Leicestershire Partnership NHS
NHS Trust

Leicestershire Adult Eating Disorder Service

Friends, Families & Carers Pack

CONTENTS

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, sibling, 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. A recent review of research in this area has demonstrated high levels of distress and burden associated with the caring role[1]. 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 and practical strategies to help you cope with the difficulties of the caring role.

We hope that this booklet will help to give you hope, enable you to take good care of yourself and provide you with ideas and information to support 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 to offer you support but it should not stop you from seeking further professional help if you require this.

1. Managing Role Strain:

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 and Limits:

It may be helpful for you to set limits and boundaries on the amount of time you spend being with or worrying about your relative/partner. This may not be easily achieved but in reality these constant efforts to offer support may not make a substantial difference and may reduce your capacity to support a sufferer effectively by wearing you down physically and mentally. It may also mean that you neglect your other relationships and commitments. Many people find that looking after a loved one with an eating disorder can distort family life through the effect on relationships and activities and that this is usually unhelpful and often isolating. It is important that you try not to spend all your time with the sufferer as this may have unintended consequences. A lot of time spent together may encourage unhelpful dependency and undermine the sufferers' belief in their own capacity to manage their affairs and make important life decisions. The shifting balance of responsibilities may also lead to high levels of resentment in you the carer as you take on more and more responsibility for your loved one. What is important is that time spent with your relative is balanced, effective and retains a sense of healthy relationship with the whole person with all their strengths and weaknesses and not a relationship to the illness

Clarify Roles:

You may also find it helpful to reassess and clarify 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 pressure 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. One of the challenges of caring for a loved one with an eating disorder is that it can highlight issues in how you manage stressful situations and your beliefs about life in general; so for example you may have to confront that a loved one who has lived independently is back at home and old patterns of relating may be activated in unhelpful ways for example trying to take control by applying sanctions "if you don't finish your meal, you can't come to the shops with me at the weekend". An important message for you as a carer is to realise that you are human with your own frailties and weaknesses and you are not empowered to solve and sort out all that is thrown at you.

2. Managing Contact Time:

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 and your hobbies and 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. Remember a consequence of this is that you may quickly become exhausted and resentful.

Look after yourself and get support:
Living under extreme long-term stress has recognised physical and emotional effects[1]. To be able to survive let alone support someone else, it is necessary to find strategies which help that survival. It is important to be kind to you and to avoid wasting time blaming yourself for the eating disorder. Blame will accomplish nothing and will only make you 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 Smiths experiences as a parent of someone with an eating disorder. It is called 'Coming up for Air – A survival guide for carers'[2], and has lots of practical information on how to cope. To find out more please see the reference/ 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 and 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 nearly, anything from conversation 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. Shaky 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:

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., 1992)[3], 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 several 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 a mental and physical health recovery.

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).

The Stages of Change:
‘How ready, wiling and able is the individual to 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! Its 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.

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 of 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-judgemental 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 that logic alone with not shift.
- 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 usually help them. Encourage them to look for evidence or the rational answer themselves.
- Try to look after yourself. Maintain your own interest 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 (eg., feeling cold, tired, lacking concentration, withdrawing socially, looking unhappy etc).
- Educate – leaflets, books, self-help, typical treatments, outcomes and prognosis.
- Provide medical and nutrition information (eg., about bones and the nutrition they need).
- The last three points might be reinforced if the sufferer can be engaged in discussion with the GP.

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 and feelings openly.
- It can also mean that the person is rehearsing in their minds reasons not to change in order to prepare for confrontations which on the whole is not helpful

Contemplation:

The person is aware there is a problem but they are 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.

- 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, what might need to be in place to promote change further for example support of others or specific resources
- Discuss possible plans of action
- Encourage talk about the negative consequences of the eating disorder, when it occurs for example physical symptoms such as poor energy, feeling cold all the time, disruption to contact with friends, hobbies, work and education if these things are valued.

Preparation:

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

At this stage it can be very useful 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?
- 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 and 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 their fears
    - set themselves tasks
    - break goals down into steps
    - minimise sick role behaviours
    - encourage independence
    - encourage use of skills and the acquisition of new skills
- 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 several months – the patient is in maintenance

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

- Have a list of signs and triggers of relapse
- Provide support and encourage coping skills
- Reinforce their bonds with support resources
- Encourage new healthy interests
- Encourage 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 to communicate concerns and worries by providing time and a safe environment.

Empathy (not sympathy)
Reflecting the difficulties that a sufferer faces accurately can be very supportive and create a very positive sense of being understood 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.

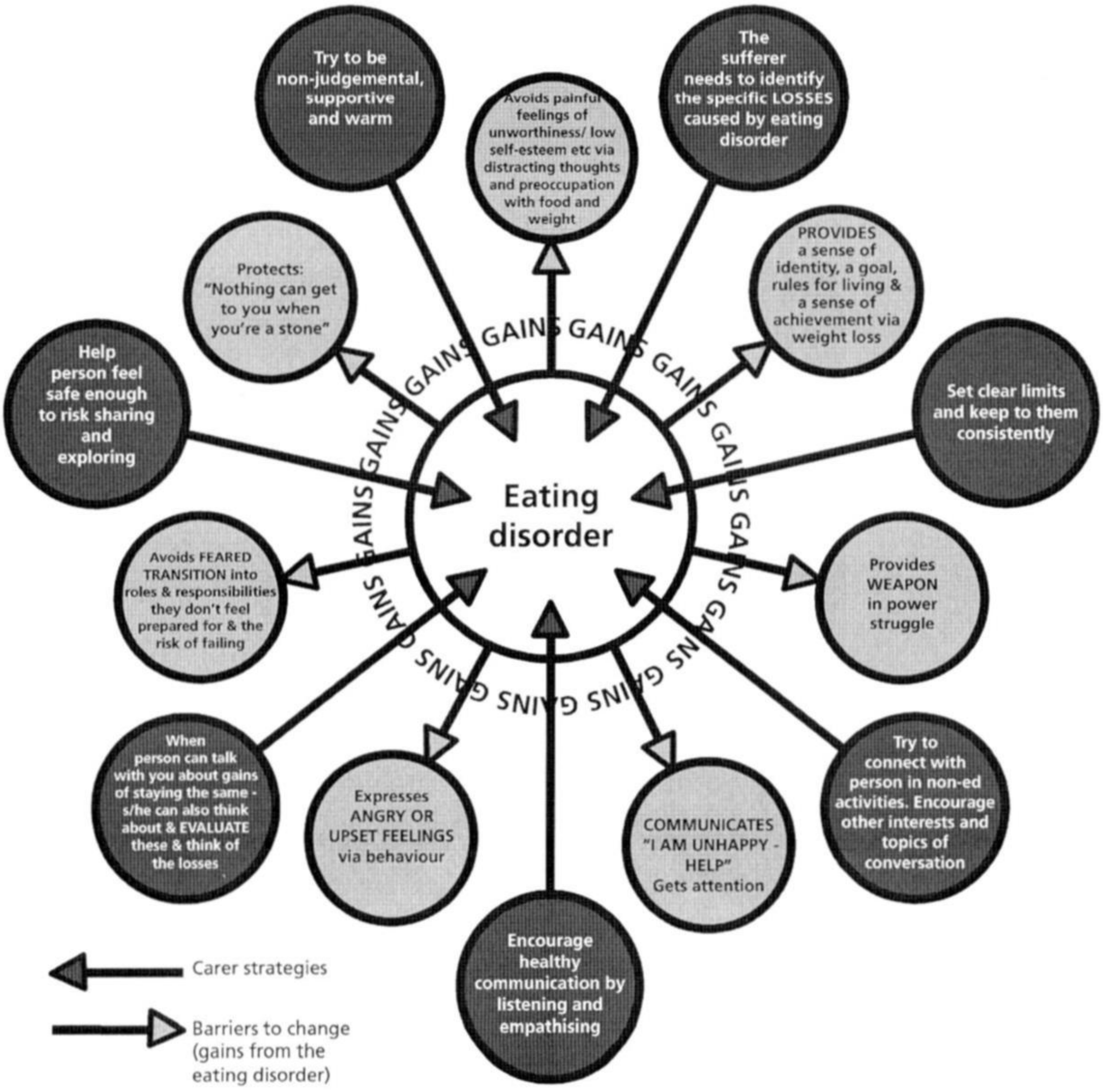
Share
Join their non-eating disorder life, any other interests, thoughts or opinions

Support
Help the sufferer gain confidence through seeing themselves achieving things and in a new light. Offer support to reflect on positives especially when they are feeling hopeless or negative

Eating Disorders:

A paradox of gains and losses

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



4. Managing Stigma:

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 or understood its nature and complexity. Experiences like this can lead to a plethora of feelings including feelings of isolation, wanting to withdraw from others (sometimes vital sources of support) etc. It may be important to talk to others who have gone through similar situations and feelings. Carers support groups and eating disorder charities can be a good place to get this sort of support. Groups can often powerfully reflect the “carer experience” in a way that may be experienced as helpful. They are often places to exchange the experience of managing difficult situations such as mealtimes, anxieties about physical health, anxiety that a loved one may die etc. or simply to share feeling tired and exhausted.

Many carers feel guilty or to blame when a loved one suffers from an eating disorder (often reinforced by stigma) and this can sometimes affect behaviours, thoughts and feelings in unhelpful ways. The causes of an eating disorder are complex and incompletely understood so it is important not to jump to conclusions about whether you are responsible for the illness or not. In a lot of cases, carers experience a shift in their feeling states over time; so for example at times of feeling very low, feelings of guilt and blame may be more pronounced. It may be important for a carer to identify these feelings and to develop ways of making sense of their feelings and beliefs. It can be very helpful to have the perspective of a supportive other especially at times when you feel more vulnerable and at sea with things. Few carers feel in control all of the time and some acceptance of your limitations and vulnerability can be helpful as you experience yourself at sea with several troubles. It is for this reason that paying attention to your reserves and resources and looking after you is of paramount importance. It is difficult to provide support adequately without support for yourself.

Crisp et al [4] (2000) looked at sigma associated with mental illness in a national survey. Over 1/7 of respondents felt that people with eating disorders could pull themselves together, have only themselves to blame and would be hard to talk to. It was felt that eating disorders were self inflicted and that it was easy to recover from them, therefore trivialising the difficulties that others face. Stigma can come from outside or inside the family. Indeed carers may hold stigmatising views themselves. In general it is important to have access to credible information to combat stigma. Equally, when situations are tough and seem intolerable this may be a time that stigmatising remarks or views raise their head and exert an effect in the relationship with the sufferer. A useful way of managing stigma is to develop a stance of separating the “person” from the “illness”, so for example when a difficulty arises (deceitfulness around eating disorder behaviours e.g. under eating) it may be helpful to frame things as “I understand that your eating disorder is making it hard for you to be honest about your eating and that you are not a deceitful person in general”

5. Managing unmet Needs:

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 common feelings of helplessness. It may be useful to make a list of areas in which you are experiencing difficulties and to give thought to who might be best placed to help you with each problem. I have suggested some areas that may be relevant based on NICE guidance [5] (the comments made from the carers group that was consulted and assisted in drawing the guideline together), but also from comments and experiences of carers in our service. The list may not be exhaustive and you may wish to add your own areas of unmet need.

- Knowledge and information about eating disorders and the associated risks especially to physical health. In connection with this support to manage associated feelings of fear and anxiety.
- Developing a joint understanding of the illness with the sufferer and involved professionals as well as understanding how care will be delivered
- Information to understand the stress and strain brought to bear on the carer and help to manage this optimally
- Specific help with coaching the patient with under-eating and other eating disorder behaviours
- Support with understanding change processes and issues of relationship and communication
- Specific help with financial, housing and benefits issues.
- Accessing a carers assessment and carers rights
- Access to advocacy services
- Contact numbers of agencies involved and information on who to contact in a crisis

We have tried to give you some ideas and information in this booklet and recommended some further books and websites.

6. Managing Interpersonal Relationships

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. This can lead to feeling frustrated and to maintain an atmosphere of hopelessness, anger and despair which is unlikely to help those who suffer or those who care. These relational styles can be summarised as:

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

This area is dealt with more comprehensively via the reading list enclosed specifically the “skills based learning for caring for a loved one with an eating disorder”. Condensed information about this issue is available free online in PDF format at the following website (courtesy of the Institute of Psychiatry Eating Disorders section).

http://www.iop.kcl.ac.uk/sites/edu/downloads/carers/TOOLKIT-FOR-CARERS-FEB3-09.pdf

7. Managing Eating Disorder Related Problems:

Certain eating disorder behaviours can have a big impact on family life. Anything food related can become difficult (eg, buying, preparing and eating food), and the compensatory behaviours that an individual engages in (eg., 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 persons low mood, apathy, loss of pleasure in doing things and feelings of worthlessness may cause them to avoid their friends and life in general. Eating disorder concerns are usually amplified at lower weight such as preoccupation with weight shape and eating.
- 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 can be tackled with the following strategies.

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

Problems Solving:
This strategy is detailed later.

Functional Analysis:
Looking at the behaviour in terms of what it achieves for the person, can help you and the sufferer to have more understanding of it and help you both think of alternative ways to meet those needs (so for example the eating disorder may be entangled with fears about growing up and function as a means of “putting the brakes on” to manage these anxieties.

8. Surviving:

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)[6]. 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 emotional 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 recover (Butzlaff, R. L. & Holley, J.M. 1998)[7]. 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 child is choosing not to eat normally in order to punish them.

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 many 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 overcome, "if only they 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 the relative/partners physical health and safety. You may also fear that your own or the rest of the family 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 permanently.

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. It is important for everyone to try and separate the manifestations of the illness from the person suffering the illness

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

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 others and to help us choose between the different options available to use 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.

Mindfulness:

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

Mindfulness practice is the art 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 judgement, 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 the 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 relative/partner, (eg., an anorexic minx or a bulimic boa constrictor).

At times your relative/partner will be talking anorexia nervosa talk, for example, when they start 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/watch 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 them, however small, that is in two minds about the illness. There is a part of them that would like to be different if they could. It is important that you find that part and try to develop it.

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.

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 others 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. However the model of blame and causation can by very counter-productive. Focusing on acceptance and tolerance is likely to be much more useful.

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 relative/partner 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 wish to agree limits on what activities you think it is safe to do at a particular weight, eg., a safe body mass index for driving may be 15kgs/m^2 (BMI 15)

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/watch a TV show with you. I would love to spend time listening and talking to you on non anorexia 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 casual factors or to worry and ruminate about what may be the problem.

All of us make mistakes. If, with the benefit for 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, acknowledgment 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.

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 relative/partner 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 relative/partners nutrition remains adequate.

Instead try to engage in pleasant conversation about non anorexia nervosa things. If your relative/partner 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 anymore. Last year my husband had a heart attack after an awful incident at home and he died. My daughters 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 spoilt. 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 can last several years.

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 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 relative/partners 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.

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 ie., 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 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 eg., 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 much 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 weigh range then the long term outcome is better.

General Prognosis for Recovery from Anorexia Nervosa:

A summary of 68 treatment studies published before 1989, with a length of follow-up between 1 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)[5].

General Prognosis for Recovery from Bulimia Nervosa:

Many people with bulimia nervosa do not receive any from 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)[5]

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.

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.

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 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.

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
- Leicestershire Eating Disorder 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.

References:

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   Grainne Smith

3. Prochaska, J.O. and Di Clemente, C.C. (1992) Stages of Change and the modification of problem behaviours.
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4. Stigmatisation of people with mental illnesses: Crisp et al
   The British Journal of Psychiatry (2000)

5. National Institute for Clinical Excellence (2004)
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6. Treasure, J Murphy, T Szmuckler, G Gavan, K & Joyce, J (2001)
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   in *Social Psychiatry and Epidemiology* 36: 343-346

7. Butzlaff, RL & Hooley, J.M. (1998)
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   In *Arch of Gen Psychiatry* 55:547-552

Directory of useful contacts

Organisations for Carers

Crossroads (http://www.crossroads.org.uk/) provide support to carers and have schemes in most parts of England and Wales

Carers UK (http://www.carersuk.org/Home) campaign for carers, and provide information and advice

Princess Royal Trust for Carers (http://www.carers.org/) provide information, advice and support services for carers

Young Carers Net (http://www.youngcarers.net/) provide information, advice and an online community for young carers

Carers Direct (http://www.nhs.uk/CarersDirect/Pages/CarersDirectHome.aspx) is an NHS service for carers including a website and phone line (0808 802 02 02)

Caring with Confidence (http://www.nhs.uk/CarersDirect/carers-learning-online/Pages/Welcome.aspx) provide local group sessions, self-study workbooks and online courses to help support carers by increasing their knowledge and skills

Carers Information (http://www.carersinformation.org.uk/) provide up to date information and resources relative to people in a caring role

Parentline Plus (http://familylives.org.uk/) provide information and advice to parents, and have a website or can be called on 0808 800 2222 (24 hours a day, 7 days a week)

The Institute of Psychiatry (http://www.iop.kcl.ac.uk/sites/edu/?id=15) have some downloadable resources for carers on their website

The New Maudsley Approach website (http://www.thenewmaudsleyapproach.co.uk/) offers resources for carers of people with eating disorders.

CLASP Leicester: http://www.claspthecarerscentre.org.uk/

Useful information may also be obtained via the following link:
http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

Legal Information

Citizens Advice Bureau (http://www.adviceguide.org.uk/) provide advice about your rights, responsibilities and entitlements

Carers Direct website has a Money & Legal section

Community Legal Advice (http://www.communitylegaladvice.org.uk/) offer free, confidential and independent legal advice to residents of England and Wales

Mind run a Legal Advice Service (http://www.mind.org.uk/help/advice_lines) and can be contacted by phone (0845 225 9393), email (legal@mind.org.uk) or letter (Mind Legal Advice Service, PO Box 277, Manchester, M60 3XN)

Rethink have a Rights & Laws section on their website (http://www.rethink.org/)

Carers Information has a Legal Issues that Affect Carers section, and a Carers Legislation section on their website

Useful information may also be obtained via the following link:
http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

Finances and Benefits

Carers UK provide a downloadable Guide to Carers' Rights and Benefits on their website

Rethink have a Money, debt & benefits section on their website

Citizens Advice Bureau provide information about benefits for carers and financial advice

Carers Direct have a Money and Legal section on their website

Direct Gov (http://www.direct.gov.uk/en/index.htm) have a Money, Tax and Benefits section on their website

Carers Information have a Benefits & Finance section on their website

Useful information may also be obtained via the following link:
http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx.

Employment Law

Citizens Advice Bureau provide information about laws affecting employers and employees

Carers Information have a section about Carers & Work, Learning, Leisure on their website

Employers for Carers provide advice and support for employers to help them retain and support carers in their organisation better

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Personal Websites

AnorexiaCarers (http://www.anorexiacarers.co.uk/) shares Rob and Helen's experience of an eating disorder and their journey to recovery, with helpful tips and ideas of how carers can help

Men Get Eating Disorders Too (http://www.mengetedstoo.co.uk/) provides information, advice, and links to support relevant to male sufferers of eating disorders

Working Together Care (http://www.workingtogethercare.com/component/option,com_frontpage/Itemid,1/) is a web magazine aiming to help carers (professional, family and home) to work together

This list of resources is derived from the B-EAT website

http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx