Western Australia Eating Disorders Outreach and Consultation Service (WAEDOCS)

What can my loved one expect from an admission?

This handout has been prepared by someone who has recovered from an eating disorder and provides you with information to help you understand why your loved one needs to be in hospital. The WA Eating Disorders Outreach & Consultation Service (WAEDOCS) is a multi-disciplinary specialist team who are here to support and advise your loved one's treating team, to help their stay be as successful as possible.

Background to eating disorders

- Eating disorders are serious illnesses, with both physical and mental consequences, that require specialist care and treatment.
- They can affect anybody regardless of life circumstances, gender, age and weight
- Starvation affects thinking and can make it difficult for your loved one to understand the need for treatment.
- Nutritional restoration is essential if your loved one is underweight or has lost a large amount of weight in a short time, or if they haven't eaten much recently or have been purging food.
- Families/loved ones can provide valuable support during treatment and recovery.

Why have they been admitted to hospital?

They have been admitted because their health is at risk. The nature of the eating disorder influences them to have limited understanding about the serious effect it has on their body and their mind. They may think they don't need to be in hospital because they believe that it is not serious – when in fact it is. It is not unusual to have mixed feelings about being admitted to hospital for an eating disorder.

It is common for someone with an eating disorder to be terrified of eating, food and regaining weight. This fear can become so intense that it drives the person to avoid getting help, and is part of the eating disorder itself. It will take time to go away and will often need therapy and ongoing support from loved ones. At times, it may be necessary to be admitted ("involuntarily") under the Mental Health Act. This can be confronting but necessary where the illness has affected decision making. The treating team are here to treat your loved one's eating disorder and keep them safe.

Remember, an eating disorder is a mental illness, not a lifestyle choice. Your loved one didn't choose to get ill and they will need help towards becoming well. Recovery is possible for anyone.

Malnutrition and Starvation Syndrome

Malnutrition from not eating adequately can occur at any weight and can be life-threatening. People at very low weight or low BMI are clearly malnourished but so is anyone who has lost a lot of weight in a short space of time or has been eating less than the minimum their body requires.

Severe malnutrition can cause a number of physical and psychological symptoms that we call "starvation syndrome". There are two main reasons that admission to hospital can be necessary for someone with an eating disorder and the resulting starvation syndrome:

- 1. Starvation tends to distort the way we think so severely that the person cannot make healthy decisions or look after themselves properly (even though they think they can).
- 2. Starvation creates physical problems that need to be addressed in order to save life. If untreated, the consequences of starvation can be very severe, for example:

Physical	Psychological
Heart attack or irregular heartbeat	Obsessive thoughts about food
Fainting, feeling dizzy and weak	Restlessness, agitation
Digestive problems	Low mood, depression
Organ failure	Mood swings
Dehydration and electrolyte Imbalance (e.g. low	Loss of concentration
potassium)	Difficulty making decisions
Hair falling out	Destructive, negative self-talk
Feeling cold	Loss of interest in social interactions
Loss of normal hormonal functioning	Ritualistic behaviours
Osteoporosis (brittle bones) – irreversible	Rigid thinking
	Self-harm and/or suicidal thoughts

We've attached a handout on Starvation Syndrome if you'd like to read more (pages 5-6).

What can you and your loved one expect?

Whether your loved one has come to hospital voluntarily or involuntarily, there are many common aspects of the treatment experience that will be helpful for you to understand. For example:

- They've been admitted into hospital because they are very ill. That's why their blood will be taken daily and pulse, temperature and blood pressure will be measured throughout the day.
- Bed rest is often necessary, because of their physical frailty and to help keep their body safe from further damage.
- Specialist nurses may be required to supervise them 24/7. While this may be challenging, it is to keep your loved one safe and to help them manage eating disorder behaviours.
- Food is considered to be a vital "medicine" required to treat an eating disorder, to restore nourishment to the brain and body and to get a person back to medical stability.
- It is common for people with restrictive eating disorders to require a Nasogastric (ng) Tube to be
 inserted, to receive nutrition in liquid form, as it can be challenging to consume the amount of
 food their bodies require. This can be very anxiety-provoking and the treatment team can offer
 strategies to help your loved one manage these feelings. The NG tube will only be necessary
 until they are capable of eating on their own and are medically stable.
- With nourishment, your loved one will restore their health and some body weight, which may be confronting emotionally. The influence of eating disorder thinking may tell them not to trust the treating team because 'they just want to make you fat'. That is not the goal. The team is focused on helping your loved one become medically stable and safe.
- A starved body can react erratically when food is re-introduced this is known as Refeeding Syndrome. The dietitian will be looking out for this and monitoring your loved one's health carefully.
- Your loved one may feel uncomfortably full and it may seem they are expected to consume more food than they or you feel is necessary. However, it takes a very high amount of energy to restore and stabilise a starved body - when a body has experienced malnutrition, its metabolism changes and 'normal' eating isn't enough.

- Repairing the damage done to your body will take time and energy. The content of nutrition you
 receive will be essential, such a vitamins and proteins. Low calorie and low-fat foods will not
 restore your body to become medically stable.
- As your loved one resumes eating, they may feel torn between a sense of relief and a sense of terror. This is very to be expected, and distress tolerance techniques can be helpful throughout this stage.

A symptom of your loved one's eating disorder is the focus on 'numbers': e.g., calories, food, exercise and weight. In hospital, staff will avoid talking in those terms and will refer to "BMI bands" - this relates to the general trend of a person's weight, which can vary from day to day, and is used so that they don't get stuck on the details of weight gain or loss or the specific number. Clinical decisions will be made based on their health status rather than on their specific weight.

The dietitian will take charge of your loved one's food plan, the psychiatrist addresses their psychiatric/ psychological state and nurses care for them throughout the day and night. Many aspects of treatment will be "non-negotiable". This might feel unfair or frustrating, which is understandable, however, remember the team are doing this to care for your loved one and help them get well, not to punish them. This is why they are here, to receive treatment and support towards overcoming their eating disorder. As their health improves and eating becomes more manageable, your loved one will have more freedom to make decisions, as long as their body is in a medically stable state The main priority for the admission is regaining medical stability. Therapy is important for recovery, once your loved one is medically stable.

The family can be a valuable support during your loved one's hospital stay and afterwards. However, many family members don't fully understand the complexities of an eating disorder. For that reason, several organisations in Perth run support/skill sessions for family members.

We've attached a handout on how to access those support / informational sessions (page 7).

How might my loved one think and feel?

Eating disorders can twist ideas, comments and actions in ways that are harmful to your loved one. They might experience intense self-criticism during their hospital stay, be extremely scared of certain foods or drinks, or feel untrusting of people who are trying to help them. This is to be expected when somebody has a severe eating disorder but gradually over time and with renourishment, your loved one's thinking will become more balanced. However, for some time they may experience anxiety about certain things, particularly the changes in their body, and having to eat 'feared foods' and reduce other behaviours associated with an eating disorder.

Medical teams may need to overlook the anxiety and fear your loved one is experiencing as they're often most focused on their medical status. It's really important to talk to the treating team and ask for support and help.

There are many self-coping strategies to use while they are in hospital. These could include:

- Having someone supportive to talk to that understands their concerns.
- Learning as much as possible about recovery from an eating disorder.
- Journaling, writing or drawing can be very therapeutic and can help your loved one to gain insight into their eating disorder.
- Distraction techniques that take their mind away from the anxiety and give them a break from the eating disorder thoughts, e.g., watch a movie, read a book, play a board game, do craft.
- Phoning an eating disorder helpline such as the Butterfly Foundation support service.
- Sometimes medication can help reduce anxiety.
- Sleep, rest and regular nutrition can greatly improve general wellbeing.

We've attached a handout on resources to help manage anxiety that might interest you and your loved one (page 8). We've also added some resources especially for families / carers (page 9).

Leaving hospital and recovery

Hospital admission addresses the most severe aspects of the eating disorder and when your loved one is well enough to leave, a discharge plan will be discussed with them and your family. They should be medically stable and out of immediate risk but they may have a long road in front of them to fully overcome their eating disorder. Psychotherapy is required, often in conjunction with group work, bodywork and skills development. And remember, your family can be a helpful resource to support your loved one in their recovery journey.

Most outpatient psychotherapy for eating disorders is conducted by clinical psychologists, and research indicates that CBT-E and DBT can be very helpful to someone with an eating disorder. Many people also benefit from relaxation techniques such as mindfulness, yoga, meditation. Many people consult a dietitian or seek out a trained Peer Support Worker (someone who previously had an eating disorder). They may also benefit from relaxation techniques such as mindfulness, yoga and meditation.

We have attached a handout with treatment that your loved one can pursue (page 10).

Eating disorders tend to affect people who have a predisposition to be anxious and are high-achieving. They have a genetic component and are also influenced by our environment. We live in an extremely confusing media culture which over-emphasises fad diets, an ultra-thin body shape and external validation for the way we look. While no-one is immune from these confusing messages, someone with an eating disorder can be particularly vulnerable. For that reason, your loved one should take time to recover and build resilience in order to navigate both the emotional and the genetic vulnerability they may have, combined with the cultural messages we all receive.

Recovery from an eating disorder can be challenging and takes time. It is possible and very much worth it. An eating disorder can rob a person of their quality of life. Recovery offers the opportunity to pursue passions such as travel, work, study, having meaningful relationships, raising children and most importantly living the life they deserve.

Over time your loved one will find that their anxiety reduces, eating becomes more manageable, decisions become more balanced and they will regain motivation, purpose and hope for the future. Relapse is possible during times of stress, but it becomes less likely as they develop a strong healthy relationship with themselves and learn ways to manage challenging times.

Your loved one can be free of their eating disorder!

All the best.

The WAEDOCS team

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This document can be made available in alternative formats on request for a person with a disability.

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Starvation Syndrome

The effects of starvation on the human body are well documented. When starved of calories, the human body responds with "Starvation Syndrome". People with Anorexia Nervosa suffer from starvation as a result of severely restricting their calorie intake. People with Bulimia Nervosa suffer from starvation by engaging in restriction and purging behaviour (which also reduces caloric absorption) and from irregular intake of vital nutrients.

The Minnesota Experiment

In the 1940s, there was an experiment involving 32 fit young men who had been drafted into the US army. They were conscientious objectors to military service and had volunteered to do humanitarian work. They became subjects of a year-long experiment. This involved:

- 3 months of normal eating
- 6 months where rations were cut by 50%
- 3 months of full rations

For the first three months, when they were receiving normal rations, the men engaged in normal behaviours, getting along well with one another, playing games, following the war on the radio and in newspapers.

After six months of half rations (semi-starvation), the men experienced not only the expected physical changes, but dramatic mental changes too.

Physical changes: On average, the men lost 25% of their body weight, both fat and muscle. Their hearts (muscle) also reduced by 25%, and slowed down. Their basal metabolic rate slowed down so that their bodies could conserve energy—about 600 calories per day. Body temperature decreased so they felt cold all the time. Many reported dizziness and momentary blackouts. They lost strength and were constantly tired. Hair often fell out; hair and skin were dry. Many suffered from fluid retention. Their hormone levels decreased, resulting in loss of sexual desire and performance.

Personality changes: The men became depressed and apathetic, self-centred and less interested in life going on around them. Their mental alertness decreased and they became moody and irritable, restless and anxious. They reported poor concentration and decision making. Their thinking became more rigid and they obsessed more.

Social changes: The men lost their sense of humour and became sarcastic with one another. Group spirit deteriorated and social interaction became stilted. When they talked to each other it was mainly about food.

Food preoccupation: The change in attitude to food was one of the most surprising outcomes of the study. The men became preoccupied with food, including having persistent thoughts and dreams about food. There was a change in mealtime behaviours, including toying with food, or being ritualistic about the way they ate and taking longer to finish a meal. They even collected recipes—unusual in males during the 1940s!

These symptoms are experienced by anyone who is starved of calories. If you recognise these symptoms in your own life, it is important to remember that they all stem from one thing: starvation.

Recovery from Starvation

The men in the Minnesota Experiment recovered from their physical and mental symptoms once they were given regular rations, although it took some men a while to normalise their eating. Many men reporting feeling full and some developed binge eating. Their mood remained low for a while and usual social behaviours took longer to return.

How is this relevant to eating disorders?

We now believe that ANY kind of weight loss (from dieting or even having a stomach bug) can push someone into developing anorexia nervosa or an eating disorder.

People with anorexia nervosa and anyone who has lost a lot of weight will probably be suffering from full-blown starvation syndrome. Starvation does not just affect weight and food, it affects all aspects of your psychological and social functioning.

However, there are some major differences. The men in the Minnesota Study wanted to eat, they weren't afraid of regaining weight, whereas people with anorexia nervosa are terrified of eating and weight regain. So anyone with anorexia nervosa will be suffering from BOTH starvation AND an eating disorder.

We need to remember that eating disorders are mental illnesses, and the most relevant point about anorexia nervosa is the **intense** fear of weight regain. This is NOT merely the commonly held fear of gaining weight experienced by many women and some men. It is a fundamental characteristic of anorexia nervosa, and it is usually a fear so strong that it keeps them ill and underweight.

So having an intense fear of weight regain makes starvation syndrome in someone with an eating disorder different from starvation in the men in the Minnesota Experiment. And the paradox is that the only way out of anorexia nervosa is first getting out of starvation mode — which means gaining weight, the scariest thing for someone with anorexia nervosa!

Getting out of starvation

The fear of weight regain is something that your therapist will understand. He or she will be very empathic, but will be encouraging you to relearn to eat, since it is not helpful for them to support you to remain in a state of starvation.

The physical and mental changes you have experienced will also be reversed when you increase and normalise your food intake, giving your body the energy it needs. The mental changes often take longer. Through regular and healthy eating, your body can regain its strength and fight these symptoms of starvation. You may need to consult a medical practitioner, psychologist, dietitian or other health professional for support with this.

Your brain will not function as it should without adequate nutrition. A starved brain will have problems processing and regulating emotions, which means your moods and reactions to situations might be unpredictable.

You will find that you feel stronger and have more energy when you return to a weight that is healthy for you. Your hormones and your heart will be functioning in a healthy way, but for a while you may still feel anxious about food. Your brain will take longer to return to its former levels of functioning, but it will catch up!

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See website www.cci.health.wa.gov.au for more handouts and resources.

Family sessions to support someone caring for a person with an eating disorder

Centre for Clinical Interventions (CCI)

Eating Disorders Support & Skill Building Group for Family & Friends

These interactive groups are designed to provide information about eating disorders in addition to giving participants the opportunity to share their personal experiences and to learn and practice helpful strategies relating to their loved ones eating disorder.

Groups run for 2.5 hours in the early evening and will be held on the same day across two consecutive weeks. The groups are free, but registration is essential.

For enquiries, call 9227 4399 or email: info.cci@health.wa.gov.au

Body Esteem Program

Supporting a Person with an Eating Disorder

The Parent/Partner Education and Support Program (PESP) provides information about the nature of an eating disorder and recovery, in order to help people gain a deeper understanding of what their loved one may be experiencing, strengthen family communications, and learn strategies for self-care.

These sessions are held on a Saturday from 9.30-4 and cost \$75 each or \$100 per couple. Registration is essential. For enquiries, call 9300 1566 or email: BEP@whfs.org.au

Perth Children's Hospital (PCH)

Parent and Family Support Workshop: ED Essentials

The PCH Eating Disorders Program (EDP) runs monthly free education workshops for parents, carers and family members. It explains how physical health, emotions, developmental milestones and family relationships are impacted by an eating disorder, as well as their role in supporting a loved one towards recovery. We know that families do not cause eating disorders, but they are instrumental in helping a young person recover. The workshop is open to all parents / carers in the community who have a loved one experiencing an eating disorder, regardless of age or whether they are receiving treatment through EDP.

Please speak to the triage officer at EDP on (08) 9340 7012 for more details and upcoming workshop dates or email: pmhedp@health.wa.gov.au

Resources for Emotional Regulation

There are now many very helpful online tools to be found, for example:

The Centre for Clinical Interventions (CCI) has some very useful online self-help booklets. The following relate directly to managing your moods:

Facing Your Feelings

https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself/Tolerating-Distress

Overcoming Disordered Eating, especially Module 7: Moods & Disordered Eating https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself/Disordered-Eating

Beyond Blue has put together resources to help start a conversation when someone you know isn't acting the way they usually do. There are some videos that can help you with what to say and what to do as well as some more tips and a check in app:

https://www.youthbeyondblue.com/help-someone-you-know/thecheckin

Mindshift is an app designed to help teens and young adults cope with anxiety: https://www.anxietybc.com/resources/mindshift-app

Mindspot has a telephone and online service for Australian adults troubled by symptoms of anxiety or depression: https://mindspot.org.au/

MoodKit draws upon the principles and techniques of Cognitive Behavior Therapy (CBT) and provides a wide variety of suggestions for specific steps you can take to improve your mood: http://www.thriveport.com/products/moodkit/

MoodMission is an evidence-based app designed to empower you to overcome low moods and anxiety by discovering new and better ways of coping: http://moodmission.com/

ReachOut WorryTime is a free mobile app that gives you a place to store your worries, and alerts you when it's time to think about them. When a worry no longer matters to you, you can ditch it and move on: http://au.reachout.com/reachout-worrytime-app

Smiling Mind is a not-for-profit organisation that works to make mindfulness meditation accessible to all: https://smilingmind.com.au/

Snapshot was designed by researchers at the Black Dog Institute. It's an online tool that enables you to measure and monitor your mental health and wellbeing: http://digitaldog.org.au/programs/blackdogsnapshot/

This Way Up provides information if you feel that your worrying is out of control and you need some help with understanding and dealing with it: https://thiswayup.org.au/how-do-you-feel/worried/

The Butterfly Foundation has an Eating Disorder Helpline on 1800 334 673: https://thebutterflyfoundation.org.au/

Online Resources - Eating Disorders

Information for People with Eating Disorders and their Families

www.eatingdisordersinfo.org.au

 Resources for the prevention and management of eating disorders, with links to the National Eating Disorders Collaboration (NEDC) website and the Butterfly Foundation Helpline.

www.howfaristoofar.org.au

Relates to the risk factors and warning signs related to eating, exercise and body image.

www.feast-ed.org

• Provides families with information and mutual support via forums, events and information.

www.feedyourinstinct.com.au

 An interactive tool designed to support parents of children and young people experiencing different types of eating and/or body image problems

www.carerswa.asn.au

The Carers Association of WA is the peak body for carers throughout the State. It
provides education and training, counselling, social support, and advocacy and
representation.

www.helpingminds.org.au

Mental health services and carer support, with links to a Family Helpline.

Specialist Treatment Options in WA

Centre for Clinical Interventions (CCI)

CCI is a public specialist state-wide psychological service offering evidence-based treatment to people aged 16 and over with Anorexia Nervosa (AN) and Bulimia Nervosa, CCI offers an active treatment called Cognitive Behaviour Therapy (CBT), focusing on the 'here and now' and working to change the behaviours and thoughts that keep the eating disorder going. For adolescents with AN, CCI also offers Family-Based Therapy (FBT). Treatment focuses on empowering parents to help their adolescent recover from this life-threatening illness. A GP referral is necessary. For enquiries, call 9227 4399 or email: info.cci@health.wa.gov.au

The Swan Centre

The Swan Centre is staffed by clinical psychologists, a dietitian and a psychiatrist. It offers Cognitive Behaviour Therapy (CBT), focusing on the 'here and now' and working to change the behaviours and thoughts that keep the eating disorder going. For adolescents with Anorexia Nervosa, the Swan Centre also offers Family-Based Therapy (FBT), a treatment that focuses on empowering parents to help their adolescent recover from this life-threatening illness. A GP referral is necessary. For enquiries, call 9382 8775 or email: reception@swancentre.com.au

The Hollywood Clinic (THC)

THC offers a range of evidence-based programs providing differing levels of support: Inpatient treatment (medical and psychological care to stabilise physical health, restore weight towards a minimally safe BMI, and develop normal eating patterns), Day Program (4 days per week; a 'step down' from inpatient treatment or a 'step up' from outpatient treatment, with supported eating at breakfast to lunch, dietetic support and focus on transferring skills to home. The bulimia nervosa group runs for three hours each week over 10 weeks, providing a less restrictive, yet highly focused, environment. Treatment at THC is funded by clients' private health insurance. A GP or medical specialist referral is required. For enquiries, call 9346 6801.

Body Esteem Program (BEP)

BEP is a community based program designed to help participants to take control of their own recovery using the support and experience of peer-facilitators. BEP is a complementary service which caters to women (18+) who experience eating disorders. Services include: a 20-week group for women with Anorexia and/or Bulimia Nervosa and a 20-week group for women with Binge Eating Disorder. For enquiries, call 9300 1566 or email: BEP@whfs.org.au

For those outside of Perth

If you live outside of the Perth metropolitan area, you won't have access to specialist services. Make sure you go to your GP and get support in the community. This might be help from a dietitian, a nurse, or a psychologist, who can access the CCI website modules to work through with you: https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself/Disordered-Eating

Perth Children's Hospital Eating Disorder Program (PCH EDP)

PCH EDP is a public specialist state-wide multidisciplinary service providing assessment, treatment and support. It only takes new referrals for young people up to 15 years. For enquiries, call (08) 6456 0201or email: PCHOutpatients.CAMHS.EDP@health.wa.gov.au