Eating Disorders - Symptoms of Distress

Part 3

"What can I do?"

Support for Carers

Norfolk Eating Disorders Association

- **Could I have seen sooner that there was a problem?**
- **So how can I tell if someone has an eating disorder?**
- **How do I approach someone I think may have an eating disorder?**
- **What can I say or do to help?**
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- **Aspects of different relationships:**
  - **Mothers**
  - **Fathers**
  - **Brothers & sisters**
  - **Children**
  - **Husbands, wives, or other partners**
  - **More distant relatives**
  - **Friends**
  - **Employers and colleagues**

2 Poems by carers

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INTRODUCTION

If you have a family member or friend who has an eating disorder, then you know how frustrating, and desperately worrying these illnesses can be for people who care but feel powerless to help.

This booklet is for those who are trying to understand and help a close friend or relative, colleague or employee with anorexia nervosa, bulimia nervosa, or compulsive overeating. We use the terminology “sufferer” to denote the person who has the eating problem, and “carer” to represent you as friend or relative. However, it is evident that where an eating disorder is concerned, **everyone** suffers – and it may be arguable who suffers most.

Eating disorders have their roots in psychological and emotional problems, but the physical effects often cause most concern to the “onlooker”. This may be because physical aspects of the illnesses are most simple to notice and focus on. They also appear to be the easiest to put right:

> If you’re losing weight, just eat more.
> If you’re overweight, just eat less.
> It’s easy - Yes?
> Well, No, actually it isn’t easy at all.

What makes recovery particularly difficult is the psychological aspect of the problems concerned. The physical effects may be alarming but, for the most part, they should right themselves as the body becomes better nourished.

Eating disorders are symptoms of distress and strategies for survival. They are not just about today's distress, they are also a sum of everything in a person's life that has chipped away at self-confidence and self-esteem. The end result is often self-hatred and a feeling of worthlessness in a person who feels the need to please others and to succeed in a world of high achievement. To the outside world they may be doing just that, but nothing they do can meet their own standards, and these feelings are hidden behind an assumed mask of confidence.

Secrecy can be such an important part of an eating disorder that its existence often comes as a real shock to the very closest friends and relatives.

Could I have seen sooner that there was a problem?

Realising that an eating disorder may be present is difficult for a variety of reasons, including:

- The most usual age for people to show signs of an eating disorder is early teens - mid twenties. This is a time of physical and emotional upheaval for both boys and girls and it is not always easy to tell that development is not quite as it should be. There is a delicate balance between knowing what is appropriate concern and what is being fussy, neurotic, or interfering.
- It is unexpected for people to show the first signs of eating problems at a very young age, or when they are past their 20s, or for boys at any age, but they do. Because it is unexpected, and the signs are usually carefully hidden, doctors can easily miss the fact that a patient's presenting symptoms may be indicating (or masking) an eating disorder.
- Many people have some sort of hang-up, problem, or peculiar relationship around food and drink. Some refuse to eat vegetables, some will not take hot drinks, some will eat half a dozen small meals, others won’t touch breakfast. Few families eat together sitting round a table these days. Fashions in eating come and go, and people’s habits alter as their lives change. Sorting out what is a fad and what is a problem is fraught with difficulty.
- Young people live in a busy, competitive world where schools are geared to academic and sporting achievement and meal times are filled with extra-curricular activities
- We all live in a diet culture where thin and/or muscular is the ideal. Most of us are used to our own and /or other

people's weight and shape changing with the seasons.

- We also live in an exercise and keep-fit culture where obsession with fitness may be missed
- Other physical or psychological illnesses and the effects of medication may mask what is happening if people lose or gain weight
- Many people are confused by what is "healthy eating" when the media focus on emaciated fashion, diets and fitness alongside fast food, cookery and "naughty but nice". It is easy to lose sight of what is "normal" and necessary for healthy development.
- Obesity is a real problem that increasingly concerns the medical profession, and there is a genuine need for many people to lose weight. This problem may or may not be linked with an eating disorder.

There are signs, symptoms, behaviours and emotional links common to the different eating disorders. Sometimes people move from one type of eating disorder to another, perhaps experiencing all three at different times. Although medics may need to use a specific set of known criteria to put a distinctive name to an illness, the reality is not clear cut and tidy. In the end, putting an exclusive label to what is wrong may be less important than identifying that there is **a problem** for which the sufferer needs help.

So how could I tell if someone has an eating disorder?

Bearing all this in mind, what you are looking for are physical, psychological and behavioural signs, such as:

Anorexia - often a severely restricted in-take of food:

- rapid weight loss or, in a young person, failure to develop and gain expected weight during a growth spurt
- hormone disturbance – shows as absence of periods in women (amenorrhoea) and affects sperm development in men, but may only become evident to a carer as lack of interest in sex
- loss of calcium from the bones, leading to osteoporosis - more common in women, but also happens to men. This results in brittle bones which may break more easily than expected in someone young
- other physical effects of starvation and dehydration may include constipation, swollen stomach and ankles, dizziness, poor circulation shown in coldness, blue fingers and toes, and growth of fine, downy hair on the face and body
- fears around "fat" and weight - i.e. fear of being of normal weight as well as becoming fat
- fears around shape - the mind of someone with anorexia shows them a "bloated whale" in the mirror when others can only see a virtual skeleton
- a belief that the more weight they lose, the closer they come to being worthwhile
- feelings of paranoia, that people are staring at them because they are fat and ugly
- if challenged, they may deny that they have a problem, and refuse to believe they are dangerously thin
- they are unable to accept rational argument around their eating habits and weight
- personality changes may include violence, mood swings and depression

- sufferers become secretive around food, their body and eating habits. Food may be hidden, baggy clothes worn, and people claim to have eaten when they have not.
- rituals and superstition may build up around food and drink: specific times when “meals” may be eaten, precise measurement of portions and the way food is prepared and presented. Being faced with the need to eat outside these conditions may lead to panic.
- excessive exercise is often linked with eating disorders and sufferers are often unable to rest, relax, or keep still
- inappropriate use of large numbers of laxatives or diuretics
- irritable bowel syndrome (IBS) with alternating constipation and diarrhoea, and accompanying pain.
- panic attacks

Bulimia - often bingeing on large amounts of food followed by vomiting:

- weight may stay steady or fluctuate
- hormone disturbance - absence of periods in women (amenorrhoea) are easier to spot than effects in men and boys
- physical effects of vomiting may include worn tooth enamel, sore throat, bloodshot eyes, puffy face through infected salivary glands, calluses on fingers and hands from inducing vomiting
- total preoccupation with thoughts of food
- feeling totally out of control during binges
- fear of weight gain
- self-evaluation is centred on weight and shape
- personality changes may include violence, mood swings and depression

“She became very self-absorbed, lost in her own thoughts, and was very touchy and irritable, unlike her usual self.”

- a need to succeed and a feeling that no achievement is enough
- self-hatred, feelings of shame, guilt and low self-esteem
- large amounts of food may disappear during binges
- people may become secretive and avoid socialising, especially where food is involved
- sufferers may disappear to the loo after meals, and there may be signs of vomit not completely cleared away, or hidden in bags in the bedroom
- evidence of purgative medicines may be found - laxatives, diuretics etc
- other techniques to counter the effects of food may be excessive exercise or fasting
- associated problems may include self-harm such as cutting, alcohol or other substance abuse or shoplifting for food
- many people with bulimia spend vast amounts on binge food and run into debt

Compulsive overeating - bingeing but not vomiting:

- may be steady or sudden weight gain, or marked fluctuation in weight if yo-yo dieting is involved
- health may be affected by excess weight or through repeated weight changes
- feelings of disgust around weight and shape
- depression, anxiety, self-hatred and low self-esteem
- feelings of distress, detachment and suffocation around the binges
- secretiveness - bingeing alone
- food is the choice for treats, rewards, comfort or celebration
- eating pattern or weight affects relationships or ability to work

- sufferers tend to take on too much work, to keep busy and avoid facing problems

These lists are not mutually exclusive. Some signs and symptoms are common factors in all of the eating disorders. There are others that may be classed as separate syndromes, such as the "chew and spit" syndrome where people chew the food for the taste, but then spit it out without swallowing anything at all. Sometimes people eat inappropriate substances, such as tissues, to fill themselves up without calories.

The main thing that links these illnesses is that food and eating become a problem when they are used as coping mechanisms. They act as a focus for sufferers when life is difficult because of other problems they are unable to face or cannot resolve. People can be stuck in anorexic ways of thinking and perceiving at any weight.

For someone who is in a caring role, focusing on sorting out the food and weight aspect in isolation is not the answer. What the sufferer needs is support, and encouragement while they try to understand the feelings that lie behind their use of food. They will also be trying to learn other ways of coping as they stabilise their eating. This will not be an easy process for them and it will not be easy for you.

How do I approach someone I think may have an eating disorder?

Confrontation is never easy. Different approaches may be appropriate in different situations, and will depend on your relationship to the sufferer, his or her personality, and how the problem has come to your attention. Whatever the circumstances, the following general comments may be useful:

Assessing the problem

- Despite the shock, take time to sort out in your head what you have observed to make you feel there may be a problem. Once you have got that sorted out, and are reasonably sure you have cause for concern, do not be deflected by other family members or friends who may try to brush it aside and tell you that you must be mistaken.

- Register how **you** are feeling about this problem. You may feel you are to blame, you may be angry, confused and hurt. All these are natural feelings and responses, and realising that they are there is helpful. Basing a confrontation on these feelings would not be helpful.

- Talk your worries through with someone, e.g. via the Norfolk EDA helpline. This will help you to clarify the situation for yourself. A response from someone who understands will allow you to check that you are going in the right direction.

- Become better informed about eating disorders in general, and find out what sources of help are available in your area. Ask Norfolk EDA for a leaflet or come in and borrow a book.

The confrontation

- Think about and/or discuss how the person concerned should be approached.

- Who is the best person to talk to them? Is it you, or would another family member or friend be more

appropriate? Think about whether it would be a good idea to have more than one family member or friend present when the subject is broached. Getting back-up from another person can be a good idea, if only as a witness to what has been said and/or agreed.

- Decide where and when it would be best to talk. Mealtimes should be avoided. A place of privacy at a time when you are unlikely to be interrupted would be ideal. A time when people are calm and not already feeling guilty or angry is likely to be most productive. Ideally, the whole situation needs to be one in which everyone feels able to be open and honest about what is going on and how it affects them.

- One aim of the confrontation will be to enable the sufferer to open up and talk about their problems. This is likely to be very hard for them as secrecy is a major factor in the development and maintenance of an eating disorder. Breaking the silence around this secrecy may well be the first step towards a recovery.

- Practice what you want to say and, prepare yourself for how you might feel when you are saying it. You could try writing it down, and/or talk it through with someone else, face to face or over the phone. You probably need to talk about what you have observed to make you think there is a problem – be specific about what you have heard or seen, without being judgemental about it. Say why and how this has made you concerned.

The outcome

- Think realistically about what you want the outcome of this confrontation to be. Stopping the damaging eating behaviour overnight is not a realistic option, but

encouraging the person to talk may be one possible outcome.

- Another aim could be to encourage the sufferer to get some help and support. In bringing your fears into the open, you may be able to move forward yourself and change the way that the eating disorder affects you.

- If nothing else, the outcome will be a new beginning in some way. You will have taken a brave step and moved things on even if, at first, it does not feel very positive.

The response

- You also need to prepare yourself for how the sufferer may respond. A variety of reactions are possible, bearing in mind that he or she will be struggling with all sorts of fears, shame and self-hatred. They will be hanging on to the eating disorder in a desperate attempt to cope with what they are experiencing as a difficult and painful life.

- Responses to confrontation may range through outright denial and fury, through to grateful relief. However, the person with an eating problem may well change their minds about their initial response once they have had time to think about it, so be prepared for that too.

- Whatever the response, keep the focus on the person with the eating problem and don't be deflected by

I tackled it rather clumsily, but from the point of view of her unhappiness, rather than her eating behaviour. Her words were "I'm so scared" which just about sums it up for me as well.

counter-attack, ridicule or being told to mind your own business. Keep checking out in your mind how the response really measures up against your experience of the situation, and remain firm.

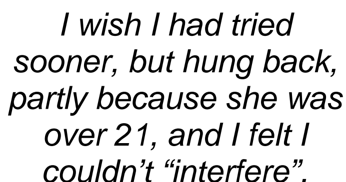
If their response is positive, finding outside help and support would be the ideal next step.

A positive move on your part may be to say that you are also getting support and help for yourself. However, some sufferers are outraged by the thought that you feel the need to talk about them with someone else and demand secrecy from you. You need to think how you would respond to this.

Contact Norfolk EDA on 01603-767062 (Mon, Tues, Thurs 10am-2pm) to talk about your problems around the eating disorder, or the Norfolk Carers Helpline on 0 808 808 9876 for general information and support (open 24 hours a day)

Some ways forward for sufferers of eating disorders, and which may be enlightening for carers too, are suggested in our booklet about Recovery.

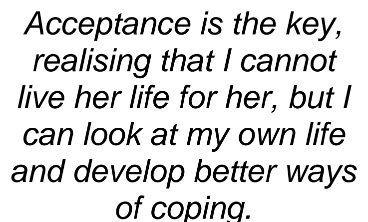
The GP may be able to refer the sufferer to a counsellor or, possibly, for help through the psychiatric services (but there would certainly be a wait for this), or they may suggest a referral or self-referral to Norfolk EDA.



What can I say or do to help?

What the sufferer needs most from you is the assurance and reassurance of your love and support of him or her as an individual, regardless of the illness. You can show this through your readiness to listen, efforts to understand and honestly communicate your thoughts and feelings, without judgement or giving advice. This assurance will probably add to the feelings of guilt and shame they carry, but it is also the bedrock on which they may be able to base their recovery.

On the whole, eating disorders are about survival – an individual's way of coping with problems, and happen to people who are strong willed. This being the case, in general it will be the sufferer who will win any head-on clashes around food and eating. What may help is "letting go" and encouraging the sufferer to make his or her own decisions. It may be easier to do this if you can understand that the sufferer probably sees the disorder as the only thing in his or her life over which they have control. If that is the case, they will obviously strongly resist someone else's attempt to "take over". It is a learning process for all concerned, so it is important that "letting go" does not become "washing one's hands" of the person, who will need sensitive support and guidance. What helps is acceptance of the person where they are, and that it is "OK" for them **not** to be "OK" all the time.



An eating disorder can disrupt the lives of many people and can split whole families apart if allowed to do so. However much you ache for the pain of the person concerned, the most important thing you can do is to begin to set clear guidelines and boundaries around their behaviour – what is and is not acceptable to you and the rest of the household. This requires a delicate balance between flexibility and being consistent.

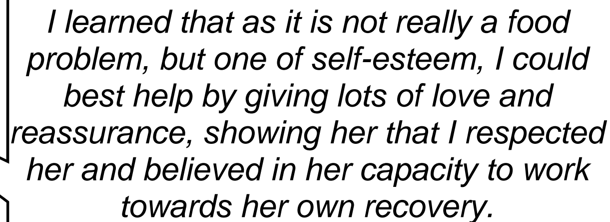
Food

Food is an obvious area of contention, and agreement must be reached about boundaries here too, without having a head-on battle. You may also need to set some boundaries a round how much you talk about food and the eating disorder. Focusing talk too much on food and eating can act as a smokescreen concealing all the other aspects of the illness.

The most productive way forward is to try to negotiate an eating pattern that is acceptable to the sufferer, and ways in which they would allow you to encourage them to keep to it. This needs to be done without taking away their responsibility for their own decisions and actions. It is an area fraught with problems, and the sufferer is unlikely to be able to keep to it without relapsing from time to time. (Carers may relapse too!)

Respect from the sufferer towards the needs of other family members or friends has to be part of the equation. For example, someone with bulimia will need to binge, and they may use other people's food to do so. If the sufferer is expected to replace the food, or pay for it, they are starting to take responsibility for their actions. Often, someone with anorexia will want everyone else to eat lots, cooking wonderful meals for family and friends, while he or she eats nothing.

Colluding with this vicarious eating may lead to health problems and weight gain for others, and could become a bizarre infringement of their rights and needs. Obsessions, rituals and food fads and fancies, including a sudden conversion to vegetarianism in a non-vegetarian family can also be a problem. It is helpful if these behaviours can be kept from impinging on the needs and habits of the rest of the family.



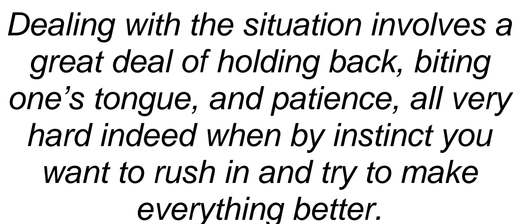
Behaviour

As well as issues around food, other behaviours may also need boundaries round them. The sufferer should be expected to clear away any signs of vomit, for example. Some people who have an eating disorder may have problems around other substances as well, such as alcohol or drugs, others may self-harm.

Many people get into debt through buying binge food, and there may be issues around how this is to be handled. Other areas where negotiation may be needed are social events, eating out, Christmas, holidays. All these can be very threatening to people with eating disorders, but may not be a total disaster if you can plan ahead and come to sensitive agreement about what their involvement will be.

The family or circle of friends which retains a strong life of its own, without being totally sucked into the eating disorder has the best chance of offering long-term support. It will

also provide a useful model of "normal" as a reference point for the sufferer.



Will anything I do or say make it worse?

Although there is no blueprint for supporting someone with an eating disorder – there is no magic formula for getting it right – there are things which may complicate or compound the situation. For example:

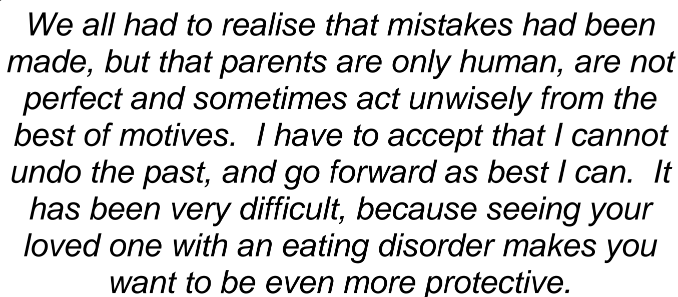
Eating disorders are illnesses, they are not just people being difficult. The situation will not be helped through judgement, punishment, sanctions, personal criticism or emotional blackmail, all of which would only reinforce the sufferer's feelings of low self-esteem, guilt and shame.

The person who has an eating problem may ask for someone else to take control of monitoring their food intake, weight or spending. They may ask you to put locks on kitchen cupboards or the fridge to prevent them being raided. Perhaps you may be asked to make excuses to friends, teachers, relatives or employers. If you do this, it may appear to help in the short term. However, any of these actions could simply delay the sufferer taking full responsibility for their illness, or their recovery.

Making observations about an individual's appearance can be a minefield. Typically "You look well/better" can be interpreted as "I've put on weight. I'm fat". At the same time, do not collude with the sufferer's mistaken perceptions. "Thin" is not good of itself, and "fat" is not bad of itself. Such black and white thinking is not helpful in an eating disorder. However, it is very difficult to refrain completely from making a comment about a person's appearance, so try to find a positive, non-weight-related comment to make, such as "your hair looks good" or "I like those shoes" etc.

Talking about your own or another person's reducing diet, weight, or negative body image is not helpful. Talk of diets may elicit a competitive response from someone with an eating disorder – it is something an "anorexic" is good at, a "bulimic" aspires to spasmodically, and makes a "compulsive eater" feel a dreadful failure. They will all hate themselves more.

Blaming is also not helpful – yourself, the sufferer, or another person. Sorting out where different responsibilities lie is an essential part of trying to make sense of the problems, but that's different from laying blame. In the end, allocating blame and responsibility is less important for all concerned than letting go of the past and moving on.



It is a normal mothering (and fathering) instinct to want to protect your young one. However, being over-protective can be damaging if it means that children are unable to grow and learn to be independent, autonomous people. Equally, the urge to protect is unhelpful in an illness that has powerful issues for the sufferer around control and feeling out of control. Letting go should allow everyone space to assess the situation and possible ways forward.

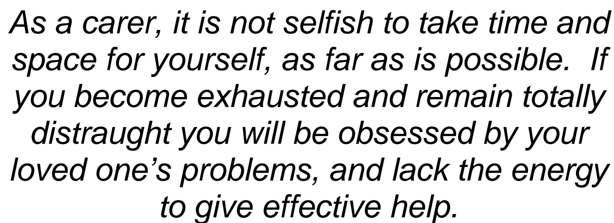
What about me? I'm suffering too.

Yes, watching someone you love struggling with an eating disorder can be agony. It is as though everyone concerned is held to ransom within a kind of cage. The mood swings and character change sufferers may go through often feel as though they are used as deliberate ways of piling guilt onto those who love them.

People involved with an eating disorder sufferer need to look after themselves as a High Priority. It is not a selfish response to do so; it is essential for a number of reasons:

- Eating disorders are exhausting illnesses for all concerned, because of their complexity – high emotional levels including guilt and shame, worrying physical effects, psychiatric involvement and the acute/chronic nature of the course they often run.
- The low self-esteem of the sufferer means that he or she feels that they are selfish, worthless and do not deserve to look after themselves. They need to be shown as their model that adults are responsible for looking after themselves, they are expected to, and that it is right for them to do so.
- If you are beaten down and become ill because of your loved one's illness, it will not help them.

- The whole set of problems can be very long term. The groundwork leading up to the illness could go back a long way. It may be some time before the sufferer is able either to admit to having a problem, or prepared to seek help and work towards a recovery. The recovery process could take a long time, and relapses are almost inevitable. You will need somewhere safe to "dump" your negative feelings, so that you can be helped to let go of some of the anger and distress within the relationship.



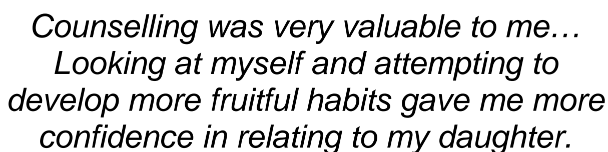
Educating yourself about the different aspects of eating disorders will mean that you are better armed for what will feel like very real battles ahead. For example:

If you can understand that your skeletal anorexic daughter sees a "bloated whale" when she looks in the mirror, it will make a difference when you are so frustrated that you want to shake her and scream "Why can't you just eat?"

If you can understand that a bulimic binge is feeding a huge, gaping hole of emotional hunger, but the food then turns to something ugly and repulsive once eaten; and if you can understand that vomiting brings on a feeling of purity and emptiness as well as a kind of numb, emotional "high", it is less bewildering than focusing on the waste of food and the starving millions.

If you can also register that someone who eats compulsively is overtaken by the same desperate need to fill emotional emptiness; yet cannot find the painful relief of vomiting, but have instead the added punishment of uncontrolled weight gain; you may catch a glimpse of the trap they are in and the pain that they feel.
Many carers can benefit from counselling in order to help them cope with the situation: to adjust to change as a sufferer recovers, or to bring about change in themselves which may in turn allow the sufferer space to change.
Eating disorders are complex and confusing illnesses. It is hard enough for sufferers themselves to understand what is going on, or know how they really feel, so it is not unreasonable that carers often feel totally bewildered and intensely hurt by it all.

These feelings can grow and fester, fuelling depression or anger if effective help and support is not found.
Counselling can help untangle what is going on and make some sort of sense of it all. The counsellor's job is to enable people to draw on their own wisdom to work out what is the best way forward for them.



As well as counselling, you could find real help and support through a self-help group. You are not alone in your problem. Others have been in on the struggle and have come through, some are still there. They have a lot to teach – most of the quotations used in this booklet are from people who have been helped through our group. Group members can offer the support of a good "family" in a safe

setting when you feel your world is falling apart.
You will also be best helped and supported if you can encourage the person who has the eating disorder to find and use appropriate professional help for themselves. This may be counselling, medical help, self-help group support or, best of all, a combination of all those. You need to stay in your role whatever it may be - parent, partner, friend – because they need you just to be on their side, and to be there for them - simply as you, not for you to try to be an indifferent counsellor or amateur medic.

There will be times when this doesn't feel nearly "good enough" to you, and other times when the sufferer will be very critical of you as you are, or as you used to be. This is all part of the scenario of the illnesses and the dynamics from which they spring and in which they exist.

The truth is that you are not "to blame". You are of value for the person you are. This is true despite of any mistakes you may have made in the past or will make in the future. It is also true despite any wrongs that have been done to you and that have caused you to feel worthless.

My husband and I both came to realise that instead of encouraging our children to learn from their own experience, we tended to shelter them and try to avoid all problems in advance. We also took her very much for granted, seeing her as the "good girl" of the family who could be relied on to cope.

Warning to all Carers

You also need to be aware of the dynamics involved in your relationship with someone who has an eating disorder if you have ever been, or think or feel you may be, vulnerable to using food yourself to cope with stress. Listen to your instincts and, if necessary, consider getting counselling for yourself. You are too valuable to risk becoming ill yourself through taking too much strain.

Particular words for special people.
(mothers, fathers, brothers, sisters, husbands, wives, or other partners, children, more distant relatives, friends)

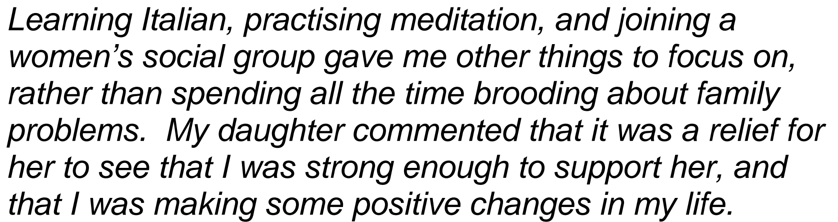
The most particular words for all involved in caring for someone with an eating disorder include **PATIENCE; HOPE; LOVE; HONESTY…**

MOTHERS

There is a painfully ironic quote that goes “A mother’s place is in the wrong.” Perhaps it’s meant to be funny, but it doesn’t make mothers of people with eating disorders laugh much. You feel guilty, and you are the obvious person, for people looking for a scapegoat, to blame. Some sufferers may feel they have “the mother from hell”, but most recognise that the scenario is not like that.

There is no blueprint for perfect motherhood. The “perfect” mother of Christianity had to watch her son on the cross, and you may feel that your child is up there with Him, and you are at the foot of it. The most we can all do is to try our best, and for everyone there will be times when that is not good enough. We all make mistakes and we all try to make amends. It’s about being “good enough”, or even about “doing it badly” sometimes, because it’s the best we can do. Sometimes love works miracles, often it doesn’t. Sometimes it has to be “tough love”, but love helps, and it is the only thing that really does.

What did you do wrong? Lots and nothing. If you could go back and do things differently, what would you do? Whatever your reply, it is the reply of hindsight and, at the time, most likely you could have done nothing differently. So stop blaming yourself. You are not to blame. You have realised a problem and are looking for a solution – who could ask for more than that?



FATHERS

Eating disorders are not "women's problems" even if the sufferer concerned is female. Men suffer too, be they "sufferers" or fathers. The truth is that you are needed in the family much more than you may think you are. Your loved ones need you to offer the kind of emotional support that can only come from a loving father. We hear a lot about "absent" fathers, and that does not just mean that they work away from home. It can mean all sorts of things. If you are divorced, the absence may be physical. If you are part of a cohesive family, the "absence" may be emotional – because men aren't supposed to be emotional are they? Well, yes, actually, they can be more healthy if they are emotional.

Love is an emotion. It is, of course, also about "doing" – perhaps going out to work and earning the money to pay for the family's needs, if you are employed. It is about doing practical things with your sons, or being the model for your daughter's ideal of masculinity. It is about giving practical support to your wife in a dispute with the children. But it is essentially about being prepared to get in close and become subjectively involved with the sometimes messy and painful bits that are the emotions.

Many men have been brought up not to share or show their feelings. This can be a real barrier for people with eating disorders. If there is the polarity of mother showing

desperate worry and concern and father keeping the situation at a seemingly calm distance, it can be confusing. Anger is another confusing emotion – some people are comfortable with expressing it – many are not. Many people feel a lot of guilt around feelings of anger, which may make them bottle up these uncomfortable sensations until they explode unpredictably.

Such feelings need to be let out safely so that pressure can be released from the situation. Norfolk EDA may be able to help with this. There is plenty of scope for anger around eating disorders, for all concerned, and this will build up around the fears and frustrations involved. For example, many men feel their role to be that of “problem solver”. When something can’t be easily solved, the result may be uncontrollable anger and frustration.

If you can think about how you **really** feel about the person with the eating disorder, and take your courage in your hands and tell them, it could make a lot of difference to everyone.

BROTHERS AND SISTERS

Brothers and sisters of people with eating disorders often get - or feel - pushed to the background, and have their own share of suffering. Alternatively, someone may develop an eating disorder partly because brother or sister is much more the focus of attention for one reason or another. Whatever the family situation, and however close or distant the relationship between you may be, brothers and sisters play a very special place in the life of the sufferer.

Siblings share a strange ground somewhere between friend - or enemy - and parent or child. Most often there is an aspect of one of you taking on the part of "role model" – positive or negative, an inspiration or to be used as a

measure of rebellion. Often, however much you may fight between yourselves, you can be united against an outside influence – sometimes including parents. You may compete with each other, actively support and protect, or wage war. Often, if one of you is hurt, the other suffers. If you share suffering, perhaps responding in different ways to that experience, it may pull you closer together.

You will most likely share a childhood history, have a deep understanding of what makes the family tick, be able to identify what you have inherited from different family members in different generations, and where you differ from each other and the rest of the family group. Each of you is unique – even twins are unique – and you each have a unique part to play in helping to make sense of the eating disorder.

Your love, support and special understanding are vital to the sufferer, even though you may hate each other at times through the trauma of the illness. The brother or sister you have always known is still there, trapped within the illness. Knowing that normality is still there for them outside it will be an immeasurable help.

From childhood she always wanted to do things perfectly, feeling overprotected by both her dad and me. We were reluctant to let her try things for herself and made her feel she wasn't trusted. As teenager, she envied her older brother who fought for his independence in a way she didn't dare. She felt she was in his shadow, and felt she had to compete with him academically etc.

CHILDREN

Whatever age you are, if you are aware that one of your parents – most likely mother – has an eating disorder, you will be in a difficult, complex and confusing situation. You may feel that you should take on the role of parenting your parent. This would probably mean taking upon yourself some of the responsibility for practical issues - such as trying to get them to care for themselves properly, whether that is eating more, eating less, or eating more regularly. Feeling that such a role change has happened inevitably involves shock, a sense of loss, bewilderment and possibly anger. You will need understanding, help and support just as much as a parent or partner of someone with an eating disorder, but may feel awkward or disloyal about seeking it.

The whole situation may make you begin to question your own behaviour around food, as well as attitudes towards your own and others' weight and shape.

Habit patterns that you have taken for granted up to now may be seen in a new light and found to have unexpected implications. "So that's why mother always disappeared to the loo after meals." "I always thought it strange that she never ate with us – she had always eaten by the time we got home from school." "I thought it was my brother who used to eat my Easter eggs, but it must have been mum." Putting pieces of the puzzle together in this way may make you feel angry or hurt, relieved, or may lead to feelings of panic or scorn, and may even make you question your own identity. It is important to remember that eating disorders develop to help someone to cope with the difficulties of their life.

It is very hard to accept your own place in this scenario - that you may be part of these difficulties or, alternatively, that you may be the saving grace that, together with the

eating disorder has enabled your parent to cope. There is plenty of scope here for inappropriate feelings of guilt and responsibility. The classic response a parent may have to an illness such as an eating disorder is “What did I do wrong? Is it my fault?” and these questions may also be asked of themselves by a sensitive, caring child. Norfolk EDA may be able to help you to find ways of putting the situation and your part in it back into its proper perspective.

Love, understanding and acceptance are the kind of support your parent will most need from you, and you may find that counselling is necessary for yourself before you can attempt to give all that.

HUSBANDS, WIVES AND OTHER PARTNERS

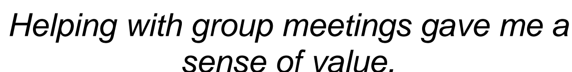
As it tends to begin in the pre-teen to early twenties age group, for the most part, an eating disorder will have been around in the sufferer before a couple ever got together. This means that, whether you were aware of its presence or not, you chose to share your life with someone with an eating disorder. Whether you already knew about the problem, it came as a total shock, or made many pieces of a puzzle fall into place, the situation has implications for your relationship. Eating disorders have made many relationships founder and fail. But the good news is that people can and do recover from eating problems. Others are able to work out ways of managing the illness in ways that others in the situation can accept.

When you love someone deeply, the hope is that you will be “enough” for them, that you will be able to fulfil all their needs, comfort and support them, perhaps change them, most of all, that you can “make it better.” However, even if you have not been instrumental in the development of the eating disorder, your love alone is unlikely to allow the

person to recover and, in any case, recovery will not happen overnight because of your relationship. A close relationship will very often make the sufferer feel more guilty about the effects of her or his eating problems. A good relationship may enhance feelings of unworthiness, and a difficult relationship may well cause self-esteem to drop even further.

Once you have made a commitment to your partner, the responsibility your love brings is to encourage them to change what they can, at the pace they can, while you try to remain supportive. You can't do it for them – they are responsible for themselves and their own actions, but you can help to share the burden. You can't do it alone - finding help and support for yourself in the situation is vital if you and the relationship are to survive in the long or medium term. They can't do it alone – if recovery were simple, they could work it out for themselves, but an eating disorder is a complex illness. If you have children, getting support for you all is even more important, as your responsibility for them may at times clash with your responsibility towards your partner.

Dealing with an eating disorder is fighting against something that, for your partner, is both enemy and friend at the same time. It is bewildering for both of you, but if you can work together against its damaging effects, you could find huge strengths in your relationship. Your love will be the secure foundation on which the tentative steps towards recovery can take place. Overcoming a common enemy, if the relationship survives it, can strengthen the bonds between you.



"Good days are great, warm, loving, expressive days, not wanting them to end in case tomorrow is a bad day. It doesn't even matter that on good days you cannot enjoy going out for a meal together as food is off limits or, if something is said wrong it's not the end of the world, but is talked about calmly.

"Bad days are the worst nightmare: being frightened, lonely and not knowing what will happen. Frightened of saying the wrong thing, which you know will end up having such a devastating effect on both of you. Not being able to give a hug of reassurance ("Go away I want to be on my own.") – total rejection and then hurting so much as you would have liked a hug yourself.

"Not knowing what to do or say to make things better: you cannot always make things better and have to stand back to give space and not smother. Feeling so alone and unloved, but yet knowing it's the way things have to be for now.

"Hoping each new day will be better than the last. Wanting so much, that you would give anything – your own life – to see a smile, and to hear laughter. It would be like winning the lottery and, if it did happen, hoping with all your heart it would stay for a while, so we could enjoy life together.

"Having to eat alone.
Having to visit friends on your own.
Feeling guilty having interests to occupy your time
Feeling very tired at trying to please and to give the right answers.
Trying to define what is normal.
Not being able to wave a magic wand.
Having to cope watching the person you love soul-destroy themselves and you cannot do anything to help, except wait and try to help pick up the pieces and, in time, join them together again."

MORE DISTANT RELATIVES

Grandparents, Uncles and Aunts, Godparents, Cousins, may all have their own concerns about a relative with an eating disorder. Trying to give support or "get something done" at a distance can be desperately frustrating and worrying. Sometimes you may feel that you are the only person to see there is something wrong and cannot understand why the sufferer's parents or partner is either unable to see it or refuses to do something about it. Family politics can be extremely sensitive where eating disorders are concerned. You are in a difficult position if you love the sufferer and/or his or her family deeply, but have no power of responsibility in the situation. Not having responsibility does not mean that you can't have any influence, however.

As with anyone else concerned, you may be helped yourself, and better able to offer support, if you increase your own knowledge and understanding about the illnesses. The Norfolk EDA self-help group, literature, library and one-to-one sessions are available for you as they are for anyone else involved. You may be able to combine your new awareness of eating disorders, their effects and implications, and sources of help available, with your own special insight into the family, to enable some kind of movement in the situation.

Sometimes the distance of relationship and, perhaps, geography, can be a real advantage. Eating disorders can enmesh everyone in the close family circle, so that no-one is able to see or think clearly about what is happening. Outside intervention is often needed to help things to move on. Relatives who are a little "removed" may be uniquely suited to providing some enlightenment. Many people feel closer to a Grandparent, for example, than to their own parents with whom they may have a more complex, love/

hate, relationship. Wisdom coming from this sort of distance can be very influential, even if its effects are not immediately apparent. The fact that you remain able to offer your own special love and support through all the pain will be invaluable.

In a life-threatening situation, some very "tough love" may be needed in the form of seeking urgent medical intervention, however unwelcome this may be to the sufferer.

FRIENDS

So what about friends? Your part in the sufferer's illness or recovery will depend very much on the ages of those involved. If you and your friend are teenage or younger, it is essential that you seek the help and advice of a caring, responsible adult, perhaps a teacher, school nurse or youth worker if you can't talk to their parents. Phone or drop in to Norfolk EDA if you need to talk this through. The closeness of friends, of peer pressures and the influence of society, fashion and the media makes the whole area of food, eating, dieting and appearance very complex. The person affected will not be able to take in or act on any reasoned, logical arguments you may present around how worried you may be about them. It will need the intervention of an adult to contain a situation which could be life-threatening if it gets out of hand.

The sooner an eating disorder is identified and effective help is found, the more likely it is that the person concerned will have a complete recovery. You can remain a loving, supportive friend and help the sufferer through, and still make sure that people in a position of responsibility are taking appropriate steps to help him or her sort out what problems are involved.

If your friend is older, perhaps a work colleague, neighbour or “old school friend”, you may be in an even more difficult situation. Trying to get another “responsible adult” involved may not be an option for you, so you may feel very much on your own. For some people it can be hard to strike a balance between being there - in a supportive role, and trying to force your friend into better eating habits - taking over. Once again, talking the situation through with someone at Norfolk EDA may help you to sort out what would be an appropriate approach to take. You may need to inform yourself about the problem, find support - for yourself, and offer the possibility of help to your friend.

Many people who visit the Norfolk EDA Centre, for a 1:1 appointment or a self-help group meeting, come with a friend – as support the first time, or each time they visit. The camaraderie that exists between people who share an eating disorder, or share the common ground of supporting someone with an eating disorder, is a strong and strengthening experience. Sufferers often say that they could not have got through their eating disorder, or survive living with it, without the caring support of their friends. This role also sometimes involves “tough love” which can set boundaries without taking over control.

People need therapists, but those relationships have a set use and, usually, time-span. Friends are needed always if someone is to achieve a balanced life. The burden placed on you by the sufferer may be very great, unconsciously or deliberately. The changes in mood and sociability eating disorders bring with them can alienate the closest of friends, and then leave both parties bereft. As with all other carers, you must take care of yourself if you want to remain supportive in your role as a friend as opposed to a pseudo-therapist.

EMPLOYERS AND COLLEAGUES

Why should an employer or colleague do anything about someone with an eating disorder?

Because an eating disorder does not just affect the person concerned (the sufferer). It has implications for everyone with whom they come into contact. At work colleagues could be affected as individuals and, in one way or another, as team members. "Production" may be disrupted and there are potential cost implications through staff absence. Also, an eating disorder is an indication that you have a caring, gifted and conscientious staff member who is currently unable to fulfil his or her potential, but has a lot to give. There are particular problems in the workplace, outlined in the following pages.

If a colleague or employee has an eating disorder, how would I know?

Society today regards weight loss as "success", but what do you, as a responsible employer or colleague do if you become aware that:

- a staff member looks ill from drastic weight loss
- colleagues are worried about someone who never eats at work
- an individual's mood swings are making life difficult for friends or colleagues
- food has been disappearing from a communal fridge or cupboard
- someone is making long, frequent visits to the loo, or there are regular signs of vomit which has not been properly cleared away
- an employee has debt problems or has been caught shoplifting food
- someone exercises compulsively, eats all the time, is obsessive or ritualistic around their work or compulsively overworks

These can be signs of an eating disorder. You will find a fuller picture in our other booklets.

Supporting someone with an eating disorder is not easy. All concerned need help at one time or another. Talking it through with someone who understands can be very helpful. So do contact us at Norfolk EDA*.*

What can I do if a staff member appears to have an eating disorder?

Although there is help and support for people with eating disorders, many sufferers and their families still struggle on alone. This could be for one of a number of reasons:

- they might not recognise there is a problem
- they may have acknowledged the problem, but be trying to keep it secret
- they may desperately want help, but not know where to go

Whatever the home situation may be, there are times when intervention in the workplace, or by a friend, is necessary for the good of all concerned. Here are some suggestions around how to go about trying to help.

Broaching The Subject

First of all, consider **who would be the best person** to approach the person concerned. Is it you, or would another staff member be more appropriate? This may be determined by the nature of your staffing structure, personality factors, whether you have an occupational health nurse, and how the problem has come to your attention.

Where and when would be the best place to raise the issue? In a busy organisation finding non-threatening privacy may be difficult. Would a formal or informal approach be best? This could influence the choice of both time and venue.

As far as both the employee and the organisation are concerned, what do you need the **outcome** of the encounter to be? Obviously, the needs of the employee are one major concern, but if his or her health is affecting personal performance and upsetting the work of colleagues, the needs of the organisation may have an equal priority. What is your balance of responsibility towards each set of needs?

- When thinking about **what to say**, it is important to remember that eating disorders are not just about young girls being silly and dieting. They are an indication that the person concerned is in great emotional pain and distress and simply does not know how else to handle it. Many people who develop eating disorders are high achievers and perfectionists. However, although they may appear to be confident and work to a high standard, they lack confidence and feel worthless. Bear in mind the value of the person as an individual and that this person has problems. These problems are made evident by the eating disorder symptoms, which you are currently viewing in the context of the work situation.

- You could be faced with **a variety of responses to your intervention**, so be prepared. Denial of there being any problem is quite usual, as are anger, relief or tears. If he or she is depressed, you might get a very flat response. It would also not be unusual for an individual to acknowledge the problem with gratitude at one point, only to deny it with anger at a later meeting. How you handle their response will depend on what you are able to offer in the way of help or support. Colluding with denial is not helpful for anyone, so be sensitive but firm about what has been causing such concern about this person's health.

If you decide that **someone else** in the organisation should **broach the subject**, you may need to talk the situation

through with them first, bearing in mind the above points and issues around confidentiality.

For some people with an eating disorder, learning that someone else knows and cares can bring great relief and ease the pressure on them.

Educating your workforce about eating disorders could bring understanding and a new perspective for many of them.

Help and support may be available through your own organisation - through occupational health, welfare staff, counsellor, or a private health scheme. If not, you may want the person concerned to go to **his or her own GP**. Depending on the age of the individual, you may need to consider whether or not you need to involve his or her parents.

A staff member is talking to me about an eating disorder – how can I help?

- If you want to understand someone with an eating disorder, it is helpful to examine your own attitudes. Think carefully about your own behaviours around food, what your feelings are about your own body image and how you judge other people. Do you make comments or judgements based on the size, shape or appearance of your colleagues? Can you observe discriminatory behaviour among the management around these issues? Are there also any unhelpful issues around sexism, racism or ageism, which would further lower self-esteem? How do you view the “perfect" employee who works all hours? This may be of **apparent** benefit to the company - until they finally go off sick.
- What is the working ethos of the company? Trying to help someone who has problems around food and socialising may be easier if proper meal and rest breaks are part of

the time-table of the working day. People with eating disorders feel they do not deserve nourishment of any kind. The pressures of modern working often reinforce such feelings by making it difficult for people to take proper breaks. If you make it clear that you expect colleagues to take such breaks, it is evident that you care for your staff, **and** that you expect them to be responsible for taking care of themselves.

- If the organisation provides food and drinks for staff to buy, a range of choice apart from chocolate, crisps and carbonated "Diet" drinks would be helpful. These are often "binge trigger foods" and some people may be discouraged from eating anything at all if there is nothing else on offer.
- The support that a staff member will need from you begins with clear boundaries. If you know what the limits to flexibility are as far as the organisation is concerned, you will be able to decide how much help can be given by yourself, supervisory staff and occupational health. You will then be in a position to negotiate with the person concerned about areas needing outside intervention.
- Take time to listen to what the person is trying to say about problems and difficulties, accepting what they have to say without judgement. what implications do these problems have for the work situation? For example, there may be problems around eating in a public cafeteria, but the company of one other person would be helpful. Could you help the employee to sort this out? Or a forthcoming break - weekend or holiday - feels threatening and will have a knock-on effect for work next week. Suggesting some strategies for coping may be useful. Just talking about it may help.
- If appropriate, involve the employee's supervisor as someone who can provide daily, on-going support. Make sure that all concerned know what has been agreed - in the way of what help is to be sought, expectations around behaviour at work, and attitude to time off sick for example.

- Try to support your staff member in the help they are getting. This may mean backing off and relaxing any pressure you have had to bring to bear to encourage them to seek help in the first place! If it is difficult for you and your colleagues to get this balance right, do telephone us - or come in and see us - and talk the situation through. We are here for you too.
- Let people know that you are aware of Norfolk EDA and the support we have to offer. Display our material. Suggest that he or she talks to us, perhaps even make the call for them and hand the phone over - with their permission - once you have made the first contact. After the call, let them tell you how it went, how they feel, and if they found it helpful. Be prepared for them not to know. Follow this up with them later in the week or the next week, so you know what is happening and they know that you are concerned.

Many of these suggestions may be impractical for you as a colleague or employer, but some may be helpful for your situation.

Whatever the situation or problem, a point will come when asking “why?” or “how?” is less helpful than saying “OK, this is what happened - nothing can change that now - and this is how things are at present. So, what am I going to do about it?” History is important, but, in the end, what really matters is how we respond to our experiences and whether we grow through them or allow them to destroy us.

FROM A CARER TO A SUFFERER

Am I a carer, or a sufferer
who really knows
no-one can tell me
where the dividing line goes
I'm a carer, yet I suffer
though I suffer in silence
I'm here to help you
and give you some guidance.

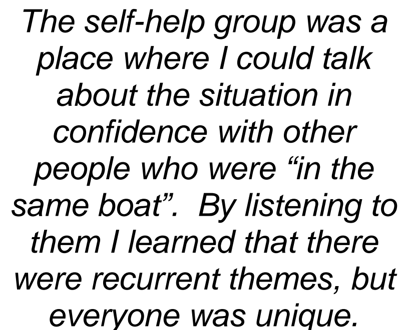
I try to encourage
and give you some praise
I try to support you
in all kinds of ways
sometimes I can't help you
when you're falling apart
to see you like that
it just breaks my heart.

when I look at your body
you're so painfully thin
I just feel like crying
but I keep it all in
I've got to be strong
got to be there for you
I know that you need me
to help you pull through.

There's a long road ahead
yes a long way to go
let's both get it right
let's both take it slow
I know that you're trying
You're doing your best
one step at a time
And then take a rest.

One thing I must say
that I must ask of you
please don't forget
that I'm just human too!

Dean



“SMILE, THOUGH YOUR HEART IS BREAKING”

The smile is stapled to her face
It’s a damned hard act to beat
You wouldn’t believe the agony
If you met her in the street
But in closeted terror
Of solitary “sin”
Doubled-up horror
Of vomit and spit
Laxative luxury
Dried from within
Passion for purity
Can’t face the shit
It’s so easy for you
To purge all your guilt
Whilst I listen in fear
Buried deep in my quilt
It must end…
Soon!
And what if it does not?
Will all my prayers and care
Anger and sadness
Hope and hate
Be wasted?
If you are on the cross
I am surely crying beneath it
I cannot remove the nails
Just love you whatever
And watch this space.
SF

The Self-Help Group has been my lifeline as a carer. The love, friendship, support and knowledge gained from the group have been invaluable. My daughter has acknowledged that since attending the group “You understand me, and the illness, so much better.” And I do.

"Speaking to people who had recovered gave me, and my daughter, hope for the future, and meeting people in a worse situation helped to put our trials into perspective. Realising that you are not alone helps take some of the weight off your shoulders."

Norfolk EDA Publications

- **1: Anorexia & Bulimia nervosa, Compulsive or Binge Eating. Disorder & the Grey Area**
  Also includes Norfolk statistics and influence of the media.
- **2: Strategies for Recovery**
  This is intended for people who want to work to control or overcome their eating disorder, but need some help or support at hand. May also be helpful for carers.
- **3: Help for Carers**
  Especially for families, friends, colleagues and employers of people with eating disorders, offering practical help and support.
- **4: Men and Eating Disorders**
  So much information is aimed specifically at women, men often feel it is irrelevant to them. This begins to redress the balance.
- **5: Eating Disorders and Pregnancy**
  Issues around fertility and pregnancy are often problem areas for women with eating disorders. This booklet looks at some of these issues.
- **6: Eating Disorders - Information for Young People**
  Adapted from our original schools hand-out, this is aimed at young people over the age of 16 years.
- **Supported Self-help Group Programme**
  Available quarterly.
- **General Information Leaflet**
  About Norfolk EDA services: group meetings, 1:1 appointments, outreach services and counselling

To request copies of our booklets contact 01603-665974 (admin)

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HELPLINE
01603 767062

Disclaimer
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