

strive Monthly Carer Support Group

Topic Sheet – April 2022 Carer Coping and Wellbeing

Caring for someone with an eating disorder can be a lonely, frightening and overwhelming journey. Eating disorder symptoms are pervasive and intrusive into family life, and interpersonal relationships become entangled with the disorder in a complex manner. Carers themselves have their own practical and emotional reaction to the illness and it can be easy to lose sight of the importance of our own wellbeing.



Figure 1 Source: Your Mind Matters

1. It is a marathon, not a sprint. We need the mental and physical resilience to last the journey. If we try to do too much and don't take care of ourselves, we will run out of gas. Many carers don't feel entitled to take a break and recharge their batteries because the eating disorder is unrelenting.
2. It may be necessary to simplify life. Eating disorders impact every aspect of life so think about how you can get more help from others or drop a role until things improve. Add an eating disorder to an already busy life and expecting we can keep everything going, puts our mental and physical health at risk, and jeopardises our ability to support our loved one.
3. We cannot directly change others' behaviour, we can only change our own. Becoming aware of our thoughts and behaviour, what is helpful and what is not, means we can start to change it.

Carer related - indirect control

- Eating Disorder Behaviours - so varied and often unpredictable, impossible for us to always be a step ahead of ED.
- Treatment options - finding the right treatment support in an under-resourced health system.
- Cost of Treatment - strain due to lack of financial support and investment in the treatment of eating disorders. The Eating Disorder Plan (EDP) provides financial support for up to 40 sessions of evidence

based psychological treatment and up to 20 sessions of dietetic care.

Refer to EDP information for more details at <https://bit.ly/3v3kFaU>

- Stigma - lack of understanding and judgement from others
- Unwillingness to accept help - We can't always change where they are at however they need us to stay with them. Anosognosia is a condition that can present in conjunction with eating disorders or other mental health illnesses. It means a lack of understanding, awareness, or acceptance by a person that they have a medical condition. This is possible even if there's extensive proof that they do.

Carer related - direct control

- Beliefs about the illness – the common myths. Parents or families are to blame, it's just vanity, it's a choice, they'll grow out of it.
- Information and new skills - recognising we're in uncharted territory and have a very steep learning curve.
- Accommodation to symptoms – it can feel like we're walking on a tightrope always thinking about the best way to help rather than hinder.
- Interpersonal relationships – listening and how we communicate becomes more important than ever. Our stress can spill over to interactions with our loved one, and other family and friends.
- Role strain – Feeling unable to share the load with others. Asking for and accepting help can be difficult. Maybe others can help to prepare meals, spend time with other siblings, shop for groceries. Conflicting ideas about roles and responsibilities can cause also distress.
- Our health - self care, getting enough sleep, nutrition, exercise
- Contact time – sometimes the superhuman effort can be counter-productive

Self-care ideas from the group - what do they do to look after themselves?

4. **“Every mistake is a treasure”** - It's important we can show that we're not frightened of admitting that we've made a mistake. Being flexible and able to shift our approach is kinder to ourselves, and also shows our loved one an important life skill.

5. Unmet needs:

To avoid burnout and stress related problems, it's essential that we have our own survival strategies. Try to timetable some pleasurable activities into the week. Meet a friend, keep up a hobby, do something for fun or for a sense of achievement. It can be easy to fall into a pattern of isolating ourselves from others and stopping other activities. Many carers benefit from seeking professional support for themselves and it may help the broader family as well.

Remember - Modelling self-care also teaches the person with the eating disorder how important it is.



Figure 2 Source: Anxious Little Monsters

The Disruptive Companion Podcast

The first of an SBS podcast series, with contributions from EDFA families who shared their stories to highlight the reality of caring for someone with an eating disorder.

Link: <https://bit.ly/369aU2l>

This Topic Sheet can be found at <https://bit.ly/3LObcex>



References

Eating Disorder Plan <https://bit.ly/3v3kFaU>

Treasure, J et al. (2016), *Skills Based Caring for a Loved One with an Eating Disorder, the New Maudsley Method*, 2nd Edition

The Disruptive Companion, SBS <https://bit.ly/369aU2l>

Shared knowledge and generosity of those with lived experience

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