

Yorkshire Centre for Eating Disorders (YCED)

An Information Pack for Carers 2016

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Introduction

The Yorkshire Centre for Eating Disorders (YCED) is part of the Leeds and York Partnership NHS Foundation Trust (LYPFT) and falls within the Specialist care Services. We aim to provide evidence-based treatments for eating difficulties. Treatments may be inpatient, outpatient and Leeds residents may be offered a community based service. The inpatient ward is a 19 bedded unit situated in the Newsam Centre, Seacroft Hospital. Structural changes have been made to the inpatient environment to include two bedded male service user area, in line with the requirements of mixed sex provision. LYPFT is a teaching hospital and provides clinical education and training to future and current doctors, nurses, occupational therapists, dietitians and psychologists.

The aim of this booklet is to provide you with information about eating disorders, how to support your loved one with an eating disorder, general practices on ward 6 and useful resources.

Becoming a Carer

Becoming a carer for a family member with an eating disorder is very difficult, challenges your attitude to mental health conditions and above all, will test your love and patience for someone dear to you.

It happened to us almost overnight, when our loved one who had been living and working in another part of the UK, suddenly asked if she could come home to live and by the time she arrived three weeks later was seriously ill. It was only six months since we had seen her but now she was thin, her skin was grey, her hair falling out and she would only eat tiny amounts of fruit or vegetables; we had entered the 'unknown' and gradually discovered that we were carers!

After six months of wrestling with everything that an eating disorder could throw at us including eating problems, deceit, over and under reaction to minor events at home and a variety of unexpected challenges, our loved one was admitted to the Newsam Centre at the Seacroft Hospital in Leeds. We were unsure what was happening and to test us even more, we met a confidentiality wall of silence because our loved one is over eighteen years old although confidentiality rules are different for under eighteens.

Gradually, from books, online searching and a carers' workshop we began to understand why some things happened and more importantly, how to react. Our loved one received fantastic treatment from the Newsam Centre and was eventually discharged after seven months with a safe BMI and vitally, the knowledge of how to maintain it.

From our experience, there are three main things to be ready for when you become a carer of an adult with an eating disorder. First, expect the unexpected; remember it is a mental health illness not a fad! Second, be prepared to quiz the professionals

caring for your loved one until you understand what is happening. Finally, never give up, lose hope or doubt that a recovery is possible!

What are eating disorders?

Eating disorders are serious and often fatal illnesses that affect all aspects of a person's life. Common eating disorders include Anorexia Nervosa, Bulimia Nervosa and Binge Eating Disorder.

Table 1 – Types of eating disorders

Types	Characteristics	Aims of treatment
Anorexia nervosa	<p>Extreme weight loss – BMI less than 18.5.</p> <p>Intense fear of weight gain or becoming fat.</p> <p>Self-evaluation is excessively influenced by body shape and weight.</p> <p>Binge eating and purging behaviours may be present.</p>	<p>To restore the person to a healthy weight</p> <p>To treat the psychological issues related to ED</p> <p>To reduce/eliminate behaviours or thoughts that lead to insufficient eating – eg dietary rules</p> <p>To reduce or eliminate binge eating and purging behaviours</p> <p>To gain greater understanding of nutrition and use this to help change behaviour</p> <p>Relapse prevention</p>
Bulimia nervosa	<p>Bulimia is when a person goes through cycles of bingeing and purging.</p> <p>Bingeing is eating a lot of food in a short amount of time. Purging is when an individual tries to get rid of the food by vomiting, using laxatives, or excessive exercise.</p> <p>The person may be normal weight or overweight.</p> <p>Self-evaluation is excessively influenced by body shape and weight.</p>	<p>To reduce or eliminate binge eating and purging behaviours</p> <p>To treat psychological issues related to ED</p> <p>To reduce or eliminate maintaining factors eg dieting</p> <p>To reduce or eliminate binge eating</p> <p>To gain greater understanding of nutrition and use this to help change behaviour</p> <p>Relapse prevention</p>
Binge eating disorder	<p>Binge eaters feel out of control.</p> <p>They binge on food – eat a lot of food in a short amount of time.</p> <p>Binge eater's weight may constantly</p>	<p>To reduce or eliminate binge eating</p> <p>To explore and treat underlying psychological factors</p>

	change, and they may only eat in private. Eat large amounts of food when not feeling physically hungry. Feel disgusted, depressed, or very guilty after overeating.	To gain greater understanding of nutrition and use this to help change behaviour Relapse prevention
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In some cases, people with eating disorders, especially anorexia nervosa, are admitted to hospital. In these situations, your loved one may:

- be highly anxious
- be fearful of change in their routine
- be terrified to be in a position where they feel they have no control over eating and drinking
- feel and see themselves as “too fat”, even if they are emaciated
- have an intense fear of gaining weight
- intense fear of food
- have a history of excessive exercise even when medically unstable
- have a history of vomiting and/or abusing laxatives, though this is not always the case
- be likely to have restricted their food and fluid intake to a level resulting in chronic weight loss and leading to a high level of medical instability and risk
- be in denial of their illness despite the fact it has led to a medical emergency

It is helpful to remember that people with eating disorders not only suffer from a serious and chronic psychiatric disorder but also will be suffering from psychological problems secondary to starvation. These may present in different levels – please see the following Table:

Table 2 – symptoms of eating disorders

Physical changes	<p>Extreme weight loss or frequent weight changes. Lowering of minerals in the blood e.g. magnesium, calcium, phosphate, potassium Low blood sugar. Sore throat, tooth decay and bad breath caused by excessive vomiting. Swollen salivary glands making the face rounder. Constipation and abdominal pains. Anaemia. Muscle weakness. Irritable bowel syndrome. Bloating stomach, puffy face and ankles. Poor blood circulation and feeling cold. Poor skin condition and possible hair loss. Loss of ‘periods’, loss of interest in sex. Loss of bone mass and eventually osteoporosis (brittle bones).</p>
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	<p>Lethargy and tiredness.</p> <p>Malnutrition - caused by under eating or overeating.</p> <p>Dehydration - caused by lack of intake of fluids.</p> <p>Symptoms include dizziness, weakness, or darkening of urine. It can lead to kidney failure, heart failure, seizures, brain damage and death.</p> <p>Oedema - swelling of the soft tissues as a result of excess water build up.</p>
Psychological changes	<p>An obsession with food, or feeling 'out of control' around food.</p> <p>Distorted perception of body weight and shape.</p> <p>Low self-esteem, shame and guilt.</p> <p>Lowering of mood/depression.</p> <p>Mood swings (elation to low periods).</p> <p>Irritability, frequent outbursts of anger.</p> <p>Increased anxiety.</p> <p>Neglect of personal hygiene.</p> <p>Severe emotional distress.</p> <p>Isolation - feeling helpless and lonely.</p> <p>Avoiding social situations.</p> <p>Decrease in sexual interest.</p> <p>Disturbed sleep pattern.</p> <p>Poor concentration.</p> <p>Impaired judgement.</p> <p>Body image distortion.</p>
Behavioural changes associates to food	<p>cutting food into tiny parts</p> <p>smearing food on the plate to get rid of calories</p> <p>hiding food</p> <p>dropping food on the floor or bed to avoid eating it</p> <p>spending long periods of time over eating</p> <p>fear of "calorific" foods, butter, foods that are not low fat</p> <p>untrusting of others preparing food</p> <p>difficulty eating in front of others</p>
Social changes	<p>social isolation</p> <p>disengagement with friends</p> <p>emotionally detached from others</p> <p>hostility towards others</p> <p>social anxiety</p>

This is not an exhaustive list, rather an indication of the types of difficulties people with eating disorders may face.

More information on eating disorders is available from the following websites:

-  www.b-eat.co.uk
-  All about anorexia nervosa - Mental Health Foundation
-  Anorexia nervosa & Bulimia nervosa - Royal College of Psychiatrists
-  Understanding eating disorders - Mind

How you can support?

Supporting a loved one with an eating disorder can often be anxiety provoking for a carer. It may be that you are worried about what to say in case you make things worse or that when you have tried to support them in the past it has led to disagreements. A good starting point may be to ask them **how they would like to be supported**. It may be helpful to have a meeting with a member of staff and they may be able to offer suggestions of what may and may not help. If an informal family meeting is suggested it may be an ideal opportunity to start discussions about what support can be offered. Any meeting however will need to be with the consent of your loved one.

In the absence of their consent it may still be helpful to have a discussion with a member of staff who may be able to talk to you generally about supporting individuals with an eating disorder.

Home leave can be particularly stressful for both you and your loved one. Again we would encourage you to meet with staff to talk through your concerns and perhaps identify practical and emotional ways to support your loved one whilst they are on leave. if at any point during the leave period you have any concern you can contact ward 6 and speak to a member of the nursing team.

A number of carers have expressed concern about what their loved ones diet should be whilst at home and how much they should be eating. Ultimately it is the responsibility of your loved one to discuss their diet with you. We will encourage your loved one to share their menu plan with you so you are aware of what diet they have agreed to eat whilst at home. Prior to their leave we can try and involve carers in the practical aspect of portioning meals.

For further information on how best to support you loved one, please see 'Toolkit for carers' by Janet Treasure. <https://issuu.com/instituteofpsychiatry/docs/toolkit-for-carers-feb3-09>

Home leave is discouraged during the initial two week assessment period. Subsequent to this, leave can be negotiated with the MDT. If your loved one requires intensive care interventions, then leave will not be negotiated due to your level of risk.

Information about the unit and the programmes

Our philosophy

We aim to provide treatments recommended by the National Institute for Clinical Excellence (NICE)¹ Guidelines on Eating Disorders to facilitate change in individuals with eating difficulties. We provide a multi-disciplinary approach to care, which allows the service users to develop and achieve personal growth. We believe that the quality of care that is given is dependent on the collective commitment and expertise of the team. Clinical practice is based on collaborative participation by all members of the multi-disciplinary team (MDT) as well as the service users and carers.

The Residential Unit (Ward 6)

The unit treats both males and females living with a variety of eating difficulties. As the unit is a teaching area, medical, nursing, psychology, dietetics and occupational therapy students are periodically on placement and may be involved in the service users' care.

Service users have their own bedroom. Personal items e.g. pictures, laptop, TV, books and plants may be brought in to make the room more comfortable. There is a lockable wardrobe in each room. **The Trust does not take responsibility for loss or damage to personal property.**

In most cases the service users and their carers will be given the option to visit the unit prior to admission. This visit will be facilitated by a member of the nursing team. It provides the opportunity to visit the ward and ask questions.

Legal status

Informal - As an informal patient, the service users have agreed to come into hospital voluntarily. They are not subject to statutory powers and cannot be held on the ward against their will.

We operate an open door policy. This means that the doors are not locked during the day. The unit is locked at night for security purposes. This is not to prevent service users from leaving and they can open the doors by pressing the door release button.

Formal – In some instances, the use of Mental Health Act may be needed. If this is the case, MDT will provide in-depth verbal and written information on what this means to you.

The Multi-Disciplinary Team

The service users will be cared for by a multi-disciplinary team (MDT). The team consists of Psychiatrists, Registered Nurses, Health Support Workers, Dietitians, Occupational Therapists and Psychologists. All members of the team provide practical and psychological interventions. This may be in the form of one to one or group work.

¹ <https://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/eating-disorders>

Family Meetings

During their stay on ward 6 your loved one may be offered a family meeting(s). These can be where members of the inpatient team meet with you to discuss the care and treatment that is being offered. The focus of the meetings will be dependent on the goals of treatment. For example, promoting a shared understanding of the emotional changes your loved one is experiencing and how these changes may impact on the family group. Any such meeting will have to be with the consent of your loved one. Without consent a meeting will not be offered.

If a meeting isn't offered you may wish to speak to a member of staff and this can be arranged. It may be that staff are unable to discuss your loved one's personal care and treatment if they do not have their consent, but they will be able to talk about treatment of individuals with an eating disorder in broader terms. This may help you gain further understanding of eating disorders. If you are uncertain or have any concerns about any aspect of family meetings it would be advisable to speak to a member of staff who will be able to explain more about what to expect.

Every five weeks your loved one will have a review of their treatment by the multi-disciplinary team. It may be that you will be invited to attend the review but these are not family meetings. Invites to attend the five week review will also have to be with the consent of your loved one. Whilst we encourage them to share their decision with you, in some instances, your loved one may not inform you that they have withheld consent.

Blood and other tests

During their admission, your loved one will have a number of physical tests for example:

- a bone scan (once only)
- regular monitoring of blood glucose level (via finger prick testing) in particular during the first 72 hours of admission.
- blood pressure, pulse, and temperature
- ECG, which may need to be repeated at any stage during their admission if there are any concerns about heart function.
- a record of fluid intake and output will be monitored for minimum of 72 hours after admission.

The aim of the above tests is to minimise potential physical health risk. Medical tests and results are discussed at the weekly medical review and will be shared with your loved one by the team.

Care Programme Approach (CPA)

The term CPA describes the approach used in secondary mental health care to assess, plan, review and co-ordinate the range of treatment. This enables the MDT to help your loved one to address their needs. Your loved ones are involved in deciding who they want to invite to their CPA including carers. Your loved one should be involved in a minimum of two CPA meetings during their stay.

Residential programmes

Our Services

The treatment programmes are designed to focus on change in relation to an individual's eating difficulty and also to address the underlying and maintaining factors. Treatments may be on an inpatient, community or outpatient basis.

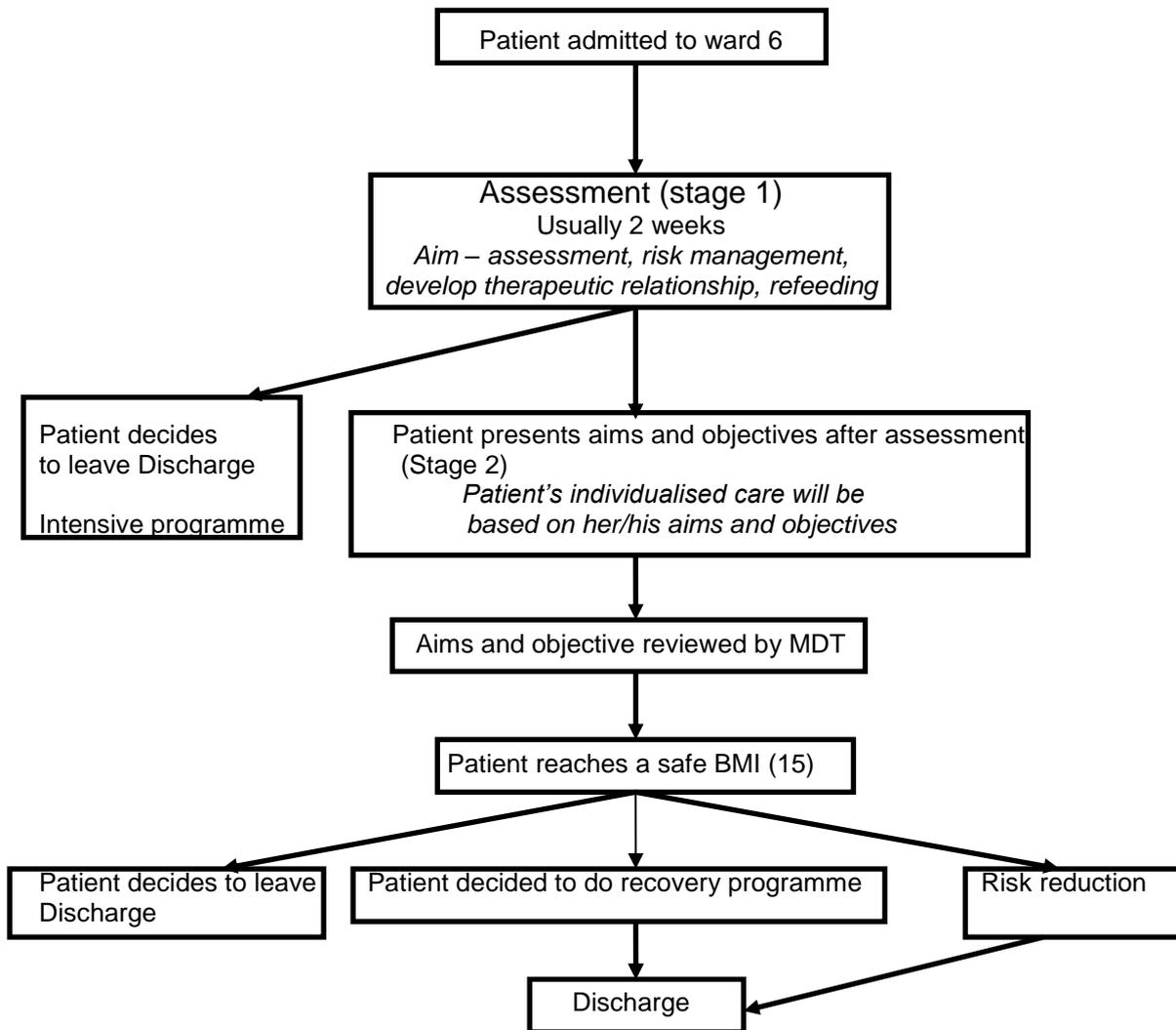
Inpatient Treatment and Programmes

We provide a specialist service delivered by an experienced multi-disciplinary team (dietitian, occupational therapist, psychologist, nurses, health support workers, psychiatrist and administrators). Outlines of the programmes we offer are shown in table 3. Figure 1 shows the inpatient treatment pathway.

Table 3 –Treatment programmes on the inpatient unit

Programme	Description
Intensive Care	This programme is for patients whose weight has dropped to such a level that their life is in danger. We have two beds dedicated for individuals on the intensive care programme; this may include naso-gastric feeding. The programme concentrates on weight restoration to a safe level.
Recovery	The Recovery programme is designed to enable patients to explore and tackle many aspects of their eating difficulties whilst achieving and maintaining a healthy body weight. This programme offers the opportunity for individuals to explore and manage the dietetic, occupational, psychological and emotional changes they have made during weight gain. The average length of stay is between three and four months.
Risk Reduction	This is for patients who have a diagnosis of anorexia nervosa but are not yet able to fully undertake a Recovery programme. This is a short-term programme and it is designed to help patients live with their illness in a safe way. It focuses on helping the individual make the changes that they can both feel in control of and believe that they can then maintain after their discharge. We are happy to discuss with referrers specific short-term packages of care, to dovetail with their own treatments.
Stepped-Approach	This is similar to the recovery programme for those that prefer a staged approach to Recovery. This enables those wanting to recover but who may have long-standing complex needs and issues or are likely to struggle with their ambivalent feelings around the pace of change. With this programme, the individual will have two periods of admission to the residential unit.
Symptom Interruption	We also provide a programme for sufferers of severe bulimia nervosa, which is a relatively short-stay with the intention of breaking the cycle of binge eating and purging.

Figure 1 - Flowchart of inpatient treatment pathway



What happens after residential stay?

Discharge is planned by the MDT in collaboration with your loved one and other people involved in their care. For **Leeds patients only** this planning will include the YCED Community Treatment Service.

- There will be a follow up within 72 hours of discharge by a member of YCED. This may be face to face or telephone contact.
- Outpatient appointments will be provided by YCED or your local services.

Other useful information about the unit

Confidentiality

Any information shared with carers **has** to be with your loved one's consent. Without this we will not be allowed to discuss their direct care and treatment. We will encourage service users to give their consent to you being involved in their treatment but this is not guaranteed.

If we are not given consent to discuss their direct care we will ask your loved one to inform you of this. Whilst this may be the case it doesn't prevent members of the MDT from informing you about the general care and treatment of individuals with an eating disorder. Please ask a member of staff for time to discuss your own needs and any difficulties that you may be experiencing as a result of caring for your loved one. Staff will be able to give advice and guidance in broad terms to support you in trying to resolve any difficulties. Staff will also be able to signpost you to services that can support you in your role as a carer.

NHS Confidentiality Policy

<https://www.england.nhs.uk/wp-content/uploads/2013/06/conf-policy-1.pdf>

Carer needs assessment

You can request an assessment of your needs by contacting Carers Leeds on 0113 3804300 or ask a member of staff on Ward 6 for more information.

Carers Leeds - <http://www.carersleeds.org.uk/>

Evaluation and clinical audit

The team is committed to on-going evaluation of the effectiveness of the service we offer. We use information from the questionnaires we ask your loved one to complete for this purpose. We welcome your feedback about the programme and are committed to changing aspects of treatment and practice, when and where appropriate.

Equal opportunities

The service is available to everyone, irrespective of gender, ethnicity, sexuality, and physical disability.

Children visiting the ward

We acknowledge the importance of children being able to visit family members on the ward. We aim to provide a safe and secure environment. We can be flexible with the visiting time. Please discuss any requirement with a member of MDT. Children must not be left unsupervised. Responsibility for the visit, its appropriateness and relevant supervision arrangements remains the responsibility of the nurse in charge.

Raising a Concern, Compliments, Comments and Complaints

The Trust publish a leaflet which can be found on the ward. Further information can be sought from staff if needed. If you have concerns, comments or complaints, we would aim to resolve them at service level. This would be through the clinical team manager and service manager. However, you can approach any members of the

MDT for advice and support. If resolution cannot be achieved, a formal investigation will be carried out through the Trust's Complaints Department (please see a member of staff for details).

Patient Advice and Liaison Service (PALS)

PALS is a confidential and free service providing information, advice and help to resolve concerns of patients, relatives and carers. Leaflets explaining PALS' roles and contact details are available on the ward.

Spiritual and Pastoral Care

The Spiritual and Pastoral Care team delivers a service to patients, carers and staff across the Trust. They provide a confidential listening, counselling and support service. Please ask staff for their contact details.

Please note a Peace room is available on the ground floor, next to the pharmacy.

Smoking

Our Trust is a smoke free organisation because we care about providing a safe, smoke free environment for all service users, carers, visitors and staff. This means that smoking is not permitted in any Trust buildings, grounds or car parks from 4th April 2016.

Alcohol, illegal substances and verbal and physical violence

Alcohol, illegal substances and verbal and physical violence are not allowed anywhere within the hospital or its grounds.

Visiting times

15:30 – 20:15 weekdays

11:00 – 20:15 weekends and bank holidays

Visitors are requested to avoid meal times and rest periods.

Resources

Groups

The Carers Group currently provides a monthly support group for carers. Helpline No. 0113 206 3334

Links

beat website

https://www.b-at.co.uk/.../Supporting_an_adult_with_an_eating_disorder_original.pdf
https://www.b-eat.co.uk/.../Supporting_a_partner_with_an_eating_disorder

Supporting someone with an eating disorder – NHS Choices.

<http://www.nhs.uk/Livewell/teengirls/Pages/treatmentforeatingdisorders.aspx>

Something fishy website

<http://www.something-fishy.org/helping/whatyoucando.php>

Get self-help –Free CBT Worksheets

<http://www.getselfhelp.co.uk/freedownloads2.htm>

Centre for Clinical Intervention

<http://www.cci.health.wa.gov.au/>

Books

Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method by Janet Treasure book

Eating difficulties

- The Anorexia Workbook: How to Accept Yourself, Heal Your Suffering, and Reclaim Your Life
- Overcoming Anorexia Nervosa
- Anorexia Nervosa: The Wish to Change
- The Anorexia Workbook
- Overcoming Bulimia Workbook: Your Comprehensive, Step-by-Step Guide to Recovery
- Overcoming Bulimia Nervosa
- Getting Better Bit(e) by Bit(e): Survival Kit for Sufferers of Bulimia Nervosa and Binge Eating Disorders
- Overcoming Binge Eating
- The Overcoming bulimia Workbook
- Overcoming Body Image Disturbance: A Programme for People with Eating Disorders
- The Relapse prevention Workbook
- The Body-Image Workbook
- How to cope with bulimia/anorexia-self help
- The art of starvation x2-recovered anorexic shares her experience

Anxiety

- Overcoming Anxiety Self-help Course: A Self-help Practical Manual Using Cognitive Behavioural Techniques
- Overcoming Panic and Agoraphobia Self-help Course (3 Parts): a 3-part Programme Based on Cognitive Behavioural Techniques
- Overcoming Worry
- Overcoming Social Anxiety and Shyness Self-help Course (3 Parts): a 3-part Programme Based on Cognitive Behavioural Techniques
- The Mindfulness and Acceptance Workbook for Anxiety: A Guide to Breaking Free From Anxiety, Phobias, and Worry Using Acceptance and Commitment Therapy
- Overcoming Obsessive Thoughts: How to Gain Control of Your OCD
- Living with fear – understanding anxiety
- Feel the fear, and do it anyway – self help

- Book of calm - relaxing techniques
- Panic attacks - how to manage these
- Relax - helpful ways to relax

Depression

- The Mindful Way Through Depression: Freeing Yourself from Chronic Unhappiness (includes Guided Meditation Practices CD)
- Overcoming Depression : a Self-help Guide Using Cognitive Behavioural Techniques

General

- Overcoming Low Self-Esteem Self-help Course - 3 parts
- Breaking Free Workbook: Practical help for survivors of child sexual abuse: Help for Survivors of Child Sex Abuse Breaking Free: Help for Survivors of Child Sexual Abuse (Insight)
- Overcoming Childhood Trauma
- Mind Over Mood
- The Mental Health Handbook:
- Woulda, Coulda, Shoulda: Overcoming Regrets, Mistakes, and Missed Opportunities
- Managing anger
- Overcoming Anger and Irritability
- Reinventing Your Life: How to Break Free from Negative Life Patterns
- Get Out of Your Mind and into Your Life: The New Acceptance and Commitment Therapy
- Self-esteem – interactive approach to change your life
- Learn to meditate
- Beat the booze
- Cutting x2 - understanding & overcoming self-mutilation
- Learn to sleep well
- Sleep really well
- Dream sharing-dreams explored
- Working with dreams-dreams explained
- Self-help for nerves
- Pain explained