

CONNECT

The West Yorkshire and Harrogate
Adult Eating Disorders Service

The Yorkshire Centre for Eating Disorders

Carers booklet

CONTENTS

1.0 Introduction	3
2.0 Becoming a Carer	3
3.0 Eating Disorders	4
4.0 Services Provided at YCED	6
4.1 Background.....	6
4.2 YCED Leeds Community Treatment and Service (CTS) & Outreach.....	7
4.3 YCED Outpatient Service.....	7
4.4 Inpatient treatment (ward 6, Newsam Centre).....	7
5.0 Supporting a Loved One with an Eating Disorder	13
5.1 General support.....	13
5.2 YCED carers support group.....	13
5.3 Recommended reading and online resources.....	14
6.0 Other Information	16
6.1 Confidentiality.....	16
6.2 Evaluation and clinical audit.....	16
6.3 Equal opportunities.....	16
6.4 Raising a Concern, Compliments, Comments and Complaints.....	16
6.5 Patient Advice and Liaison Service (PALS).....	17
6.6 Smoking.....	17
6.7 Alcohol, illegal substances and verbal and physical violence.....	17
7.0 References	17

1.0 Introduction

The Yorkshire Centre for Eating Disorders (YCED) is a national, award-winning specialist service for adults with eating disorders and is part of Leeds and York Partnership NHS Foundation Trust (LYPFT). YCED began treating individuals with eating disorders in 1978 and was originally known as the Leeds Eating Disorders Team before being modernised in 2005. The service has since rapidly developed into one of the largest eating disorders service in the north of England and is at the forefront of innovative research. Our vision is wedded to recovery from eating disorders and we aim to assist those who use our services to return to a state of health and well-being and promote independence and improved quality of life. Our priority is the people who use our services and we aim to provide a comprehensive and flexible clinical service that will meet and treat the needs of individuals with eating disorders. We believe that quality of care is dependent on the collective commitment and expertise of the team, including service users and carers, and we have a commitment to developing new treatment techniques and to actively pursue research interests.

YCED provides community, outpatient and inpatient treatment for adults (>17 years of age) with eating disorders from Leeds and across the UK. We aim to provide high quality treatments as recommended by the National Institute for Clinical Excellence (NICE) guidelines on eating disorders (NICE, 2017) to facilitate change in individuals with eating disorders. We provide a multi-disciplinary team (MDT) approach to care and treatment which allows individuals to develop and achieve personal growth. YCED won the B-eat 'Service of the Year Award' in 2012 and is accredited by the Royal College of Psychiatrists Quality Network for Eating Disorders (QED) and the Care Quality Commission (CQC).

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 information about YCED and provide information on self-help resources and support groups.

2.0 Becoming a Carer

A case study

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!

3.0 Eating disorders

Eating disorders are serious conditions that affect all aspects of a person's life which can sometimes prove fatal. Common eating disorders include anorexia nervosa, bulimia nervosa, atypical anorexia nervosa and avoidant restrictive intake disorder (ARFID) and a summary of how these conditions are diagnosed are outlined in Table 1 (APA, 2013).

Table 1: DSM-5 criteria for eating disorders (APA, 2013):

Anorexia Nervosa	Bulimia Nervosa
<p>BMI<18.5</p> <p>Restriction of energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health.</p> <p>Intense fear of gaining weight or becoming fat, even though underweight. (This may be exhibited through behaviour or verbalised).</p> <p>Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.</p>	<p>BMI>18.5</p> <p>Recurrent episodes of binge eating characterized by BOTH:</p> <ul style="list-style-type: none"> • Eating in a discrete amount of time (within a 2-hour period) large amounts of food. • Sense of lack of control over eating during an episode. Recurrent inappropriate compensatory behaviour to prevent weight gain (purging). <p>The binge eating and compensatory behaviours both occur, on average, at least once a week for three months.</p> <p>Self-evaluation is unduly influenced by body shape and weight.</p> <p>The disturbance does not occur exclusively during episodes of anorexia nervosa.</p>
Atypical Anorexia Nervosa	Avoidant Restrictive Food Intake Disorder
Some of the criteria for anorexia nervosa	An Eating or Feeding disturbance as

<p>are met. Despite significant weight loss, the individual's weight could be within or above the normal (BMI>18.5).</p>	<p>manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:</p> <ol style="list-style-type: none"> 1. Significant loss of weight (or failure to achieve expected weight gain or faltering growth in children). 2. Significant nutritional deficiency 3. Dependence on enteral feeding or oral nutritional supplements 4. Marked interference with psychosocial functioning <p>The behaviour is not better explained by lack of available food or by an associated culturally sanctioned practice.</p> <p>The behaviour does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way one's body weight or shape is experienced.</p> <p>The eating disturbance is not attributed to a medical condition, or better explained by another mental health disorder. When it does occur in the presence of another condition/disorder, the behaviour exceeds what is usually associated, and warrants additional clinical attention.</p>
---	--

It is helpful to remember that people with eating disorders not only suffer from a serious psychiatric disorder but can also present with an array of physical, psychological and social problems which can impact on their health and overall well-being (see Table 2). Please note that this is not an exhaustive list, rather an indication of the types of difficulties people with eating disorders may face.

Table 2 – symptoms of eating disorders

<p>Physical changes</p>	<p>Extreme weight loss or frequent weight changes Blood electrolyte abnormalities e.g. potassium, magnesium, calcium, phosphate 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 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 osteoporosis (brittle bones) Lethargy and tiredness Malnutrition caused by under eating or overeating Dehydration caused by lack of intake of fluids</p>
--------------------------------	---

	Oedema - swelling of the soft tissues as a result of excess water build up.
Psychological changes	An obsession with food or feeling 'out of control' around food Distorted perception of body weight and shape. Low self-esteem, shame and guilt Lowering of mood Mood swings Irritability, frequent outbursts of anger Increased anxiety Neglect of personal hygiene Severe emotional distress Isolation - feeling helpless and lonely Avoiding social situations Decrease in sexual interest Disturbed sleep pattern Poor concentration Impaired judgement Body image distortion
Behavioural changes associated with food	Cutting food into tiny pieces Smearing food on the plate Hiding food Dropping food on the floor or bed to avoid eating it Spending long periods of time binge eating Fear of "calorific" foods (e.g. dairy, carbs) Not trusting others to prepare food for them Difficulty eating in front of others
Social changes	Social isolation Disengagement with friends Emotionally detached from others Hostility towards others Social anxiety

4.0 Services Provided at the Yorkshire Centre for Eating Disorders

4.1 Background

We aim to provide evidence-based care and treatment for adults with eating disorders in line with the National Institute for Clinical Excellence (NICE) guidelines (2017). We provide a multi-disciplinary (MDT) 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 MDT as well as the service users and carers.

YCED utilises a Care Programme Approach (CPA) system to provide coordinated, holistic and person centred care. The CPA process includes family and carers and your loved one may want to invite you to CPA meetings to ensure that you feel involved in their care but also to address any questions or needs that you may have.

4.2 YCED Leeds Community Treatment and Service (CTS) & Outreach

The YCED Leeds Community Treatment Service (CTS) is a service specifically designed to provide home-based community care for patients registered with a GP within the Leeds catchment area who have moderate to severe anorexia nervosa (BMI<17) or severe bulimia nervosa (daily bulimic behaviours). CTS offers a range of evidence-based treatments based on a recovery model of care in line with NICE (2017) and MARSIPAN (RCPsych, 2014) guidelines with the aim of promoting weight restoration, healthy eating and a reduction in eating disorder related symptoms alongside psychological change and increased quality of life. Moreover, CTS aims to offer a home-based assessment and treatment service and offers an alternative to inpatient treatment thus reducing hospitalisation and promoting earlier and smoother transitions from hospital to community settings. The CTS team is made up of psychiatrists, psychologists, therapists, nurses, dieticians, health support workers and administration staff who work together with service users and carers to provide high quality, evidence-based treatments on both an individual and group basis. Since it was established in 2012, CTS has consistently delivered high quality clinical care whilst demonstrating a reduced need for hospitalisation and promoting earlier intervention in the community.

The YCED Leeds Outreach Service (part of the YCED CTS service) is a community-based service specifically designed for adults with severe and enduring eating disorders (SEED), i.e. illness duration > 5 years, severe symptoms, marked socio-occupational dysfunction. The Outreach Service aims to manage the complex needs of patients with SEED without the need for hospitalisation. The Outreach service has consistently shown that it improves quality of life, reduces the need for hospitalisation (30-40% reduction in number of hospital bed days), promotes collaborative working with other health providers and increases patient and carer satisfaction.

4.3 YCED Outpatient Service

The YCED Outpatient Service is a service which offers outpatient treatment and care for patients registered with a GP outside of the Leeds catchment area who have moderate to severe anorexia nervosa (BMI<17) or severe bulimia nervosa (daily bulimic behaviours). This service offers a range of evidence-based treatments based on a recovery model of care in line with NICE (2017) and MARSIPAN (RCPsych, 2013) guidelines with the aim of promoting weight restoration, healthy eating and a reduction in eating disorder related symptoms alongside psychological change and increased quality of life.

4.4 Inpatient treatment (ward 6, Newsam Centre)

Our 19-bedded inpatient unit, situated on ward 6 at the Newsam Centre (Seacroft Hospital, Leeds), offers a number of different evidence-based treatment programmes (see Table 3) tailored to individual need which have recently been reviewed and modernised in line with NICE (2017) and MARSIPAN (RCPsych, 2014) guidelines. This review process involved input from service users and carers as well as NHS England and local and regional community services ensuring that our inpatient treatment programmes are evidence-based, responsive to feedback and individualised based on service user and carer needs.

Structural changes have been made to the inpatient environment to include a two bedded male service user area, in line with Eliminating Mixed Sex Accommodation (EMSA) and CQC requirements. Our inpatient MDT is made of up psychiatrists, psychologists, nurses, dieticians, dietetic assistants, occupational therapists, health support workers and administration staff who work together with service users and carers to provide high quality, evidence-based treatments on both an individual and group basis. Our inpatient unit is able to provide nasogastric feeding if required and can facilitate admissions for individuals detained under the Mental Health Act. Our inpatient team works closely with community services to ensure that the length of hospital stay is kept to a minimum whilst ensuring that individuals care needs are met and to ensure that the necessary care and support is in place in the community at the point of discharge from the inpatient unit.

Please refer to the YCED inpatient welcome booklet for more information which is available at <https://www.leedsandyorkpft.nhs.uk/our-services/services-list/yorkshire-centre-for-eating-disorders/>.

Table 3. Inpatient treatment programmes

<p>Foundations for recovery</p>	<p>Our ‘foundations for recovery programme’ is specifically designed for individuals with anorexia nervosa who want to build the foundations necessary to recover from their illness and move towards a life without an eating disorder. This programme takes into account individual needs as well as an individual’s views about recovery and supports and guides you in making the necessary changes in your life to ensure that you have the best chance of achieving and maintaining recovery following discharge from the inpatient unit.</p> <p>As part of the ‘foundations for recovery programme’ there will be a focus on weight restoration and stability (BMI 20-25) alongside evidence-based psychological interventions, socio-occupational interventions, carers support and practical skills training. Your treatment will be delivered by the MDT on both a one-to-one and group basis.</p> <p>The length of your inpatient stage 3 treatment will depend on your individual needs and whether or not you have access to intensive home-based treatment from a community eating disorders team in your area. Whilst the length of inpatient stage 3 treatment is usually fixed (16 weeks if intensive home-based treatment from a community eating disorders team is not available, 4 weeks if intensive home-based treatment from a community eating disorders team is available), in some circumstances this can be extended if your needs cannot be met by the community team for whatever reason. Any decisions regarding potentially extending inpatient stage 3 treatment will be discussed and agreed with you at the weekly MDT review meeting with input from your community team.</p> <p>Once you have chosen the ‘foundations for recovery programme’ there is no option to change to another programme so it is important that you think carefully about this with your team before you decide.</p>
<p>Stepped Approach Programme</p>	<p>Our ‘stepped approach programme’ is very similar to the ‘foundations for recovery’ programme but offers an 8 week period when you reach a BMI of 18 where there is an emphasis on weight stability (BMI 18-18.5), consolidation of skills learned during stages 1 and 2 of treatment and enhanced graded leave. Your treatment prior to this 8 week period will be the same as you would receive as part of the ‘foundations for recovery programme’ with a focus on weight restoration alongside evidence-based psychological interventions, socio-occupational interventions, carers support and practical skills training. Your treatment will be delivered by the MDT on both a one-to-one and group basis.</p>

	<p>During the 8 week period you will spend the first weeks building up home leave in a graded and structured way. Weeks 5-8 will involve you spending the majority of time at home but returning to the unit for 1 night per week. The days you return will coincide with your weekly inpatient MDT review meeting so that your progress can be monitored by your MDT. On the days you return to the unit you will be expected to participate in the individual or group based work outlined in your care plan and you will have a 1 hour therapy session with a member of the inpatient MDT.</p> <p>Following this 8 week period, inpatient treatment is resumed as per the 'foundations for recovery programme' and the length of your inpatient stage 3 treatment will similarly depend on your individual needs and whether or not you have access to intensive home-based treatment from a community eating disorders team in your area. Whilst the length of inpatient stage 3 treatment is usually fixed (16 weeks if intensive home-based treatment from a community eating disorders team is not available, 4 weeks if intensive home-based treatment from a community eating disorders team is available), in some circumstances this can be extended if your needs cannot be met by the community team for whatever reason. Any decisions regarding potentially extending inpatient stage 3 treatment will be discussed and agreed with you at the weekly inpatient MDT review meeting with input from your community team.</p> <p>Once you have chosen the 'stepped approach programme' there is no option to change to another programme so it is important that you think carefully about this with your team before you decide.</p>
<p>Stabilisation Programme</p>	<p>The 'stabilisation programme' is specifically designed to offer an alternative treatment programme which adopts a 'rehabilitation' model of care where the focus is shifted away from 'recovery' in its traditional sense and is centred on promoting increased physical stability (BMI>15), motivational enhancement and improved quality of life. Individuals are only accepted onto the 'stabilisation programme' if they fulfil at least one of the following criteria:</p> <ul style="list-style-type: none"> • they are detained under the provisions of the Mental Health Act • they are receiving nasogastric feeding • they have a severe and enduring eating disorder defined as: <ul style="list-style-type: none"> ➢ a prolonged history of severe symptoms (e.g. BMI<15, daily bulimic behaviours) ➢ treatment resistance, i.e. lack of clinical progress despite receiving a number of evidence-based treatments in differing clinical settings (e.g. inpatient, day-patient, community-based services, outpatient treatment) <p>The length of your inpatient stage 3 treatment will depend on your individual needs and whether or not you have access to intensive home-based treatment from a community eating disorders team in your area. Whilst the length of inpatient stage 3 treatment is usually fixed (16 weeks if intensive home-based treatment from a community eating disorders team is not available, 4 weeks if intensive home-based treatment from a community eating disorders team is available), in some circumstances this can be extended if your needs cannot be met by the community team for whatever reason. Any decisions regarding potentially extending inpatient stage 3 treatment will be discussed and agreed with you in the weekly MDT review meeting with input from your community team.</p> <p>Individuals who choose the 'stabilisation programme' will have the option to change to an alternative treatment programme during stage 2 of treatment. Any decisions regarding a change of treatment programme will be discussed and agreed with you at the weekly inpatient MDT review meeting with input from your</p>

	community team.
Enhanced Stabilisation Programme	<p>As part of the 'enhanced stabilisation programme' there will be a focus on weight restoration and stability (BMI 18-18.5) alongside evidence-based psychological interventions, socio-occupational interventions, carers support and practical skills training. Your treatment will be delivered by the MDT on both a one-to-one and group basis.</p> <p>The length of your inpatient stage 3 treatment will depend on your individual needs and whether or not you have access to intensive home-based treatment from a community eating disorders team in your area. Whilst the length of inpatient stage 3 treatment is usually fixed (16 weeks if intensive home-based treatment from a community eating disorders team is not available, 4 weeks if intensive home-based treatment from a community eating disorders team is available), in some circumstances this can be extended if your needs cannot be met by the community team for whatever reason. Any decisions regarding potentially extending inpatient stage 3 treatment will be discussed and agreed with you at the weekly MDT review meeting with input from your community team.</p> <p>Individuals who choose the 'enhanced stabilisation programme' will have the option to change to either the 'foundations for recovery programme' or the 'stepped approach programme' during stage 2 of treatment. Any decisions regarding a change of treatment programme will be discussed and agreed with you at the weekly inpatient MDT review meeting with input from your community team.</p>
Symptom Interruption	<p>The 'symptom interruption programme' is specifically designed for individuals with bulimia nervosa where community or outpatient treatment has been unsuccessful in promoting sustained change or where the associated risks are such that community-based or outpatient treatment is not clinically appropriate. This 16 week inpatient programme focuses on promoting behavioural change thus enabling individuals to break the cycle of binge eating and purging and includes a course of inpatient cognitive behavioural therapy (CBT) in line with NICE guidelines (NICE, 2017) however other psychological interventions may be considered as an alternative if needed. This programme also includes socio-occupational interventions, carers support and practical skills training. Your treatment will be delivered by the MDT on both a one-to-one and group basis.</p> <p>Individuals who do not have access to a community eating disorders service in their area will have the option to continue treatment with our outpatient department if clinically appropriate. Any decisions regarding post discharge outpatient treatment will be discussed and agreed with you at your discharge CPA meeting with input from your community team.</p>
4 week assessment	<p>In some cases there may be some uncertainties about diagnosis or the appropriateness of pursuing inpatient treatment. In such cases it can often be helpful to arrange a planned admission to a specialist eating disorders unit to clarify diagnosis and make recommendations about longer-term treatment based on individuals care needs. With this in mind our inpatient unit offers a 4 week inpatient assessment programme. Once the 4 week assessment period has been completed a CPA meeting is arranged to discuss and agree with you the best way forward. If it is felt that you have an eating disorder and that continued inpatient treatment would be beneficial then you will have the option of choosing one of the inpatient treatment programmes which best meets your needs. If continued inpatient treatment is not felt to be clinically appropriate for whatever reason then we will discuss and agree recommendations with you and your community team at your CPA meeting. In some cases where an eating disorder diagnosis has been excluded it may be recommended at the CPA meeting that further inpatient treatment is needed to ensure physical stability or to practise and consolidate practical skills. In these circumstances the unit can offer a further 4 weeks of</p>

	inpatient care in line with stage 3 treatment boundaries.
--	---

Physical health monitoring

During their admission, your loved one will have their physical health assessed and monitored closely throughout the course of their inpatient treatment. For more information on this please refer to the YCED inpatient booklet available at <https://www.leedsandyorkpft.nhs.uk/our-services/services-list/yorkshire-centre-for-eating-disorders/>.

The inpatient group programme

Individuals with eating disorders can often feel a sense of isolation and group-based interventions can be extremely helpful in helping someone realise that they are not alone and to support them through their journey back to health and wellbeing. With this in mind our inpatient unit has developed a diverse inpatient group programme which offers an array of practical and therapeutic-based interventions with input from service users, inpatient staff and external facilitators. The group programme allows you to share experiences in a safe and contained environment build confidence and learn the knowledge and skills you need to hopefully move on to a life without an eating disorder.

You will be invited to join the inpatient group programme after day 3 of your admission once your physical health assessment is complete. Thereafter there is an expectation that you attend all of your recommended groups and contribute to group sessions in meaningful way. We appreciate that for some people this may difficult and our inpatient team will offer you additional support if needed to help you get the most out of the inpatient group programme. Access to the inpatient group programme is temporarily stopped if an individual is on eyesight nursing observations, is medically unstable or if they are receiving nasogastric feeding.

Family meetings

During their stay on ward 6 your loved one may be offered family meetings if they agree and consent to this. These meetings can be an opportunity for members of the inpatient team to 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 and your loved one's as well as your own needs. 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.

If your loved one does not agree or consent to a family meeting then 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 ones 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 four 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 four 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.

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.

Visiting times

Weekdays: 15:30 – 20:15.

Weekends and bank holidays: 11:00 – 20:15.

Visitors are requested to avoid meal times and rest periods.

Children visiting the unit

We acknowledge the importance of children being able to visit their family members on the unit and we aim to provide a safe and secure environment at all times. The team will aim to be flexible with visiting times if your loved one has children who wish to visit the unit. Responsibility for the visit, its appropriateness and relevant supervision arrangements is the responsibility of the nurse coordinator on the unit.

Discharge

Discharge from the unit will be planned together with your loved one, the MDT, family and carers, the community team and any other people your loved one may feel are important in their care. Whenever possible we aim to agree a discharge date well in advance so that arrangements can be made to ensure that there is a smooth transition from the unit to the community. A member of the inpatient team will contact your loved one within 3 days of discharge, either face to face or by telephone, to ensure that they are safe and to see if there have been any difficulties since leaving the unit.

Following discharge we will often recommend follow-up from community eating disorders services if this is available in your loved one's area. Service users who are registered with a GP in the Leeds area will have access to home-based treatment through the YCED Community Treatment Service (CTS). If your loved one does not have access to community eating disorders services in their area then they may be offered outpatient treatment here at YCED if clinically indicated.

5.0 Supporting a Loved One with an Eating Disorder

5.1 General support

Supporting a loved one who has an eating disorder can often be challenging and can evoke an array of mixed emotions. Family and carers often report that they feel unsure about what to say and what to do to support their loved one. If this is the case then it can often be helpful to ask them how they would like to be supported. We strongly advise that all service users have at least one family meeting during their treatment which can be a helpful forum for you and your loved one to raise any concerns that you may have such as understanding the nature and treatment of an eating disorder or any other worries you may have. In some circumstances service users may wish to opt out of these family sessions which is their right. In such circumstances family and carers can still approach a member of the team to seek help and although they may not have consent to discuss the finer detail of the service users' care they can still offer you general advice and support.

For family and carers of those accessing inpatient treatment, they may express concerns about what their loved one is eating during periods of home leave. In such circumstances we would encourage you to speak to your loved one about this in the first instance and we also encourage service users to share their diet plans with their family and carers prior to home leave where clinically appropriate. We also encourage service users to involve their family and carers in the practical aspects of self-catering and portioning meals. Please note that if you have any concerns about your loved one during periods of home leave you can contact the unit on 0113 855 6397 to discuss this with a member of the team.

5.2 YCED carers support group

The YCED carers support group aims to support people who care for anyone over 17 who is living with an eating disorder. The group provides a safe forum where carers can share their knowledge and experiences and offer each other empathy, support and understanding. The group is co-facilitated by YCED and the local charity Northpoint Wellbeing. Meetings are held every 4 weeks on a Wednesday evening (1900-2030) at YCED, Newsam Centre, Seacroft Hospital, Leeds.

For further information please visit their website (<http://ycedcarers.org.uk/>) or contact the YCED (0113 855 6400) or the YCED carers support group helpline (0113 206 3334).

5.3 Recommended reading and other resources

The following is a list of evidence-based self-help materials and other resources which service users and carers may find helpful. Copies of these should be available on the unit but if not please discuss this with a member of the inpatient team who will arrange for these to be provided.

Self-help materials

Family and carers

- Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method (Treasure 2007).

Anorexia nervosa

- Overcoming Anorexia Nervosa: A Self-Help Guide Using Cognitive Behavioural Techniques (Freeman 2009)
- The Anorexia Workbook: How to Accept Yourself, Heal Your Suffering, and Reclaim Your Life (Heffner 2004)

Bulimia nervosa

- Overcoming Bulimia Self-help Course: A Self-help Practical Manual Using Cognitive Behavioral Techniques (3-Book Set) (Cooper 2007)
- Overcoming Bulimia Nervosa and Binge Eating: A Guide to Recovery (Cooper 1993)
- Overcoming Binge Eating (Fairburn 1995)
- Getting Better Bit(e) by Bit(e): Survival Kit for Sufferers of Bulimia Nervosa and Binge Eating Disorders (Schmidt 1993)

Eating disorders in men

- The Invisible Man: A Self-help Guide for Men with Eating Disorders, Compulsive Exercise and Bigorexia (Morgan 2008)

Anxiety and OCD

- Overcoming Anxiety Self-help Course: A Self-help Practical Manual Using Cognitive Behavioural Techniques (Kennerley 2006)
- Overcoming Panic and Agoraphobia Self-help Course (3 Parts): a 3-part Programme Based on Cognitive Behavioural Techniques (Silove 2007)
- Overcoming Social Anxiety and Shyness Self-help Course (3 Parts): a 3-part Programme Based on Cognitive Behavioural Techniques (Butler 2007)
- The Mindfulness and Acceptance Workbook for Anxiety: A Guide to Breaking Free From Anxiety, Phobias, and Worry Using Acceptance and Commitment Therapy (Eifert 2008)
- Overcoming Obsessive Thoughts: How to Gain Control of Your OCD (Purdon 2005)

Depression

- The Mindful Way Through Depression: Freeing Yourself from Chronic Unhappiness (includes Guided Meditation Practices CD) (Williams 2007)
- Overcoming Depression: a Self-help Guide Using Cognitive Behavioural Techniques (Gilbert 2009)

Mindfulness

- Mindfulness: finding peace in a frantic world (Williams & Penman 2011)

General

- Overcoming Low Self-Esteem: a Self-help Guide Using Cognitive Behavioural Techniques (Fennell 2009)
- Breaking Free Workbook: Practical help for survivors of child sexual abuse: Help for Survivors of Child Sex Abuse (Ainscough 2000)
- Mind Over Mood: Change How You Feel By Changing the Way You Think (Greenberger & Padesky 1995)
- Overcoming Anger and Irritability (Davies 2009)

Support groups

- YCED support group – a weekly support group available to anyone over 17 years of age with an eating disorder. Held every Wednesday (1730-1830) at the Newsam Centre, Seacroft, Leeds. Please contact 0113 855 6400 or visit <https://www.leedsandyorkpft.nhs.uk/our-services/services-list/yorkshire-centre-for-eating-disorders/> for more details
- Beat (www.b-eat.co.uk) – formerly the Eating Disorders Association, Beat is the UK's leading eating disorders charity. This website includes information about eating disorders, a section specifically for young people, helpline telephone numbers and information about other help and support available.
- Bodywhys (www.bodywhys.ie) – Bodywhys is the Eating Disorder Association of Ireland. The website contains information and support service details.
- Anorexia and Bulimia Care (www.anorexiabulimiacare.org.uk) – a national Christian charity offering help and support to people with eating disorders and their carers.
- Student Run Self Help (www.srsh.co.uk) – a website about a project aiming to improve support available to students and young people with eating disorders by setting up a network of student-run self-help groups. The website contains information about existing self-help groups and on how to get involved.
- Men Get Eating Disorders Too (<http://mengetedstoo.co.uk>) – a website for men who have been affected by anorexia, bulimia, binge eating disorder, compulsive eating and/or compulsive exercise.
- Carers UK (www.carersuk.org) – an organisation of carers.
- Mind (<https://www.mind.org.uk>) – a UK based mental health charity which provides advice and support to empower anyone experiencing a mental health problem. Campaigns to improve services, raise awareness and promote understanding.
- The YCED carers group – a monthly family and carers support group run by Northpoint and YCED. For more information please visit <http://ycedcarers.org.uk/>.

6.0 Other Information

6.1 Confidentiality

Any information shared with carers has to be with your loved ones 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 with you 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.

6.2 Evaluation and clinical audit

The team is committed to ongoing evaluation of the effectiveness of the service that we offer. We will ask your loved one to complete questionnaires on entry into the service and prior to discharge for this purpose. We will also ask your loved one to participate in a pre-discharge exit interview to hear about their views and experiences of their treatment and explore any areas of the service which worked well or they feel could be improved upon. Please be assured that the information from these questionnaires and exit interview are anonymised and confidential and will only be used to inform and improve the treatment we offer.

6.3 Equal opportunities

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

6.4 Raising a Concern, Compliments, Comments and Complaints

If you have a concern or wish to make a complaint we would always advise raising this with the team in the first instance. If you feel that this does not resolve the issue at hand then staff can offer guidance on how to raise a concern and/or make a complaint. 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 LYPFT complaint's department (please ask a member of staff for details).

6.5 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.

6.6 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 of April 2016.

6.7 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.

7.0 References

American Psychiatric Association (2013) DSM-5. 5th Edition. ISBN: 978-0-89042-554-1.

National Institute for Health and Clinical Excellence (2017) Eating disorders: recognition and treatment. NG69. Leicester: British Psychological Society.

Royal College of Psychiatrists (2014) MARSIPAN: Management of really sick patients with anorexia nervosa, Council Report CR189. Royal College of Psychiatrists.