ARFID (Avoident/Restrictive Food Intake Disorder) and Restricted Eating

BURY2GETHER members have raised their concerns that there is no ARFID or restrictive eating service in Bury. BURY2GETHER shares these concerns as ARFID and restrictive eating is often found in neurodivergent people, including autistic people and those with ADHD. Autism and ADHD diagnoses are rising and so the numbers of children and young people with ARFID or restrictive eating is rising too. With no support, families find themselves under huge pressure and stress.

BURY2GETHER asked its members for information on their experiences of getting support for ARFID and restrictive eating and how the conditions affect family life. This information below was gathered from BURY2GETHER's private members' Facebook page that were then sent to Health in November 2024.

Comments received via Facebook from BURY2GETHER members regarding ARFID and restricted eating:

"Two paediatricians have advised us that our child more than likely has ARFID but that unfortunately there is no service available to be referred to or help support us. We have been seen by the community dieticians after a lengthy wait and were advised that there was nothing they could do to help us. My child's restrictive eating impacts every area of our life, we cannot eat out as a family. We have to be extremely regimented to ensure that all of their food is prepared, cooked and looks and tastes the same every single time. My child's meals consist of vegan cheese spread sandwiches, vegan sausage rolls and McDonald's chicken nuggets on rotation. This has been the case for at least two years. We need support to help ease anxiety and help us to help our child try new things or include new things into their diet. Unfortunately nothing exists for us so we are forced to keep going doing the best that we can."

"The only support I got was a leaflet ['*Selected Eating Advice*']and, "Look online". Will add we were under a dietician for 22 months, also bloods, but been discharged now. This leaflet was given to me by a paediatrician and I was told to look online for info/support groups. We're still under paediatrics and other people now for various things, however for my child's eating. Fr lack of nothing at all, following a few people on Instagram for help/tips but not exactly same as professional support."

"I've often thought if my child falls under ARFID. They have very restricted food. They will eat, repeatedly eats same food over and over again for months, then out of the blue goes off that food and this can last for months again. My child has been referred to a dietitian but this was months ago and still not been seen. I did receive a referral letter stating at least a 20 week wait time on appointments. This massively impacts us as a family going anywhere for food as it's not the same, ie McDonald's nuggets are not the same as chicken nuggets in a restaurant, for example."

“No dietician support received whatsoever. No diagnosis of ARFID given but both children definitely have extremely restricted diets with one child being very demand-avoidant, so is almost impossible to add foods that they don’t already eat to their diet.”

“Had a referral for the dietician coming up for a year ago. No contact. Have tried to chase up. Restrictive and rigid stuff around food seems to be "normalised" by many professionals. Yet my child is not getting all the nutrients they need.”

“The single hardest challenge we face and the one with very little support. We have faced this challenge since birth with our child and they are now nearly 4. From the start we have found there is diagnostic overshadowing - ‘It's because they have Down Syndrome’, therefore they will be delayed in eating. We had some support from a feeding lady but she has now left the Trust and I'm not sure if she has been replaced. In other areas there are specialist feeding clinics to support.
When I sought and paid for private advice and therapy the NHS therapist said there was no evidence for the methods they suggested so my childcare setting was reluctant to implement the advice. When I asked my paediatrician for a referral to the feeding trust she said you can try but, ‘There is no money in Bury’ and laughed. The dietician parent-blamed me sending a letter stating my child's dietary needs were not being met with lots of patronising advice. When I challenged her and said if I change anything at a meal time there can be a complete meltdown and food refusal, she said.’Your child will eat when they are hungry,’ even though I don't believe my child has an awareness of being full due to having an NG tube for 14 months. I get given a leaflet [‘*Selected Eating Advice’*] every year and that is it.
I am completely at a loss how to move my child's feeding journey on and it is soul destroying. It impacts every aspect of our lives and I worry how we will navigate it as they get older. For my child, it's so hard as you can see the difficult relationship they have with food: they want to eat but struggle hugely. The support is not there, it is very misunderstood and different professionals give different conflicting advice leaving you completely unsure how to support your child. There is support available in the private sector and the NHS needs to either support that or provide their own services. Joined-up clinics, sensory,diet,feeding and swallowing, etc. It's happening in other areas. Why should our children miss out?”

“This is absolutely disgraceful.” [Response from one parent/carer to the above post.]

“My child is 3-and-a-half and had a G-tube inserted 1 month ago due to ARFID presentation. I could write an essay on the absolute trauma, despair and lack of support for my child. They have a diagnosis of ASC and severe sensory processing disorder. They are also non-verbal. They never weaned onto solids at all. They were seen at around 10 months old from the feeding SALT specialists for a number of months. They have a safe swallow and their issues were deemed sensory, so they were discharged from their service and referred to the dieticians who never received the onward referral. Our health visitor then referred my child for a sensory needs assessment, but Rehabilitation for Independence would not see them or support until they were aged 2. We were seen at the CDC and the consultant wrote to the dieticians requesting an urgent appointment. My child

was still just on first infant formula and tolerating around 3 teaspoons of fruit puree that we could hide multivitamins in. When seen by the dieticians (eventually!) they were prescribed "neutral" flavoured Fortini to disguise in their formula. My child detected this, even when reduced to 5mls in an 8oz bottle. They then refused to feed at all for 17 hours. As a result we lost feeding at nursery and at my Mum's and my child would only feed on a specific beanbag in our front room.
It was requested that we had an urgent MDT appointment with the paediatrician, health visitor and dietician. My child's growth was stunted for around 5 months. At that appointment, parents and professionals all agreed my child wouldn't tolerate an NG and referred to gastro surgeons at RMCH to discuss a gastrostomy. We had to wait 5 months to see the surgeons who placed my child on the 'urgent within a month' waiting list for surgery, but then advised that the waiting time would be 72 weeks all while they were starving and not growing. After 3 months of PALS complaints we got a cancellation slot and had the surgery 4 weeks ago. In the first 2 weeks he gained half a kg and has grown over 3cm since the review with the dieticians in July.
We were told that there is an ARFID service at RMCH, but this is only commissioned for children with a central Manchester postcode. From what I understand about it there is a psychiatrist and specialist dietician and there are therapy options. This wouldn't be appropriate for a non-verbal child with a learning difficulty as they cannot engage. My child is demand-avoidant with everything and only engages with things on their terms. As a family, we can cope with their autism, communication challenges and sensory difficulties, but their feeding (or lack of) has totally dominated all of our lives for the last 3 years. Apparently Evalina used to accept referrals, too, for ARFID children out of area, but they no longer do this either. There was nowhere to refer to, no help. I am pleased to say that my child is thriving with the tube in the short time it has been placed, but if referrals have been made immediately from before their first birthday and we have had to complain and complain to be seen sooner, it is ridiculous that it has taken 3 years to be find some sort of nutrition they will accept."

"Similar to others, we have been advised as part of sensory assessment and by Paediatrics that my (autistic non-speaking) child more than likely has ARFID but that no service exists to support or even formally diagnose. My child struggles to eat and our entire household has lives structured to ensure that they are able to eat their very limited safe foods, which have to be specific brand and cooked a specific way/time and with a specific sensory feel in order for them to eat them. It's not an exaggeration to say my child sometimes goes days without eating, purely drinking water/ milk. We were told we were very lucky to even get in front of a dietitian but when we did we were told that they were unable to help as my child was within the regular weight range. They shouldn't wait until there's significant health concerns or a tube is needed. More support should be given. My child has never been able to access school meals or anything like that. We never eat out as a family as my child can't eat anything on the menu. I think there's still an old-school attitude of "if they're hungry enough they'll eat" - that's not the case. I am extremely worried about my child's on-going health as they continue to develop on such meagre nutritional items and how this will impact their health as an adult. I think it's short-sighted not to consider this."

“Autistic, non-verbal child who has very restrictive eating. Issues with vomiting at school, which despite not being cause by the type of food they eat, we are still asked by the school nurse to try and diversify their diet. So, I accept their restricted diet and the fact that there’s not much that can be done about it (prepared to be enlightened), but it is frustrating that a school nurse based in a specialist setting throws out such suggestions as if we haven’t thought of that!”

“I have a child with an ARFID diagnosis - given by Galaxy House circa 2014. This was relatively new at the time. They were also the first child that Bury HYM eating disorder service treated and the clinical lead used my child as a case study for other professionals. Unfortunately, it's life-long and doesn't go away. At 22 my child is still taking 2 Fresubin milkshakes daily and it is a heartbreaking situation with zero support now they are an adult. They had a lot of scaffolded support due to their extremely low weight and they were really supportive to us as a family. My child has a diagnosis of ASC, ADHD, ARFID and SPD.
My youngest child (5) has, unfortunately, not had as much luck with support. They eat four things on rotation and have dropped four safe foods since starting primary school. They have a diagnosis of non-verbal autism. The dietetic service tried to discharge them with four safe foods - plain couscous, sausages, Kinder bars and Cornettos. My child was given a failure to thrive diagnosis after dropping 2 centiles and they still tried to discharge them. The support has been appalling. There appears to be a huge lack of training around ARFID within Bury dieticians and a diagnosis is unavailable. We are going to pay privately for a diagnosis appointment with Gillian Harris for them.
ARFID controls and consumes every part of our family's life. It has done for years - based upon how many calories they have consumed depicts what activities we can do as a family, where we can go and what my child can eat.
Having been through the struggle with a child already I have a good amount of understanding and experience and know that it is also life-long for my other child.
The support for ARFID is a postcode lottery, which is appalling. It has brought me to my knees on several occasions and I have a lot of trauma centred around food because of it. School comments such as, "We don't know what else to offer them, we don't know how they go all day eating as little as they do" are upsetting. School have been supportive with food therapy, food exposure therapy, etc, but for my son he engages in food play, etc. It's the final 32nd step of putting the food in their mouth and eating it.” [There are considered to be 32 steps a child with eating difficulties needs to go through in order to progress with eating.]

“Autistic child with sensory processing issues. Spits food back out if anything gets stuck inside their teeth and cries. No referrals given as they eat some plain beige foods. Even though it’s the same repetitive meals and foods they didn’t need a dietician. Not like it would make any difference, but absolutely no support or no recognition of their needs.”

“I recently spoke to our paediatrician about my child having ARFID. She said at this time they don’t, but I strongly disagree. I agreed their eating is based around it being sensory, such a restricted diet and they hardly eat. Not food motivated and will not try new foods. Zero support around this, yet more and more kids need this support and have nowhere to go. The dietician we did have was hopeless and no help at all that I couldn't wait for us to

be discharged. Our kids are being failed in every area but this definitely needs to be addressed as it's getting critical. My child is autistic and has sensory processing disorder and is no- verbal. I try not to make meal times negative as we are so restricted to what they do eat I am scared that they will eventually turn away from what they do [eat]."

"I attended a feeding talk when my child was a baby. How I inwardly tutted when one parent said their toddler only had four foods they would eat. Surely that parent knew if they did not feed the child they would get hungry and eat? When my child turned 2-years-old I wanted to find that parent to say I completely understand now. Despite following toddler feeding books my child never progressed from pureed food to more than a couple of different meals. Looking back, they clearly had sensory issues but I was unaware of this at the time. Unfamiliar food brought on huge anxiety and meltdowns. Changing a brand was impossible. My child lived on tuna pasta and fish fingers for about two years. Then, both of those were suddenly rejected. The only advice I managed to find was online from other parents/carers or in a book about ARFID that I wish I had read years ago.
At nursery the chocolate biscuit in my child's lunchbox that I put in as a safe food to ensure something was eaten was banned as unhealthy. At primary school we tried school meals but had to stop as the lunchtime supervisors withheld pudding if the main course was not eaten. Eventually the school put my child's photo on the kitchen wall to remind staff not to interfere with this child's eating. Family piled on pressure with well-meaning, but useless information, such as, 'They'll eat when they are hungry,' and, 'In my day, you ate what you were given and that was it.' My child would rather not eat all day than tackle something they could not tolerate the smell or taste of.
Around age 10 my child was diagnosed autistic. Around age 12 something changed - possibly increased tolerance to texture/small sensitivities - and they began to show an interest in other foods. A couple of years later and they will tackle pretty much anything. We're lucky - for many autistic people food issues are for life. We had no help and no idea where to go for help and judging by comments from other parents/carers we would have wasted our time looking for help."

"Four-year-old child with ASC diagnosis, recently acknowledged has ARFID at CDC check-up appointment because when their routines change (eg, school holidays) they go into crisis-and stops eating and sleeping altogether. Consultant was very understanding but no service to refer to, only leaflets given. Thankfully my child's weight has stayed the same since their last weighing (last December) as the only current option for treatment is tube feeding.
My child has had feeding issues since the age of one, dropping most foods they were eating up until then almost overnight. They have been seen by Paediactric dieticians, referred onto feeding and swallowing SALT team because they also overfill their mouth to the point of choking, then referred on to Rehabilitation for Independence as it was identified as sensory seeking behaviour. No treatment/therapy given by any of the above, just refer to next person and wait on waiting list.
Eating and sleeping are our biggest struggles as a family, despite our child being non-speaking with high sensory needs. The knock-on effects are severe constipation and pain, leading to difficult behaviours when chronic - which has also been mismanaged in terms of treatment. This has also affected them being able to potty train. I could go on, there's so much that restricted eating impacts!"

“Yes, my child will only eat certain foods. Very restricted. All through their life I was told by GPs and CAMHS they are a good weight and they are active, don't worry about it. My child was never referred anywhere. They are now 15, nearly 16, and is even worse now than they were as a young child. They are diagnosed ASC with high anxiety and has EBSA and doesn't sleep.”

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