

## strive ARFID Carer Support Group

### Topic Sheet – June 2022

### Managing Difficult Behaviours

Eating disorders bring with them a whole new world of challenging behaviours. **Remember these behaviours are usually a sign of extreme emotional distress and a response to fear and anxiety. We need to respond with empathy, compassion and reassurance to build trust and help our loved ones tackle their fears with eating.** Validation of their feelings and making it clear you are there for them is important. Sometimes it may not be with words, but just a hug or kind gesture. e.g. 'I know this is really hard and I am here for you. We will get through this together' or 'You are brave, you are strong, you are awesome, you are amazing...'

**With ARFID, there may be sensory issues at play.** They may not be able to tolerate smells, tastes, textures, sounds and sights of their own or other's foods. Sometimes, a step-ladder approach is needed, e.g. SOS program – tolerate the food in the same room, then at the table, then on the plate – all before even starting to try touching or tasting the food. If necessary, move to another area to eat where they feel comfortable.

**Anxiety is a HUGE part of ARFID.** This can relate to fear of bad consequences such as vomiting, choking or allergic reaction. What can be done to decrease the sense of overwhelm in the moment? Move to a quieter area or away from others watching? Will the use of a weighted blanket or toy, or a heat pack help? Do you need to introduce distractions like fidget toys, allow screen watching, introduce a card or board game to divert focus from the food?

**Rigid thoughts and behaviours can be common with ARFID.** e.g., only one brand, type of food, crockery, where it needs to be *exactly* the same or will be refused. Changes to packaging and being able to find safe foods can be a nightmare for parents and carers! Any changes can cause anxiety and meltdowns. This can lead to food juggling when they continue to eat the same foods over and over again.

**Physical and verbal aggression are also common behaviours with eating disorders.** Never feel you must tolerate it and be clear with your loved one that it's not ok. Lashing out also causes huge shame in your loved one. It's torture to watch your them so distressed, and the anger thrown at us is very distressing. **De-escalating the anxiety and emotional dysregulation is important with ARFID.** Patience and small, slow steps towards change or new foods will help them adapt more readily, but **we**

need to remove any pressure or expectation and instead gradually build trust and rapport to gain their confidence in trying something new.

Examples:

1. At the peak of ARFID we experienced **physical and verbal aggression**. Screaming pitch swearing, slamming doors, hitting, bashing walls it was like a tsunami. My husband had great difficulty dealing with the bad behaviour and abuse and he mirrored her bad behaviour as a response, which only escalated the situation. He had to learn to walk away, calm down and then address her behaviour when the situation allowed. His response was that he was doing this to support me for the way I was being treated. It took us a long time to work out the right approach and involved really understanding her triggers to prevent it getting out of control. **What bought her undone in our case was chaos, noise, too much pressure, too many therapists with conflicting information and people forcing her to eat.**
2. Spitting food and hiding food was another awful behaviour. We would find food in couch cushions, vases, under beds, in heating ducts, fireplace, car and drawers. Her therapist told us to point it out to her every time we found it and make her clean it up and be accountable. I felt this was incorrect advice and used my gut feel on this one. She was already ashamed and embarrassed and fearful, so I didn't mention any of it just removed it before the dog! **It stopped happening once I used a more compassionate approach.**
3. **Running away, hiding, and hiding car keys** so we couldn't find her was really challenging and frightening. It created a lot of angst between my husband and I. He was furious. We argued a lot on this as he felt we should just leave her, as it was attention seeking. This probably would be a normal reaction if she didn't have ARFID. He had fury and I was afraid and there was blame and punishment. FBT really helped us here as we all went individually at first and then came together, it helped us understand more about panic attacks and high level anxiety and how to approach it as a family. **When the anxiety was at its peak our daughter needed some form of release, so anything physical, aggressive, that involved movement, helped.** We encouraged her to channel this in more positive ways, such as hide and seek (when she was younger) brisk walks, yoga, jumping on the trampoline, running the dog, or smashing a cricket bat into a pillow.

If more than one carer is involved, it can help to tag-team to give each other a break. If the behaviours are extreme, it may be necessary to call for outside assistance such as a mental health crisis team (different in each state), the police or the ambulance service. If you are concerned for your own safety, or the safety of your loved one, don't be afraid to reach out for help. We know that in some cases, ARFID can morph into Anorexia Nervosa, where a focus shifts to body weight/shape or size or calories become problematic. This can give rise to more aggressive outbursts, so be aware and do what you can to validate how they are feeling, while maintaining the need to get through the meal.

it's my goal to be this calm when things  
are falling apart

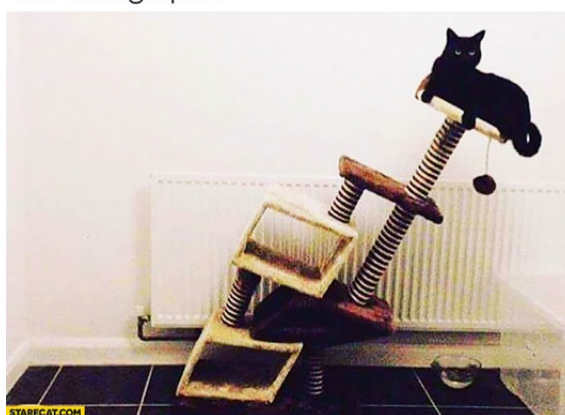


Figure 1 Source startcat.com

Feeling shocked, distressed, angry, overwhelmed and afraid are all very normal reactions for carers. Difficult behaviours impact the whole family and social functioning. It's common to feel helpless and that you're failing if these behaviours occur. It can be incredibly hard to regulate our own emotions when we're feeling hurt, lost, afraid and sometimes angry too. Whilst all these feelings maybe happening on the inside, being calm, compassionate and consistent on the outside is the key.

Carers often deal with these behaviours on a daily basis and it can be exhausting. Creating boundaries allows the person with ARFID and the rest of the family to feel better about expectations and the pressures of living normal lives. Knowing what to do or how to respond is important, so your loved one does not control everything, but learns to adapt to different situations



Try not to beat yourself up and remember the ARFID creates genuine fear around new or unfamiliar foods and situations. We need to remain calm, go at a pace that works for your loved one, celebrate the victories and be their cheer leader for finding ways to increase food variety, frequency or quantity.

Remember this is a whole new ballgame and it's very normal to feel inclined to enable or allow eating disorder behaviours. With ARFID, maintaining weight or avoiding weight loss is preferable, so allow them to eat preferred foods in high quantity, if necessary, while working gradually on exposure to new or unfamiliar foods.

You learn as you go and get stronger and more confident about what works best for you and your loved one.

*Your connection to your loved one is your most powerful weapon against the eating disorder - trust yourself*

*What has worked for you?*

This Topic Sheet can be found at [bit.ly/3MBMJJj](https://bit.ly/3MBMJJj)

## References

Mental Health Foundations [bit.ly/3JvjWFJ](https://bit.ly/3JvjWFJ)

Shared knowledge and generosity of those with lived experience

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