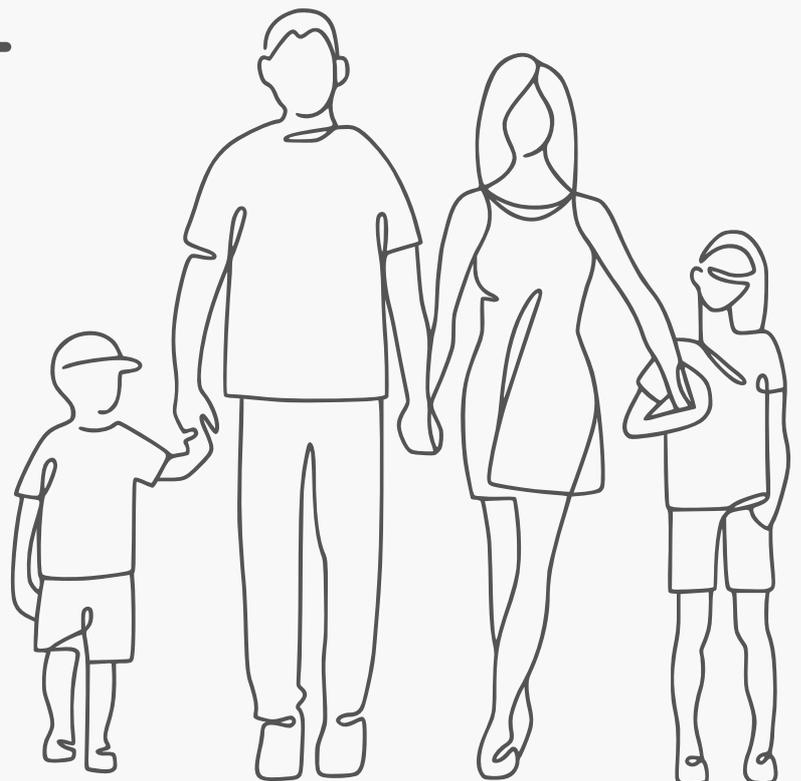




# A parent's guide to **ARFID**

(AVOIDANT/RESTRICTIVE FOOD INTAKE DISORDER)

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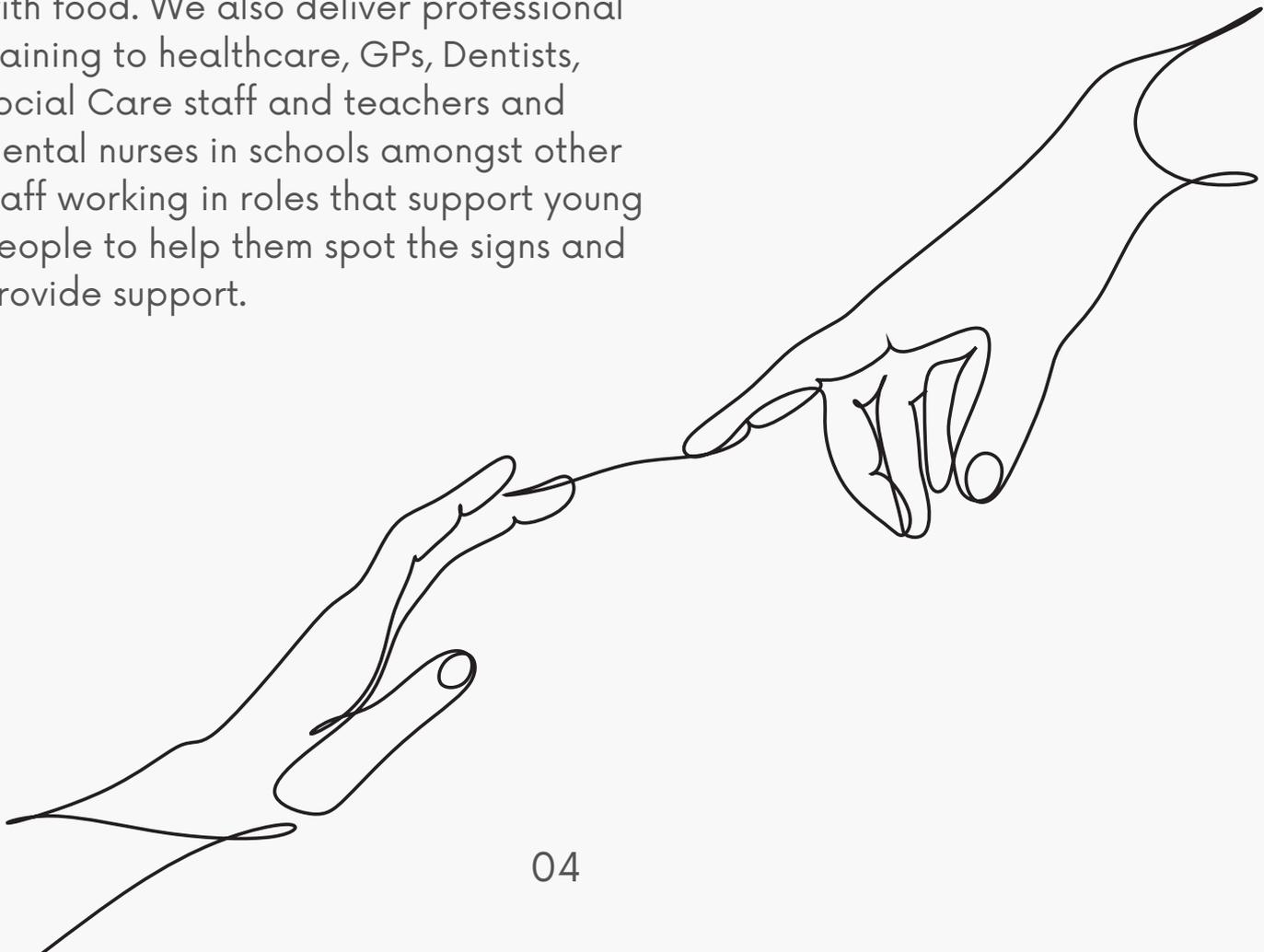
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## ABOUT FIRST STEPS ED

First Steps ED is a leading specialist eating disorder charity, offering an array of therapy and person-centered support services to people of all ages, genders and backgrounds.

Our programme of counselling and psychotherapy, befriending, peer support groups, and creative therapies helps those with eating difficulties and the associated mental health problems and our work with tailored psychoeducational workshops in schools helps young people change their body image perception and relationship with food. We also deliver professional training to healthcare, GPs, Dentists, Social Care staff and teachers and mental nurses in schools amongst other staff working in roles that support young people to help them spot the signs and provide support.



# WHAT IS ARFID?

## (AVOIDANT/RESTRICTIVE FOOD INTAKE DISORDER)

The National Eating Disorders Association defines ARFID as “similar to anorexia in that both disorders involve limitations in the amount and/or types of food consumed, but unlike anorexia, ARFID does not involve any distress about body shape or size, or fears of fatness.”

In children (where the disorder is more common) this means a daily food intake that is insufficient for growth and development. In adults it can become difficult for the body to perform basic daily function. Not forgetting weight loss and malnutrition which can often be the result.



### ARFID IS NOT...

- ... controlling diet based on ideas of weight or body shape.
- ... just picky eating.

Anyone of any age, weight or background can develop ARFID. It can present later in life or exist as an enduring condition.

# TYPES OF ARFID



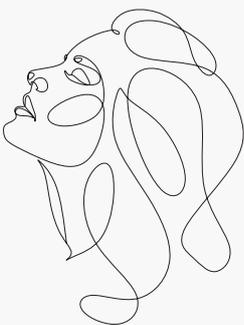
## **SENSORY/AVOIDANT**

When an individual struggles with specific foods due to sensory difficulties with it such as taste, texture, smell or sound of the food when eating it. These individuals tend to enjoy 'predictable' foods which look and taste how they are expected.



## **PHOBIA/AVERSIVE**

When an individual struggles with specific foods due to previous negative or traumatic incidents with food. These can include choking on food, falling ill after eating a specific food or experiencing pain due to food.



## **DISINTEREST/RESTRICTIVE**

When an individual does not find food interesting, they may not want to eat it and not feel the need to have meals. Sometimes, individuals can lack hunger cues which just does not make them feel hungry or want any food.

# WHO DOES ARFID IMPACT AND HOW?

As with all eating disorders, ARFID can affect anyone regardless of age, body and gender. It is most commonly recognised in infants and young children where early intervention can prevent any long term suffering. ARFID presentations in children can be misdiagnosed as anorexia or bulimia due to the similarities in signs and symptoms, especially in malnutrition and body shape or size. A difference however, is that individuals struggling with ARFID do not typically have poor body image, a desire to be thin or other body image issues, unlike anorexia or bulimia.

It has been found that boys are more likely to develop ARFID, and research suggests that there is a link to other mental health difficulties such as anxiety, ASD, OCD & ADHD. ARFID can develop any time during adulthood too.

## ACCESSING SUPPORT

As there are varying types of ARFID, there are also varying types of treatment that exist, including Cognitive Behavioural Therapy (CBT), Exposure Therapy, Dialectical Behaviour Therapy (DBT) and Eye Movement & Desensitisation & Reprocessing Therapy (EMDR).

Some individuals with ARFID can have malnutrition or deficiencies due to a very restrained diet, so it is often recommended that they also seek support from a nutritionist or dietician. This approach will enable them to determine whether there are any deficiencies and provide the necessary supplements or vitamins to maintain the individual's physical health.

# OUR APPROACH TO ARFID

At First Steps ED, we have developed a treatment plan for children and young people, co-designed by our team and families with lived experience. The approach uses elements of CBT and Exposure Therapy and allows us to work with your child to understand their experience and move towards peace and acceptance when it comes to their relationship with food.



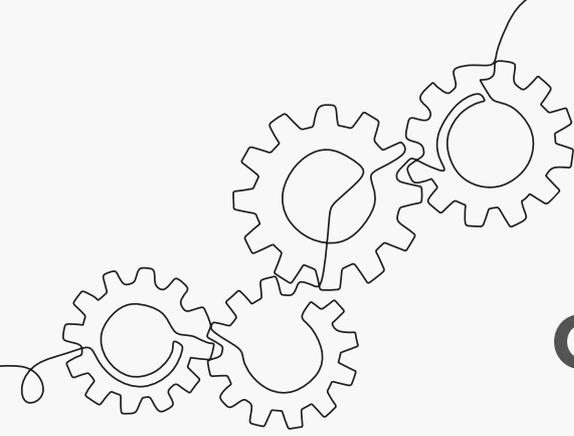
ARFID recovery is something that takes time. Our eight-week ARFID pathway is designed to help young people learn new skills and techniques which can be used to help increase comfort around food including sensory work and distraction tools. Together we will collate a list of tools which work for your child and create a unique maintenance plan to use once our sessions have concluded.

It's important to remember that recovery is never linear. ARFID experiences will differ from person to person, and progress made in these sessions will depend on a number of factors. All goals that are achieved should be celebrated, no matter how big or small they are to help your child feel supported and motivated.



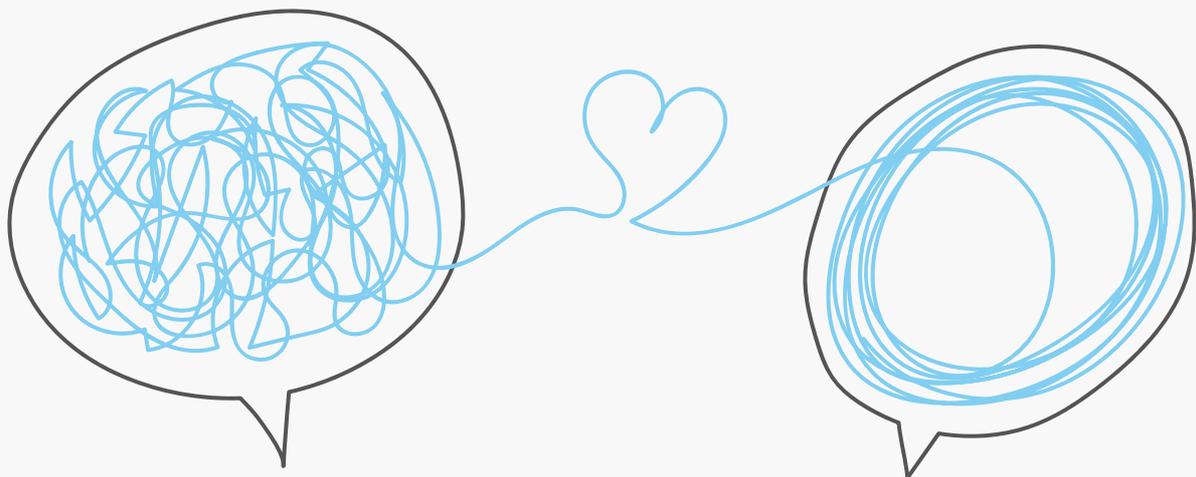
"I just wanted to thank you for your time just now. You were very supportive and handled our child so well. I'm pleased with how well he engaged, I didn't expect him to manage it so maturely. It is invaluable for families, such as ours, to have access to a team who understand the frustrations and challenges of ARFID. Please don't underestimate the impact and difference this support can give to easing families worries. Thank you"

*a grateful parent x*

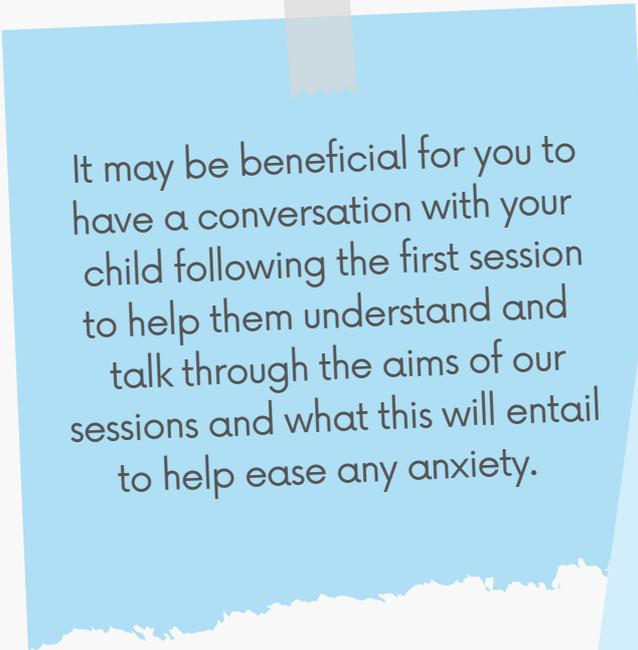


## GETTING STARTED

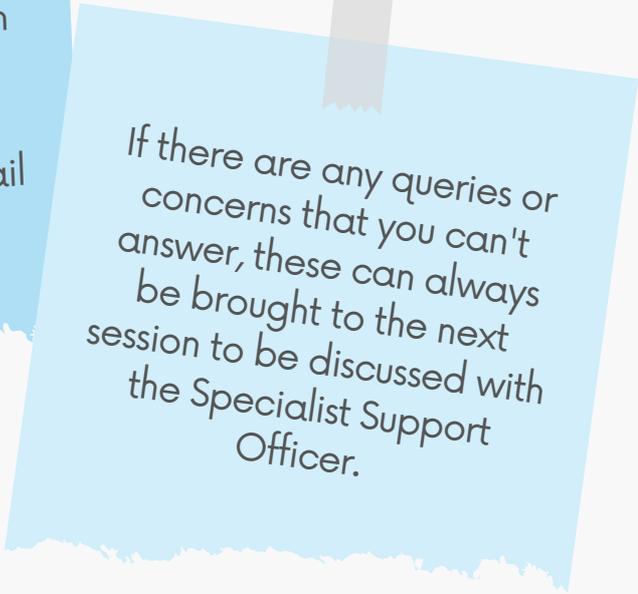
The aim of this session is to build a relationship between your child and our team, specifically the specialist support officer you've been assigned to. Before doing any work around eating, it is important to establish some trust and comfort. This will enable your child to feel more able to express how they're feeling.



We'll ask some questions about their eating behaviours and body image. These questions may include some of what we asked during the initial assessment so we can review any changes which have occurred since we last spoke. Together we will work through the support plan we'll be using over the next few weeks and then we can answer any questions you have about this pathway and support at First Steps ED.



It may be beneficial for you to have a conversation with your child following the first session to help them understand and talk through the aims of our sessions and what this will entail to help ease any anxiety.



If there are any queries or concerns that you can't answer, these can always be brought to the next session to be discussed with the Specialist Support Officer.

Any questions or concerns?

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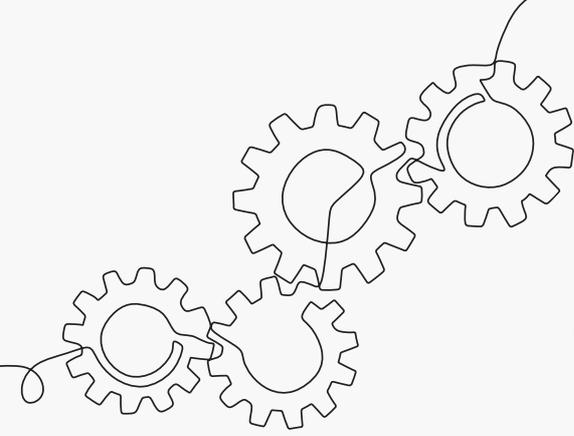
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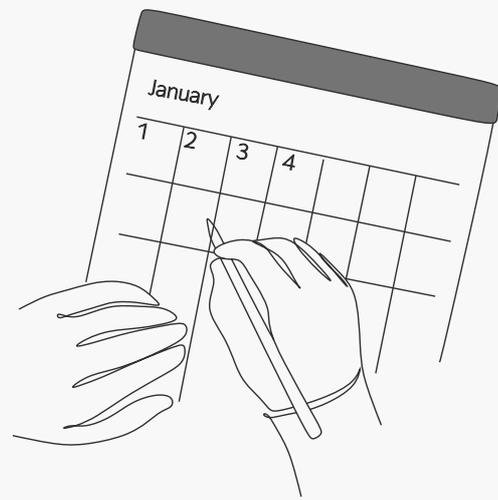
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## CREATING A LIFELINE

It is important for our team to learn about your child's life to see if there are any external factors that could be related to their ARFID. The way this is done is through creating a timeline, which we like to call a 'lifeline'.

When creating this lifeline, we'll ask your child to identify key moments or memories in their life that they remember without thinking about its relevance to ARFID.



Once all key moments or memories have been identified, they will be explored and can help the member of staff determine with your child if there is any connection with their ARFID symptoms.

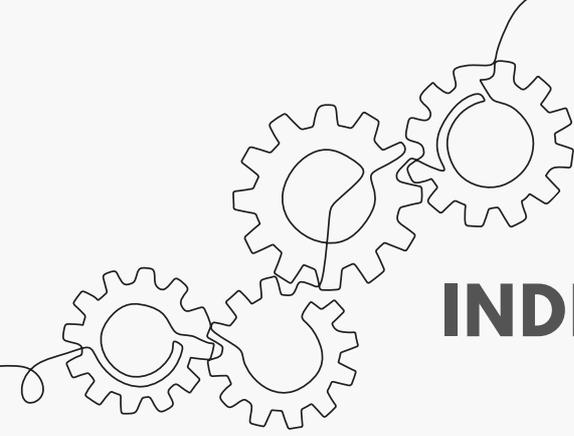


# AT HOME...

Over the week, it may be helpful to have a conversation and think about the types of foods that your child likes or does not like. In a future session our team can review these to help inform next steps!

LIKES	DISLIKES





# IDENTIFYING FEAR FOODS

To help expose your child to foods that they fear, we'll first have to identify them. Our team and your child will look at some foods that they currently fear, as well as things they'd like to try. Together we'll create a list of food items to try and make a plan to gradually expose them to the defined 'fear foods'. Fear foods will be ranked which will determine the order of exposure.

FEAR FOODS	FOODS TO TRY

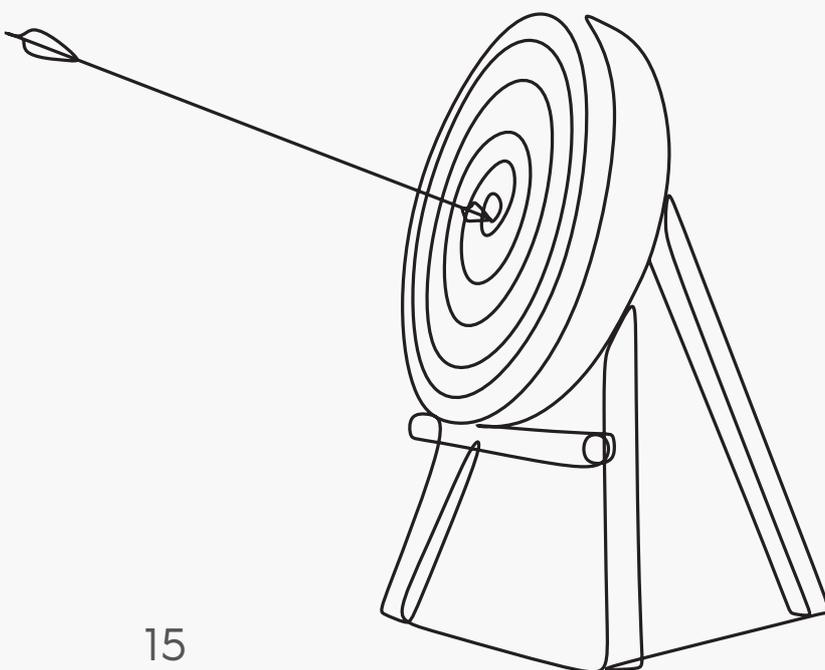
(Please note: If they're already working with a nutritionist, recommendations from them can also be used to determine which fear foods can be addressed first.)

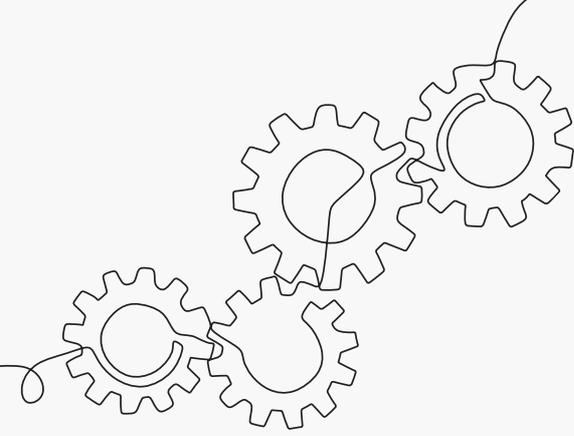
To help motivate your child to try these foods, SMART goals will be created. The SMART goals are Specific, Measurable, Achievable, Relevant, and Time-Bound. Together we will define these goals, how to achieve them and who can help. Your child might choose you as one of their supporters or someone who can help them meet one of their goals and we can share this with you after the session.



## AT HOME...

It can be helpful to talk to your child about their food lists and SMART goals. Together you might decide to write these down somewhere for inspiration, motivation or some accountability. Find what works for you in your home.





## SAFE SPACE

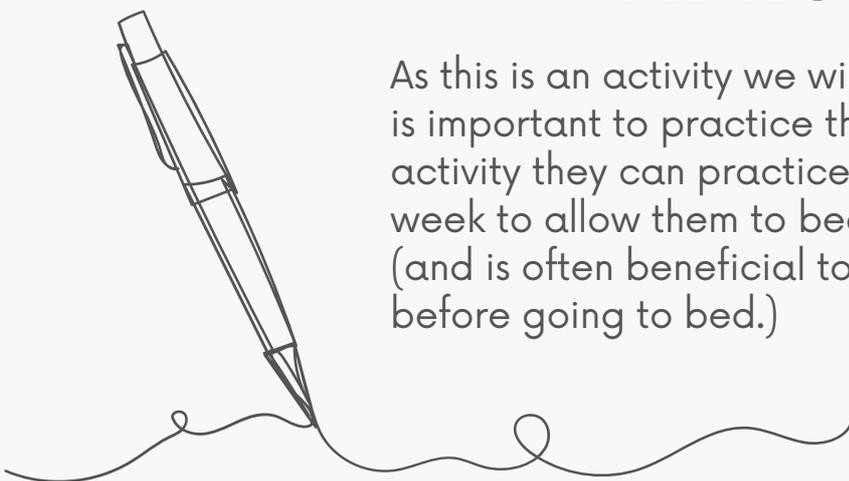
Safe space is a relaxation technique based on mindfulness and can be used as a grounding tool for when we're feeling overwhelmed. Exposure to fear foods can induce anxiety and stress which is a normal response. The stress and anxiety levels will be monitored during exposure and this tool will help to reduce any stress and anxiety during these time either in the sessions or at home.

This activity will involve your child either drawing or visualising a place that is unique to them using all five senses. This becomes a place just for them where no one can harm them, and all stress and anxiety disappear.

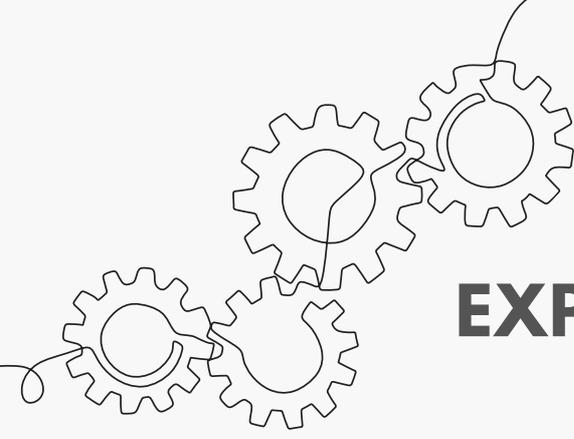
Creating this safe space will allow your child to collate things that bring them serenity and reduce anxiety around the fear food if they become too overwhelmed.

## AT HOME...

As this is an activity we will use a lot in sessions, it is important to practice this at home. This is an activity they can practice every day over the week to allow them to become an expert on it (and is often beneficial to practice at night before going to bed.)



My safe space...



# EXPOSURE TO FEAR FOODS

This will be the beginning of exposure to fear foods. Your child will be asked to bring a specific fear food to the session for this activity. The food will be explored using the five senses, whilst looking at how the food impacts your child's feelings in relation to those senses. The gradual exposure will allow their anxiety to be measured throughout to ensure that they are not too overwhelmed by the fear food.

## 1

### INTRODUCE THE FOOD

The activity will begin by having the food near your child while they are having a conversation about a topic that interests them. This will allow them to become comfortable with the food in their proximity.

## 2

### HOLD THE FOOD

The next step will be for them to hold the food. They will be asked to pick up the food with their hand and play with it to explore the texture and colour of the food through touch and sight.

# 3

## **SMELL THE FOOD**

Once they feel comfortable with these two senses, they'll move to smell by having the food closer to their nose. By smelling the food, it will allow them to understand it better and build up a tolerance to it.

# 4

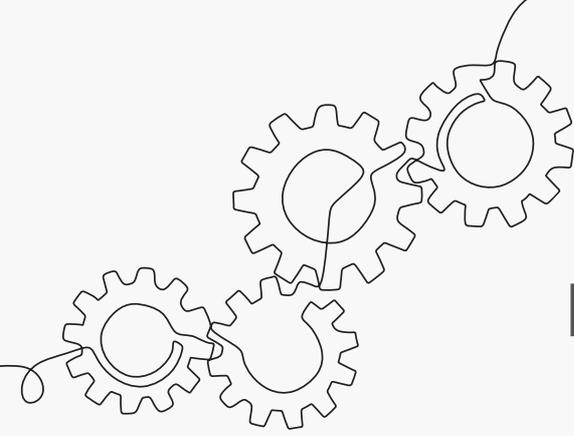
## **TOUCH THE FOOD**

The last senses that we'll acknowledge are textures, taste and sound. We'll be thinking about how the foods feel in their hands and how it could feel in their mouths. By breaking the food into pieces or touching them to the mouth, your child will be able to explore these final senses (which are often the most difficult step in exposure.) Throughout this process, we'll continue to work on the comfort levels towards their fear foods and observe any anxiety levels.

# 5

## **TASTE THE FOOD**

At home, this activity will need to be continued. Have your child practice these steps at home whilst you supervise them and record any anxiety or stress levels. Ask them to follow the instructions that they learnt in the session, and this will allow them to build their tolerance to these fear foods over time.

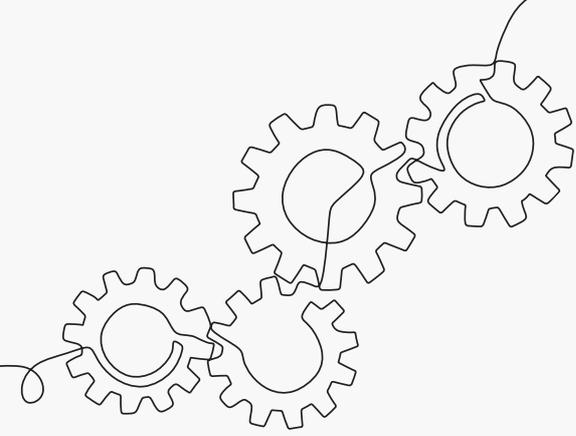


## DISTRACTION TOOLS

Individuals often find that if they are being distracted by something else, they will not focus so much on the food. This activity will start off by asking them to note some things that they would like to speak about or be entertained by. Once this list has been created, they will be asked a series of questions and will have to think of the answer whilst eating a bite of food. This helps your child not focus on the way the food feels in their mouth or the flavour of the food. At first, only small bites will be taken, and the size of bites will gradually increase over the session.





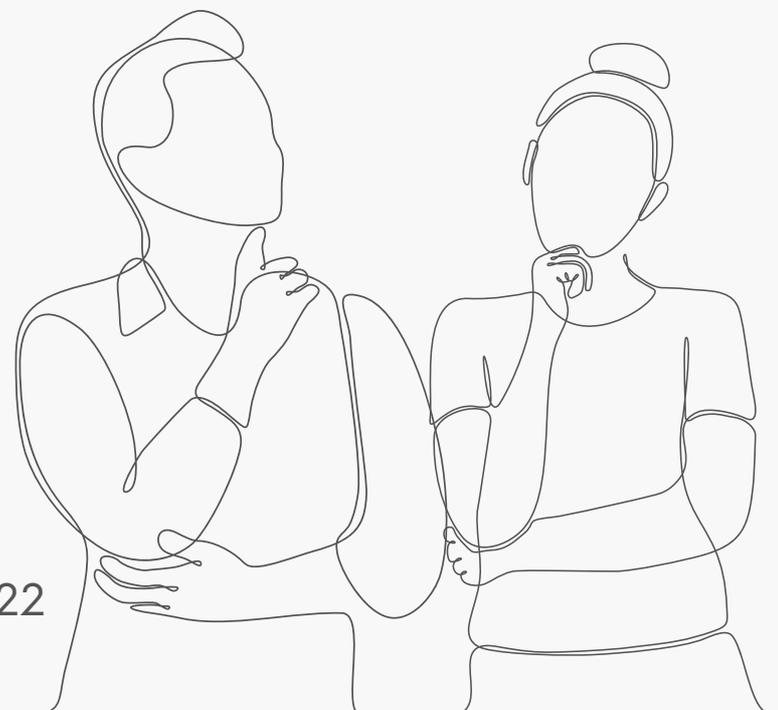


# VISUALISATION

This activity draws on the safe space activity that we've already discussed. For the visualisation activity, your child will be asked to imagine their safe space and explore all of the positive emotions it brings. Once they are happy with this, they will be asked to imagine a fear food in this safe space.

The fear food will be explored using the five senses just like in 'exposure to fear foods', but it will all be done while the is in their safe space and they will not actually be touching or making contact with the fear food.

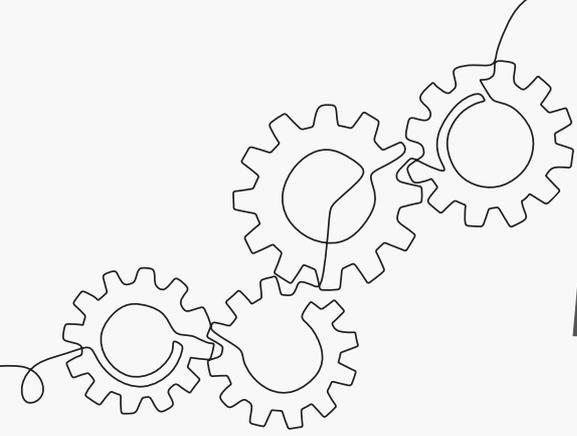
Once they get comfortable with exploring the food in their safe space and are able to visualise eating the food, they will measure anxiety levels and try to actually eat the food in the session while imaging that they are in their safe space.



# AT HOME...

This week, speak to your child about their safe space and have them describe it to you. If you can, introduce this conversation at mealtimes and have them describe the safe space in detail. This can help them work through any mealtime anxiety and overcome their fear foods. It is important to keep track of your child's anxiety levels and bring this to the sessions.

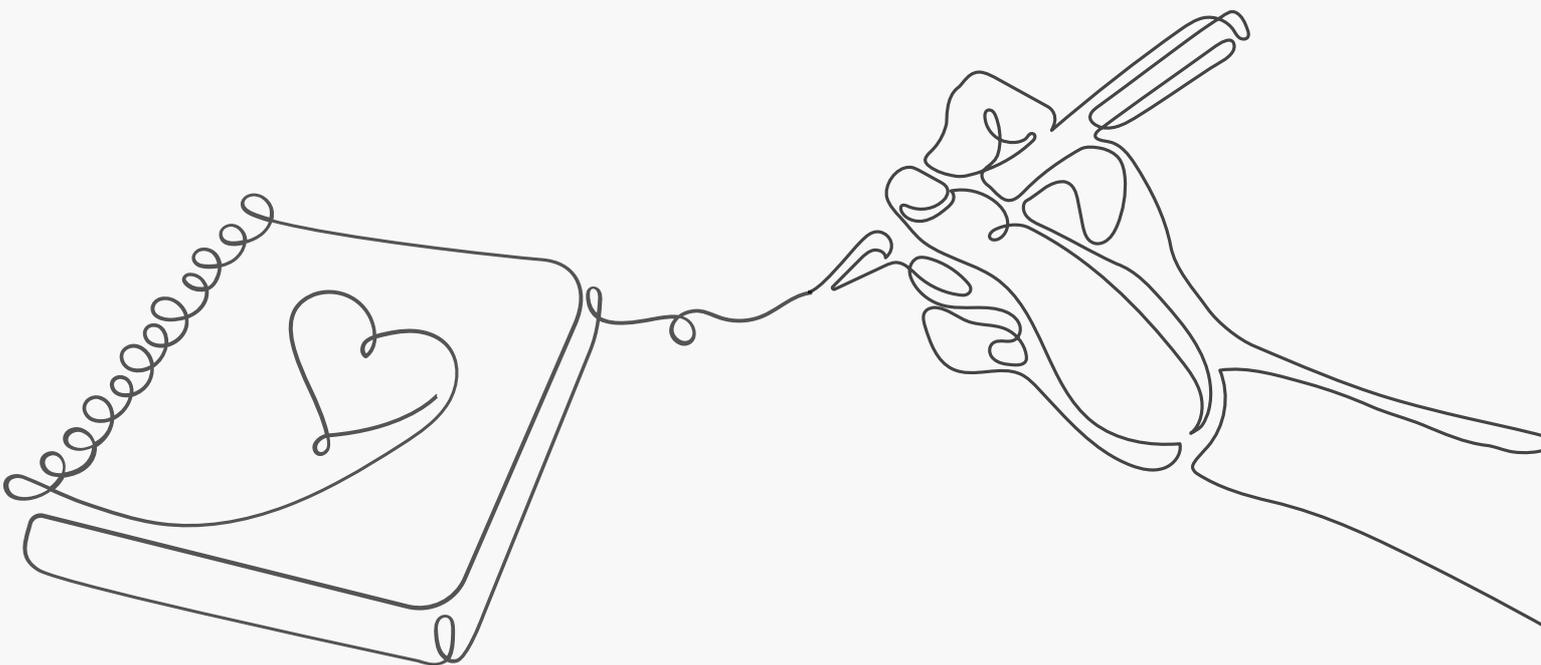
Use this space to take  
some notes on any progress  
or difficulties...



## MAINTENANCE PLAN

In our final session, we will look to the future and create a maintenance plan. This will allow your child to identify what tools they've learnt over the last few weeks which ones to take with them whilst they continue to work on their relationship with food.

This will also include creating a list of grounding tools that work for your child to help prevent them from feeling too overwhelmed. This will also help yourself and your child identify if or when you may need to seek out support again, and offer your child independence and control in this journey (knowing they can reach out for help if needed.)



# A GRADUAL TRANSITIONING

After our eight sessions of one-to-one support, our team will get in touch again to see how you're doing, we call these our four-week check in and our eight-week check in.

**The four-week check in** will take place four weeks after the final session where we will see how you and your child are doing. If needed, our team can provide some further advice and encouragement for you to continue this journey. It's important to be honest with our team at this point, and let us know of any successes and failures so we can be accurate with any advice and signposting.

**The eight-week check in** happens eight weeks after the final session where we'll review how well you've done independently since our one-to-one support has concluded. This will be an opportunity to look at other support options and next steps in recovery, this might be further support with us or one of our partner organisations as a step-up or step-down.



# OUR FOUR-WEEK SUPPORT GROUP AND WORKSHOP

Our research-informed four-week ARFID support group is peer-led, developed by staff and volunteers with first-hand experience. We'll look at the symptoms, it's impact, as well as distractions, coping strategies and setting personal goals.

- **Introduction & Information**

During our introductory session we'll get to know each other. We'll explore the nature of ARFID, the causes, symptoms and triggers. Before we finish, we'll have a think about our goals, what we want to tackle and how.

- **Understanding the impact**

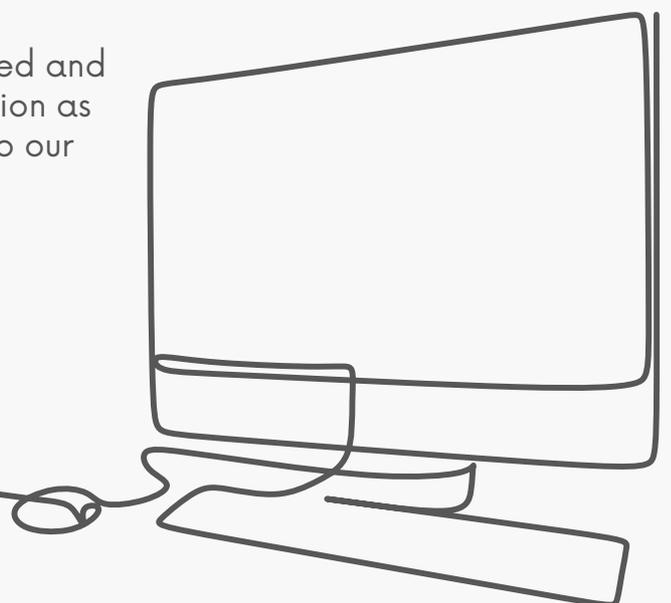
This week we'll discuss how ARFID impacts our lives. We think about relationships, social lives, health. body image and how it affects us day-to-day.

- **Advice & Support**

Time to look at some coping strategies, positive distractions and learn how to manage triggering or difficult situations. We'll also explore communication and how we can talk about our feelings and emotions to loved ones and peers.

- **Reflection & Goal Setting**

Reflecting on everything we have learned and covered will be the aim of our final session as we look back at our goals and ahead to our next steps in recovery.



“ [My child] is finally trying new foods! We've adopted so much from the sessions already and we can't believe the progress we've made. There is still a long way to go but I'm so so grateful for this service. ”

“ Knowing that there is support and professionals working on new support and resources is so important. I struggled for a long time with very little assistance from my doctor. I'm glad to see that services like yours are doing something about it for future generations. ”

“ The workshops are a great option for [my child.] I know she is often motivated by others but it must also be nice to know she isn't alone. There isn't much out there for this sort of thing! ”

# DOING MORE FOR FAMILIES

Caring for someone with an eating disorder can feel overwhelming so it is ok to feel it impact your own mental health. This is why it's important for parents and relatives to establish your own network and coping mechanisms during this time. At First Steps ED, there are a number of support options available.

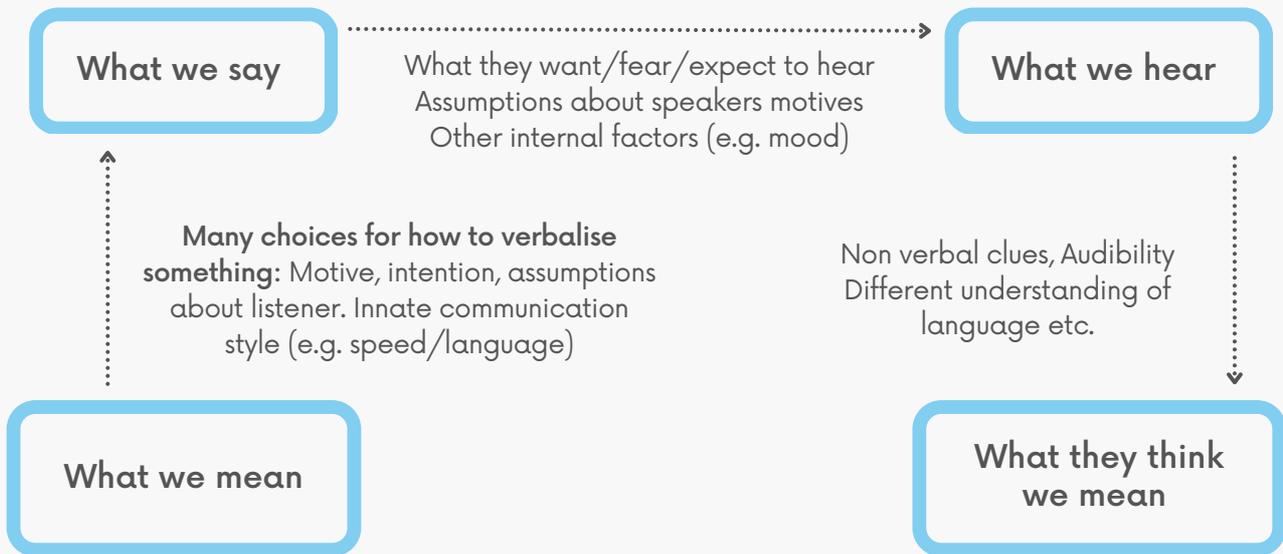
## SKILLS FOR CARERS

Our ARFID 'Skills for Carers'\* is a three-week course for parents, partners and siblings who wish to understand their role in a loved one's recovery. The course offers new skills, knowledge and tools needed to be an effective carer during challenging moments. To learn more visit our website or scan our QR code.



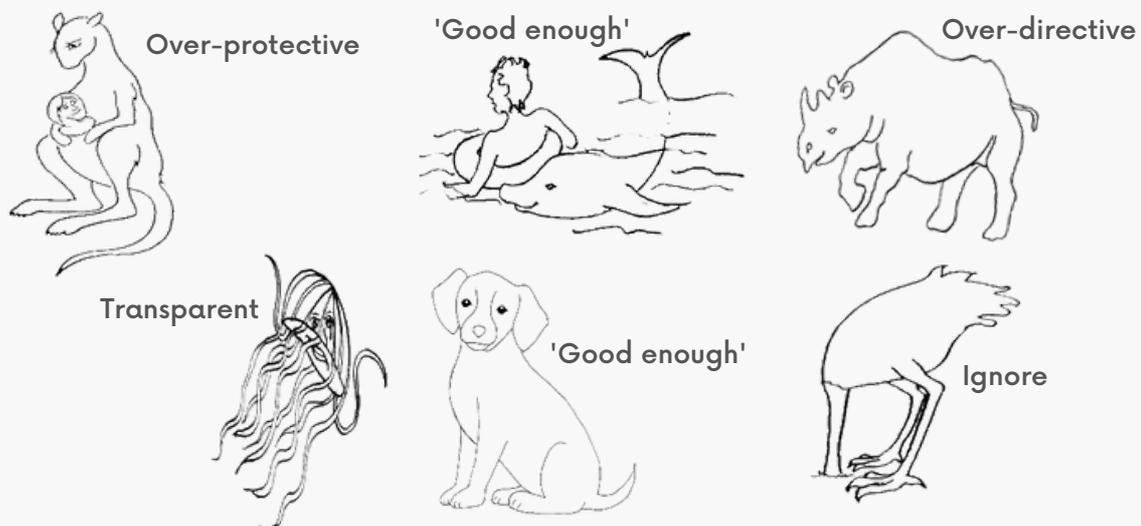
\*Our 'Skills for Carers' workshops are based on the New Maudsley approach, supported by Professor Janet Treasure (author of Skills-based Caring for a child with an Eating Disorder: The new Maudsley method.)

Together we'll cover key topics around the '**Model of Communication**' (see next page) and tools to manage challenges and difficult situations in recovery.



We'll also talk about effective **carer styles** (see below), in a positive peer-group setting where you can connect with other parents and carers working through similar struggles.

The New Maudsley Method approach uses animal analogies to describe some common reactions to the stress of caring for someone with an eating disorder. Understanding your caring style can help you become an expert change coach.



(Kangaroo, Rhino and Dolphin are behavioural. Jellyfish, Ostrich and Dog are emotional.)

# WHOLE FAMILIES CAN BE IMPACTED BY EATING DISORDERS

There is lots to cover in our four-week workshop with parents and carers, but some key points we'll cover include:

- Eating disorders are not about food, it's about feelings and the development of an eating disorder is NOT under conscious or wilful control.
- There is no evidence that family factors are the cause, but family support has been shown to improve likelihood of good outcome.
- Identifying and reducing maintenance factors is key for treatment.
- We'll cover key skills and tools to help you provide a calm, emotionally warm and safe environment to promote recovery.
- Early intervention greatly improves prognosis - do not give up!
- Remind yourself and your child that MOST people DO make a form of recovery from an eating disorder.

We also have our **monthly drop-in group** for parents and carers to get together online and share any successes or challenges they've experienced. It's a relaxed group available in-person or online, with no commitment to attend each month.



# LET US KNOW WHAT YOU THINK

Please consider leaving us some feedback via our INSPIRE form. Your comments and suggestions help us develop our services and support channels, as well as find future funding for this service. You can also review our resources and support new projects. Scan the QR to be directed to our feedback forms.



## THERE'S MORE...

Don't forget to check out our website for more blogs and resources. Here you'll find more guides, information real stories and advice from our team and community.

[www.firststepsed.co.uk](http://www.firststepsed.co.uk)

NEED HELP NOW?

## Crisis Lines

In case of emergency and if you or a loved one can't keep yourself safe right now, call 999. Some other useful services:

**SHOUT: 85258**

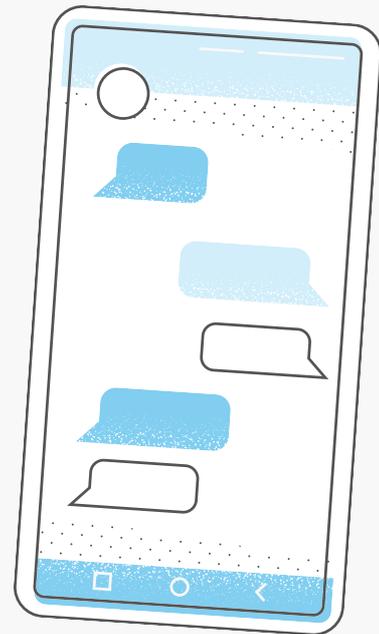
A 24/7 text line for when you feel need support with your mental health.

**Samaritans: 116 123**

A 24/7 helpline to talk to a person over the phone when struggling with your mental health or suicidal thoughts.

**BEAT: 0808 801 0677**

9am–8pm during the week, 4pm–8pm on weekends and bank holidays. For eating disorder support and information.



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NEED MORE SUPPORT?

## Visit our website

[www.firststepsed.co.uk](http://www.firststepsed.co.uk)

