Resources for people caring for a loved one with an eating disorder

The WA Eating Disorders Outreach and Consultation Service (WAEDOCS) is a Statewide Service that aims to ensure youth and adults in WA with an eating disorder can access optimal best practice care. This is facilitated through up-skilling and inspiring health care professionals to deliver evidence-based high quality eating disorders care.

Although WAEDOCS is unable to support consumers and carers directly, we have developed some resources: two sets of guidelines (what to expect from an inpatient admission, for consumers and their supports) and a set of resources. Here are the resources.

Online Resources

- [www.eatingdisordersinfo.org.au](http://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](http://www.howfaristoofar.org.au)
  Relates to the risk factors and warning signs related to eating, exercise and body image.

- [www.feast-ed.org](http://www.feast-ed.org)
  Provides families with information and mutual support via forums, events and information.

  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](http://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](http://www.helpingminds.org.au)
  Mental health services and carer support, with links to a Family Helpline.
Resources for Emotional Regulation

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  

Overcoming Disordered Eating, especially Module 7: Moods & 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](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](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/](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:  

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/](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:  

Smiling Mind is a not-for-profit organisation that works to make mindfulness meditation accessible to all:  

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:  

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:  

The Butterfly Foundation has an Eating Disorder Helpline on 1800 334 673:  
[https://thebutterflyfoundation.org.au/](https://thebutterflyfoundation.org.au/)
**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

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**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

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**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 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: pmhededp@health.wa.gov.au
Specialist Eating Disorder 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 dietician, 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 0201 or email: PCHOOutpatients.CAMHS.EDP@health.wa.gov.au