

Kimmeridge Court

Eating Disorders Service

Carers Information

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This booklet has been put together as a resource for the friends and families of people who have an eating disorder.

Introduction

Caring about someone with an eating disorder can be difficult. Whether you are a parent, partner, brother or sister, a friend, or a colleague, you may be feeling concerned, confused and unsure about how to help. Many people in this role report negative effects on their health, family life and on other areas of their life. Some of the common feelings that have been reported by carers are confusion, self-blame & guilt, exhaustion, a sense of loss, hopes and dreams fading, fear and anxiety, resentment, anger and feeling rejected.

This booklet aims to help you avoid or lessen these negative effects, so that you and other members of the family do not become stressed or unwell.

We have included information to help you understand the complexities of an eating disorder, practical strategies to help you cope with the difficulties of the caring role and also information about Kimmeridge Court's specialist Eating Disorder Service.

At the back of this booklet you will also find a guide to other services that can help people with eating disorders, and their families and friends.

We hope that this booklet will help to give you hope, take good care of yourself, and provide you with ideas and information to enable you to give support to somebody who has an eating disorder.

Although the booklet will not be able to answer all of your questions, it includes many strategies that have helped other people. It is not intended to replace seeking professional help, or to put extra pressures on you, but to offer you support.

From the Kimmeridge Court Team

#1 **Managing role strain**

Partner and siblings / parents
Juggling work / other commitments
Feeling stressed / drained as a result

People who are devoting a lot of time and energy to a caring role commonly find that they have difficulties managing their other commitments. Dealing with this problem is an important part of reducing the stress of the role.

Boundaries & Limits

It may be helpful to you to set limits and boundaries on the amount of time you spend being with, or worrying about your relative/ partner, so that you don't neglect your other relationships and commitments. It is important that you try not to spend all your time with the person; this will only encourage them to be more dependent on you and could make others in your life resentful.

Clarify roles

You may also find it helpful to clarify all your roles with others by negotiating what you can and cannot do.

Accept Being a 'Good Enough' Carer

It can often be helpful to lower the pressures you put on yourself. Thinking that you have to be perfect and do everything right is unrealistic, and will probably leave you feeling stressed and unhappy with yourself.

#2 Managing contact time

Spending longer periods with the sufferer

Reducing the amount of contact time with the sufferer

Respite breaks

It is vital that you feel you can set limits on the amount of time you spend with the person suffering from an eating disorder. If possible, get support from others to allow you to have time to yourself and for other activities.

Make time for you & your hobbies & interests

It is not selfish or indulgent to take time to look after yourself, to 'come up for air' regularly; it is essential for both you and the person you are trying to support. It can often be tempting to give up your own interests and hobbies so that you can devote yourself to helping your relative get better. Unfortunately this will not accomplish much and you may quickly become exhausted and resentful.

Look after yourself & get support

Living under extreme long-term stress has recognised physical and emotional effects. To be able to survive personally, let alone support someone else, it is necessary to find strategies which help that survival.

It is important to be kind to yourself; to avoid wasting time blaming yourself for the eating disorder. Blame will accomplish nothing and you will only make yourself miserable.

It can be more helpful to gather information and review your options, then decide what to do next. **Most importantly, finding ways of strengthening your inner resources will help YOU get through the ups and downs.**

A helpful book has recently been published which details Gráinne Smith's experiences as a parent of someone with an eating disorder. It is called "**Coming Up For Air - A survival guide for carers**" and it has lots of practical information on how to cope. To find out more please see the reading list at the end of this booklet.

Here are a few of Gráinne's suggestions to help you plan your own survival.

- **A personal haven**

Consider where you can retreat to for peace, consider setting up your bedroom or spare room as a haven. Consider the shed...

- **Regular breaks**

Perhaps a coffee, a meal out of the house every week? With friends or in a café accompanied by a good book? An overnight stay once a month? A weekend away?

- **Walking the dog**

Consider borrowing one if necessary...

- **Talk to friends and family**

Talk about how you feel, share your sorrows as well as joys. Then friends will feel able to share their own too. Sometimes you need to off load, sometimes you need distraction. Be willing to share and ask for support.

- **Exercise**

There are different kinds of yoga and tai chi to try, dance classes, Pilates, judo, as well as tennis, badminton, golf, football, walking, cycling. Lots of different types of massage - you could try them all.

- **Hobbies**

What did you used to enjoy when life had a smoother path? What new hobby do you fancy trying? Any interesting evening classes nearby, anything from conversational Spanish to upholstery, painting to...?

- **Music**

Try different types of music for different moods and to help express different emotions - look for what suits and helps you.

- **Writing**

You may like to keep a journal, write letters to an imaginary, very supportive friend, make up stories or plays about imaginary - or renamed - characters. All sorts of things can happen when you are writing... and it doesn't need to be for publication or sharing. Sparky spelling and gruesome grammar don't matter if it's to be shredded - but the writing puts feelings into a new perspective, out of your head and onto more manageable paper!

It is really important that you carry on with your leisure pastimes as these can help you relax and recover from stress.

#3 Managing sufferer's denial

Denial of symptoms

Resistance to treatment

Duration of illness

Coping with the sufferer's unwillingness to accept they're ill

Often people with eating disorders are in denial or 'stuck' at the beginning of the illness and this can cause them to feel unwilling to accept the help and care offered by friends, relatives and professionals.

This difficult situation improves as the person begins to realise they have a problem. Research on 'health behaviour change' (Prochaska, J. O. & Di-Clemente, C. C., 1983) has been helpful in showing effective ways of motivating individuals at the different stages of recovery. The illness can have a long and protracted course and the process of change is often a slow one. It can take an average of 3-5 years to arrive at the stages of preparation and action.

1 Stages of Change

Is the sufferer 'ready, willing and able' to work at recovery? This model describes recovery from an eating disorder as a process where progress is not necessarily linear—it can include starts and stops, steps forward and back, eventually leading to mental and physical health.

The model allows those involved in supporting someone with an eating disorder to target their actions so that they have a better chance of having a positive effect on the sufferer.

2 Motivational Enhancement Techniques

This involves matching your behaviour so that it fits with the sufferer's feelings of readiness and belief in their ability to change (their stage of change).

How People Change



The Stages of Change

"How ready, willing and able is the individual to change?"

1 Pre-contemplative Stage (Denial)

"I don't have a problem – you're the one with the problem".

2 Contemplation

"Something is not right with me, but I'm not sure I want to give it up just yet".

3 Preparation

"I may be ready to seek help; what would change mean?"

4 Action

"I hate this illness; I'm going to do whatever it takes to beat it".

5 Maintenance

"This process is so very hard! It's taking more time than I ever thought possible. I WILL keep going. I must keep going!"

6 Termination

"I am recovered!"

Trying to intervene at the wrong stage of change often causes negative outcomes, such as increased resistance and conflict. (For example, trying to encourage the sufferer to make changes when they are in pre-contemplation will probably cause stronger resistance against change).

#3 Managing sufferer's denial

Denial of symptoms

Resistance to treatment

Duration of illness

Motivational enhancement tasks for friends and relatives at each stage of change

Firstly it is important to identify where your loved one is on the cycle of change. The tasks suggested for that stage will show you the sort approach that has been found to be helpful.

Pre-contemplation

At this stage the eating disorder is not seen as an illness or problem by the person. Pressure from others to make changes is seen as interfering and completely unnecessary.

In this stage aim to 'get alongside' the sufferer and to help them increase their self-awareness and self-reflection so that they can come to realise for themselves the reasons to change:

- Try to connect with the person, talk about current affairs, in fact, any non-eating disorder subject.
- Spend time with them doing things you both enjoy.
- Try to be non-judgmental and remain warm and accepting, yet have firm boundaries and limits.
- Try not to reason logically with the eating disorder as this does not work – the eating disorder involves an abnormal emotional attachment.
- Try and separate the person from the eating disorder in your mind.
- Do not let the eating disorder take over the whole family's life.
- Try not to get into endless cycles of reassuring the person as this does not actually help them. Encourage them to look for evidence or the rational answer themselves.
- Try to look after yourself. Maintain your own interests and life and encourage the rest of the family to do the same.
- Provide feedback about their health - Connect the eating disorder and its consequences (e.g. feeling cold, tired, lacking concentration, withdrawing socially, looking unhappy etc)
- Educate – leaflets, books, self-help, typical treatments and outcomes, prognosis.
- Give medical and nutrition information (e.g. about bones and the nutrition they need).

However:

- Remember at the pre-contemplative stage, any argument for change from you will result in more resistance from the person and stronger arguments to stay the same.
- Conflict can make it harder for the person to talk about their worries.

Contemplation

The person is aware there is a problem, but they're not yet ready to make any changes.

At this stage encourage exploration of the pros and cons of change, validate their struggle and their fear of losing the gains the eating disorder has been providing for them (please see diagram 'The Paradox of Gains and Losses' on page 8).

- Encourage the person to talk about what the eating disorder does for them in depth. They then may feel safe enough with you to explore the negative consequences of the illness as well.
- Help the person generate a list of the pros and cons of change, for self and others.
- Keep making the connection between the eating disorder and the consequences.
- Explore the cons of change – what would be difficult? Do they want to think of alternative strategies yet?
- Discuss possible plans of action.
- Encourage talk about the negative consequences of the eating disorder, when it occurs.

#3 Managing sufferer's denial

Denial of symptoms

Resistance to treatment

Duration of illness

Preparation

The person plans to take action soon and they are taking small steps.

At this stage it can be very helpful to support the sufferer to work on their plans and to visualise themselves implementing their planned changes.

- Ask if the person would like your help to make a concrete plan for symptom reduction, or if they would like to include you in the plan in some way.
- Would they like you to help them in a certain way?
- What do they find unhelpful?
- What would success look like? Having a clear set of goals can be very helpful.
- How will the person know if they are achieving their aims? How will they monitor this?
- Help them to think of all the support that is available to them, and explore realistically what might make it hard to use the support.
- What is their plan B?
- Try not to **enable** them to be ill (e.g. allowing them to turn the heating up whilst the household is warm enough; letting them avoid their responsibilities etc)
- Continue to help them explore the difficulties if change were to occur.
- What strategies could help the person deal with difficulties? You could help them explore and practice these.

Action

The person puts their plans into motion - they change their behaviour & the environment; they show commitment and energy.

When the sufferer is in the action stage, they need support to make the changes, take risks and to learn from mistakes.

- Offer to help them learn new strategies for coping with feelings and urges to engage in old habits.
- Review and learn from past relapses. Make a list of signs of relapse.
- Explore difficulties as change occurs.
- Assist with problem solving.
- Allow the person to take risks:
 - Discuss your fears
 - Set tasks
 - Goals broken down into steps
 - Minimise sick role

- Encourage independence
- Encourage patient's use of skills
- Set clear limits though

- Attend to creeping signs of denial.
- Ask if they have noticed any benefits from the changes they've been making.

Maintenance

The person works to prevent relapse and consolidate change – the action stage has been successful for more than 6 months.

In this stage the aim is to help the person review their progress, and work with them to prevent relapse.

- Prevent relapse
- Have a list of signs of relapse
- Provide support and encourage coping skills
- Reinforce their bonds with support resources
- Watch for creeping denial
- Encourage new healthy interests
- Encourage more independence

L.E.S.S is more

This is a handy 'rule of thumb' if you're not sure what to do to support the person (at any of the stages of change).

Listen

It is good to help the person with an eating disorder communicate verbally, by giving them time and safety.

Empathy (not sympathy)

It can be helpful to remember that an eating disorder is not about food, it often functions to communicate distress, help the person to feel safe, stifle emotions and avoid adult responsibilities.

Share

Join their non-eating disorder life, any other interests, thoughts or opinions.

Support

Help person gain confidence, through seeing themselves achieve things.

#3 Managing sufferer's denial

Denial of symptoms
Resistance to treatment
Duration of illness

Eating disorders:
The paradox of gains and losses

The reasons people need help to move from the early stage of an eating disorder



#4 **Managing stigma**

- Highly visible illness
- Prejudice
- Isolation
- Blame / suspicion

Challenging Stigma

Because the illness is often highly visible, some people have found that they encounter unwanted attention, prejudice or critical comments from others. Occasionally, these can be from friends and family members who have not learnt about the illness.

Experiences like this can lead to feelings of isolation, so it can be important to talk to others who have gone through similar situations and feelings.

Carers' support groups and eating disorders charities can be a good place to get this sort of support. There are details of these organisations at the end of this booklet.

#5 **Managing un-met needs**

Lack of knowledge

Lack of skills

Lack of support

Addressing Needs

The role of carer is made easier by having information, skills and support. Knowing what sorts of things can assist in the recovery process can feel very empowering, and can counteract the common feelings of helplessness and hopelessness.

We have tried to give you some useful ideas and information in this booklet, and have recommended some further books, leaflets and websites at the end of this booklet where you could get further support.

Kimmeridge Court also runs a monthly support group where you can meet others who have had experience of caring for someone with an eating disorder. Details are on page 27.

#6 Managing interpersonal relationships

Unhelpful patterns of relating
to sufferer

Stage of change (see page 5)

Confrontation

Control

Avoid issues

Over protective

Distracted by own emotion

Patterns of Relating to the Sufferer

Many people who support those with an eating disorder have reported that they often find themselves falling into unhelpful patterns of relating. These can be summarised as:

- 1 Confrontational & Controlling approaches** (arguing, trying to persuade with logic, blaming, wishing to control and stop the eating disorder by force)
- 2 Avoidance** (not wanting to tackle issues, walking on eggshells)
- 3 Over-protective Approach**
(compulsive caring, wanting to wrap sufferer in cotton wool)
- 4 Over-emotionality** (difficulty processing the emotional response to anorexia nervosa, frequently expressing distress and/or demands for recovery)

However, an **empathic approach** is usually more helpful.

#6 Managing interpersonal relationships

Unhelpful patterns of relating to sufferer

Stage of change (see page 5)

Confrontation

Control

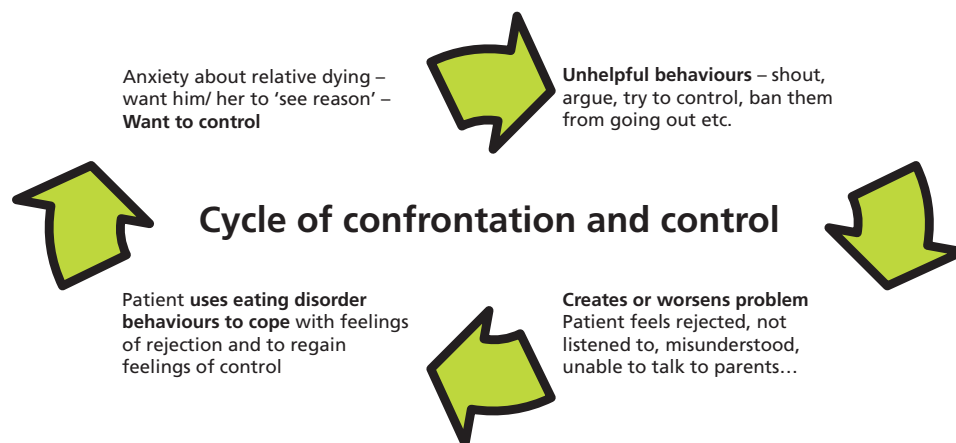
Avoid issues

Over protective

Distracted by own emotion

The unhelpful interpersonal patterns of relating to the sufferer

Confrontational & Controlling approaches



Confrontation → clashing/arguing → resistance → frustration → anger → impasse
(Outcome = Patient and relatives locked in conflict, patient stuck)

Reducing the Logical Confrontational or Controlling Approach:

Feeling attacked or controlled often causes people to feel they need to defend themselves and people often come to believe what they hear themselves saying, which can, in turn lead to stronger attachments to reasons to stay with the illness.

In effect, relating to the patient as if they were in the Action Stage of Change, when they are not, CAN REDUCE THE LIKELIHOOD OF CHANGE HAPPENING. By remembering that the person has an abnormal emotional attachment to their eating disorder, making it difficult to change through reason of logic. Try to remember that although the illness can be very strong at times, your relative is still there – separate from the illness.

Reducing Over Control and Criticism

- Work out what are the triggers?
- Plan to do something different in response.
- Practice role-play of situation.
- Understand the illness to increase empathy.
- Provide empathy, warmth and listen to patient.
- Set consistent limits with consequences.

#6 Managing interpersonal relationships

Unhelpful patterns of relating to sufferer

Stage of change (see page 5)

Confrontation

Control

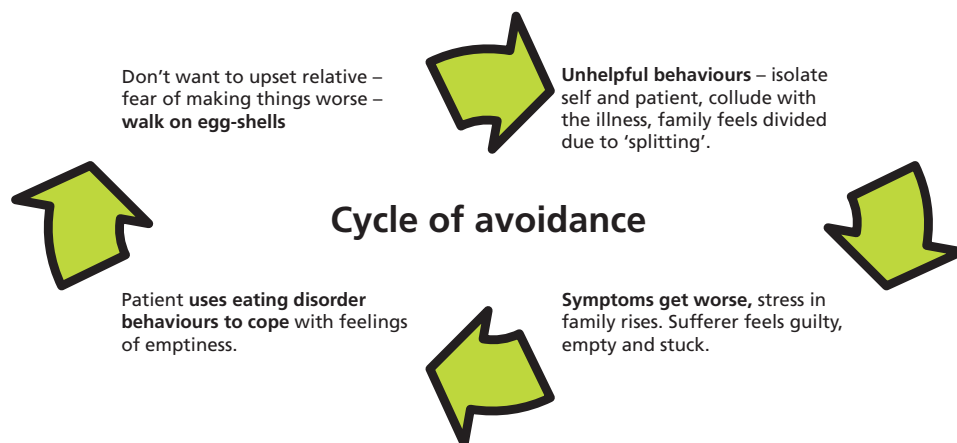
Avoid issues

Over protective

Distracted by own emotion

The unhelpful interpersonal patterns of relating to the sufferer

Avoidance



Fear → **avoidance** → inaction → collusion with the eating disorder → fear

(Outcome = Patients go their own way, further into the eating disorder, you feel like you are walking on eggshells, your fear of making things worse gets stronger)

Tackling Avoidance: Assertiveness, Clear limits, Boundaries

It may be that the eating disorder has made it hard for you to say no because you have tried to avoid upsetting your relative. It is okay to set clear and consistent limits on what you will and will not put up with.

#6 Managing interpersonal relationships

Unhelpful patterns of relating to sufferer

Stage of change (see page 5)

Confrontation

Control

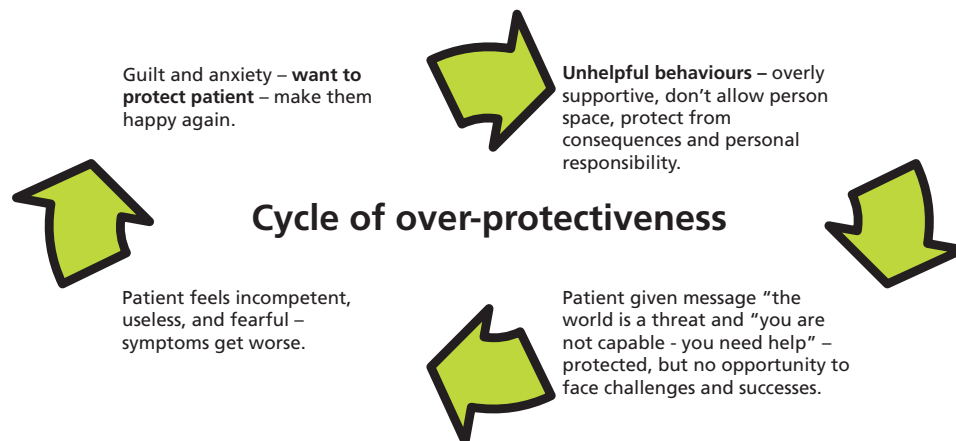
Avoid issues

Over protective

Distracted by own emotion

The unhelpful interpersonal patterns of relating to the sufferer

Over-protective approach



Safe Risk Taking

- Discuss fears.
- Set tasks.
- Goals broken down into steps.
- Minimise 'sick role'.
- Encourage independence.
- Encourage patient's use of skills.
- Set clear limits.

#6 Managing interpersonal relationships

Unhelpful patterns of relating to sufferer

Stage of change (see page 5)

Confrontation

Control

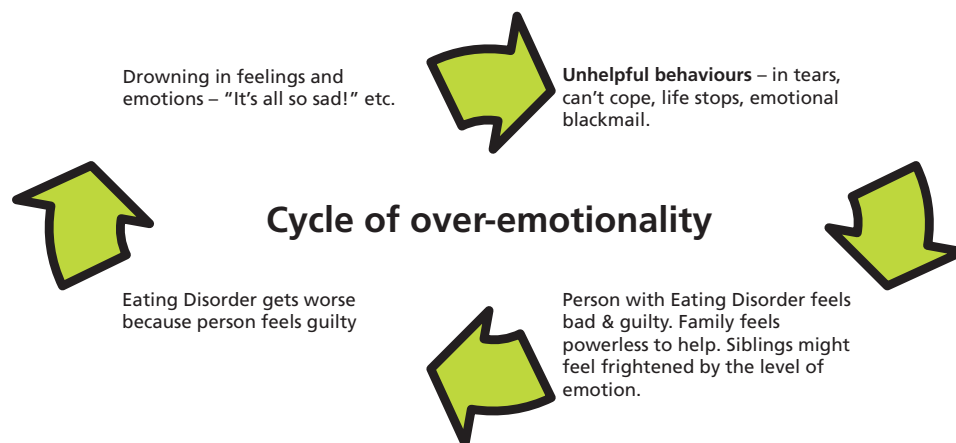
Avoid issues

Over protective

Distracted by own emotion

The unhelpful interpersonal patterns of relating to the sufferer

Over-emotionality



Managing difficult emotions

- Grieve & let go
- Reach out for relationship with person
- Develop other interests
- Use relaxation and ‘mindfulness’ (see p.20) to become more objective
- Take practical steps – problem solving

#6 Managing interpersonal relationships

Unhelpful patterns of relating to sufferer

Stage of change (see page 5)

Confrontation

Control

Avoid issues

Over protective

Distracted by own emotion

A helpful interpersonal pattern of relating to the sufferer

Empathic approach



Empathy → gentle approach → safety → sharing space → exploring together → resolving ambivalence → supporting → increasing confidence

#7 Managing eating disorder related problems

Not eating / bingeing / purging

Compensatory behaviours

Ill health

Low mood

Social isolation

Anti-social behaviours

Certain eating disorder behaviours can have a big impact on family life. Anything food related can become difficult (e.g. buying, preparing and eating food) and the compensatory behaviours that an individual engages in (e.g. vomiting, laxative abuse or excessive activity levels) can cause conflict and anxiety.

There are also many physical and psychological effects of starvation (however caused), and the lower the weight the worse the effects. These can have an impact on others, not just through the anxiety they cause, but also directly. A few of these are detailed below:

- You may have noticed the heating needing to be up high constantly because the person is always cold;
- The person may disturb the household by being up and about during the night because of sleep disturbances and due to physical discomfort when lying in bed; They may also be exercising in their room.
- A common side-effect of starvation is poor concentration. This can cause the person to have problems with remembering things and focusing on what they are doing.
- Starvation has also been found to cause depression. The person's low mood, apathy, loss of pleasure in doing things and feelings of worthlessness may cause them to avoid their friends and life in general.
- OCD (a common side effect of starvation) can cause the person to have obsessional fears, high anxiety levels and to engage in rituals and compulsive behaviour to try and alleviate this.

Strategies for Dealing with Eating Disorder Related Problems

Many of the problems outlined above can be tackled with the following strategies:

SMART Goal Setting: Helping your relative set themselves mini-goals which are **S**mart, **M**easurable, **A**chievable, **R**ealistic and **T**ime limited can be a good way of embarking on the challenges of recovery.

Problem Solving (this strategy is detailed on page 23).

Functional analysis - Looking at the behaviour in terms of what it achieves for the person can help you to have more understanding of it, and help you both think of alternative ways to meet those needs.

#8 Surviving

- Sadness
- Fear
- Frustration
- Loss
- Feelings of failure

Managing stress and emotions

In themselves, the eating disorder behaviours can cause a wide range of intense emotions. Many carers report overwhelming sadness, fear, frustration, and feelings of loss and failure (Treasure, J., Murphy, T., Szmuckler, G., Gavan, K. & Joyce, J. 2001). On a practical level, it can be difficult to know how to deal with these behaviours constructively.

Many of these emotional reactions are understandable. It is terrifying and sad to see someone you love with a life-threatening illness. Research has found though, that high levels of stress, distress and expressed emotion are not only likely to make the caring role more burdensome, but there is also evidence to suggest that the emotional tone at home might affect whether the sufferer gets better. It has been found that reducing the level of difficult emotions at home can improve the likelihood of their recovery (Butzlaff, R. L. & Hooley, J. M. 1998). In some cases the emotional reactions may arise from misperceptions about the illness either in terms of the symptoms, the causes, the time course or the treatment.

Shame

Some parents feel ashamed that the symptoms of anorexia nervosa are an obvious sign that they have failed in their role of nurturing their child. The symptoms of bulimia nervosa (bingeing, vomiting, laxative abuse) arouse instinctive reactions of disgust and shame. Some carers are angered by aspects of the illness which go against some of their core values. Examples of these are the waste of food, and the stealing and lying that occur to protect and support the anorexia nervosa.

Self-blame

Families often blame themselves for causing eating disorders, although they are uncertain what they may have done wrong. Some families jump to the conclusion that their daughter is choosing not to eat normally in order to punish them.

Note:

This section on Managing Stress & Emotions was adapted from 'The Eating Disorders Unit: Information for Carers', South London and Maudsley NHS Trust

Loss

Many parents experience an overwhelming sense of loss because their child's social and emotional development is stunted. It is hard to watch your child undergo the deprivation and punishment of anorexia nervosa, and it is sad that you may not see some of the rewards of later life such as grandchildren.

Frustration

You may have thought or have been told that anorexia nervosa will be nothing more than a passing phase. The frustration of the protracted time course is hard to bear. On the face of it the symptoms of an eating disorder seem so simple to be overcome: 'If only she would just eat!' It is exasperating that the solution seems so simple and yet so hard to implement.

Fear

Most carers are terrified about the dangers to their relative/partner's physical health and safety. You may also fear that your own or the rest of the family's physical or psychological health is put at risk. Anorexia nervosa can cause such a strain on a marriage that partners drift apart or children in the family leave home prematurely.

Divide and rule

When there is any chance for anorexia nervosa to divide and rule, it will do so - it thrives on mixed feelings within the home. Many successful marriages work because each partner brings a different and complementary perspective on things. However, anorexia nervosa often succeeds in making these complementary approaches antagonistic unless you are very careful. It is important to make time to discuss these differences of opinion in a non-blaming fashion.

#8 Surviving

Sadness

Fear

Frustration

Loss

Feelings of failure

Emotional Processing

All the thoughts and emotions described above - and many others not mentioned here - may be a cause of stress and distress. When emotions get too intense they can appear to be a nuisance or downright harmful. However, emotions are very important signals, which give us the drive and curiosity to reach out to the world and to others, and to help us choose between the different options available to us, and which match our personality and values.

Often we are unaware of any emotional reaction, but are guided by our emotions unconsciously. It is only when they become very strong or when we have confusing, mixed emotions that we may become aware of them.

Analyse your Thoughts and Emotions

Anorexia nervosa automatically triggers extreme and often mixed emotions in others. It is helpful to spend time analysing your own emotional reaction to the illness.

- What are the first thoughts or feelings that come to mind?
- Do you have layers of other thoughts and feelings which go deeper?
- Are you aware of some thoughts and feelings in your head and others in your gut or heart?
- Do you have nightmares that focus on a particular mood state?
- Do you suddenly switch into another state e.g. calm/irritable, peaceful/sad?
- What are the triggers to such switches?
- Can you follow through the thought process that trips this switch?

Acceptance

Negative emotions alert us that all is not well in our world, and suggest that we need to do something to set it right. However, it is not always possible to find immediate solutions, and sometimes we need to accept things as they are for the time being. In this sort of situation it is helpful to alleviate the stress and distress by various soothing strategies.

Self-Soothing

Physical relaxation can be very helpful. Yoga, massage, and all the 'physical therapies' including exercise can also be helpful. You may need to have some time and space on your own to do things that comfort and nourish you.

#8 Surviving

Sadness
Fear
Frustration
Loss
Feelings of failure

Mindfulness

The key elements of mindfulness are non-judgmental acceptance and connection with one's own experience in the present moment. It involves developing openness to one's experiences alongside a compassionate approach/regard for self.

Mindfulness practice is the act of directing your attention to only one thing in each moment (the focus). This can help you develop your capacity to have more awareness, without judgment, of life as it is, yourself as you are, other people as they are, in the here and now, via direct and immediate experience.

When you are mindful, you are awake to life on its terms – fully alive to each moment as it arrives, as it is, and as it ends, rather than getting stuck in thoughts and ruminations. Mindfulness can help us to see life more freshly, as we are less likely to be caught in past conditioning.

People who practice mindfulness will tell you that they get better at enduring pain, better at solving problems, better at not creating misery for themselves, and better at participating fully in those moments of life that are joyful.

Attitude Change

Sometimes it is helpful to change your thoughts about something, so that it does not trigger the part that gets you upset or angry. Many of the difficult behaviours and attitudes that drive you up the wall are merely anorexia nervosa symptoms that are seen in every case. They are not unique to your relative/partner.

It is often helpful to think of anorexia nervosa and its associated thoughts and behaviours as an interloper that has come to settle in your family or as a separate objective entity from your daughter (e.g. an anorexic minx or a bulimic boa constrictor).

At times your relative/partner will be talking anorexia nervosa talk, for example, when she starts to talk about weight and food. It is impossible to reason logically with the anorexia nervosa talk. It is something that has an abnormal emotional attachment to it.

When you get drawn into arguing with the anorexia talk, try to stop, think and deflect the conversation in this sort of manner: "I can see that you are distressed. Experts/the hospital say that it is not helpful for me to engage with you in the anorexia talk. I will

happily spend time going for a walk/giving you a foot massage/watching a TV show with you. I would love to spend time listening and talking to you on non anorexia subjects when you want".

However, it would be wrong to think that the sufferer is entirely taken over by the illness. There will be a part of her, however small, that is in two minds about the illness. There is a part of her that would like to be different if she could. It is important that you find that part and try to develop it (see section on 'Stages of Change', page 5).

Practical approaches

It is probable that there are both external events and internal thoughts, memories and worries that trigger emotions. It will be helpful if you can gradually try to unpick the threads of your emotional tangle. You need to separate each of them, reflect on how they have arisen and decide, 'can I do something to lessen my emotion of x, or is it something I need to accept and embrace?' Thus if you are terrified of the medical consequences it is sensible for you to talk to your daughter about this and agree on some practical measures to reduce your anxiety. For example, you may request that your relative/partner goes to the practice nurse each week to be weighed.

- You can also request that your relative/partner has a medical risk assessment done at regular intervals.
- You may set limits on what activities you think it is safe to do at a particular weight, e.g. a safe body mass index for driving may be 15kg/m² (BMI 15).

#8 Surviving

- Sadness
- Fear
- Frustration
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- Feelings of failure

Focus on the Positive

There is no reliable evidence that family factors cause anorexia nervosa. However, there is some evidence that once anorexia has developed, what families do can affect the course of the illness. It does not help recovery from anorexia nervosa if the family turns on itself with blame and criticism. Nor is it helpful for the family to be angry and critical of professionals involved in care.

All basic psychological theory and research teaches us that the most effective way to foster behaviour change is to focus on the positive and the rewards, rather than using punishments. This is a recurring theme in all interactions with anorexia nervosa, with each other and with professionals.

Try to show mutual respect, to accept each other's strengths and weaknesses and to work with the resources you have to maximise the good aspects and buffer the less good aspects.

Of course, this is not always easy, as it is an instinctive response which has been emphasised in our culture to want to blame someone when things go wrong. But this model of blame and causation can be very counter-productive. Focusing on acceptance and tolerance is likely to be much more useful.

Positive communication

Whenever you are asking for any changes to be made, try to follow these guides to positive communication:

- 1 Be brief
- 2 Be positive
- 3 Use specific (measurable) terms
- 4 Label your feelings
- 5 Give an understanding statement
- 6 Accept partial responsibility
- 7 Offer to help

You will notice that the statement about how to deal with anorexia nervosa talk has several of these elements: "I can see that you are distressed. Experts/the hospital say that it is not helpful for me to engage with you in the anorexia talk. I will happily spend time going for a walk/giving you a foot massage/watching a TV show with you. I will love to spend time listening and talking to you on non anorexia nervosa subjects when you want".

Acknowledging Mistakes

It is common for people to want to find an easy answer to the question of what has caused the eating disorder. It is less satisfying to think that there are several interacting factors, some of which may always remain mysterious. Therefore we suggest that it may not be helpful to try to pinpoint causal factors or to worry and ruminate about what may be the problem.

All of us make mistakes. If, with the benefit of hindsight, it is apparent that you have made a mistake then it is useful to acknowledge that and apologise, even if the mistake has no relevance to the cause of anorexia nervosa. In our work with people with eating disorders and their families WE make a point of acknowledging our mistakes. Sometimes we set goals that are too ambitious and at other times we are too pessimistic.

It is useful for the person with anorexia nervosa to see this process of reflection, acknowledgement and making amends in action. People with anorexia nervosa are so driven to perfection and so fear making mistakes that it is important for them to realise that getting things wrong and making reparation is an important part of life.

#8 Surviving

Sadness
Fear
Frustration
Loss
Feelings of failure

Focus on Non Anorexia Things

What we DO encourage families to do is to analyse the factor or factors that contribute to the maintenance of the eating disorder. These should be the targets of scrutiny and problem solving.

Examples of maintaining factors:

- Are you inadvertently reinforcing the anorexia nervosa behaviour by getting into long drawn out discussions about food and weight?
- Does most of your life now revolve about food etc?
- Are you ensuring that you reinforce or spend time and attention on non anorexia nervosa things?

For example when your daughter comes in from college do not immediately ask, 'What have you eaten today?' It is not necessary to pay attention to the day-to-day minutiae of eating as long as there is a regular consistent medical check to ensure that your daughter's nutrition remains adequate.

Instead try to engage in pleasant conversation about non anorexia nervosa things. If your daughter tries to seek your reassurance about her eating try to deflect the conversation: "I am sorry that you are anxious. The expert/hospital recommends that I do not give you reassurance, as this will only ensure that over time you will stay anxious. Stay with the anxiety now. It will go in time".

Warmth And Firm Boundaries

It can be difficult to show warmth and affection when you are fearful of the consequences of the illness on the family, and if you blame your daughter for her symptoms. Here is a quote from a distraught carer:

'I can't use your idea of saying "I love you very much but don't like it when you e.g. clear the cupboards and there's nothing left for anyone else". If I said that, I'd be lying because I don't feel that I love my daughter any more. Last year my husband had a heart attack after an awful incident at home and he died. My daughter's behaviour over the last six years has blighted our lives and now my husband is gone too. So I can't say I love her at all. I try to help and support her because it is my duty as her mother, but I don't love her.'

It is easy to let the habitual behaviour of anorexia nervosa rule the household. Much more difficult is it to show warmth and care and to have firm boundaries that do not allow the anorexia nervosa behaviours to take a hold.

Some of the usual approaches to an acute illness may be counterproductive when used in the context of a chronic illness like anorexia nervosa. For example, when people have an acute illness social rules change, and the person with the illness is excused their usual responsibilities and can be indulged and spoiled. However this type of adaptation is inappropriate with a chronic illness such as an eating disorder. It can serve only to maintain the condition, which is not self-limiting, and lasts on average six years but in some cases much longer.

Consistent Approach

It is important that family members, especially those who take on the main role of caring, agree on a consistent approach, which can be enacted over time.

Remember that you are in with this problem for the long haul. It can be all too easy to fall into the trap of pandering to the obsessive rituals and routines of your daughter's illness. This only serves to maintain the rigid straight jacket of the illness. The whole family may be dominated by the power of the eating disorder symptoms and live their life as if walking on eggshells.

It is important to ensure that the illness does not totally disrupt family life. However this is easier said than done. The natural reaction to people who are anxious and fearful is to give them comfort and reassurance.

#8 Surviving

Sadness
Fear
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Problem solving

It is important that you try to recognise what triggers an emotional response, and then to find ways to get around or eliminate these triggers.

Try to analyse the problem with others in a systematic way. The following pointers may prove useful:

- 1 Try to **define the problem** clearly and in very specific terms.
- 2 **Brainstorm** an array of possible solutions. Do not inhibit this process in any way i.e. do not criticise or question any idea at this phase as it is important to have quantity rather than quality. Write down all suggestions and ideas so that all family members can see. It is best if you can have at least ten suggestions.
- 3 **Eliminate undesired solutions.** Cross out any that you cannot imagine trying in the upcoming week. Explanations are not required.
- 4 **Select one potential solution.** Review the remaining solutions, and select one to commit you to try over the next session.
- 5 **Think of possible obstacles.** Consider what potential obstacles there will be in the next week that might interfere with carrying out the solution you have selected e.g. forgetting, becoming too busy.
- 6 **Devise a plan for each obstacle.** If some obstacles cannot be circumvented, select a different solution.
- 7 **Evaluate the effectiveness of the solution.**
At the next meeting to review progress, discuss whether the solution needs to be modified somewhat. At times a new solution is decided upon instead.

Outcome

We have found that one of the things carers want to know is the likely outcome of the illness. It is generally agreed that it is difficult to predict the outcome of an individual case. None of the predictors that we have alter the odds of recovery greatly. Thus clinicians shy away from giving a prognosis. To a degree most of the things that affect the outcome are what might be expected from common sense:

- The longer someone has had the illness the more difficult it is to recover.
- It is harder to overcome the illness if there is associated obsessive-compulsive disorder particularly if this was present before the illness began.
- If the problem began in adult life rather than adolescence it may be harder to get over it.
- It is more difficult if there are harsh weight control strategies such as vomiting and laxative abuse.
- Finally how the person responds to treatment is an important predictor. For example, if someone is able to gain weight during therapy and accept being at a weight within the normal weight range then the long-term outcome is better.

#8 Surviving

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General Prognosis for recovery from Anorexia Nervosa:

A summary of 68 treatment studies published before 1989, with a length of follow-up between one and 33 years found that **43%** of people recover completely, **36%** improve; **20%** develop a chronic eating disorder and **5%** die from anorexia nervosa (NICE Guidelines, 2004).

General Prognosis for recovery from Bulimia Nervosa:

Many people with bulimia nervosa do not receive any form of help, so it has been hard to study the course and outcome of bulimia nervosa generally. Of those who do not receive help it is expected that the majority will suffer chronicity or a relapsing course of illness.

For those people who do receive specialist help, about **50%** are asymptomatic 2 – 10 years after treatment, **20%** continue with a chronic course of illness, whilst **30%** have a course of illness characterised by remissions and relapses.

One study has shown that at follow up of around 11 years, of 222 people, only 11% still met the criteria for Bulimia Nervosa. (NICE Guidelines, 2004)

Conclusion

In this section we have discussed how your emotional response to anorexia nervosa can be harnessed to maximise the chances of recovery. If you let bad feelings build up, this maximises stress and tension and fuels anorexia nervosa thoughts and feelings. When your emotions are being triggered, stop and think:

- 1 Can I change something to stop this having such a profound effect?
- 2 Can I change the way I think about it?
- 3 Can I get comfort and solace to take away some of the pain?

It is a long and difficult process, it is important to stress that nothing is likely to be achieved overnight. You will need to persevere with your efforts and expect frequent setbacks. However, if you can master your emotions you will be modelling important coping strategies for the person plagued with an eating disorder.

Carer's Rights

The Carers Needs Assessment

As a carer, under The National Services Framework 1999 (standard 6) you are entitled to have an assessment of your caring, physical and mental health needs repeated on at least an annual basis.

This is so that if it is necessary, a care plan can be drawn up and implemented to support you with your role. The sorts of questions covered in this assessment are to do with: -

- What you do to support the person?
- What effect does being a carer have on your life?
- Do you get enough time to yourself?
- What is the effect of the eating disorder on your relationship with the sufferer?
- What support do you receive in your role?
- Do you feel you need more information?
- Is the care that you give affecting your own health?
- Is the service provided to your relative flexible enough to meet your needs too?
- What other support or services could make a difference to your role?

If you feel that you might benefit from a carer's needs assessment, you can ask:

- Your relative/ partner's Care Co-ordinator,
- Social Services, or
- Your local Community Mental Health Team (CMHT).

Kimmeridge Court

Philosophy

The Team believes:

- 1 That the people who come to us for care and treatment are trying to cope with difficult life issues and often feel out of control in their lives.
- 2 The eating disorder can be a solution to these difficulties and that it has costs and benefits for the individual in all aspects of their life.
- 3 That the eating disorder can place strains on family and other close relationships.
- 4 That these individuals and their families can be unsure and anxious about treatment and change.
- 5 That the care and treatment offered must address the physical, psychological and social needs of the individual and their families.

Services Provided

Carers Support Group

- Kimmeridge Court holds a monthly Carers Support Group held on the last Wednesday of every month, between 7.00pm and 8.30pm.
- Two members of the Eating Disorders Team facilitate the group.
- It is a confidential group where people can meet others who have had similar experiences.
- It provides opportunities to learn more about Anorexia Nervosa and Bulimia Nervosa.
- It aims to help members gain new ways of coping with the effects of the illness on themselves and their family.
- We have a wide range of information leaflets and other helpful reading materials available.
- We offer refreshments of tea and coffee etc.

Out-patient Service

- 1 Kimmeridge Court Therapy Service for those resident in East Dorset.
- 2 Out-reach clinics with Community Mental Health Teams for individuals resident in West Dorset.

The following interventions are available and each individual's plan will draw from these.

- a) **Psychological therapies** – cognitive behavioural, interpersonal, cognitive analytical, family/systemic therapy, art therapy, Dialectical Behaviour Therapy,
- b) **Groups** – body image, bulimic group, psycho-education
- c) **Dietetics** advice and counselling
- d) **Psychiatric** assessment and medication
- e) **Physical** assessment (in-patient only)

In-patient unit

There are 10 beds, 4 of which are for residents of Dorset. We also provide in-patient services to residents of Somerset, Hampshire, Cornwall, Wiltshire and the Isle of Wight.

Visiting & contacting your relative/ partner

Maintaining contact with friends and family can be important to individuals in hospital and we wish to encourage and facilitate it.

Visiting times are:

Monday – Friday:

5.00pm to 9.00pm except at meal time
(6.00 till 6.45pm)

Saturday – Sunday and Bank Holidays:

All day except around meal and snack times (see below) unless prior arrangements have been made with the nurse in charge. Children are welcome if supervised by an adult. Pets may be brought to the hospital grounds but cannot be brought inside the unit.

Meal Times:

Breakfast	0800 hrs
Snack	1000 hrs
Lunch	1200 hrs
Snack	1515 hrs
Supper	1800 hrs
Snack	2100 hrs

There is a **pay telephone number**: 01202 701755. Your relative can be contacted on this number, but there may be times when s/he is unavailable due to meals, groups and post-meal support.

Confidentiality and Carer Involvement

Carers of people with eating disorders often feel high levels of anxiety and frustration because of the highly visible symptoms of starvation, abnormal food behaviours and personality change. Understandably, this can lead to a desire to have information about the treatment, progress and well-being of their relative. The team work hard to include carers and family members in treatment, not only to reduce the anxiety of not knowing, but to also call on the resources and skills they have to assist the individual in their recovery.

There are Laws protecting individuals' rights to privacy and guaranteeing them confidentiality which means we are unable to share any personal information with carers without the permission of the individual patient. All in-patients are however given the option of choosing the level of carer involvement they would like and we encourage an open dialogue and close involvement whenever possible. Any permission then given is an individual arrangement which is flexible to the wishes of the patient.

The rules of confidentiality can occasionally be overridden - when it is justified by risk or required by Law. For instance, when there is a high level of risk we have a statutory obligation to let others involved in care know if there are health and safety issues which need to be considered.

We do however aim to provide carers with sufficient information to help them provide care effectively (routinely and upon request).

We are able to give information on:

- Issues related to the illness in general.
- The danger signs that can alert you to medical risk.
- What to do in the event that you are concerned about health and safety.
- Kimmeridge Court's service and treatment programme as well as other services available to you and your relative.
- Further information about your Rights as a Carer.

Summary

We hope that this booklet has gone some way to helping you to cope with the role of caring for someone who has an eating disorder. We have looked at the difficulties inherent in this role, particularly the effect of eating disorder symptoms which can cause great distress, frustration and hopelessness in family members. We hope that you will find the ideas presented here useful and will contact us if you require further information.

Recommended reading

The EDA Carer's Guide: a practical guide for carers of people with an eating disorder

Anorexia & Bulimia in the Family – one parent's practical guide to recovery by Gráinne Smith

Anorexia Nervosa: A Survival Guide for Families, Friends and Sufferers by Treasure, J.

Eating Disorders – a Parent's Guide, Bryant Waugh, R. & Lask, B.

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Treasure, J., Whitaker, W., Whitney, J. & Schmidt, U. (2005), **Working with families of adults with anorexia nervosa**, in *Journal of Family Therapy*, 27: 158-170

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Service	Address	Tel no	Information
Dorset HealthCare NHS Trust Eating Disorders Service	Kimmeridge Court 69 Haven Road Canford Cliffs Poole BH13 7LN	Outpatient Dept 01202 492147 Weekdays 9.00am – 5.30pm Inpatient Unit 01202 492151 Flexible	Specialist eating disorders service, which provides an outpatient therapy service, and an in-patient service. It also holds a monthly carers support group.
Out of Hours Service: Bournemouth Social Services Emergency Team	n/a	Helpline 01202 314577	Available from 5.15pm – 8.40am every weekday; 24 hrs weekends and Bank Holidays
Somerset & Wessex Eating Disorder Association (SWEDA)	SWEDA Strode House 10 Leigh Street Street BA16 0HA	Helpline 01458 448 600 (Answerphone when helpline closed) www.swedauk.org	A charitable organisation which offers a range of services to people with eating disorders in the Wessex region.
Eating Disorders Association (EDA)	Eating Disorders Association 1st Floor Wensum House 103 Prince of Wales Road Norwich NR1 1DW	Helpline 0845 634 1414 Weekdays: 8.30am – 8.30pm Saturdays: 1.00pm – 4.30pm Youth line (up to 18 yrs) 0845 634 7650 www.edauk.com email info@edauk.com	A national charity offering help and information to people with anorexia and bulimia nervosa, their families and friends.
Cornwall Eating Disorder Association (CEDA)	CEDA P.O. Box 54, Truro TR4 9JX	Helpline 07745 809 967 www.cedaonline.org email enquiries@cedaonline.org	A charitable organisation which offers a range of services to people with eating disorders in Cornwall.
MIND (National)	n/a	Helpline 08457 660 163 www.mind.org.uk	Phone for mental health advice and information – 9.15am – 4.45pm, Mon, Weds and Thurs
Carers Line	n/a	Helpline 0808 808 777	A help and advice line for carers open Mon – Fri 10.00am – 12 noon and 2.00 – 4.00pm. Can give benefits advice.
NHS Direct	n/a	Helpline 0845 4647 www.nhsdirect.nhs.uk	24 hour helpline staffed by expert nurses and website with general and mental health information and advice.
Saneline	n/a	Helpline 08457 678000	Helpline opens every day 12 noon – 2.00am. Offers emotional & crisis support and advice and information on mental health.
Samaritans (National)	n/a	Helpline 0345 909090	A confidential helpline.

Dorset HealthCare NHS Trust

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