



Family Matters – Tips for families from families

Telling people

Eating Disorders are a disease of secrecy. The sufferer may have kept it secret for a while before diagnosis. Many families feel the need to keep the diagnosis of their child secret, either on request of the child, to protect the child or for fear of blame, stigma or judgement from others. Sometimes it feels too complicated to explain to others in a way that makes sense. And you are too tired to even just think how to frame it!

The reality is that there is a level of ignorance and misconceptions out there about eating disorders and there is always a chance that someone you tell will respond in a way that is not helpful.

However, there are some strong arguments for being more open about your child's diagnosis

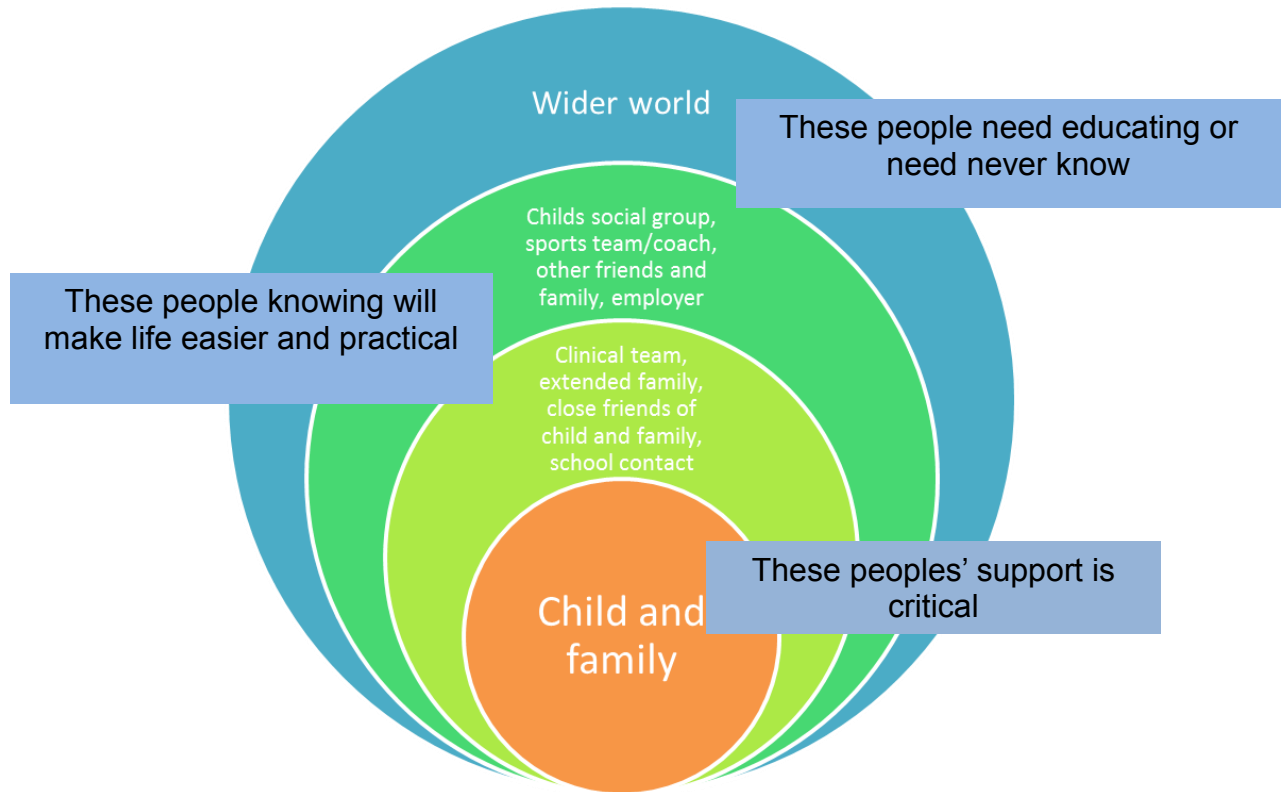
- AN thrives on secrecy and the less people who know, the more opportunities there are for AN behaviours to increase in the absence of people to hold the AN to account
- Informed family and friends can provide a network of safe social opportunities and even provide respite for you as a family. As your child moves to more independent eating, it can be reassuring for them to know a couple of close friends or grandparents will keep an eye on them. It can make it easier to tell the AN voice, which by then is softer, to go away.
- Remaining connected to friends and extended family is key to avoiding or minimising the social isolation that frequently accompanies this illness.
- Finally, while not the responsibility of any individual family, the more families who are open and matter of fact about their child's eating disorder, the less stigma and misconceptions there will be for families following on.

Developing a 'spiel' in advance can be useful for when you get caught unawares. This 'spiel' will be different for each family but it is good to

1. go on the front foot
2. address the possible misperceptions and/or correct any quickly
3. and then talk about what is involved in treatment.

I used to say something along the lines of "L has been unwell/off school etc as she developed anorexia nervosa a couple of months ago. Not sure how much you know about anorexia nervosa, I always thought it was a vanity thing or wanting to be thin but researchers in recent years have found that it is actually a brain based disorder which is triggered by weight loss (in our case L went trekking in Nepal) which for some reason causes the person to become phobic about eating and needing to exercise compulsively - bizarre. Anyway the most effective treatment involves us as a family making sure she eats 6 times a day and stops exercising until she regains the weight - which is pretty intense, I can't work at the moment unfortunately etc". You may be pleasantly surprised by the responses of people when it is framed like this – there is a level of uncertainty for other people in talking to families whose kids have a mental illness.

It can also be useful to think of who to tell by looking at the below diagram



Useful resources to point people to who want to know and understand more are

- www.feast-ed.org
- www.maudsleyparents.org
- Brave Girl Eating by Harriet Brown is an easy read for those friends and relatives wanting to understand what is going on

Below is a sample letter written by a parent prior to a family gathering. Some of it you could also use for a general email out to family and friends whose support would be helpful. If you ask for their support, be specific about the ways they can assist e.g. cook some high calorie meals, provide some respite for you between meals by entertaining your child, assist with other siblings by taking them for a few days or taking them on special outings, taking on some of the other tasks you need to do e.g. school stationery shopping, house cleaning etc. By being specific you can avoid well-intentioned but potentially damaging attempts at help.

Developed by Belinda Caldwell – CEED Carer Consultant, and the mother of a daughter with anorexia nervosa.

Tips collated from the lived experience and wisdoms of parents on the FEAST website (www.feast-ed.org) and other sources.



Sample letter to family and friends before a gathering (amend details as needed)

Dear

As you may know <child's name> is suffering from anorexia nervosa and will find the upcoming family gathering/shared holiday challenging. We hope this gives you an idea of what she is going through and how best you can support her.

Anorexia is a serious ILLNESS. It is not a personality trait or intentional stubbornness about food. This illness causes <child's name> very real anxiety and fears about eating. This can be confusing, since most of us struggle to not be overweight and have a hard time relating to a fear of eating the high-fat foods that most of us crave. As a result, we may trivialize or even joke about anorexic behaviours, without realizing this can be very hurtful.

To help put it in perspective: think of **your** worst fear (heights, claustrophobia, snakes, etc.) and being expected to face that fear (climb a tall ladder, ride in an elevator, encounter a snake) 6 times a day, every day. That would be really scary! That is what eating is like for <child's name> right now.

<child's name> is being treated with Family Based Treatment which is the current evidence based treatment for AN and involves us as a family requiring her to eat 6 times a day, eat enough to regain the weight loss and return to normalised eating. As a family, we receive support from <our local Child and Adolescent Mental Health Service> to do this. Currently we need to be with <child's name> 24/7 and supervise all meals, including those at school. We have to prioritise eating and not exercising over anything else in our lives currently until <child's name> is better.

We have all been learning a great deal about this illness. Anorexia causes sufferers to think about food almost constantly as a substitute for actually eating it. That is why we need to focus on activities and distractions that have nothing to do with food or physical exertion. <child's name> is taking up crocheting again; despite the fact that she has the LEAST crafty mother on the planet!

I realize everyone at the reunion cares deeply for D, and wants to assist in her recovery. Here are a few practical guidelines:

1. Do not comment or ask questions about her weight or what she is (or is not) eating.
2. Refrain from comments about your own weight and/or desire to be thinner. Many of us do this without even realizing it... usually in a self-deprecating way.
3. DO spend time with D as you normally would and include her in a variety of activities. One caveat is that we are restricting her physical activities. Other good options are Cards, crafts, talking, watching movies, playing games, playing with babies, etc. Please bring your favourite board games – I will bring several!
4. Be aware and respect that D's meals and snacks will be prepared and monitored by me. That may or may not include items from the 'group' meal/s.
5. D is **not** allowed to participate in meal planning, food preparation or meal clean-up.
6. If you have questions about what she is (or is not) allowed to eat, please refer those questions to me. D is not to be consulted about food choices.
7. Do not ask 'why' or other questions designed to figure out how this happened. While I realize that these conversations would be initiated with good intentions, there simply is no good answer. Conversations about the root cause of the illness can cause feelings of guilt and stress. **Any 'blame' should be laid squarely at the feet of the illness itself.**