



talking about eating disorders



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This booklet reflects many discussions, suggestions and comments made by health professionals, professional bodies, lay and voluntary organisations, people with eating disorders and their friends and family.

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All the quotes in this booklet are from real people.

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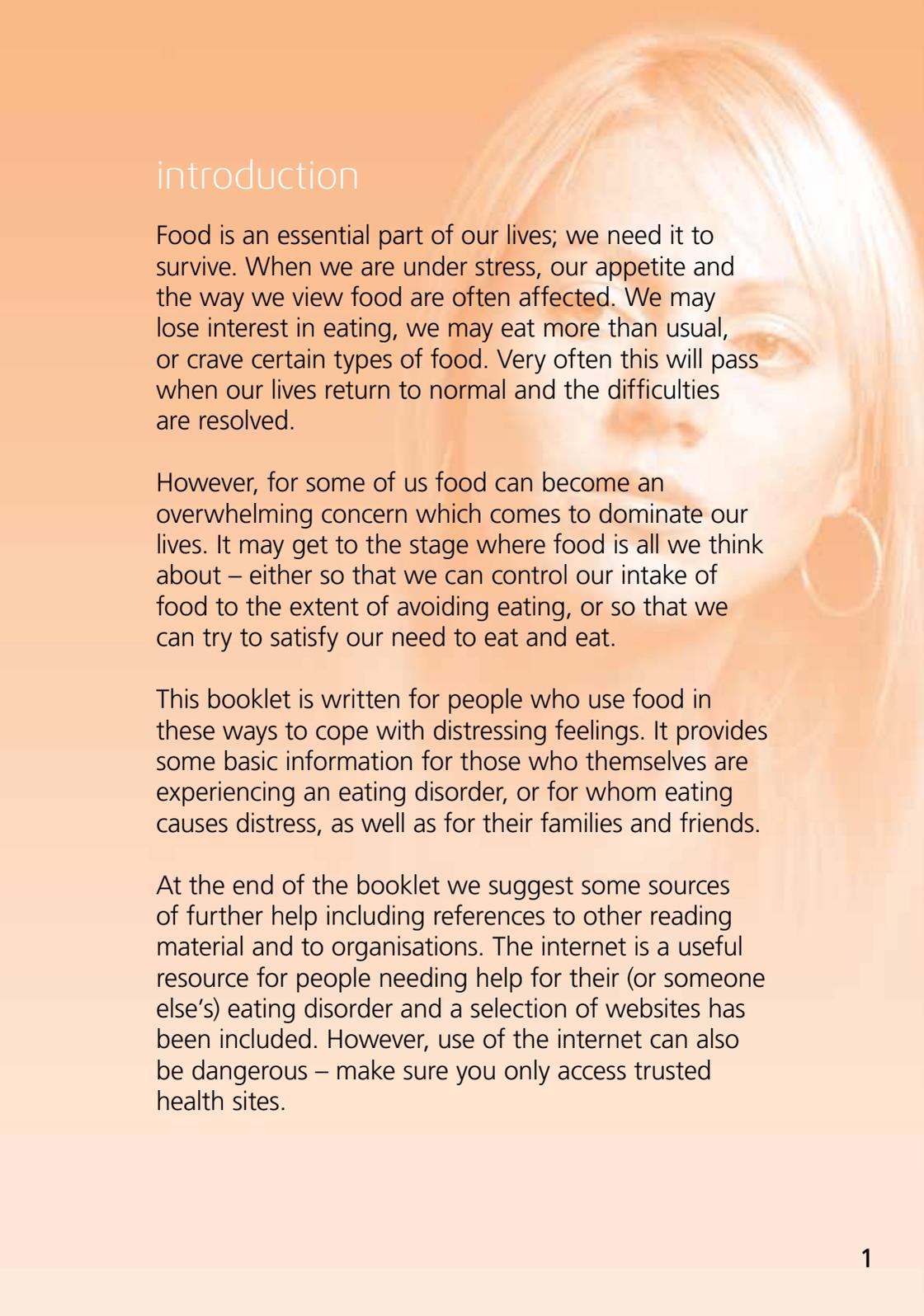
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introduction

Food is an essential part of our lives; we need it to survive. When we are under stress, our appetite and the way we view food are often affected. We may lose interest in eating, we may eat more than usual, or crave certain types of food. Very often this will pass when our lives return to normal and the difficulties are resolved.

However, for some of us food can become an overwhelming concern which comes to dominate our lives. It may get to the stage where food is all we think about – either so that we can control our intake of food to the extent of avoiding eating, or so that we can try to satisfy our need to eat and eat.

This booklet is written for people who use food in these ways to cope with distressing feelings. It provides some basic information for those who themselves are experiencing an eating disorder, or for whom eating causes distress, as well as for their families and friends.

At the end of the booklet we suggest some sources of further help including references to other reading material and to organisations. The internet is a useful resource for people needing help for their (or someone else's) eating disorder and a selection of websites has been included. However, use of the internet can also be dangerous – make sure you only access trusted health sites.

what are eating disorders?

A preoccupation with food can conceal all sorts of confused and painful feelings. It may seem to be the only way we can cope with stress or uncertainty in our lives. It may seem to be the only way we can express the turmoil and confusion inside us.

It is very common for people – especially women – to be unhappy about their weight and shape. We are constantly being urged by advertising and by the media to believe that ‘slim’ means ‘beautiful’ and ‘fat’ equals ‘unattractive and undesirable’. We are given more and more advice about the types of food that are good for us.

‘I had just left university, had no job and felt as if I was adrift on the ocean. I felt helpless, frightened.

The only thing I could control was my own body and what it consumed. That became more and more important. It was the only thing that made me feel safe.’

Not surprisingly, many of us are becoming increasingly aware of our appearance and of what we eat. In an effort to lose weight, which we are told will improve our looks, we may adjust how much we eat and what we eat. This can make us very dissatisfied with ourselves but it does not usually stop us getting on with our everyday lives. However, those of us who have eating disorders find that our lives revolve around food in terms of planning what to eat and how to avoid eating, or how to rid ourselves of what we have eaten.

But while this way of behaving may help us get by for a time, it only creates further distress. Not only can we do real harm to our bodies, we may also be plagued by feelings of anxiety or guilt about our eating.

Both men and women are affected by eating disorders, although women far outnumber men. Each person's experience will be unique, but all eating disorders can have serious effects on our bodies as our weight drops, rises or fluctuates:

'I really hate myself for what I'm doing. I binge and binge and then starve for days to compensate, but I don't know how to get out of it. It has become a way of life.'

- We may find our usual sleep pattern is disturbed.
- We may feel very depressed or lethargic.
- After many years our bodies can become damaged. We may have to live with a weak heart or kidney. However, if treated early our bodies can fully recover.
- Women may have problems conceiving because the menstrual cycle is disturbed.
- We increase our chance of osteoporosis in later life. Osteoporosis means that our bones become brittle and more likely to break.
- With one type of eating disorder: anorexia nervosa, we are likely to be extremely sensitive to cold.

'It's like you're holding two conflicting things in your head at once. You want to get better, put on weight. You know you have to and at the same time you'd do anything to avoid the next meal, the next bit of food you put in your mouth.'

We gradually become more and more fixed in our attitudes to food and more rigid about following the eating routines we have started. It grows increasingly difficult to break out of these patterns. For much of the time we may not even want to, because living our lives in any other way seems unimaginable.

There are three main forms of eating disorder – anorexia nervosa, bulimia nervosa and overeating or binge eating.

People with eating disorders often have other issues like depression or anxiety (see *Talking about Depression* or *Talking about Anxiety*).

anorexia nervosa

Anorexia nervosa is most common among young women on the verge of adulthood, but can also affect people in other age groups. An older person who has successfully managed an eating disorder may find a major life change causes it to start again. However it is unusual for someone to develop an eating disorder for the first time in later life. Anorexics are often thought of as only being female. This is misleading. Boys and men can also be anorexic and the numbers are increasing. We should also not be misled into viewing anorexia as an excessive form of slimming. It is much more than that.

In our teenage years it can feel as if life is very challenging and very uncertain. It may feel as if we are going to be overwhelmed by new demands and expectations on different levels:

- Intellectual, as we make decisions about our future.
- Emotional, as we establish our independence from our families.
- Sexual, as we explore our physical needs in close relationships.

Making sense of what is going on, and making choices for ourselves is not easy. Yet one area where we can assert control is over what we eat. It can give us a great sense of satisfaction to push our bodies to the limit and survive on less and less nourishment. We may deeply resent other people's concern about how little we eat, and resist their efforts to get us to eat more.

Gradually the way we see ourselves becomes distorted. Others tell us we are painfully, even dangerously, thin yet the slightest gain in weight throws us into a panic and makes us feel bloated and fat.

'I became really deceitful – an expert liar: I'd say I'd just eaten, or had a bug. I'd stay at home rather than face going somewhere if I knew there'd be food.'

People with anorexia nervosa:

- Weigh less than would be expected (a body mass index of 17.5 or less is common) and keep their weight down by avoiding 'fattening' foods as well as getting rid of food by vomiting, using laxatives, exercising or simply not eating.
- Skip meals, avoid certain foods and refuse to eat with others. Offer to cook dishes for friends and family to hide the fact they are not eating.
- Have cold hands and feet, feel faint and suffer from hair loss.
- Refuse to believe that they aren't overweight and may dress in baggy clothes.
- Dread being 'fat' to the point where their main aim in life is to control their weight.

bulimia nervosa

Bulimia nervosa is less obvious than anorexia nervosa in that other people would not necessarily know someone was affected from their appearance alone. Indeed we may seem to be coping well with life, and look happy and confident when really we may feel very different. We may feel very unsure of ourselves, and frightened of not achieving what's expected of us. We may desperately want reassurance and acceptance.

People with bulimia nervosa:

- Have a persistent preoccupation with eating, and an irresistible craving for food. Someone who has bulimia nervosa will have repeated bouts of overeating, secretly consuming huge amounts of food in a very short time.
- Try to offset the 'fattening' effects of food by making themselves vomit, purging and starving themselves, and using drugs to suppress their appetites.
- Set themselves a desired weight that is well below what is considered to be healthy because they dread being fat.
- Are commonly found to have had anorexia nervosa at an earlier time.

For people with bulimia nervosa, eating may seem like the only way to satisfy needs and calm uncertainties. We may find ourselves eating huge amounts of food and then, because of the guilt and disgust we feel, dispose of it by vomiting or using laxatives. It is like a trap, not knowing how to cope and at the same time feeling ashamed and revolted at how our lives are evolving. Withdrawal from other people and increasing isolation seems to confirm the lack of congeniality and attractiveness.

binge eating disorder

Some of us may find it hard to regulate what we eat, particularly if we are upset or distressed. Two per cent of adult women are affected to some extent by binge eating. Eating large amounts even when we do not feel hungry appears to help block out disturbing feelings.

'After I split up with my boyfriend – it was the evenings that were the worst. I'd feel so empty and lonely. I'd just start off with one small snack, and then I'd keep on and on, eating anything at all.'

Such a 'binge' is often followed by a determination to eat more carefully, and periods of cutting down on food intake to compensate for past excesses.

Binge eating disorder is similar to bulimia nervosa but it does not involve vomiting or taking laxatives and other drugs to prevent weight gain. People with a binge eating disorder are often overweight.

understanding eating disorders

There are various possible factors that may contribute to the development of an eating disorder and the way in which these factors combine will be different for each individual. Different reasons may operate at different stages of the development of the disorder: something that may act as an initial trigger may be less important later on while other factors may come in to play as the disorder begins to take hold. We may be prone to an eating disorder because of our family history or we may be responding in later years to something unpleasant that happened in childhood.

Many of the physical, psychological and social changes that happen because of eating disorders, such as malnourishment or feelings of worthlessness, can themselves become factors which then further reinforce the eating disorder, creating a vicious circle where it becomes difficult to separate out cause and effect.

It may also occur at a time when we are uncertain of how to cope with major changes. We may face important decisions about what to do next as one chapter of our lives comes to an end. We may then turn to food to console ourselves, or to deny ourselves so that we feel safe and in control at last.

Society's preoccupation with looking slim may be another factor. The assumption that we should all aim to look like the willowy models on the fashion pages can put severe pressure on us to conform so that we are acceptable and accepted.

There are other sorts of expectations, which may make us very uneasy. Perhaps we feel pushed into achieving, into living up to other people's standards. Sometimes achievement can appear all-important, so we may push ourselves harder and harder because we do not know how else to define ourselves as individuals.

Women may feel obliged to fit in with the roles society expects of them, yet with all the different images to live up to – the sex object, the mother and wife, the career woman – it is difficult for them to define their roles, to acknowledge their own needs and to recognise what they really want.

Relationships that are important to us can sometimes cause us distress. In some families, young people may find it hard to assert their own individuality as they grow up. Food may become part of their way of trying to claim their independence. In families that tend to be protective of one another this can lead to growing anxiety making it more difficult for young people to lead a separate life as a grown up. In other situations when young people have been badly treated or abused, they may see themselves as worthless. We may find comfort in controlling our eating when everything else in our lives is out of control.

For men it can be difficult to come forward and seek help for an eating disorder. It is still considered by some to be a 'woman's disease' although the reasons men develop a disorder tend to be no different from the reasons women or children do. The signs of a disorder may vary between the sexes making it harder for friends or family to suggest to men that they seek help.

Whatever the reason for it, the fear of not being able to cope and of being overwhelmed is something experienced by many people who develop an eating disorder. We feel so unsure of ourselves, so powerless and unable to express what we want in other ways that we become totally pre-occupied with food and eating. This is more than just seeking comfort. It is an attempt to escape or to control our deepest insecurities. Yet it is a false solution since we become more trapped than ever.

what you can do

Overcoming eating disorders generally starts with helping ourselves, and if we have some guidance and support with a self-help programme, it will enhance our chances of success. There are many self-help groups around, and many good self-help books and computer based self-help programmes.

But we may feel that what we can do on our own is not enough, that it is too hard to be open about our fears and anxieties and take up help from people we do not yet know or trust. But we may find on the other hand that it can also be an enormous relief to accept help.

There are various sources of support available, and a good starting point might be an organisation called 'beat'. Details can be found for this and other organisations at the end of the booklet.

We can do a lot to help ourselves. Even if we feel very uncertain about wanting to change things, we can take some small first steps. It is likely to be a long slow process, so it is important not to expect too much of ourselves. What works for each of us may be different, but these are some things that may help:

- Join a self-help group and read self-help books about eating disorders.
- Find ways of 'spoiling' yourself (apart from with food). Do things you enjoy, or used to enjoy but perhaps have not been able to do for a while.

- Focus your energy into different channels. Find things you are good at, and that give you satisfaction.
- Try to make sure you get a chance to do what you want, not just what other people want, at least some of the time.
- Try not to become over-concerned about reaching a target weight. You are making good progress if you are getting to the point of liking yourself and being more at ease with yourself.

‘Some people use drink or cigarettes when things get rough. With me, it’s my eating which goes haywire. I find it really hard to eat for days on end if I’m stressed, but I now know that won’t last.’

Inevitably there will be ups and downs. In times of crisis, you may find you go back to the ‘old ways’ but this is usually just a phase that will pass.

As our lives become less and less focused on ourselves and what we eat, we may be pleasantly surprised to find how much scope there is to spend our time in more fulfilling ways.

getting help from others

‘It was a huge relief in the end, when someone else stepped in and helped me. I knew I couldn’t go on as I was.’

Accepting there is something wrong and that we need help can be extremely difficult. We may have struggled so hard for a long time to cope by ourselves that offers of help can be very threatening. The more

concerned those close to us are, the more they may pressurise us into accepting help. It can feel like we are being backed into a corner. There are situations where an eating disorder becomes life-threatening, and action may have to be taken to preserve someone's life even without their consent. However, it is important that we find help that suits our own particular needs, when we are ready.

'I felt terrible, life was dreadful. The pain and hunger were overwhelming. I felt very frightened. I realised I could die... I knew I needed help. Someone to trust, someone who could understand what I was feeling.'

There are different sources of support available, each offering different kinds of help. It is worth contacting the organisations listed later in this booklet to find out what is available in your area.

counselling and psychotherapy

People sometimes find it hard to talk about their difficulties but it is important to seek help and support. Counselling and psychotherapy give people the chance to talk through problems. Both focus on present day feelings and difficulties, which may be current or rooted in the past, and enable us to take more control of our life and to cope in the longer term. It helps to know we have someone we can trust, who will listen to us, and be a contact with the world. But making real changes sometimes requires more than counselling. It is important to find a counsellor or therapist you can relate to, and trust. For those of us with an eating disorder, the pre-occupation with food can be

a way of dealing with emotions that we cannot otherwise show or express. If we are able to find a counsellor or therapist we trust enough to confide in, this can provide a great release and enable us to begin resolving some of our concerns.

‘Without one-to-one counselling, I would not have got through it. It may not be right for everyone, but for me it was invaluable.’

‘Some other people at the hospital had little time for me and they had no sympathy, as they saw my problems as self-inflicted. My counsellor was not at all like that.’

Treatment for eating disorders is usually offered on an outpatient basis and is likely to be a particular form of therapy. It may be cognitive behavioural therapy, for example, which research has shown to be most effective for people with bulimia nervosa. The duration of treatment can vary greatly depending on the needs of the person being treated, but often 16 to 20 sessions on a weekly basis over four to five months would be enough to produce significant change in many people with bulimia nervosa. Some people with bulimia nervosa and most people with anorexia nervosa require longer-term treatment.

In some cases, group therapy may be offered, and family therapy is often provided for younger people with anorexia nervosa. Sometimes reluctance to involve other family members is due to the young person feeling that they have already caused too much trouble and distress and perhaps an uncertainty that family members can/will really help. Involving family members in treatment is not about pointing a finger of blame but about mobilising family

resources even when family members themselves may feel helpless and unsure about what they can do. The extent to which the families of older people may be involved in the therapy is likely to depend on the willingness of the person to involve his or her family.

In some of the more remote parts of Scotland where access to therapy is a problem, it can be offered via videoconferencing.

self-help

Meeting other people who have been through similar difficulties can be very valuable. It is all too easy to become isolated and to feel we are the only ones who feel and behave as we do. Being part of a group provides an opportunity to share experiences, to be understood and accepted without blame or guilt.

With self-help groups like the beat Self Help Network, we can find support in ways that suit us best. It may be that we prefer to attend a group, or phone and write to others in the local area. For some of us, the relative anonymity of email may prove more helpful in letting us talk about how we feel.

medical treatment

In seeking professional help, the first port of call is usually a family doctor, who has an important role in making an initial assessment and may refer you for specialist help.

There are many types of help available with more services planned across the country to add to those already in place. In some parts of the country, specialist help is provided by mainstream services involving psychiatrists, psychologists, nurses and others. In some areas, there are specialist teams designed to respond to eating disorder needs.

If the situation is serious it may be necessary to go into hospital for assessment and treatment. There are independent providers in Scotland that offer a range of inpatient treatments. Some people may be expected to follow a care plan agreed by all involved to help bring about a change and improvement. Others might be referred for counselling and group therapy designed to help them take control of their condition.

In some cases medication may be offered to treat some symptoms, although in many cases these can be resolved without using drug therapies. No medications other than antidepressants are recommended for the treatment of bulimia. Medication can also be used to help with some of the physical side effects, e.g. vitamin and mineral supplements are commonly prescribed. In every case the care plan should be explained and agreed and may include explanations that medication is not usually the only option but in most cases will be combined with other care and support options.

the role of partners, family and friends

As a partner, friend or relative you can do a lot to help someone who is experiencing an eating disorder, although at first you may have difficulty believing that the person you care about will ever get through this, or that there is a way forward. It is important to try to encourage the person to seek help as soon as possible, to be supportive when they accept that they will benefit from treatment, to be patient and non-judgemental, and understand from the outset that the speed of recovery is different for different people. Treatment for eating disorders, like most treatments, is a gradual step-by-step process.

Your concern for their health may make you want to urge them to seek help and to rush changes in their eating, but that can often makes things worse, leaving everyone feeling depressed, and exhausted from the endless confrontation. It may result in those experiencing the eating disorder feeling even worse about themselves and becoming even more resistant to help.

Difficult though it may be, let them know you stand by them, even when they feel unable to confide in you. They may feel guilty about the distress and pain they are causing you. If you can learn to accept that their behaviour is a way for them to cope with their lives, and allow them to make their own decisions, they may be more likely to let you help them. Above all, try to show unconditional love and support.

Try to encourage them to talk more freely about what is distressing them and causes them to react in this way, and learn to be a good listener. What you say and when you say it is important. Prepare what you are going to say and choose a time when you can talk calmly and without interruption. Try to be open and honest about your own feelings without getting angry. Let them know you have noticed changes in their behaviour that concern you, and that you want to help in any way you can.

Once they acknowledge that they need help, you may be able to assist practically, perhaps by encouraging the person experiencing the eating disorder to help plan the menu (making sure the kind of food they might be willing to eat is included) and share the shopping and preparation. Be prepared for the fact that getting better may not follow a straight line, that there will be ups and downs. Encouragement from you to face up to their fears may be accepted one day and angrily rejected another. Try to avoid getting into an argument and wait for a time when you can calmly discuss what happened and find a way of moving forward again.

You could also find out about local support groups or other resources in your area. The person may be feeling very vulnerable and threatened at this stage, so reassure them as much as possible and allow them some breathing space, and to make their own choices. Encourage them to take up new interests and do things with them so that their self-esteem is improved and the focus is shifted away from food.

your needs

Watching someone close to you act in ways which harm them and disrupt the lives of all concerned is a terrible ordeal. You may feel:

- powerless, as your efforts to help are constantly rebuffed
- angry at the pain and worry caused
- guilty, that in some way you have failed the person and contributed to their current difficulties
- frustrated because the person you love will not admit there is a problem.

If you are doing a lot to help out practically, you may feel resentful and become increasingly worn out by the burden of it. If you notice symptoms of depression or find that you are no longer enjoying life as you used to, you may be experiencing symptoms of common mental health problems. If this is the case, please discuss these issues with your doctor or healthcare practitioner who can advise you how best to seek help.

Try not to let your life be dominated entirely by their needs, and try to prevent the eating disorder from splitting the family or friendship. It is important to take care of yourself too. Keep up with your own friends and interests. Make sure you find time to do the things you enjoy. Find an outlet for your feelings, someone you can talk to about your concerns. It might be your doctor, a close friend or another member of a support group for people in situations like your own. After all, if you take care of yourself, you will feel more confident in offering help.

looking ahead

Food and eating play a big part in our lives, not just because we need food to survive but also because it is something we share with people we love. Since we know that eating disorders are not about food but rather about the effect of other things in our lives, we have to try to find other ways of dealing with the distress we feel.

We may need to assert our independence to find out what we really want. We may decide to make a fresh start doing something we choose to do. Whatever route we take, we are unlikely to come out of the experience unchanged. We may even look back on it as an important landmark in our lives that helped us to find out who we are and who we want to be.

Getting over an eating disorder is a big challenge and can take a long time. There is no overnight solution so we can become frustrated, and worry that we will never be free of it. Sometimes we will hit setbacks, when something unexpected or more difficult crops up. But with patience and determination, and the support of those who care about us, we can gradually learn to confront our feelings and deal with them. With courage and a clear plan – a step-by-step approach – the future is promising.

useful addresses

The national organisations listed below can put you in touch with local sources of help in your area.

Breathing Space Scotland

Tel: 0800 83 85 87

www.breathingspacescotland.co.uk

Breathing Space is a free, confidential phonenumber you can call when you are feeling down. Advisers will listen, and try to help prevent problems getting worse, offer advice and suggest local people who can help with specific problems.

Phonenumber opening hours:

Weekday: Mon–Thur 6 pm–2 am

Weekend: Fri 6 pm–Mon 6 am

beat beating eating disorders

103 Prince of Wales Road

Norwich NR1 1DW

beat Helpline: 0845 634 1414

(For people over 18 years of age)

Helpline email: help@b-eat.co.uk

beat Youthline: 0845 634 7650

(Up to and including 18 years of age)

Youthline email: fyp@b-eat.co.uk

www.b-eat.co.uk

NHS24

Headquarters

Caledonia House

Fifty Pitches Road

Cardonald Park

Glasgow G51 4EB

Tel: 08454 24 24 24

www.nhs24.com

NHS24 is a 24-hour health service for Scotland.

Scottish Association for Mental Health

Cumbræ House

15 Carlton House

Glasgow G5 9JP

Tel: 0141 568 7000

Email: enquire@samh.org.uk

www.samh.org.uk

The Scottish Association for Mental Health (SAMH) is a major voluntary organisation in Scotland working to promote mental health.

**Scottish Eating Disorders
Interest Group (SEDIG)**
C/o Diane Whiteoak, Secretary
Huntercombe Edinburgh Hospital
Binny Estate
Ecclesmachan Road
Uphall
West Lothian EH52 6NL
www.sedig.co.uk

see me Scotland
1/3 Great Michael House
14 Links Place
Edinburgh
EH6 7EZ
Tel: 0131 554 0218
Email: info@seemescotland.org
www.seemescotland.co.uk

The 'see me' campaign was launched in October 2002 to challenge stigma and discrimination around mental ill health in Scotland.

suggestions for reading

There are many publications about eating disorders and your GP or local library will be able to suggest some for you. Here are a few that might help.

Anorexia Nervosa: A Guide to Recovery
by Lindsey Hall and Monika Ostroff.
Published by Gurze Books,
paperback, 1998.
ISBN 093-607732-8

Breaking Free from Anorexia Nervosa: A Survival Guide for Families, Friends and Sufferers
by Janet Treasure.
Published by Psychology Press,
1997.
ISBN 086-377760-0

Bulimia: A Guide to Recovery
by Lindsey Hall and Leigh Cohn.
Published by Gurze Books, 1999.
ISBN 093-607731-X

Bulimia Nervosa and Binge Eating: A Guide to Recovery
by Peter Cooper and
Christopher Fairburn.
Published by Constable and
Robinson, 1993.
ISBN 185-487171-4

**Getting Better Bit(e) by Bit(e):
Survival Kit for Sufferers of
Bulimia Nervosa and Binge
Eating Disorders**

by Ulrike Schmidt, Janet Treasure
and Tom Treasure.

Published by Psychology Press,
1998.

ISBN 086-377322-2

Overcoming Anorexia Nervosa

by Christopher Freeman and
Peter Cooper.

Published by Constable and
Robinson, 2002.

ISBN 185-487969-3

Overcoming Binge Eating

by Christopher Fairburn.

Published by the Guilford Press,
1995.

ISBN 089-862179-8

recent advances

National Institute for Clinical
Excellence (NICE) guidelines for
eating disorders

[www.nice.org.uk/page.
aspx?o=101239](http://www.nice.org.uk/page.aspx?o=101239)

Or call the NHS response line:
08701 555 4555.

Other topics covered by the *Talking about...* series are:

- Anxiety
- Attention deficit hyperactivity disorder (ADHD)
- Bereavement
- Bipolar affective disorders
- Depression
- Panic attacks
- Personality disorders
- Phobias
- Postnatal depression
- Schizophrenia
- Self-harm
- Stress

Contact your local health promotion resource service for copies. You can access their details via www.show.nhs.uk

Disclaimer

Every effort has been made to ensure that this publication is as up-to-date and accurate as possible. However, new research can sometimes mean that information and recommendations change very quickly. Changes and alterations will be made at the next reprint to reflect any new information.

While the booklet represents the consensus of good practice, please remember that different circumstances and clinical judgement may mean that you have slightly different experiences.

If you have any doubts, worries or fears, then do not hesitate to contact your doctor for reassurance and further explanations.

