

TOOLKIT FOR CARERS

The caring role in eating disorders

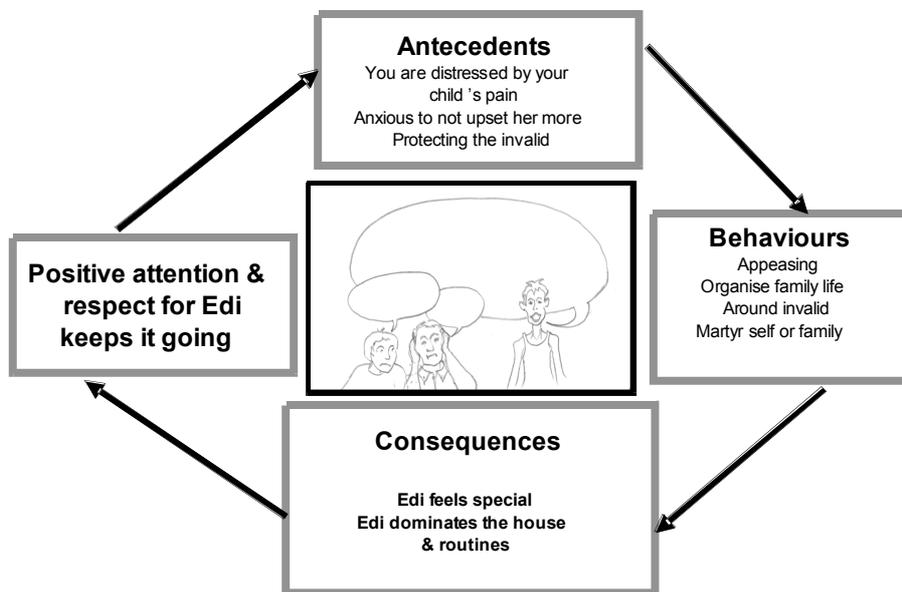


INTRODUCTION

Eating disorder symptoms can have profound social and emotional ramifications for carers. Symptoms are variable in their form and impact and are frightening, intrusive, antisocial, anxiety provoking and frustrating. (In these worksheets, please note that we use 'Edi' to represent the eating disorder - this is to represent the stereotyped clinical presentation which gets confusingly entangled with your child's personality).

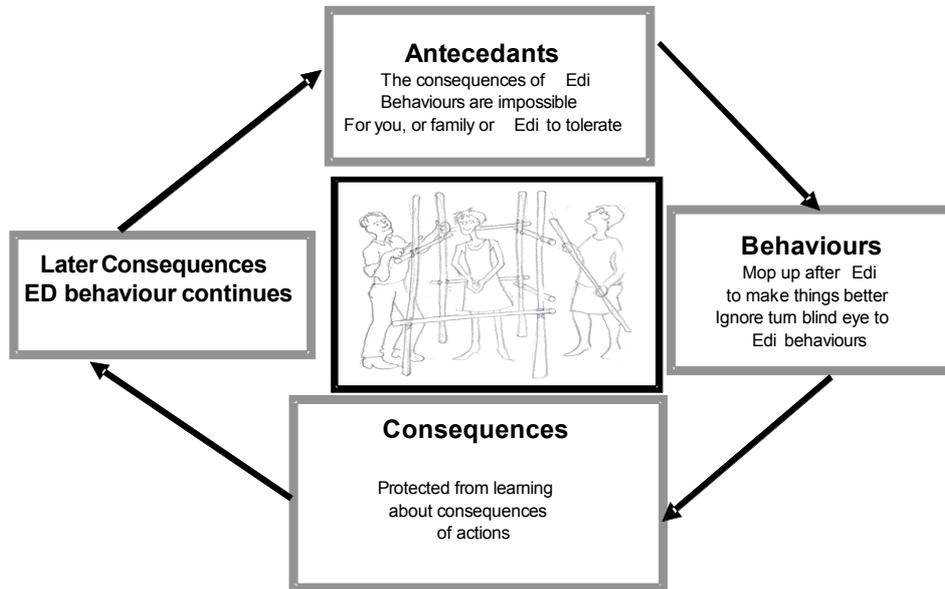
All semblance of normality disappears, social life evaporates, future plans are put on hold and interactions around food increasingly dominate all family relationships. Consequently, it is understandable that responses can be the source of hostile confrontations with family members. Unfortunately, however, the manner in which the carer attempts to *reduce* the symptoms may inadvertently play a role in maintaining or enabling the problems (Treasure et al., 2008). The result can be that the individual feels even more alienated and retreats even further into eating disorder behaviours. Carers often report they lack the skills and resources required to care for their loved ones and acknowledge their need for help and skills to manage these behaviours (Haigh & Treasure, 2003).

The ABC of Accommodating: Bullied by Edi



Does the Eating Disorder (Edi) bully you about what, when and how you eat? Are you bullied about when and how you can use the kitchen and/or bathroom? Perhaps you are controlled by Edi about what, when and how you shop?Or about when and how mealtimes are arranged?

The ABC of Enabling Edi behaviours



There again....perhaps you are covering up negative consequences of Edi behaviour ...clearing up mess, dealing with bathroom problems, buying more food. Perhaps you are turning a blind eye to antisocial behaviour, such as stealing or addictions? Perhaps you have been giving constant reassurance and being sucked in to obsessional rituals or compulsive concerns?

The caring role

Carers are the solution, not the problem. Eating disorders can... and do ... put tremendous demands on the coping abilities of family members. Carers and other family members are usually the main support for the sufferer but frequently get caught up in unhelpful patterns of behaviour that, in turn, perpetuate eating disorder behaviours.

Nobody knows the cause of an eating disorder. There is no evidence that family factors are the cause—there may be a small genetic risk but this is not something over which the parent has any control. Consequently guilt and self blame are futile and inappropriate. There is, however, evidence from naturalistic studies that the outcome of eating disorders is influenced by the emotional reactions of close others which can act as maintaining factors.

It is often necessary for members of the family themselves to change some aspects of their patterns of interacting in response to the eating disorder behaviours. The aim of our carer interventions is to highlight alternative techniques and strategies which allow both carers and sufferers to consider the impact of their responses to eating disordered behaviours and to use this information to reflect on their own unique emotional responses in guiding goal-setting and action planning.

The following worksheets describe some of the common reactions of people who provide care and support for people with eating disorders. Often these reactions can get in the way of providing effective help. Each animal analogy may be your default way of coping with stress and this response could be part of your natural temperament, e.g. over-protective, logical, overtly emotional or avoidant. In order to change these responses, you may have to experiment with trying responses which do not feel natural or spontaneous.

You may not feel motivated to change your responses and behaviour because you are coping with the eating disorder (Edi) and getting results. If this is the case, you can capitalize on what is working for you and enhance your success by sharing your strategies and skills. If you are able to role model flexible coping strategies to the sufferer you may be able to help build their confidence to try and change their behaviour.

You will find more information about these styles and reactions from the book: ‘Skills-based learning for caring for a loved one with an eating disorder: The New Maudsley Method’ (Treasure, J. et al., 2007) and from our website www.eatingresearch.com

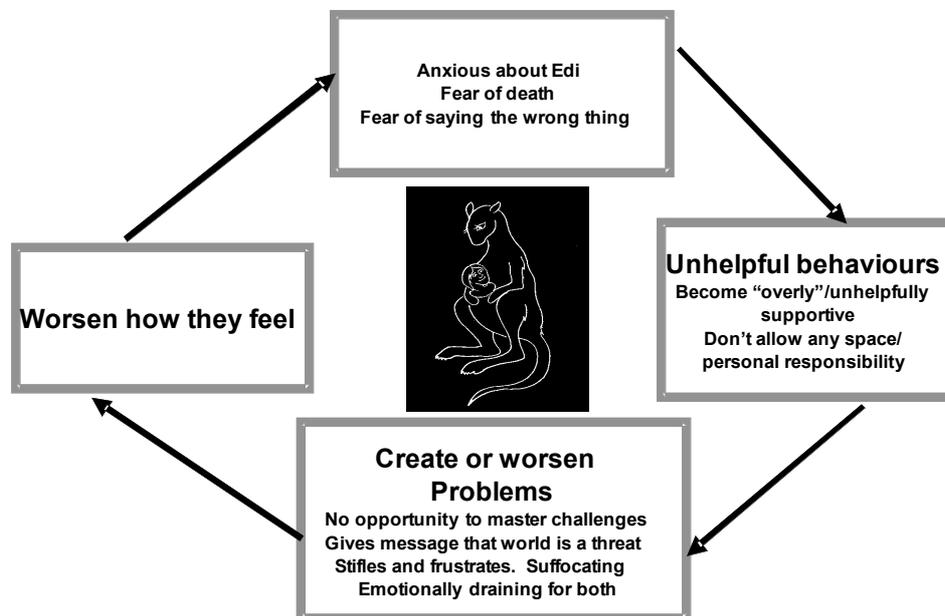
Animal analogies.....



The kangaroo **Too Much Emotion and Too Much Control**

...does everything to protect, taking over all aspects of the sufferer's life. They treat the sufferer with kid gloves, burying them in their pouch in an effort to avoid any upset or stress...accommodating to all possible demands. The downside of this type of caring is that the sufferer fails to learn how to approach and master life's challenges...become trapped in the role of the eternal infant.

The Vicious Circle of 'Kangaroo' Caring



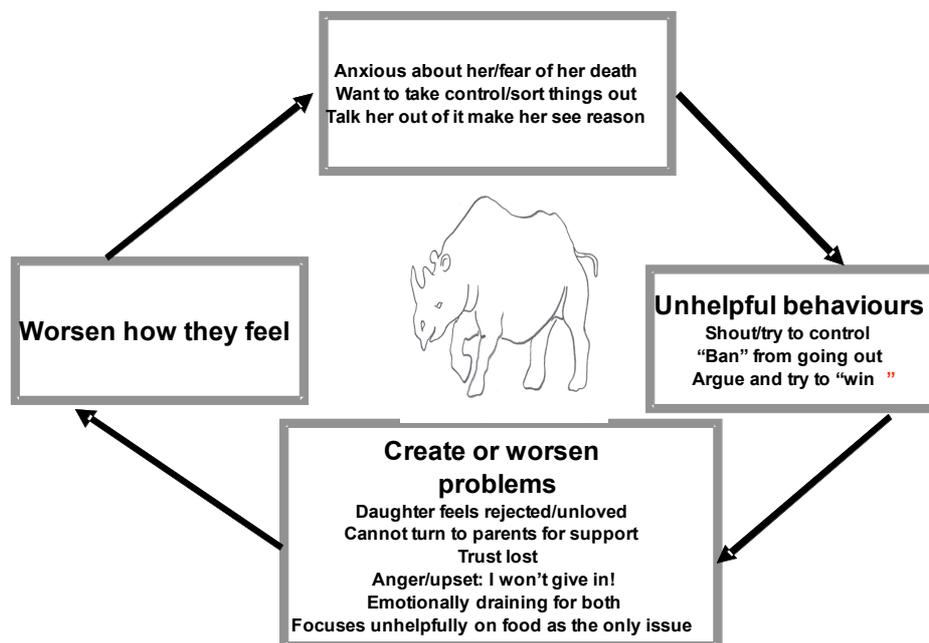
- Reflect on your kangaroo responses
- How are they working for you? If not, what difficulties are you encountering? Give an example of what's not working for you?
- What aspects of your behaviour can you experiment with?
- How important is it to address some of your kangaroo responses?
- Think back to one of your kangaroo behaviours in recent weeks. How can you change that behaviour a little? What would be the first step?

IMPORTANT! Change is tough...remember congratulate yourself after having attempted the change !

The rhinoceros  Too Much Logic and Too Little Warm Emotion

...fuelled by stress, exhaustion & frustration, or simply one's own temperament, the rhino attempts to persuade and convince by argument and confrontation. The downside is that even if the sufferer does obey, confidence to do so without assistance will not be developed. More likely, arguing back with Edi logic will merely produce a deeper hole for the sufferer to hide in.

The Vicious Circle of 'Rhinoceros Caring'



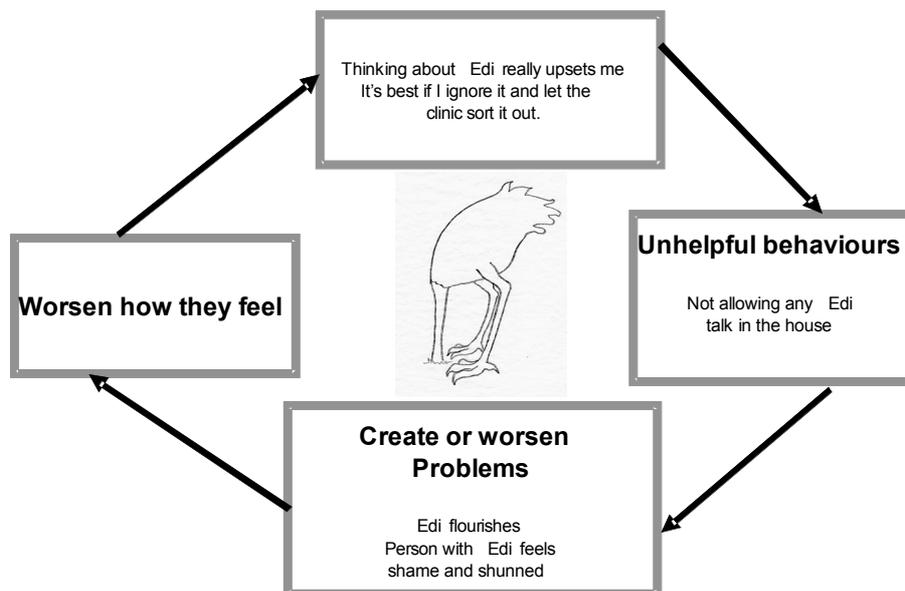
- Reflect on your rhinoceros responses. Are they working for you?
- What difficulties are you encountering?
- How can you avoid these obstacles?
- What might be the repercussions of change, both negative and positive?
- We know that any behaviour change, may encourage your loved one to up the 'anti' ...in the event of this happening, how can you safeguard or protect yourself?
- What can you think of that you can do for yourself to lower your anxiety, stress or anger levels?
- Set a goal or target for yourself?
- How do you think this will make you feel?

IMPORTANT ! If possible, try to work in coming up with ideas on how *you* can achieve some 'me' time. Remember the importance of your own well-being in both your physical and mental health. Role modeling self-care will help the sufferer to learn to change.

The ostrich Too Little Emotion and Too Little Control

...rather than confronting the difficult behaviour, the ostrich finds it difficult to cope with the distress of challenging and confronting the Edi behaviour and so avoids talking and thinking about the problems at all. The downside is that the sufferer may misinterpret this approach as uncaring and feel unloved, thus strengthening low self-esteem

The Vicious Circle of 'Ostrich' Caring



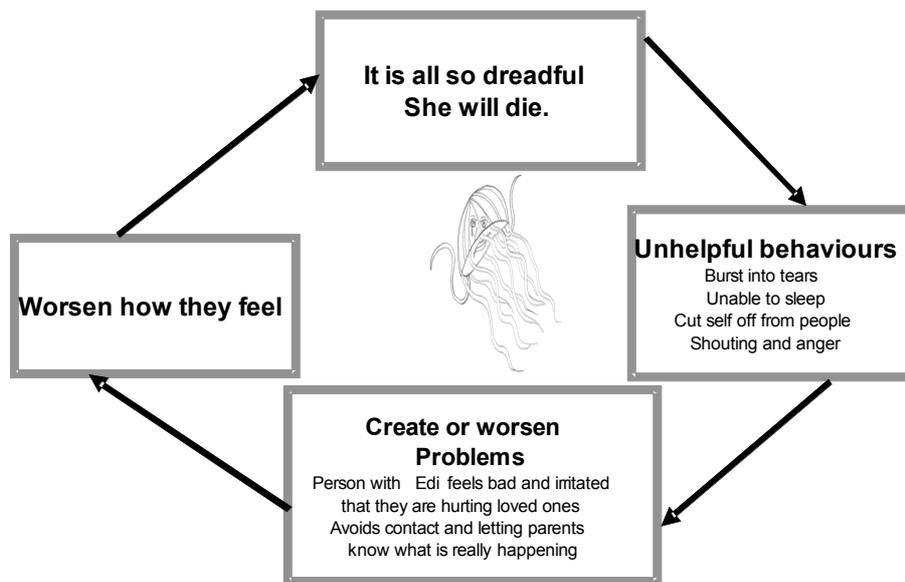
- Reflect on your ostrich tendencies. How do you feel about the above circle?
- It takes courage to change our behaviour. What small step can you take to become less of an ostrich?
- Who can support you in experimenting with new responses?
- What would you want this person to do/say? A list of suggestions is often useful.
- What do you think about involving others?
- How do you feel about making these changes?

IMPORTANT! Change can be difficult and uncomfortable. It may be worthwhile engaging the help of a supportive family member/friend to support you in your quest. Think about your own self-esteem and how role modeling confidence might help the sufferer to take a risk towards change. The fact you're reading this sheet and considering these questions is already a huge step. Well done !

The jellyfish  **Too Much Emotion and Too Little Control**

...some carers may become engulfed in intense emotional responses. They may hold some false interpretations about the illness, high levels of self blame, or perfectionist tendencies with regards to parenting skills. The downside is that the ‘sad and mad’ approach causes tears, anger and sleepless nights and worsens how everybody feels by raising anxiety levels.

The Vicious Circle of ‘jellyfish’ caring



- Reflect on your jellyfish tendencies. How do they make you feel?
- What are the effects of those responses on yourself? On others?
- How important is it that you work on your ‘jellyfish’ responses?
- If you were advising a friend with the same problem, what would your advice be?
- What beliefs do you need to work on in order for this change to happen?
- What are the green shoots that make you feel a little bit confident?
- What would you need either yourself or from other people that would help you move forward in terms of your confidence
- The fact that you are reading these worksheets shows that you are open to new ideas. Well done! What specifically could you do to get started to experimenting with different patterns of responding?

IMPORTANT!All of the aforementioned “important” points apply !! Role modeling calmness and compassion will help the sufferer think about their own self-care as a first step towards change. Well done for considering the first step.....

Our aims.....



The dolphin **Just enough Caring and Control**

An optimal way of helping someone with an eating disorder is to gently nudge ...imagine your daughter/son is at sea. The Edi is her life vest. She/he is unwilling to give up the safety of this life vest whilst living in her stressful & dangerous world. You are the dolphin, nudging her/him to safety, at times swimming ahead and leading the way, and at other times, swimming alongside with encouragement, or even quietly swimming behind.



The St Bernard **Just enough Compassion and Consistency**

An optimal caring response is one of calmness, warmth and compassion. This involves accepting and processing the pain that is involved with what is lost and developing reserves of kindness, gentleness and love to provide the backdrop of change ...A St. Bernard responds consistently...unfailing, reliable and dependable in all circumstances. He is calm and collected, even in the most dangerous of situations. He is dedicated to the welfare and safety of those who are lost ...calm, warm and nurturing.

Nobody gets it right all of the time – in challenging times it is important to remember the adage, “every mistake is a treasure” Tomorrow is a new day! For further information and support on caring for a loved one with an eating disorder, please see the following resources:

- Skills-based learning for caring for a loved one with an eating disorder: The New Maudsley Method (Treasure, J. et al., 2007)
- Our website www.eatingresearch.com
- www.b-eat.co.uk is the leading UK wide charity providing information, help and support for people affected by eating disorders

References:

- Treasure, J., Sepulveda, A., MacDonald, P., Whitaker, P., Lopez, C., Zabala, M, et al. (2008). Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers. *International Journal of Child and Adolescent Health, 1*(4), in press.
- Treasure, J., Smith, G. D., & Crane, A. M. (2007). *Skills-based learning for caring for a loved one with an eating disorder*. Hampshire: Routledge: Taylor and Francis Group.
- Haigh, R., & Treasure, J. (2003). Investigating the needs of carers in the area of eating disorders: development of the Carers' Needs Assessment Measure (CaNAM). *European Eating Disorders Review, 11*, 125-141.