Anorexia nervosa





© The Royal Australian and New Zealand College of Psychiatrists, 2009

Compiled by The Royal Australian and New Zealand College of Psychiatrists (RANZCP), this information and advice is based on current medical knowledge and practice as at the date of publication. It is intended as a general guide only, and not as a substitute for individual medical advice. The RANZCP and its employees accept no responsibility for any consequences arising from relying upon the information contained in this publication.

The Royal Australian and New Zealand College of Psychiatrists 309 La Trobe Street

Melbourne Victoria 3000

Australia

Telephone: (03) 9640 0646 Facsimile: (03) 9642 5652 Email: ranzcp@ranzcp.org

Website: www.ranzcp.org



Contents

Key points about anorexia nervosa	3
Introduction	4
What does a diagnosis of anorexia mean?	11
Getting treatment	16
Living through the journey to recovery	29
Standards and other issues	40
What families and carers can do to help	42
Appendix 1: Questions to ask	47
Appendix 2: Sources of information and support	49
Appendix 3: Common terms and acronyms	52
Appendix 4: Development of the guideline	53
Acknowledgements	55
References	56



Key points about anorexia nervosa

- 1 Anorexia nervosa is a mental illness associated with significant physical debility.
- 2 Anorexia nervosa presents in not only young women but also across all ages, both genders and socio-economic demographics. Although dieting and avoidance of weight gain are characteristics of the disease, the actual causes are varied and complex.
- 3 The severe weight loss associated with dietary restriction can be life threatening, not only due to the associated medical complications but also due to the severe mental anguish that an eating disorder causes.
- 4 If you think that you or a member of your family may have significant issues with food and dieting, it is important that you seek advice from your family doctor, local mental health services, or an eating disorder organisation who can refer you to a health service professional who specialises in eating disorders (see Appendix 2 for a directory of support services).
- 5 Anorexia nervosa can be treated very effectively, especially if it is caught early. The most effective treatment involves a multidisciplinary approach (a range of health services including psychology, psychiatry, medicine, dietetics, family therapy, social work). Anorexia nervosa can take years to develop, and recovery can take time (in some cases years).

Introduction

If you are an adolescent or an adult suffering from anorexia nervosa, or someone who feels they may be at risk of developing anorexia, or if you are a family member, carer or significant person in the life of a person with anorexia nervosa, this guide will provide you with vital information to help you navigate the journey of anorexia nervosa.

This guide has been developed by clinicians, researchers, and carer and consumer consultants. (See Appendix 4 for information on the development of the guideline).

This guide can:

- help you to make decisions about treatment
- outline the value of treatment and what to expect at critical times such as diagnosis, admission and discharge
- inform you of your rights as a sufferer and carer
- outline the standard of services you can expect.

What is anorexia nervosa?

Anorexia nervosa is an eating disorder. It is a severe, very
distressing and often chronic mental illness, which can lead
to severe weight loss, chronic physical disabilities such as
osteoporosis (bone loss with weakened bone structure and
increased risk of fractures), growth retardation, infertility, impaired
thinking and concentration, bowel and intestinal disorders
and major disruptions to emotional, social and educational
development. It can be life threatening.

- Is anorexia nervosa a mental illness or a physical one? In truth, it is a mental illness with significant physical complications. It is characterised by intense anxiety and preoccupation with body weight and shape, eating and weight control. Perfectionism and low self-esteem are common. Depression and obsessional thinking are often part of the illness. People with anorexia nervosa frequently experience other mental illnesses including depression and anxiety disorders.
- In adults, anorexia nervosa lasts an average of five to seven years. However, for some people it can become chronic over their lifetime.
- Recovery is possible, although partial relapses and remissions do occur. In children and adolescents, acute physical complications are more common, but appropriate treatment early in the illness leads to high rates of recovery after 12 to 18 months. It is most important that treatment is kept up for as long as it takes for you to be free from the domination of anorexia nervosa symptoms.
- Weight restoration is an essential first step in recovery but not
 a sign of recovery. It takes time to heal the mind from anorexia
 nervosa and restore a sufferer to a state where they are not
 dominated by negative feelings related to weight and food.
- Eating disorders are on a spectrum and sometimes the boundaries between different kinds of eating disorders are blurred. For example, sufferers who are anorexic may also binge and purge, sufferers of bulimia may move toward anorexia, and binge eating can lead to anorexia or bulimia.

Who gets anorexia nervosa and why?

- Anorexia nervosa can affect people from all age groups, and socioeconomic and cultural backgrounds.
- Although it is much more common for females to suffer from anorexia, it does also occur in males. However, where females diet to achieve a socially desirable 'thin' body, males can often abuse their bodies by using steroids, over exercising and controlling their food intake to try to achieve a 'muscular and toned body'.
- Family and twin research indicates that there is a genetic link. It is
 thought that familial personality features that increase a person's
 vulnerability to anorexia nervosa, such as perfectionism, obsessive
 compulsive tendencies and anxiety, contribute to the increased
 genetic risk.
- Many sufferers have experienced trauma of some kind, although
 this on its own is not enough to explain the development of
 the eating disorder. It is very important that sufferers adversely
 affected by emotional, physical or sexual abuse seek treatment
 for this trauma from a psychiatrist or psychologist, along with
 treatment for their eating disorder.

How common is anorexia nervosa?

Anorexia nervosa occurs in about 0.5% of girls and young women in developed societies. Of all people with anorexia nervosa, one in ten is male, with young males being most commonly affected. In children under the age of 13 years, nearly one in four affected individuals is male.

How serious is anorexia nervosa?

Anorexia nervosa has one of the highest death rates (between 10 and 20% in 20 years) of all mental illnesses. Death from physical causes is five times that expected in this age group, and death by suicide is 32 times that expected. Anorexia can start quite innocently with a diet. People can feel in control and good about themselves when they start to lose weight because they get compliments from friends and family and feel that they are achieving. When told that they have a problem, they can't see it as a problem because for them dieting and losing weight has become a solution – a solution to deeply felt anxiety and negative feelings. However, malnutrition and obsessive rituals relating to food and dieting soon make the sufferer feel out of control and caught up in a downward spiral.

Is anorexia nervosa a lifestyle choice?

No, anorexia nervosa is a mental illness. Sufferers do not bring it on themselves, and cannot just choose to stop dieting or choose to change their negative self-abusive behaviours. Sufferers need to be reassured that they have an illness and, just like other illnesses that affect other parts of their bodies, they need treatment in order to get well. The illness cannot be turned around by people telling a sufferer to just stop it.

Is anorexia nervosa caused by families?

There is no research evidence that proves a link between family dysfunction and the onset of anorexia nervosa, although research supports improved outcomes in anorexia nervosa when families are involved in treatment. Prior to illness, the proportion of families with relationship problems is about the same as the general population. It is common for families to become distressed and experience very high levels of anxiety once the diagnosis is confirmed. In spite of this, most families maintain support and are keen to help wherever possible. Many families become frustrated by the illness and sometimes with the response of health professionals. For some people, by the time they get help, problems in family relationships have developed. Families and friends are a vital part of the recovery process and should be given the opportunity to be included in the recovery journey so that sufferers can get extra support between visits to their health service professionals.

Families do not 'cause' anorexia nervosa – but they are a very important part of the recovery process.

Is recovery possible?

Yes, people can fully recover from anorexia nervosa. Research says that if anorexia nervosa is treated early in its course, particularly in children and adolescents, then recovery occurs more quickly and more often than if treatment is delayed. Those who return to a near-normal weight during their first treatment period are likely to do better than those who don't. Although weight restoration is absolutely essential in the first part of treatment for future recovery, it is important to

note that healing the mind and reaching full recovery may take years. Anorexia can steal years of socialisation and education from young people, and it can take years for them to catch up, so ongoing treatment is recommended to support people with anorexia nervosa as they progress through their recovery.

The word 'recovery' has different meanings for different people. Many who have experienced anorexia nervosa and are now living free from the illness often describe recovery as a journey of transformation and self-determination. It may be difficult to picture recovery as a place where you simply arrive one day with the absence of any eating disorder behaviours or thoughts, as this may seem so far away. However, picturing recovery as a journey often provides those who are engaged in this process with a more constructive way of living and coping, and helps to increase their confidence and pursuit of health.

Travelling on the road of recovery has been described by past patients as: 'Getting my life back... Living in peace from intrusive and repetitive thoughts... Going out to eat with friends and family and not having to worry and stress about the food... Having the space in my head to think about more important things again... Getting back to education and work... Being okay with who I am and what I look like now... Having more confidence and self-esteem to do things I never thought I could... Having more meaningful relationships... Having energy and motivation to discover, plan and follow my dreams again... Having more joy in my life and also feeling sadness in a more authentic way... Not feeling numb anymore.'

Recovery may look like some or all of these things, plus a whole lot more. Whatever it may look like and feel like along the way, the road of recovery, and the pursuit of wellness, is worth it and very possible.

Can anorexia nervosa be prevented?

Research cannot say yet if it is possible to prevent anorexia nervosa or other eating disorders. Research suggests that you can reduce its severity and impact if you treat the problem early. Research is also indicating that there are early warning signs in young children that may indicate a greater risk of developing anorexia. Prevention focuses on treating anxiety, and boosting self-esteem in young people. Teaching people to be critical of media messages that promote being thinner as being more successful in life is also a strategy that can help reduce the risk of children developing an eating disorder.

Who is at risk of developing anorexia nervosa?

- Those who play sports that focus on a high control of diet and that demand a slim or muscular build e.g. ballet dancers, jockeys, athletes, gymnasts, football players.
- Those in occupations that focus on the value of a thin body, e.g. modelling, TV, media, the fashion industry, advertising.
- Those with low self-esteem and/or perfectionist personality traits.

Denial of anorexia nervosa is very common and can delay treatment. When you suggest to a sufferer that they may have a problem, it's important to acknowledge that the eating disorder may be the sufferer's only way of coping at the time.

What does a diagnosis of anorexia nervosa mean?

Your health service professional will determine whether you are suffering from anorexia nervosa by asking you questions. There is a clear set of physical and psychological clues that are used to distinguish anorexia nervosa from other causes of weight loss

Early **physical** clues may include:

- loss of periods or failure to begin menstruating in girls
- weight loss without evidence of any other illness that would explain weight loss
- poor peripheral circulation resulting in cold mottled hands and feet
- unexplained fatigue or fainting
- unexpected dental decay.

Early **psychological** clues may include:

- an obsessive concern about body weight and shape and dieting
- an unrealistic perception about being fat
- an extreme fear of getting fat or gaining weight or of eating.

Early **behavioural** clues may include:

- cutting out foods once enjoyed
- avoiding sharing meal times with others because of food anxieties
- excessive or secretive exercise
- vomiting and using laxatives (purging) as part of a pursuit of thinness
- social withdrawal.

Get help as soon as you suspect anorexia nervosa. Anorexia nervosa causes severe malnutrition.

Starvation can cause structural brain changes, which may have long-term consequences for cognitive functioning and inhibit the ability to recover or shift negative behaviours.

Starvation and malnutrition can lead to heart failure and sudden death.

Symptoms as anorexia nervosa progresses

Mental deterioration:

- increased depression, anxiety and irritability
- increased rituals related to eating to avoid experiencing anxiety
- increase in body image distortion
- lack of concentration
- difficulty in thinking logically and rationally
- increase in irrational thoughts in relation to fear of fat, e.g. ideas that you can get fat by sitting in a cafe or from food that touches you.

Physical deterioration:

- poor peripheral circulation resulting in cold, mottled hands and feet
- blacking out (fainting)
- loss of periods
- fatigue
- changes to the texture of skin, nails and hair
- yellowing of skin associated with eating large quantities of vegetables or fruit containing carotene
- loss of hair
- fine body hair growing on the back, arms and face as the body tries to stay warm (lanugo hair)

- metabolic slowing to save energy signs include slowing of the pulse, reduced blood pressure and lowering of body temperature (you will feel cold more often when this happens)
- dental problems
- heart problems and heart failure
- swollen ankles
- dehydration and kidney failure
- liver inflammation.

A common mistake is to confuse the purging and vomiting form of anorexia nervosa with bulimia nervosa. Eating disorders are spectrum disorders and many people needing treatment do not necessarily meet specific diagnostic criteria.

What to expect at the initial assessment from a GP or medical health professional

A general practitioner (GP) is often the first point of contact. GPs, mental health centres or community health centres can provide you with a first assessment to discuss your concerns about anorexia nervosa.

GPs should provide a diagnosis and a full physical check up, and organise other health professionals who may need to be involved in your treatment team, including providing a referral to a psychiatrist, dietician, psychologist, family therapist or social worker.

Many people are teenagers when they first suspect they have anorexia nervosa. It is best to tell a family member what you suspect, and to seek their help in going to the first assessment. People you live with can give important perspectives that may be crucial to diagnosing the condition.

GPs should cover the following aspects in the initial or follow-up consultations:

- an exploration of what is going on in your life that may have led to your illness
- a physical examination, including your temperature, pulse and blood pressure
- a summary of your general state of health
- information on the medical complications of the illness
- information and explanations about the illness itself
- explanations of the roles of the different health professionals
- services and information available, including a referral to an eating disorder specialist.

At follow-up appointments, matters to discuss with the GP may include:

- results of any tests
- clarifying referral options (e.g. waiting lists)
- the aims and duration of specific treatments
- the cost of treatment with different health professionals
- tactics to regain weight
- strategies to improve your sense of self and identity
- tactics to handle the emotional feelings that anorexia nervosa produces
- discussion about whether you are at risk of harming yourself
 whether you are safe both physically and mentally.

What to expect from the initial consultation with non medical health service professionals

Other mental health workers should be able to recognise anorexia nervosa and therefore can provide a diagnosis, but cannot physically examine you. They can give you the same sort of information as a doctor can about anorexia nervosa, but physical examination and medical tests to assess your overall physical health can only be done by a doctor.

An important part of diagnosing anorexia nervosa is the mental health assessment and, in particular, the link between eating behaviour and your thoughts and feelings about eating, and your weight, shape and body.

A psychological or mental health assessment may include questions about:

- life at home, at school, at uni, at work and amongst your family and friends
- · when it all started
- whether it started with a diet
- your motivations for dieting: were you encouraged to diet by those around you or did you start dieting with someone else?
 (maybe this person needs to be involved in the healing process)
- your feelings about your weight, body and looks
- anxiety about eating
- eating problems, including dietary restriction and binge eating
- weight loss strategies, including dietary restriction, exercise, vomiting and laxative use
- other activities, including socialising, and alcohol and drug use

- general perceptions of how life is going, in particular, your perceptions about changes to your routines in relation to past activities, school or social life
- exercise routines
- relationships at home, school and work
- coping patterns and support available to you.

During an assessment by a dietician, you typically will:

- be asked to give very detailed information about your eating patterns
- be asked to keep a food diary
- be given detailed information about the quality of what you are eating
- be given detailed advice on what to eat to restore normal nutrition slowly.

Getting treatment

Research is starting to identify some effective treatments for anorexia nervosa, including family treatment for children and adolescents. However, there remains much work to be done. It is important to understand that just because there may be no proof about whether or not a treatment works, does not mean that the treatment may not be effective. It may be that the treatment works but there just hasn't been enough research yet to provide clinical proof.

The aims of treatment

The aims of treatment for anorexia nervosa are to:

- restore weight and reverse malnutrition
- achieve wellbeing
- not make you fat but to keep you safe and healthy
- give you freedom from mental anguish
- give you back your life
- identify your true values to help you discover your passions and your own identity
- set you free.

How will treatment get me well?

Effective treatment can:

- prevent physical debility by restoring nutrition and weight
- address concerns and fears about eating and weight
- treat depression and obsessional thinking
- restore normal functioning including work, school and social participation
- maintain, support and improve relationships with family, partners and friends
- · resume normal psychological and physical development
- restore autonomy and prevent relapse and disablement
- support families or partners.

Does treatment work?

Often only small numbers of people who have or who are recovering from anorexia nervosa are willing and able to participate in research. There has been very little research into the effectiveness of different treatments worldwide, however, there is good evidence that treatment can lead to recovery for the majority of people.

- Research shows the earlier treatment is started the more chance there is of recovery.
- Consensus supports that a variety of different therapies provided by a multi-disciplinary team is the most desirable way to treat a person with an eating disorder.
- The kinds of treatment available that are known to be effective include family therapy and specialist psychotherapy.
- Treatment does not have to be inpatient treatment in a hospital.
- Effective treatment can be delivered in day programs or outpatient settings.
- Inpatient treatment is an important life-saving measure for re-feeding and resuscitation, although not a final solution for the illness.
- Long-term treatment is best delivered out of hospital in an outpatient clinic or day program.
- In children and adolescents with an illness history of less than three years, there is a growing body of support for the efficacy of family therapy that focuses on food and weight restoration. The most well known of these therapies is Maudsley family therapy.
- Evidence suggests that weight restoration improves treatment response and prevents potential long-term physical complications in anorexia nervosa.

Treatment settings include: outpatient therapy, day programs, inpatient care and specialised clinics.

Treatment provided by a team is highly desirable.

Restoring nutrition – the only way forward to freedom from anorexia nervosa

It is difficult to accept that weight restoration is a non-negotiable aspect of treatment. However, it is an essential first step towards recovery. Unless your brain is fed, you can't think and therapy will not work. Every effort is made to help you do this yourself by supporting you around meal and snack times. Your dietician or nutritionist are able to help you by designing a snack plan that is right for you.

If at first you find it too difficult to eat food, there are balanced food substitutes, however the ultimate goal of treatment is to get you eating normal foods without fear. You will need to be supported by your treatment team, friends and family to help you stick to your meal plan.

In some cases, it may be necessary for life-saving nutrients to be given through a nasogastric tube. Although this may be uncomfortable, if done with compassion and care, this temporary measure can be very effective and potentially life-saving.

Restoring normal nutrition is essential for recovery, but on its own is not enough to prevent relapse. Psychological change is also needed.

What to expect from psychological treatment and why it is important

Break denial and overcome anxiety about change and getting help. Denial is very common as initially dieting seems to be an effective solution to psychological anguish.

Psychological intervention assists sufferers to move from this denial stage into a phase of contemplation, followed by acceptance and recovery.

Let family or others provide emotional support. Allow families to be a part of the journey of recovery by giving them education and reducing negative reactions or behaviours they may be displaying. Give them the tools to help.

Priority 1: Get help to eat again to restore nutrition. Restoration of nutrition helps in the processing of thoughts so that psychotherapy or family therapy has a greater chance of being internalised.

Priority 2: Maintain and normalise eating by addressing distorted perceptions and obsessional thoughts.

Priority 3: Address anxiety and depression and restore normal function. Anorexia nervosa can make you suffer from extreme anxiety and can lead to depression. Psychological intervention can help you learn to handle anxiety and can treat depression.

Maintenance: prevent relapse and address any other health impacts of anorexia nervosa by providing ongoing care that becomes less intensive over time. It is most important that once weight is restored treatment isn't abandoned. Eating disorders take many years to go away and so ongoing treatment is essential. Support around food and eating is the beginning but sufferers need ongoing support with lifestyle, including socialisation and fitting back into normal life. They need to learn new skills to handle stresses as they come up in life without reverting back to the behaviours of an eating disorder.

Medical and psychological assessment: assessing where you are at in order to define your illness and plan your treatment.

Behaviour program and special diet. Normalising eating and behaviour, breaking down food phobias and teaching you what is a normal portion size for you.

Family therapy.

Supported eating by a dietician or trained counsellor, specialist psychotherapy, cognitive behavioural therapy, and/or medications.

Specialist psychotherapy, family therapy, cognitive behavioural therapy, narrative therapy, dialectical behavioural therapy (DBT), etc. is provided by a range of mental health workers including psychologists, psychotherapists, counsellors, and family therapists. It is important that the person you go to is qualified to treat anorexia nervosa and that they work in a team that includes a doctor and a nutritionist or dietician.

Keep up with support for healthy eating if necessary by revisiting your dietician on a regular basis.

Keep up psychological help for as long as is needed – eating disorders are not over once weight is restored; they are deeply imbedded psychological illnesses that require ongoing psychological support until the sufferer feels safe to proceed on their own in life.

What psychological treatments are available?

Different treatments have very specific roles, and the appropriate treatment will depend on the severity of the illness and your stage of treatment or recovery. Treatment can be akin to a bunch of keys and a lock. The treatment options are the keys and the lock is your head – some sufferers find that they need to try a couple of different treatments before they find the one that works best for them. You have not failed if you feel that you wish to change the focus of your treatment, but this is best done through consultation with your health service professional.

Supportive psychotherapy – This is counselling conducted by either a medical or non-medical health professional. It is 'supportive' in that it discusses with you your experiences of anorexia nervosa and other life issues with respect, care and consistency to guide you to recovery without attempting to change your basic personality. Supportive listening to your experience and its emotional impact is a key component. Research and consumer feedback deem this treatment to be helpful, especially in early phases of therapy.

Family therapy – In recent years there is a growing body of evidence for the effectiveness of family treatment for children and adolescents up to 19 years of age, in particular treatment focusing on eating and weight restoration. The most well known family treatment is Maudsley family treatment, which focuses on supporting parents to feed their child with anorexia nervosa and sees families as essential to recovery. Treatment involves three phases over a 12 to 18 month period and will generally involve 20 to 30 treatment sessions supported by regular medical and psychiatric reviews. In the initial stages of treatment, parents take on responsibility for their child's eating and weight gain, while brothers and sisters focus on supporting the young person with the eating disorder. At the same time anorexia nervosa is 'externalised'

– seen as separate from the young person. Over time, once safe eating and weight gain have been achieved, the treatment supports the young person to take back control of their own eating. The final stage of treatment addresses adolescent, social and psychological risk factors for relapse of eating disorder symptoms and supports the return to normal daily functioning. It is an intensive treatment that requires considerable efforts from families, but is associated with high rates of recovery and reduced duration of illness.

Psycho-education – This term really just means getting information and education about anorexia nervosa and other mental health issues as well as information about the treatments and their purpose. It is based on listening to your information needs and readiness, and helping you become fully informed so you can take charge of your health.

Cognitive behavioural therapy (CBT) – This psychological treatment can be provided by medical or non-medical staff. It is usually performed by specially trained psychologists and involves looking at how you think and how your thoughts shape your behaviour. The treatment tries to get you to modify your behaviour by adopting more helpful thinking patterns. Modifying anxiety about foods and beliefs about weight is a key focus. In early phases it may focus on reasons to change and reasons why it is hard to change. CBT is also used to treat depression where the focus is to change negative perceptions about events in your life and promote positive activities.

Interpersonal therapy – This therapy has a role to play if a person with anorexia nervosa has identified relationships as a problem. Those with anorexia nervosa may often have strained relationships. In this therapy you are taught to approach relationship issues differently. While it is not proven to 'treat' anorexia nervosa specifically, it has been shown to reduce depression, which often exists with anorexia nervosa.

Psychodynamic oriented psychotherapy – This treatment is similar to interpersonal therapy but is often longer term, focusing on past patterns of emotion and relating to others.

Narrative therapy – This treatment helps the person to view anorexia nervosa as an external problem affecting their life story, and not one about the true self. The person is encouraged to change their life story by defeating anorexia nervosa and its negative messages and impacts.

Motivational enhancement therapy – There is emerging interest in the application of motivational interviewing to the treatment of anorexia nervosa. This approach has been evaluated as useful in the treatment of alcohol and drug addiction because its focus is upon your readiness and/or resistance to change. The therapist gives you feedback on your current stage of readiness to change, and tailors treatment advice to that stage. The therapist also helps to motivate you and support you to judge for yourself the benefits and drawbacks of change and prepare for those benefits or drawbacks. Direct confrontation is avoided. The stages of change are:

- pre-contemplation
- contemplation
- preparation/determination
- action
- maintenance.

Each stage gradually becomes more active and brings with it gradual changes in lifestyle, eating and meal routines and other psychological, social and emotional changes.

A range of other therapies may be used. These may include music therapy, art therapy and trauma counselling.

How treatment is delivered

Most often in Australia, treatment is delivered on a one-to-one basis (individual therapy), however, a range of psychotherapies may be delivered in group settings by professionals outside of hospitals in outpatient clinics. Treatments may also be delivered in day programs as part of a comprehensive program that may include nutritional counselling and re-feeding.

Does medication work for anorexia nervosa?

There is no anti-anorexia nervosa medication that is specifically designed to treat anorexia nervosa. However, medications have been found to be useful for treating some of the conditions that occur with anorexia nervosa. 'Co-morbidity' is the term used when one or more illnesses are present at once. For example, anxiety, obsessive compulsive disorder and depression are common in anorexia nervosa. Although there is no evidence that anti-depressants are effective against anxiety and depression in anorexia nervosa, if an anti-depressant is used, Selective Serotonin Reuptake Inhibitors (SSRIs) are a preferred type because they are safer for your heart. It may be helpful to think about medication as another strategy and option in treatment. Medication can help you to cope with the varied symptoms that can accompany an eating disorder.

Sometimes antipsychotic medications are prescribed. Being prescribed anti-psychotic medication need not mean that you have psychosis, or that you are going 'crazy'. These medications are sometimes used because they can also reduce anxiety, distress and obsessional thoughts about food, weight and body shape without the risk of addiction.

Examples of anti-psychotic medications include:

- olanzapine (Zyprexa)
- quetiapine (Seroquel)
- risperidone (Risperdal).

Certain medications should be avoided because of potential side effects in malnourished individuals. For example, tricyclic anti-depressants are potentially dangerous for the heart if you have anorexia nervosa.

Always discuss medication side effects with your doctor.

Treatment for women's health issues

Anovulation (not ovulating and therefore not having menstrual periods) should be treated by restoring nutrition. Hormone Replacement Therapy (HRT) or the oral contraceptive pill (OCP) are generally not helpful for women with anorexia nervosa.

Women with anorexia nervosa are likely to have complicated pregnancies and can have premature and unhealthy babies. Parenting skills can also be compromised if the anorexia nervosa is unresolved. Most mental health services can provide early intervention and parenting support to help new parents develop these skills.

Low bone density and insufficient calcium is a common health issue for women. It is severely aggravated by anorexia nervosa. The only sure way to restore bone density is by nutritional restoration and physical rehabilitation. Calcium supplements and Vitamin D are of unproven helpfulness in underweight individuals, although intake of adequate calcium through diet or supplements is important when renourished. Bisphosphanates have been used in people with chronic anorexia nervosa, but their long-term effects are unknown.

Socialisation – learning to live again

Once you start to restore your normal body weight, the road to recovery is only just beginning. This is a critical time when treatment is showing signs of working and must continue. Treatment aims to help you get the physical, behavioural and emotional symptoms of anorexia nervosa under control and manage the complications of weight loss, and thereafter, it helps you to rebuild your life. Relapse prevention is extremely important and essential to long-term recovery. It involves ongoing contact with your key health professional in regular psychotherapy and medical monitoring as needed.

Can self-help groups help me get better?

'Treatment', including that provided in groups, is usually differentiated from 'support' of the kind offered by self-help and mutual support groups. Mutual support and self-help groups are usually considered to add value to treatment rather than replace it or be a treatment in their own right. No controlled trials were found evaluating their role in recovery rates for anorexia nervosa.

Non-government organisations of people who have recovered from anorexia nervosa and their families provide referral, information, telephone support and individual advice. Many also provide selfhelp or support groups. Services vary from place to place, and have different philosophies and different structures. Some groups have professionals acting as the group facilitator, while others provide self-

advocacy or self-help groups without professionals participating. Some groups use the support of those who are former sufferers who have training in group treatment.

It is most important to find a support group that is monitored by a professional who can facilitate the group.

How do groups help?

It is not known which type of self-help or support group is most effective. However, groups can help in the following ways:

- to guard against social isolation where no other support is available
- to help persuade a person to seek assessment and treatment
- to provide encouragement to stay in treatment
- to provide information about what to expect from treatment
- to provide support to families and friends
- to provide support to those awaiting access to treatment
- to learn that the journey is best shared.

The organisations listed in Appendix 2 can provide details of where and when support groups are held, along with other information.

Living through the journey to recovery

The experience of anorexia nervosa is different for everyone. Whether you are a consumer or a carer, living through anorexia nervosa may involve periods of medical or psychological crisis, periods of improvement and periods of relapse and loss of hope. Sometimes persisting with treatment can be difficult. This section provides advice for people who have been through this experience and covers aspects of treatment, emergency situations, looking after yourself, and information for carers.

Cultural needs

Health professionals should always respect and cater for the wide diversity of cultural groups in our community. Depending on your cultural background or religious beliefs, when you are seeking treatment, or helping a person you care for get treatment, you may have special requirements that you need to communicate to the health professionals you encounter. You may need to request:

- a translator if your first language or that of the person you care for is not English
- explanations of medical or other terms that may not be clear
- respect for your religious practices and understanding of the roles of males and females in your culture
- a clinician of the same gender as you or the person seeking treatment
- treatment provided in a particular setting (you may have a cultural preference for home or hospital treatment)
- special food or access to a prayer room if you need to go to hospital
- understanding of your family's expectations of treatment.

It is very important to discuss cultural issues with your health care provider, to enable them to better understand you and so that your religious beliefs and cultural practices can be incorporated into your treatment plan.

The treatment plan

A treatment plan is your road map to recovery. Treatment planning is a partnership between you, your carers and your clinicians. Your plan should be flexible to cope with changing needs and circumstances. It may also include or inform your family or partner, especially in the case of adolescents and young people. Setbacks are common and are a part of the recovery journey. Planning for them can make them easier to deal with.

Important aspects to consider are: where is treatment provided, and are the people qualified?

Treatment is not all about food and eating – it is about you as a person and what is important to you.

Where are treatments provided and what do they cost?

Because anorexia nervosa is a long-term illness for many people, a range of settings is usually considered for treating the condition.

Settings may include the following:

- hospital in-patient treatments for resuscitation and in some instances re-feeding only
- comprehensive day programs or other non-residential programs
- intensive outpatient treatments
- intensive outpatient support programs.

Treatments are available through public or private sector providers. Private sector treatments can be expensive, even if you have private health insurance. You can tell your doctor or mental health service if you are unable to afford these costs. Some public hospitals, community mental health services and doctors with special training in eating disorders may offer more affordable treatment.

It is important to discuss all potential costs involved in your treatment with your health professional.

In Australia, some GPs bulk bill, which means that Medicare will cover the full cost of any visit. If your GP does not bulk bill, partial rebates are available through Medicare and you will need to pay any difference. There will also be an additional cost for any medication that may be prescribed.

Your GP may refer you to appropriate services, such as for psychological services provided by a psychologist or an appropriately trained social worker or occupational therapist. Any treatment provided by these health professionals will only be rebated by Medicare if you have previously claimed a rebate for a GP Mental Health Treatment Plan. A GP Mental Health Treatment Plan will be developed by your GP and tailored to your needs to find the treatment that is right for you, monitor your progress and assist you in achieving your goals for recovery.

Medicare rebates are also available for assessment and treatment by a psychiatrist. A psychiatrist may also refer you for Medicare-subsidised treatment with a psychologist, an appropriately trained social worker or occupational therapist. You may receive up to 12 individual/and or group therapy sessions in a year. An additional six individual sessions may be available in exceptional circumstances.

Your GP may also refer you to other government funded providers of psychological services depending on what is available in your local area.

What qualifications do health professionals need to treat anorexia nervosa?

It is important to seek treatment from health professionals who have expertise in anorexia nervosa, as well as having appropriate qualifications and registration for their profession. Treatments can only help if applied with skill, knowledge and experience in eating disorders. Because of the physical consequences of the illness, a doctor must supervise the treatment in order to monitor your physical health. In most cases, a psychiatrist or psychologist will have a role in directly overseeing all aspects of treatment or giving advice to those involved in your care.

What if I can't get treatment where I live?

If there is a waiting list, or if expert treatment for anorexia nervosa is not available in your area, or if you can't afford treatment being offered, you can ask for a referral for an alternative option. People from rural and regional areas regularly attend treatment centres in major capital cities. At other times, specialists from the city can work by phone to help local health professionals manage your care where you live. Your GP or mental health service are able to co-ordinate these services for you. A multi-disciplinary team can be put together for you by your psychologist, dietician or GP outside of a specialist eating disorder clinic. If you need help putting a team together, you can contact a community eating disorder association, which can help you with this. (See Appendix 2 for organisations in your State.)

How will your progress be monitored?

Reduced eating can damage the whole body and it is important that nutritional status is monitored regularly. This is done by a measure called the Body Mass Index (BMI) or Percentage Ideal Body Weight (%IBW) in children and adolescents. BMI is easily calculated as weight in kilograms divided by height in metres squared (kg/m2), while %IBW is worked out from height and weight charts for children. A low BMI or low %IBW is one of the criteria for diagnosing anorexia nervosa. Measurement of body fat may also be done.

Regular physical examination is important and involves monitoring of blood pressure, pulse rate, temperature and circulation. In children and adolescents, growth and pubertal development are also reviewed.

Your blood biochemistry may be tested for things such as potassium levels in the blood and for raised urea levels, which indicates dehydration. Electrolyte disturbances such as low potassium are especially common in people who vomit a lot and can lead to heart problems that may be fatal. (This is because potassium is important in the electrical activity of heart muscle.)

Heart failure is a potential serious complication in anorexia nervosa. An electrocardiogram (ECG), a test that checks your heart, is usually required. If there are problems, a heart specialist may do more tests including an echocardiogram (heart ultrasound).

Bone density can be affected. Osteopaenia (low bone density) leading to osteoporosis is a serious longer-term complication. It can result in stress fractures in feet and crush fractures in the spine. Bone scans are usually carried out.

Endocrine disturbances are often investigated and oestrogen and thyroid function is checked.

Do I have to go to hospital?

The majority of people with anorexia nervosa are treated outside of hospital, and hospitalisation is only one component of overall care. Anorexia nervosa can be an illness of many years' duration; hospital treatment is usually offered on a short-term basis only for resuscitation or stabilisation. To improve outcomes, maintain family and social relationships and support normal daily functioning, undergoing treatment without hospital admission is encouraged where possible. Day hospital programs provide one alternative to hospitalisation. In some cases they can be less disruptive, cost less and can be equally effective. Similarly, outpatient care can be effective in the absence of severe malnutrition.

It is more common to be treated in intensive outpatient or day program settings. However, if your life is threatened (e.g. you require resuscitation or you are at risk of harming yourself) inpatient hospital services are essential.

What about after hospital?

Because most treatment will take place outside of a hospital, it is important that all aspects of treatment are carefully co-ordinated through communication between hospital staff, your GP, your community treatment team and, for children and adolescents, their school. 'Discharge planning' involves a meeting to organise post-hospital support to help you stick with your treatment plan and keep you safe. For children and adolescents, discharge planning involves both the individual with anorexia nervosa and their families. For adult patients, it is a good idea that your family or carer be given skills to help at this stage.

Managing mealtimes and routines will typically be a key part of your discharge plan, as will scheduling follow-up counselling sessions.

This is why your family and friends are a very important key to your

recovery as they can support you after your discharge from hospital. This can be an exciting time for you and your family and friends, as you settle back into everyday living and day-to-day routines, and pursue new opportunities in life.

Relapse can occur if treatment isn't continued post hospital in an outpatient setting. Make arrangements to keep up treatment as soon as you get home.

How do I find information about a hospital admission?

It is a good idea to ask for a booklet or information prior to your admission to hospital. It is important for you to know:

- explanations of the treatments and what to expect from treatment, e.g. knowing what re-feeding involves can reduce anxiety and fear
- any treatment alternatives available
- how the treatments work
- how long you will be expected to stay in hospital
- the availability of add-on treatments such as art therapy, music therapy, lifestyle education, cooking education, shopping education, general school tutoring or education
- how your health care team will know when you can go home
- how much your hospital stay is going to cost you
- the admission procedure and the discharge procedure
- the hospital's philosophy or ethos
- whether treatments can include your family if you wish
- your rights
- the standard of care to expect

- the roles of the different health professionals
- the rules and policies of the health care agency
- information about legal orders if they apply to you and your rights in respect of these.

What medical complications and emergencies can happen?

Both medical and psychiatric emergencies can arise with anorexia nervosa, and they can be life threatening. You don't have to have a chronic form of illness for a medical emergency to arise. Lack of food over a fairly short period of time can very rapidly result in serious health consequences.

Extreme emaciation, serious electrolyte disturbances, heart irregularities, severe dehydration, low body temperature and confusion (from a starved brain) require urgent treatment in a medical intensive care unit.

If you have anorexia nervosa, you do not necessarily display the illness characteristics you might expect for someone who is starving. Your exercise routines, for example, might change your body's reactions and responses. Others might assume that you feel very well due to your exercising, when in fact you may be on the verge of a medical emergency.

In medical emergencies, hospitalisation is essential. In cases of malnutrition, adequate re-feeding is essential, although overhasty re-feeding, particularly with a high carbohydrate diet or a sugar intravenous drip, can lead to the development of the 're-feeding syndrome'. This is where a sudden increase in nutrition places overwhelming demands on the starved body's metabolism. If this should happen out of hospital, it requires hospitalisation to correct. It can cause heart failure and death.

What if I don't want treatment or refuse it when in a crisis?

Sometimes people with anorexia nervosa may find treatment and the consequences of the illness so stressful that they experience depression and suicidal feelings. Sometimes they refuse treatment and this can be life threatening. Crisis situations include when a person:

- refuses medical treatment that may be life saving
- refuses psychological treatment that may be life saving
- is at immediate risk of suicide or self-harm.

Hospitalisation is indicated in these situations. Health professionals are required by law to ensure that you are safe, which is called having a 'duty of care'. For example, they may hospitalise you against your will under the Mental Health Act, child protection legislation, through the Guardianship Board or involve a next of kin in a crisis to help ensure that you are physically safe. They should explain to you their 'duty of care', your rights and those of your family in these situations, and take into account your preferences. The goal should be to ensure the safest arrangement with your agreement wherever possible.

Legal considerations for you

Legal information for consumers and carers differs from State to State. Check with your State or Territory health department regarding mental health legislation for your location.

It is best to try to prevent the occurence of any situation where your control over making your own health care decisions is diminished. Some consumers like the idea of a written agreement in the form of an Advance Care Directive. This agreement is reached between you and your health professional and spells out what steps should be followed in a crisis situation. It is like an insurance policy – a plan in case your physical or mental health deteriorates at some future time. This approach is sometimes taken for managing other recurring or chronic illnesses.

Legal considerations for family and carers

When a person with anorexia nervosa refuses treatment, carers may obtain a 'legal order' under guardianship legislation that permits them to take temporary control over the person's care and make decisions on their behalf to authorise medical or psychiatric treatments. This is a last resort option only for the purpose of saving a life.

The law is different in every jurisdiction and more information is available about this topic on the websites of eating disorder associations and foundations (see Appendix 2).

What about confidentiality?

In Australia, the age at which you can seek a confidential medical consultation varies from State to State. Health information you agree to share with your family or carer can be provided to them by the health professional working with you. If you are below the legal age for medical confidentiality, parents will usually be included in all discussions about your health and welfare. However, it is recommended that you, your health professionals, and, where possible, those you nominate to be involved, work together to speed recovery.

No matter what your age, health professionals can share some general information with your immediate family without breaching your confidentiality. Examples are:

- general information on the illness and common complications
- advice to help them give you support
- discussion, in general terms, of common risks for people during treatment.

However, the exact medical facts in your case remain your private health information and what you discuss about your feelings and details of any psychological therapy remains private between you and your mental health professional.

Are there limits to confidentiality?

Yes, there are limits to confidentiality. Examples of situations in which your health worker might disclose information to others may include:

- informing someone else (another professional or your next of kin) if there is a medical crisis
- notifying others if you express imminent risk of suicide intent or plans, and discussing with them how they might help.

What a health professional discloses to your family or partner will depend on your age, the level of contact your family has with you, other issues concerning your circumstances, and any safety considerations.

What are my rights?

You have both rights and responsibilities in treatment. For example, you have a right to:

- confidentiality wherever possible, including knowing what is told to others and when and why
- make decisions about your treatment and to offer suggestions as to what you think might work in your case and to have your preferences respected
- being treated with respect and dignity
- having your age taken into account and being treated accordingly
- being treated in a way that respects your growing knowledge of your health over time
- decline and refuse treatment in non-life threatening situations
- complain if you are unhappy about your care.

Standards and other issues

People experiencing a traumatic and life threatening illness such as anorexia nervosa are entitled to fair and reasonable standards of care. Consumers generally agree that some things are critically important in helping them progress in treatment. For example, it is important that health professionals:

- show respect
- be kind
- not be punitive
- not be abusive
- explain their role in the treatment of anorexia nervosa
- work as a team when providing services
- recognise your medical, nutritional, psychological, social and emotional needs
- provide treatment that is holistic and provided within an open-ended time frame and in a healing environment in order to optimise chances of full recovery
- be flexible to cater for the changing nature of your needs during treatment
- provide prompt referral to other specialised health professionals so that all aspects of treatments are covered
- liaise closely with their expert colleagues if they have limited experience or expertise in anorexia nervosa
- work collaboratively within a team, co-ordinated by them or another health professional involved in your care
- act as your advocate through the treatment process
- provide moral support
- not refuse to help you without offering you an alternative
- extend help or referral to your family.

It is also recommended that you check the qualifications that health professionals hold. The following are possible qualifications that you could ask about. There may be others.

For general practitioners:

- Are they a Fellow of The Royal Australian College of General Practitioners (FRACGP) or similar?
- Are they a member of their local Division of General Practice?
- Do they have a post-graduate (e.g. Masters) degree in Psychological Medicine or other further training in psychological medicine?

For psychiatrists:

 Are they a Fellow of The Royal Australian and New Zealand College of Psychiatrists (FRANZCP) or of The Royal College of Psychiatrists (FRCPsych) or an Affiliate of the RANZCP?

For psychologists:

- Are they a registered psychologist? They need to show this on their letterhead.
- Do they have a Masters degree in clinical psychology (MPsychol) or a postgraduate qualification such as a PhD in clinical psychology or a diploma in clinical psychology?
- Are they a member of the Australian Psychological Society (APS) and of the Society's College of Clinical Psychology?
- Are they a member of the Australian Association for Cognitive Behavioural Therapy?

For dieticians:

 Are they a registered dietician? They need to show that they are registered with their appropriate State body as recognised by the Dieticians Association of Australia. Health care complaints systems and tribunals exist in each jurisdiction. You can discuss your concerns with them in confidence, and you can also write to them to lodge a formal complaint. Your complaint is then considered for mediation or investigation.

Being fully informed

Ensuring you are fully informed is often the best way to get the highest standard of treatment for any health problem and that includes for anorexia nervosa. Questions you might wish to ask about your treatment are suggested in Appendix 1.

What families and carers and can do to help

Family or carer involvement with adolescents who have anorexia nervosa is usually critical to the wellbeing of the young person with anorexia nervosa and the rest of the family.

Most people with anorexia nervosa look after themselves by keeping regular appointments with a psychiatrist or other mental health professional on an outpatient basis. Research shows that this improves quality of life, reduces suffering and improves overall chances of survival. But there is still a need for support from other people.

Most families want to help their relative recover. They can support a person by being a 'treatment ally', just as someone supports a person to stop smoking just by being encouraging.

If your family is not helpful in your recovery, you can mention this to your health service professional and they can give you alternative strategies, e.g. if necessary, social workers can help re-locate young people.

Families and carers can support a person with anorexia nervosa in some of the following ways:

- direct involvement in the treatment of their child with anorexia nervosa
- discussing with the person about what support would be helpful
- providing emotional support and encouragement
- providing financial support if needed
- communicating with health professionals when appropriate
- maintaining a caring home environment
- supporting the person after discharge from a treatment centre
- encouraging the person to keep appointments
- upgrading knowledge of the illness/reading as much as possible
- contacting an eating disorder support association for information
- being mindful of the illness and its impacts on the person
- trying not to diminish the person's overall autonomy and independence
- being supportive at, before and after mealtimes, and offering encouragement.

A 'treatment ally' helps you to stick to treatment at times when you just want to give it up.

A treatment ally is not directly involved in your therapy – your relationship with your health service professional is confidential. Your treatment ally is there to support you.

How the illness may affect the family

Families often experience grief, isolation, powerlessness and fear as they witness their loved one struggling with anorexia nervosa. They may find that they cannot understand the person's feelings and behaviour.

¹ Sometimes the whole family can become consumed with the illness. They might appear only to worry about how stressful the next meal will be because of battles over what and how much the person with anorexia nervosa might eat. But in fact, this is likely to be only the surface of their worries. They will actually be distressed about all aspects of wellbeing of the person with anorexia nervosa.

At mealtimes in particular, siblings may feel ignored by parents and the normal social event of mealtimes may be replaced by awkwardness.

Everyone in the family sometimes worries that the person with anorexia nervosa will die. For all concerned it is critical to avoid becoming isolated and feeling like you are alone.

Often there is unnecessary guilt felt by parents who are worried they are responsible for the condition. They may feel frustrated, blame themselves, and feel like they are unable to help.

Families need to identify their own needs separately from the needs of the person with anorexia nervosa, and to discuss their needs with professionals or carer support organisations.

Friends can also find it hard to help a person with anorexia nervosa, and this can result in more isolation for the person concerned. Partners of people with anorexia nervosa may not know how to help or how to feel during periods when the condition worsens.

Consumer perspectives on carers' concerns

People living through anorexia nervosa are not at fault for the condition and are distressed by the fact that the illness causes worry to others. Mostly they want carers to get professional help for their worries if this is needed, and for all the people in their lives to help create an atmosphere of hope where recovery is everyone's goal.

Carers can benefit enormously from receiving outside psychological help. Changes in their behaviour, such as reduced anxiety and learning what to say and what not to say, can affect behaviour in their loved one who is suffering from anorexia nervosa.

Working together for recovery

Despite the difficulties, family and friends need to keep talking about the problem. Even though this may not be welcomed by the person with anorexia nervosa, the problem rarely gets better by itself and it is not made worse by talking about it.

Families may find that some services and health professionals do not listen to their views about their relative. Professionals may not always give them information about their relative, particularly if the relative is an adult. Carers seem to agree that they need to know how the person is going with their illness and treatment.

Ideally, open communication between professionals, families and the person with anorexia nervosa is to be encouraged. If families share information, skills and support with their relative and the health professionals who look after them, the likelihood of recovery is generally thought to be better.

¹ The Mental Health Foundation of New Zealand (2002) provided information used in this section.

Living through anorexia nervosa can be an overwhelming, frightening and isolating experience. It is considered important for everyone to believe that the person can recover to lead a worthwhile life.

Families feel bullied by anorexia and need to know it is okay to keep talking about it and trying to demystify it.

Continued care of chronic illness in the community

Some people with anorexia nervosa will have a chronic and long-term illness. If this happens to the person you love with anorexia nervosa, it is important that all concerned maintain realistic goals, which aim to improve the quality of their life and yours. The goal at this stage is more to stabilise health as best as possible, as it may take many years for the sufferer to reach the point of change. It is not unknown for people to recover after more than 20 years of illness.

Appendix 1

Questions to ask your therapist

- What is the diagnosis?
- What can I expect if I don't get treatment? What happens if I do nothing?
- What are the treatment options?
- What are the benefits and harms (costs) of the treatment options?
- How long will it take?
- What results can I expect?
- How much time and/or effort will it take me?
- What will it cost me?
- Is there anything that would complicate treatment (other problems that may make treatment more difficult and delay the benefits)?
- Can we make a time to review progress and if necessary revise our treatment plan?
- Are these the latest treatment guidelines for my condition? Can you recommend any reading material including self-help books?
- How do the benefits and harms weigh up for me?
- Can I speak to someone who has been through treatment with you? Or can I speak to someone who has been through this procedure with other therapists?

Questions to ask about medication

- What is the name of the medicine?
- When and how often do I take the medicine?
- Are there any special instructions for its use?
- What are the side effects? Will I be tired, hungry, thirsty, etc?
- Are there any foods I should not eat while taking it?
- Can I have beer, wine or other alcoholic drinks?
- Can I take the medicine with other medicines I am taking?
- What do I do if I forget to take the medicine?
- For how long will I have to take the medicine?
- What are the chances of getting better with this treatment?
- How will I know if the medicine is working or not?
- What is the cost of the medicine?

Key questions to ask when choosing a health professional

- How many patients with anorexia nervosa have you treated?
- Do you have any special training in anorexia nervosa treatment?
- What is your basic approach to treatment?
- If you provide only one type of treatment, how do I get other treatment if I need it?
- How frequent are treatment sessions? How long does each session last?
- What are your fees?
- Are your fees subsidised by Medicare?
- If your fees are not subsidised by Medicare, can you help me determine whether my health insurance will cover fees?

Appendix 2

Sources of information and support

For further information on this guideline and other Clinical Practice Guidelines see www.ranzcp.org.

The list of organisations and information sources provided in this Appendix, whilst not exhaustive, may further support you in learning about and managing anorexia nervosa. Inclusion of these organisations and information sources does not imply RANZCP endorsement but rather aims to help people find information and to encourage communication about mental illness.

These organisations and resources are not intended as a replacement for formal treatment but as an adjunct to it. If you are unsure about any of the information you find or would like to know if a treatment you read about may be appropriate for you, you should speak with your mental health care professional.

NATIONAL AND INTERNATIONAL

The Butterfly Foundation

Counselling Service: (02) 9412 4499 NSW; (03) 9822 5771 Victoria

Counselling Email: support@thebutterflyfoundation.org.au

Email: info@thebutterflyfoundation.org.au Website: www.thebutterflyfoundation.org.au

Australia and New Zealand Academy for Eating Disorders (ANZAED)

Email: info@anzaed.org.au Website: www.anzaed.org.au

International Academy for Eating Disorders (AED)

Email: info@aedweb.org
Website: www.aedweb.org

VIC

Eating Disorders Foundation of Victoria

Phone: (03) 9885 0318

Email: edfv@eatingdisorders.org.au

Helpline: 1300 550 236

Email: help@eatingdisorders.org.au Website: www.eatingdisorders.org.au

The Victorian Centre of Excellence in Eating Disorders

Phone: (03) 8387 2669 Email: ceed@mh.org.au

Website: www.rch.org.au/ceed

QLD

Queensland Eating Disorders Resource Centre

Phone: (07) 3394 3661 Email: admin@eda.org.au Website: www.eda.org.au

ISIS Centre for Women's Action on Eating Issues

Phone: (07) 3844 6055

Gold Coast Eating Disorders Association

Phone: (07) 5522 8865

SA

Eating Disorders Association of South Australia

Phone: (08) 8297 4011

Email: support@edasa.org.au Website: www.edasa.org.au

TAS

Tasmania Community Nutrition Unit

Phone: (03) 6222 7222

Email: community.nutrition@dhhs.tas.gov.au

Anorexia and Bulimia Support Group

Phone: (03) 6225 0131

NT

TEAM Health

Phone: (08) 08 8948 4399

Email: teamhealth@teamhealth.asn.au Website: www.teamhealth.asn.au

WA

Contact Western Australian Association for Mental Health to ask for local groups in WA and for referral information.

WAHMH

Phone: (08) 9420 7277

Website: www.waamh.org.au

Appendix 3

Common Terms

Consumer – Person diagnosed with anorexia nervosa (primary consumer).

Family/carer – People who have a close relationship to the person with anorexia nervosa, and who have some responsibility for and care for the person's health and wellbeing, excluding health professionals caring for the patient.

Health professional – Professionals (including mental health professionals) who provide assessment, treatment and follow-up, e.g. psychiatrist, psychologist, general practitioner, dietician, nurse, occupational therapist, family therapist, social worker, medical specialist, counsellor.

Patient – A consumer when currently undergoing assessment, treatment or follow-up. While the word 'consumer' is used in mental health settings, anorexia nervosa is treated by medical teams where the word 'patient' is more commonly used.

Treatment centres – Facilities that provide formal treatment for anorexia nervosa.

Acronyms

BMI Body Mass Index

CBT Cognitive Behavioural Therapy

ECG Electrocardiogram

GP General Practitioner

HRT Hormone Replacement Therapy

SSRI Selective Serotonin Reuptake Inhibitor

Appendix 4

Development of the guideline

This consumer and carer treatment clinical practice guideline is based on information contained in an evidence-based clinical practice guideline developed by the RANZCP for health professionals involved in the treatment of anorexia nervosa. The booklet was produced using a rigorous development and review process undertaken in consultation with consumer representatives, carer representatives and health professionals who are experts in the field. In the original edition, any gaps in the research information were addressed by incorporating recommendations or information derived from the consensus opinion and guidance of eating disorder associations and foundations nationally.

In 2009, the content of this booklet was revised and expanded by an expert advisory panel comprising mental health professionals, and consumer and carer representatives. The purpose of the revision was to ensure that the information contained in the booklet was current and comprehensive in terms of treatment best-practice and therefore remained relevant for people with anorexia nervosa and their carers, families, and friends.

Authors

The co-writer and editor of the original edition was **Jonine Penrose-Wall**, (previously) Consultant Editorial Manager, RANZCP Clinical Practice Guideline Program.

The members of the guideline development committee for the original edition and their then affiliations were:

Ms Pamela Loveridge – Chair and Principal Researcher, representing the Eating Disorders Association of NSW

Ms Glenda Baldwin – Eating Disorders Association of NSW Inc

The expert advisory panel for the 2009 revision comprised:

Phillipa Hay – Foundation Professor of Mental Health, School of Medicine University of Western Sydney

Sloane Madden – Child and Adolescent Psychiatrist, The Children's Hospital at Westmead

Beth Shingles – Consumer Consultant, North West Mental Health at Royal Melbourne Hospital

Claire Vickery – Founder, Executive Chair, The Butterfly Foundation, Australia

Quality statement

The original edition of this guide was consulted upon bi-nationally and drafts were available for comment on www.ranzcp.org. It was appraised using DISCERN by a national workshop of consumer consultants and meets NHMRC criteria for presenting information on treatments for consumers. The 2009 revision sought to maintain the integrity of this process by incorporating updated information supported by research findings published in recent medical and other scientific literature.

Acknowledgements

The RANZCP would like to make the following acknowledgements.

The following organisations contributed to the recommendations used in drafting the original version of the booklet:

Eating Disorders Association of NSW Inc

Eating Disorders Foundation of Victoria Inc

Eating Disorders Association of South Australia

Eating Disorders Association of Queensland Inc

Eating Disorders Association of New Zealand Inc

The RANZCP Clinical Practice Guideline for Health Professionals for Anorexia Nervosa was used as the source document for the evidence-based treatment information. This document was developed by an expert committee coordinated by Professor Pierre Beumont (Chair) and Professor S Touyz (Australia). Ms Daphne Beumont, Ms Sarah Maguire and Ms Peta Marks assisted with the research.

Commonwealth Mental Health and Special Programs Branch funded the development of the original version of the guideline under Australia's National Mental Health Strategy.

The Mental Health Foundation of New Zealand granted the RANZCP permission to use excerpts from their publication *Anorexia Nervosa* (2002) revised edition.

The RANZCP drew on material published by the Medical Practitioner's Board of Victoria and the American Psychiatric Association in preparing this booklet.

The Commonwealth Department of Health and Ageing, and the New Zealand Ministry of Health funded the development and publication of the original edition of this booklet.

The Commonwealth Department of Health and Ageing funded the 2009 revision and reprint of this booklet.

The RANZCP would like to thank Dr Ira M. Sacker MD, Clinical Assistant Professor of Pediatrics, New York University Medical Centre and Bellevue Hospital Medical Centre, and Laura McDonald, MS, for reading the revised booklet and providing their comments.

References

Charnock D (1998) The DISCERN Handbook: *Quality criteria for consumer health information on treatment choices*. University of Oxford School of Public Health and the British Library. Radcliffe Medical Press. Oxon.

Loveridge P (2001) Australian and New Zealand Consumer Guidelines for Anorexia Nervosa (research foundation document of 118 guidelines compiled from consumers and carers in Australia and New Zealand which provided source material for this CPG).

Mental Health Foundation of New Zealand (2002) Anorexia Nervosa.

National Health and Medical Research Council (2000) *How to present the evidence for consumers: preparation of consumer publications.*Handbook series on preparing clinical practice guidelines. Canberra.
NHMRC.

RANZCP (2003) Australian and New Zealand Clinical Practice Guideline for the Treatment of Anorexia Nervosa. This is the Clinical Practice Guideline for mental health professionals, which can be obtained at www.ranzcp.org.



