your goal to be more realistic. Don't worry if it takes a few tries. If you were successful, well done! Can you commit to keeping up your efforts, and/or tackle one of your other goals?

Making Early Changes

You may not feel 100% ready to give up your eating disorder. However, after completing the exercises above, we hope that you might feel able to summon up the courage to make some small steps towards change.

Initial steps could include eating more regularly across the day, increasing the amount you eat, reducing purging, or reducing exercise. Alternatively, your initial goal might be to tell someone close to you about your difficulties, or to act more in accordance with your values (as identified above). If you have skipped any of the earlier sections, an initial goal might be to complete them.

Note. If you are very underweight or have been eating very little, there are risks associated with suddenly eating a great deal more, particularly if you increase your carbohydrate intake quickly (refeeding syndrome). To help you think about realistic, safe dietary goals we include below a sample re-feeding meal plan from our specialist eating disorder dietician. It is followed by a sample 'normal eating' meal plan for healthy weight individuals.

Re-feeding meal plan for underweight individuals who are not used to eating regularly

- At assessment, it was recommended that I follow this meal plan

Re-Feeding Safely

If you have been eating very little for a while, beginning to increase food intake is physically uncomfortable and carries some risk. To help you to minimise the risk and discomfort:

Ensure B vitamin intake is good before food intake is increased.

You need B vitamins to use carbohydrate safely in your body, so you need to make sure you have a good supply of these vitamins, especially thiamine, before you begin to increase the amount you eat. This will make sure you do not drive your body into deficiency. Take a vitamin B-complex supplement daily, such as Seven Seas One-A-Day Vitamin B Complex or Boots B Complex. This should be taken in addition to a multi-vitamin and mineral supplement

such as Sanatogen A-Z Complete, Boots A-Z or Centrum. Centrum Performance is a multi-vitamin and mineral with additional B vitamins, which may be a good choice.

Have regular small meals and snacks spaced over the day.

If you have not eaten for a while, the muscle of the gut wall can be weak and sluggish. This can lead to feeling full and bloated, and to constipation. Normal size meals may be very uncomfortable, so begin with small meals at regular intervals, with milk or Greek yogurt between meals.

Increase food, especially carbohydrate, slowly, and keep phosphate intake high.

Carbohydrate metabolism requires phosphate, and your body stores may be very low. It is best to begin with foods which are high in phosphate, and don't contain too much / have moderate carbohydrate, such as milk and yogurt. Avoid foods high in sugar at first. See the meal plan for guidance.

Include foods high in potassium.

Building new cells uses potassium, this takes potassium out of the blood, so and a fall in blood level can affect muscle function. Prevent this with regular intake of fruit, vegetables and potatoes. See the meal plan for guidance.

Fluid

Increasing fluid intake too quickly can stress the heart muscle by increasing the volume of blood. Fluid intake is best spread evenly over the day, with regular small drinks. See the meal plan for guidance.

Tips to Gain Weight at a rate of 1-2lbs per week:

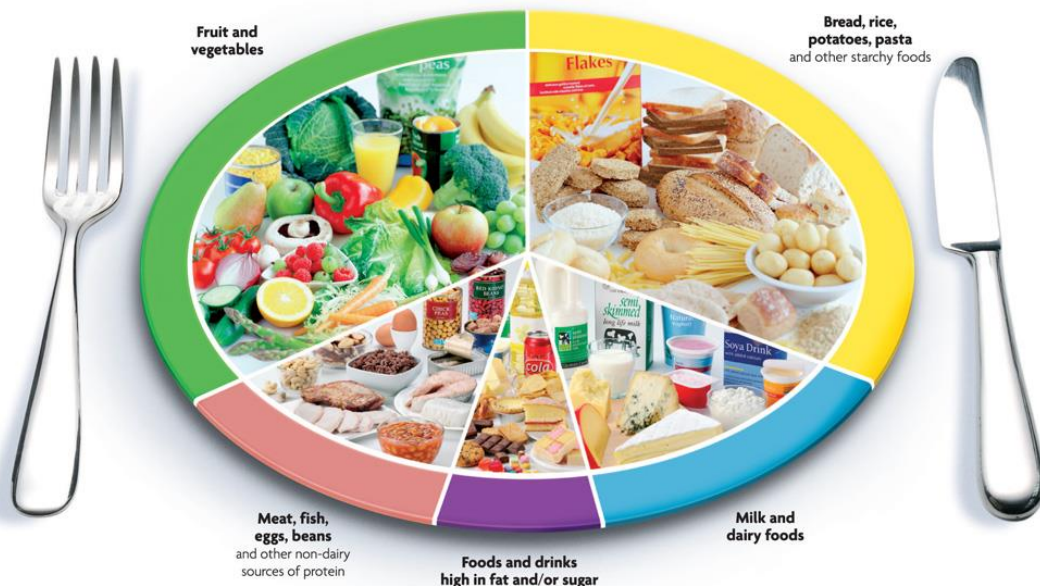
- Eat more of your preferred or safe foods. It's okay to eat cookies, chocolate and ice cream every day if these are your safe foods
- Eat on a regular meal schedule including 3 meals per day and 3 snacks a day
- Even your snacks should have multiple components (e.g. toast AND peanut butter AND milk)
- Increase your calorific intake by AT LEAST 500 CALORIES PER DAY!
- Reduce your physical activity OR replace the calories you burn by eating even more. Remember, start with your safe foods, tackling your feared foods will come afterwards.
- If you need to, ask parents, partners or friends to support you and supervise you at meal times

Main treatment goals are:

- To achieve or maintain a healthy weight
- Correct any nutritional deficiencies
- Eat foods from each of the five food groups (see the Eatwell plate below)
- To reduce avoidance and/or safety behaviours
- To feel more comfortable eating in social situations

The eatwell plate

Use the eatwell plate to help you get the balance right. It shows how much of what you eat should come from each food group.



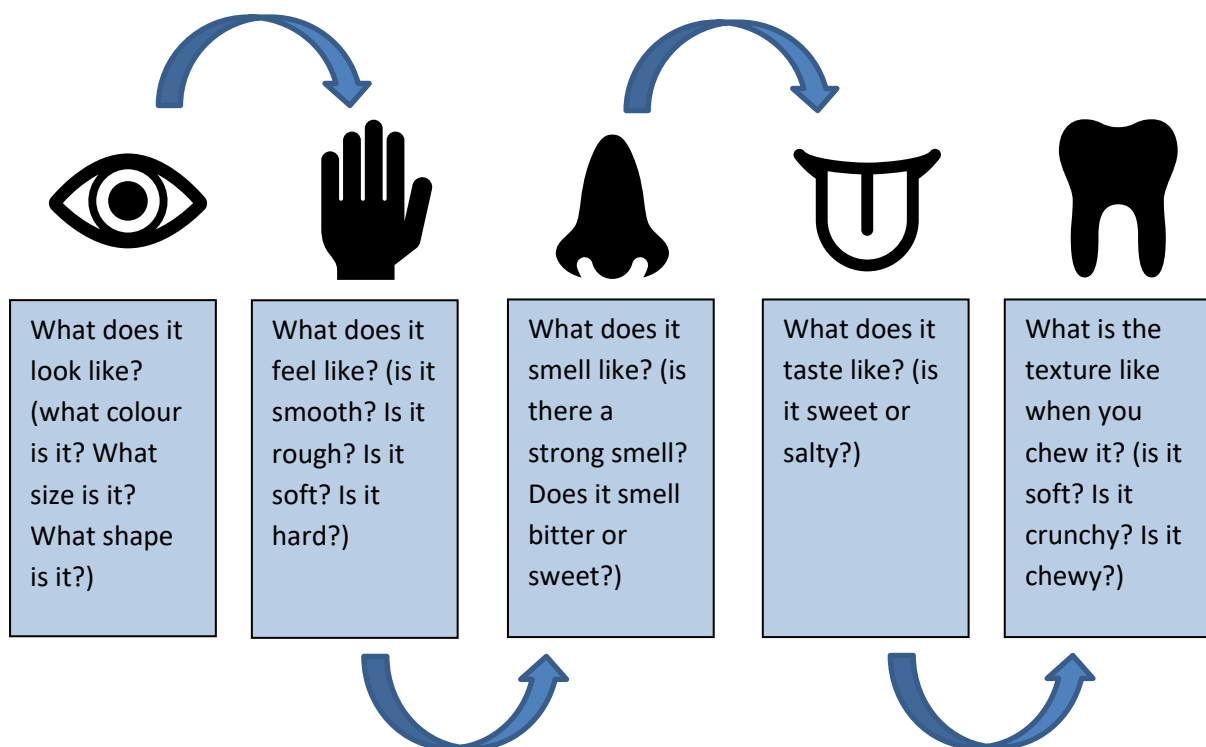
What treatment is not:

- Force feeding
- Trying to change your personality
- Making you eat weird and unusual foods
- Making you fat

Module Four: Managing Anxieties around Novel Foods

Trying a new food can be overwhelming at first. The next time you encounter a new food, slow down and give yourself a few minutes to explore it as if you've never seen it before. Try to use NEUTRAL words without describing foods as good or bad.

Ask yourself these FIVE questions when approaching a new food!



Remember, the more you practice, the more you learn. Even if you do not like a new food at first, that's ok. Research shows it can take **10 or more times** to get comfortable with a new food. Plus, trying the same food multiple times will enhance your learning.

In treatment, you first learn about new foods by **TASTING** small amounts of simple foods and practicing this at home

As you become more comfortable with these foods, it is time to **INCORPORATE** them into your meals and snacks

As you continue to learn about more foods, you will work on mixing foods together and trying complex foods

5 Steps for incorporating new foods into your meals and snacks at home

1) FADE IT IN

Start with a high proportion of a safe food (e.g., tomato soup) and add a small portion of a novel food (e.g., pieces of raw soup). Then gradually increase the proportion of the novel food while fading out the preferred food

Preferred condiments and spices can act as training wheels for trying new foods. For example, add cheese to your broccoli, ketchup to your meat, ranch dressing to your carrots, or garlic salt to vegetables

2) ADD SOME SPICE

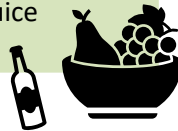


3) CHAIN TO A GOAL

Use a safe food to chain to a novel food. For example, if you currently like eating crisps, try eating vegetable crisps. Before you know it, you might feel comfortable trying raw veggies



If at first you don't succeed, try, try again -but switch it up a bit! Try different presentations of novel foods. What we mean is cooked vs. raw, salted vs. unsalted, an apple vs. apple juice



4) SWITCH IT UP

5) DECONSTRUCT



If you have never tried a new food like pizza, try starting with one component of the food and then adding on the individual components one-by-one. For example, try crust alone, then crust with cheese, then crust with cheese and sauce, and, finally, a slice of pizza!

What is the most important thing I learnt from this section?

What I will try to do this week as a result?

This is the end of the modules. There may be sections you want to look at again, or exercises you'd like to repeat.

We hope you will be able to keep setting goals and reviewing your progress with these.

If there are any parts you didn't understand or couldn't complete – don't worry. You can review these with your therapist when you meet them.