

ARFID Q&A with Dr Rachel Bryant-Waugh, Consultant Clinical Psychologist Maudsley Centre for Child and Adolescent Eating Disorders

1. "What is your take on hypnotherapy as a treatment for ARFID, both one-off sessions and a course of therapy sessions, do you believe it to be appropriate for ARFID?"

This is a very good question and one that I will try to answer as clearly as I can. Perhaps it might be helpful if I start by mentioning 'evidence-based practice' and say that I believe in the general principle that those of us providing healthcare services should be doing our best to deliver care informed by what has been shown to work. That is a very broad statement, so I need to say a little more about how this relates to treatment for ARFID. As ARFID is a relatively newly introduced diagnostic term, there are still very few published treatment trial studies conducted with people who have received a formal diagnosis of ARFID. This type of study is essential to be able to find out which treatments work best for specific conditions. Treatment trials need to involve sufficiently large numbers of people and are carried out as formal studies. They form an essential component of evidence-based approaches to care. However, in my view there are two main issues when it comes to ARFID. One is that ARFID can differ between individuals (who themselves vary considerably) and is sometimes referred to as an umbrella diagnosis for this reason. This suggests that a one-size-fits-all approach to treatment may not be realistic. Secondly, we are still at the stage where any recommendations for specific types of treatment can only be made very cautiously as we do not yet have strong evidence from appropriate research studies. There are some studies underway, including those looking at adapted cognitive-behaviour therapy approaches, family-based approaches and adapted anxiety interventions, but a proper treatment trial takes a long time to conduct and for the results to be shared.

So where does that leave things at present? I find the so-called 'three-legged model of evidence-based practice' helpful. This proposes that when it comes to decisions about treatment, three main things are **equally important**: firstly, evidence from formally conducted treatment research studies (as above), but just as important are secondly, the views, values, priorities of those directly involved (i.e. the person with ARFID/parents/carers, as well as thirdly, established clinical expertise.

So, to come back to the question about hypnotherapy, using this model I would say:

1. There is currently no strong research trial-based evidence either way for the use of hypnotherapy with people formally diagnosed with ARFID, and insufficient objective evidence that it is effective in this context to be able to recommend it as a treatment of choice. Current treatment recommendations are for multi-disciplinary, multi-modal treatment which include physical and nutritional input and monitoring alongside any intervention targeting emotions and behaviour, so hypnotherapy alone might not be enough for someone with full ARFID.
2. Clinically, I am certainly aware of some individuals who report finding hypnotherapy helpful. My impression is that this has mostly been the case when there has been an aversive event such as a choking incident which the person has understandably experienced as very scary and has put them off eating. We have seen several young people in our clinic for whom previous hypnotherapy sessions are described as having been initially helpful in allowing them to try a couple of new foods, but this did not then progress into them being able to regularly eat them. We also see some individuals for whom hypnotherapy has not been helpful. So that represents the full range – helpful, partially helpful and not helpful. I am not able to comment on one-off vs a course of sessions as I can't really recall anyone reporting their eating has dramatically changed with one session – however, this may reflect the young people we see in our clinic.

3. I think it is very important to listen to individual/parent/carer views, hopes and expectations and discuss these openly and honestly in line with points 1 and 2. I would usually acknowledge that hypnotherapy can be very effective at helping some people feel calm and relaxed and more able to face challenges, which can be very positive. I would also recognise that hypnotherapy can also result in people being able to change habits or alter their behaviour. I would encourage the family to make their own choices when safe to do so, and would always advise that any physical and nutritional risks would need to be considered alongside should they decide to pursue a course of hypnotherapy.

2. "Do you agree it can take 15+ attempts of trying a new food for it to be accepted, for someone with ARFID?" +

The general principle of repeated exposures of small amounts of a new food, often coupled with some form of reward, can certainly be effective in shaping eating behaviour. This standard technique based on behaviour therapy principles, has been well-researched, particularly with young children who may be showing limited acceptance in terms of range of preferred foods. There are several studies investigating the use of this technique to promote consumption of fruit and vegetables in such children. However, **ARFID is not picky eating** and additional strategies and supports may be required.

It is important to understand what is underlying a person with ARFID's difficulty accepting a range of foods as this can vary. In some people with ARFID, fear or disgust responses may be so high, or their avoidance behaviour so extreme, that it can be extremely difficult to get them to try even the first small taste without specifically working on these aspects first. Where it is possible to establish tasting, usually a very small amount is the best place to start, as one of the most important things is that the person succeeds in the attempt. The whole idea is to build confidence. Fifteen failed attempts may put someone off even further. Also important is the recognition that even if someone does manage to have repeated tastes, they may not spontaneously be able to work towards accepting that food as part of their usual diet without additional support. There are also a number of people who don't go through this process at all – they may have a limited range at any one time but tend to completely drop foods and pick a new one up seemingly without having to go through a slow trying process.

Having said all of this, we certainly use this basic technique with some of the children and young people and their parents/carers that we see, but only when this is indicated and as one part of a tailored treatment approach.

3. "How can I tell if my child's restrictive eating is ARFID or related to their autism?"

A good question that often comes up. ARFID is a formal diagnosis for a type of eating disorder. In order to meet diagnostic threshold for a diagnosis of ARFID, the person's eating behaviour needs to be directly leading to significant impairment in their physical health or development and/or their ability to participate in daily life as expected. There are many autistic children and adults with specific eating habits, food preferences, rituals and routines around their eating. This does not mean that they necessarily have an eating disorder. However, if they are unable to meet their nutritional needs resulting in nutritional deficiencies or their physical health and well-being is directly and significantly affected by their diet and eating behaviour, or their life is significantly negatively affected by their eating over and above their autism, then a diagnosis of ARFID might be appropriate in the context of autism. So technically, the eating behaviour might be related to sensory preferences or low interest in food and eating often seen in autistic people, but only warrants an additional label of ARFID if it requires treatment in its own right. I hope that makes sense!

4. "In your experience, can ARFID caused by a specific incident - choking - improve with therapy? If so, what type of therapy?"

Yes, in my experience onset of ARFID can be triggered by a specific event, such as choking, and this can happen at any age, and yes, this type of difficulty can improve with therapy. As always, it is important to have a good, clear and full understanding of what may be underlying the eating difficulty as well as associated risks and impact and take everything fully into account when prioritising and agreeing goals for treatment. If there is agreement that the difficulty is characterised by a specific fear of choking following a specific incident (i.e. a choking phobia) then it may be sensible to proceed with an evidence-based approach for the treatment of a phobia (e.g. a CBT-based approach). With anyone with ARFID it is always important to consider whether adaptations are required (e.g. for an autistic person or someone with learning disability) and whether additional nutritional/physical input is required.

5. "How do we deal with school healthy eating policies that don't allow chocolate or other "unhealthy" foods, if that is all my child will eat?"

This is often a difficult one as schools have a responsibility to promote positive eating behaviour on a broad scale. This can be difficult if your child has a limited diet and is most comfortable only eating snack type foods outside the home, or foods generally not considered acceptable in a school lunch box. In general, I suggest that it can be helpful to try to arrange to have a conversation with relevant staff at school. Many school staff may not be fully aware of ARFID and so might not recognise the extent of the challenges your child is facing. Children do need to eat and drink something during the school day and there may be some accommodations required to facilitate this in the school setting. Explaining your child's difficulty as clearly as you can and trying to work with the staff at school to minimise disruption for them but still making sure your child has the best chance of being able to eat at least something may be required. If your child has a formal diagnosis and is being seen by a healthcare professional and you are experiencing concerns about your child's eating during the school day, then seems sensible to discuss this with them as they may be able to assist. It can also be helpful to express a willingness to provide more information for school staff if required (e.g. one of the ARFID factsheets) or mention that further information can be found via the UK eating disorders charity, Beat, etc.

6. "When a child eats a new food, enjoys it but then suddenly drops it, is that an Autism/learning disability issue or ARFID related?"

This pattern can occur in anyone, including autistic people and those with learning disability, but not only people in these groups. It can of course also occur in people without ARFID. Sometimes this can occur when someone gets tired of or goes off a food. Sometimes it can happen because on one occasion something is 'wrong' with the food. Maybe the texture, colour, or taste has been different to usual, maybe there has been a gagging incident, or some other reason to put the person off. If your child only eats a limited number of foods at any one time this tendency to suddenly drop foods can be very stressful - many parents/carers describe to us constantly worrying that their child will drop a preferred food. It can also turn out to be expensive, especially when you have good stocks of a currently preferred food only for it to be refused. If there is a pattern like this, it can sometimes be worth going back to previously accepted foods after some time has elapsed, as they may be picked up again. In this way, it can be possible to slowly build up and introduce some variety over the week.

7. "Can we request that the GP carries out annual, basic height/weight checks and bloods as part of a screening tool to validate the concerns of parents where a child has very restricted eating?"

If you are concerned about your child, you can of course arrange an appointment with your child's GP. Waiting a year if eating is very restricted and unlikely to be meeting the child's needs seems a long time. It can be helpful to be as specific as you can about what aspects of your child's health and well-being you are concerned about and why. Healthy weight and growth can vary between children, some children are naturally smaller or lighter, others taller or heavier. Two children of the same parents can vary in terms of their own healthy weight and growth centiles and will not necessarily end up the same. If there are significant drops across centiles then your child's GP might consider a range of possible explanations, which may include dietary reasons. Your child's GP may feel that blood tests are indicated if the diet is very limited in terms of nutritional value and there are signs and symptoms of deficiencies, but blood tests may not be needed if main food groups are covered even if only through a limited total number of accepted foods. Parental concerns are also often about the impact of the child's eating on their own and other family members' daily lives. For many with ARFID, such concerns are just as valid even if weight, growth and nutritional status are ok.

8. "I would like to know, once treatment commences at GOSH or other specialist feeding settings if it is possible to set up delegated supervision sessions locally? We (the families) are doing the work but up to this point we're told to keep home pressure free and now being advised to do exposure therapy type stuff at home seems contradictory. I have no issue doing it but by having it happen at home, with the parent, then home is no longer safe. It would be better delegated to a local team - surely even if they are not ARFID trained (I am not formally trained either) then it wouldn't be hard to have a local NHS service deliver this (we live a long way from London as do many others). There is no joined up care. Why not? "

This is a question that includes several components and I will do my best to give an answer to the more general point about service delivery. Obviously, I can't comment on any specific advice or recommendations given in a particular situation by clinicians in other clinics. If there are questions or concerns about any aspect of care, I would usually advise discussing that with the team members you are working with.

In relation to the wider context, there has been a clear recognition that many people with ARFID struggle to access appropriate care and that this situation needs to be improved. This has resulted in NHS England leading quite a lot of work over the past couple of years across the whole country in relation to improving awareness of ARFID and supporting local teams to develop care pathways for children, young people, and adults with ARFID. The emphasis is on working to improve access to locally available, appropriate treatment; it is certainly not expected that people who live outside London should come to London for first-line treatment as that would be neither practical nor necessary. Initiatives include guidance documents, drawn up in conjunction with individuals and family members with personal experience of ARFID, as well as a national programme of ARFID training for clinicians working with adults and older adults, and children and young people. Realistically, it is likely to take some considerable time for changes to be fully implemented in the way that everyone hopes to see, but at least this process has been started.

9. "How do you convince your GP/paediatrician/dietician that you suspect your child had ARFID and to put your child onto the appropriate pathway for diagnosis and support. Are there standard steps of referrals or treatment paths that they can start?"

It may be helpful to anticipate that, at present, clinicians may have varying levels of knowledge and awareness about ARFID. At MCCAED we have produced a couple of short leaflets about what it is, and we generally advise signposting to Beat - [ARFID - Beat \(beateatingdisorders.org.uk\)](https://beateatingdisorders.org.uk) or the Royal College of Psychiatrists - [Avoidant/restrictive food intake disorder \(ARFID\) | Royal College of Psychiatrists \(rcpsych.ac.uk\)](https://www.rcpsych.ac.uk). If you are seeing a GP, a paediatrician or a dietitian to discuss your concerns about your child's eating behaviour, it can be helpful to make notes in advance and to try to be as clear as you can be about what aspects of your child's eating you are concerned about why. There is currently work going on in each of the 7 NHS England regions around ARFID pathway development. It might be helpful to ask specifically about arrangements in your area as these may differ somewhat depending on how ARFID pathway implementation plans have progressed in your location.

10. Why does ARFID need to be first recognised by GP/dietician before being referred on to the diagnostic pathway. ARFID is not very well understood by them and most don't even know it exists, so how do we overcome this gatekeeping which is upheld by their ignorance of ARFID and then their arrogance that they know more about it than the parent?"

This question reflects the current all-too-commonly-experienced difficulty of being able to access appropriate support. It is important to honestly acknowledge the burden and distress experienced by so many families in relation to this and for us all to try to address this as constructively as possible. Some of the content of the above answer may be relevant here. At present, arrangements currently differ, in part related to where local areas are up to in terms of ARFID pathway implementation. In some places, a wide range of people can make referrals, including schools, parents and people self-referring. If in doubt, it might be worth contacting the local community eating disorders service or perhaps the local Integrated Care Board team to check local arrangements, and if needed to raise concerns if these seem unclear.

Thank you for your questions – I hope these responses are helpful.

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February 2023