

## What is the Avoidant/Restrictive Food Intake Disorder Service?

- Our ARFID service started up in October 2019, shortly before the COVID pandemic, as part of the Maudsley Centre for Child and Adolescent Eating Disorders (MCCAED). We see children and young people aged 2 to 17 who struggle with their eating to the extent that it is causing real difficulties in terms of their everyday functioning and their physical health and well-being. We mostly see children and young people from our 7 local South London boroughs – Southwark, Lambeth, Lewisham, Greenwich, Bromley, Bexley, and Croydon, but we also see some young people from elsewhere in the country.
- We offer out-patient assessment and treatment to young people and their families. We try to support young people to better manage their eating difficulties and to reduce any negative impact they may have on their health and on their daily lives.
- We also work with other professionals
  - Sometimes through sharing our thoughts and recommendations about what we think could be helpful for people they may be working with who have ARFID
  - Sometimes through guiding other professionals through treatment
  - Sometimes co-working so everything is joined up and makes sense to the young person and their family
- As well as our clinical work we run teaching and training courses for other clinicians and professionals, and we are busy with several research projects. We are playing an important part in supporting NHS England's national roll-out programme aimed at improving services for people with ARFID.

## What kinds of people do you see?

- All kinds! We see young people and families from a wide range of different backgrounds. Each family is different, but all are struggling one way or another in relation to the young person's eating difficulties.
- Families have different traditions, expectations and experiences related to eating and mealtimes, so we need to ask questions and listen to what they have to say. That way we can make sure we are planning together how best to try to improve the situation in a way that is a good fit.
- The young people we see range in age from very little ones up to older teenagers. We see young people across the full range of neurodiversity as well as those who may be facing other mental health challenges or have physical health conditions.

## What are some of the signs / symptoms to look out for?

- ARFID is a recognised type of eating disorder that has a clear definition. It is essentially a type of eating difficulty that is characterised by not being able to eat a wide enough variety of different foods or by not being able to eat enough food overall. Some people struggle with both variety and amount.
- Consequently, they may not get the vitamins and minerals they need from food which can in some cases lead to serious physical problems. A poor diet can affect every aspect of someone's functioning, not only their physical state, but also their concentration, behaviour and general well-being. If people can't eat enough overall, they may lose weight, or in children, they may stop growing or not go through puberty as expected. Some people who can only manage a very narrow range of foods may experience a lot of weight gain rather than weight loss, depending on the foods they can eat.
- The eating difficulties can also have a significant impact on things like ability to eat at school or college, not being able to eat meals with family and friends, and not being able to go for days out or on holiday. This can be isolating, upsetting, and hold young people back from being able to develop their potential.
- It is important to stress that ARFID is different to some of the other eating disorders like Anorexia Nervosa or Bulimia Nervosa. In ARFID the difficulty with eating is not directly linked to concerns and difficulties related to weight and shape. Instead, it can be the result of several things, which tend to be present in different combinations and at different levels of severity in different people.
- Some of the most common are:
  - Extreme sensitivity to specific aspects of food, such as the texture, smell, appearance, temperature of food
  - A strong feeling or fear that something bad or unpleasant will happen if food is eaten
  - Little interest in food or eating which can result from poor recognition of hunger, struggling to eat because of feeling overwhelmed, being easily distracted, etc.
- Each person is different!

## What can service users expect when they first come to the service?

- Young people who come to our clinic, and their parent/carers, are at the heart of anything we do. They are all very different and we need to understand their experience, wishes and perspectives.
- Before meeting young people and families for the first time, we ask them to complete some questionnaires online. We send separate secure links for the young person and for their parents/carers. This is very helpful in allowing us to get an idea of how things are before the family come to the clinic.
- A first meeting will usually involve meeting with two or three of us to talk things through in more detail. We take time to try to understand what the difficulties are, why they might have developed, what is keeping them going, and what the impact is on the person and their family. We need to hear what their needs and wishes are in relation to making changes. We also usually do a brief physical check of weight, height, blood pressure - things like that.
- Once we have talked things through together with the young person and family, we also make our own assessment of any risk. We work as a multi-disciplinary team delivering evidence-based practice, so that means we have mental health clinicians, doctors, nurses, a dietitian and an occupational therapist on our team. If everyone agrees that treatment is appropriate, we discuss treatment options that are tailored to specific aspects of that person's situation.

## Treatments

- The treatment we offer is tailored to each young person's needs as an individual.
- It usually consists of some type of psychological treatment which is aimed at supporting change in eating behaviour. Alongside this, there is usually some dietetic input and some medical input, depending on risk. The psychological treatments may involve some individual work with the young person, some work with the parents, or working with the family – it depends.
- We always explain what the approach is that we are recommending and why we think it might be helpful.

## What is the relationship like between service users and staff?

- From most of the feedback we receive, families welcome our approach. We try to be as helpful as we can and to work together with young people and families, which they often appreciate. We have had some lovely feedback which is really rewarding. However, we don't always get it right and we are always open to thinking about how to change things.
- As well as asking for feedback, we carry out regular research projects to find out more about what families feel would be helpful in terms of service improvements. This includes young people and families' views about adaptations for neurodiverse young people.
- We are always keen to involve our service users in shaping and developing what we offer to make it better!