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anorexia nervosa

treatment guide for consumers and carers

This research-based
guide may become out of
date. Best before

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Contents

Introduction	iv
SECTION 1: ANOREXIA NERVOSA – THE FACTS	V
1. About anorexia nervosa	1
2. Assessment and diagnosis.....	3
3. Treatments.....	6
SECTION 2: LIVING THROUGH ANOREXIA NERVOSA	12
4. Hospitalization, access to treatment and emergency situations.....	13
5. Standards and other issues.....	19
6. What carers and partners can do to help.....	21
Appendix 1: How this guide was developed	24
Appendix 2: Cost of treatments	25
Appendix 3: Questions to ask about your treatment	26
Appendix 4: Information and support.....	28

Definitions

Consumer

Person diagnosed with anorexia nervosa (primary consumer)

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.

Family member/Carer

Persons who have a close relationship to the person with anorexia nervosa that also involves an element of responsibility and caring for the patient's health and well-being, but does not refer to health professionals caring for the patient.

Treatment Centres

Facilities that provide formal treatment for anorexia nervosa.

Health professional

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

Introduction

About this guide

This treatment clinical practice guideline is for adolescents and adults who have anorexia nervosa or who believe they are at risk of developing it. It may also assist family members or carers. Its development was part of a project to develop clinical practice guidelines for professionals involved in the treatment of anorexia nervosa and is for use in Australia and New Zealand. The guide was commissioned by the Royal Australian and New Zealand College of Psychiatrists (RANZCP) with funding from both countries. Guidelines for health professionals and for consumers/carers were developed on five other topics.

This guide was researched and developed by consumers and carers. It is an *evidence-based* guideline as defined by the National Health and Medical Research Council which means that it is based on research and not just opinion. Where opinion is used, it contains recommendations from 118 ‘guidelines’ made by carers and consumers where there are gaps in the scientific research evidence. Our method is outlined in full in Appendix 1.

Objectives

The guide contains the latest research available on anorexia nervosa and recommendations from recovered consumers, to assist you to choose the best kind of treatment. It aims to:

- help consumers to make decisions about their treatment;
- outline the value of interventions at critical times such as diagnosis, admission and discharge; and
- guide on the standard of services to expect.

The sections

The first section, *Anorexia Nervosa – The Facts* contains a research summary. It spells out the facts of anorexia, describes treatments and discusses what the research says about treatment effectiveness.

The second section, *Living through Anorexia Nervosa* describes the experience from both consumer and carer perspectives and draws upon the consensus-level evidence collected from consumer and carer opinion. It provides guidance on how to cope with treatment and the potentially disabling impacts of anorexia. The appendices provide further useful information..

SECTION 1: ANOREXIA NERVOSA – THE FACTS

1. About anorexia nervosa

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 emaciation, physical illnesses such as osteoporosis, and disruption to emotional, social and educational development. It can also be life threatening. It has a mean duration of 5-7 years, but for some people, it can be a life-long illness. Partial relapses and remissions are common, but some people show a steady deterioration.

There is confusion in the community as to whether or not anorexia is a mental illness or a physical one. In truth, it is a mental illness involving intense anxiety and preoccupation with body weight and shape, eating and weight control. Perfectionism and low self esteem are common. Depression and obsessional thinking is often part of the illness. Other mental illnesses may also be experienced with anorexia.

Who gets anorexia and why?

Anorexia nervosa can affect people in all age groups, socioeconomic and cultural backgrounds. It is much more common in females than males. It usually starts in adolescence, but those most seriously ill from it are often in the 20-45 year age group. Anorexia nervosa tends to run in families, which suggests that there may be a genetic component. Of all people with anorexia, one in ten are males.

How common is it?

Anorexia nervosa occurs in about 0.5% of girls and young women in developed societies. It is very rare in men. This is about half as common as the life-time risk of developing schizophrenia.

Anorexia nervosa has the highest death rate (20% in 20 years) of all mental illnesses. Death from physical causes is 5 times that expected in this age group and death by suicide is 32 times that expected.



Denial of anorexia nervosa is very common and can delay treatment.

Is anorexia caused by families?

There is no research evidence that proves a link between family dysfunction and the onset of anorexia. Prior to illness, the proportion of



Families do not 'cause' anorexia nervosa.

families with relationship problems is about the same as the general population.

It is common for families to become distressed once the diagnosed is confirmed, but in spite of this, most families maintain support and are keen to help wherever possible.

Many families become frustrated by the illness and with the sometimes-inadequate response of health professionals. For some people, by the time they get help, problems in family relationships have developed.

Is there an association between abuse in childhood and anorexia?

Prior emotional, physical or sexual abuse of the person with anorexia nervosa was once thought to be a possible explanation. However, research suggests that abuse may be no higher in these families than in the general population.

People with anorexia may still have experienced abuse as children since rates of abuse can be high in the general population. If it is an issue, it can be addressed in treatment to help everyone concerned.

Do people recover from anorexia nervosa?

Yes, people can fully recover from anorexia. Research says that if the condition develops at a younger age, it may be more severe form, and it might be harder to fully recover. The purging and vomiting form of illness is such an example.

Recovery is different for everyone, but possible. Those who return to a near- normal weight during their first treatment period tend to do better than those who don't.

Can anorexia nervosa be prevented?

Research can't 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.

2. Assessment and diagnosis

Anorexia may affect people in some occupational groups more than in others. Some occupations or sports which favor lower body weight (such as modeling, ballet, being a jockey or gymnast) are examples. Some people may be asked at assessment if their mother had an eating disorder because of the tendency for anorexia to run in families.

What are the early clues to anorexia nervosa?

At first onset, it may be difficult to distinguish anorexia nervosa from dieting behaviour or other forms of eating disorder. There are physical, psychological and behavioural signs that a person may have developed anorexia nervosa.

Early *physical* clues may include:

- loss of periods or failure to begin menstruating in young girls; and
- weight loss without evidence of any other illness that would explain weight loss.

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;
- excessive exercise;
- vomiting and using laxatives (purging) as part of a pursuit of thinness; and/or
- avoiding sharing meal times with others because of food anxieties.

Other symptoms as a result of weight loss and illness progression

- Weight loss can bring about a range of other physical and mental health problems. *Psychological* problems can include:



Get help as soon
as you suspect
anorexia

- starvation of the body also starves the brain and alters thinking and concentration;
- depression and irritability;
- you may become moody and angry in relation to eating;
- some people have rituals around eating to avoid anxiety; and
- body image becomes gradually more distorted.

Apart from obvious weight loss, other physical consequences of starvation may include:

- blacking out;
- loss of periods;
- anaemia (lack of iron);
- changes to the texture of skin, nails and hair;
- loss of hair may occur;
- fine body hair may grow on the back, arms and face as the body tries to stay warm; and
- metabolism slows to save energy – signs include slowing the pulse, reduced blood pressure and, lowering of body temperature (you will feel cold more often when this happens).



Anorexia causes severe malnutrition.

Starvation can cause structural brain changes, which may have long-term consequences for cognitive functioning.

Starvation of the heart can lead to heart failure and sudden death.

A common mistake is to confuse the purging and vomiting form of anorexia nervosa with bulimia nervosa. Bulimia nervosa, while also a serious eating disorder, is less likely to cause a medical emergency because by definition, its sufferers are not underweight, and do not suffer this extreme of physical consequences.

The first assessment

Your local doctor, mental health or community health centre can provide you with a first assessment to discuss your concerns about developing anorexia nervosa.

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.

General practitioners are often the first point of contact. They can provide a diagnosis, full physical check up, and organize other health professionals who may need to be involved, including a referral to a psychiatrist.

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

- a summary of your general state of health;
- information on the medical complications of the illness;
- information and explanations about the illness itself;
- the roles of the different health professionals; and
- services and information available, including a referral to a psychiatrist.

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

- results of any tests to re-affirm diagnosis;
- clarify referral options (eg waiting lists);
- aims and duration of specific treatments; and
- cost of treatment with different health professionals.

Initial consultation with another health professional

Other mental health, youth health and womens' health professionals should be able to recognize anorexia nervosa. Specialist mental health workers can provide a diagnosis, but cannot physically examine you. They can give you the same sort of information as a GP can about anorexia nervosa, but 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 behaviour around eating and your thoughts and feelings about eating, your weight, shape and body.

A psychological or *mental health assessment* may include:

- questions about current or past depression
- questions about your moods and thoughts
- feelings about your weight, body and looks
- anxiety about eating
- general perception of how life is going otherwise, and in particular, your perceptions about changes to your routines in relation to past activities, school or social life
- exercise routines, other activities, socialising, alcohol /drug use
- relationships at home, school and work
- coping patterns and support available to you

3. Treatments

This section describes treatments and summarises what is known about their effectiveness and their role at particular stages of the illness. Research has not yet found any cure. However, just because there is not proof about whether or not a treatment works, doesn't mean it should not be tried. It may be that it does work and there just hasn't been enough research of the sort that gives us proof.

What are the aims of treatment?

The aims of treatment for anorexia nervosa include to:

- prevent death by restoring nutrition;
- correct dysfunctional behaviours and thinking;
- treat depression and obsessional thinking;
- prevent or reduce absences from work or school;
- resume normal psychological and physical development;
- restore autonomy and prevent relapse and disablement; and
- support family members or partner where needed.



Research has not yet unearthed a cure.

Does treatment work? – what the research says

Because anorexia nervosa is rare, only small numbers of people participate in research. This means that it is often hard to prove that psychological treatments work. Because of its seriousness, it is also unethical to test one group in treatment against another which is denied treatment. The research then has many limitations and can only tell us the following:

- no specific treatment is known to be effective (as a cure) but some new research is promising;
- research shows that the earlier treatment is started the more chance there is of recovery; and
- alternative treatments and natural remedies have not been researched enough to advise on their role.



Your responsibilities in treatment may include keeping appointments; asking for information you need; and treatment planning.

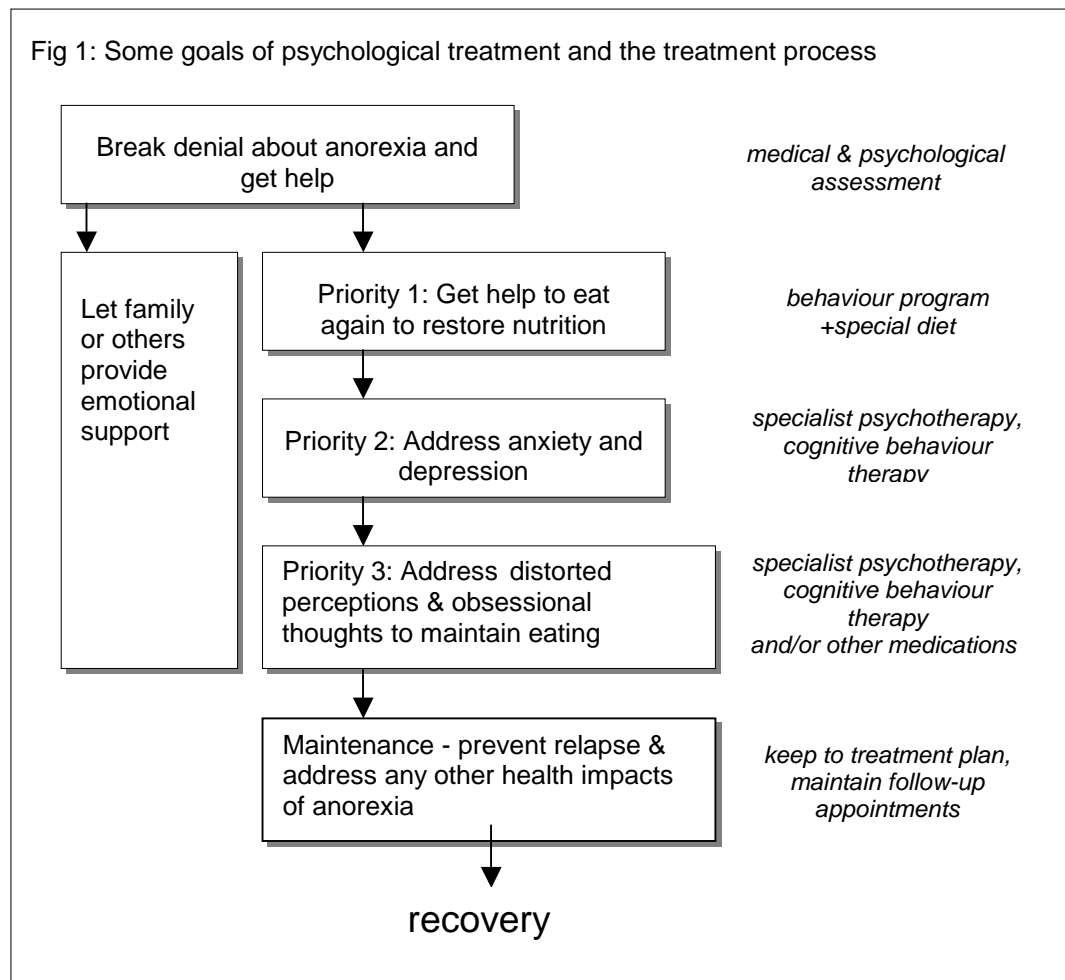
People seem to cope with the illness better if they get professional treatment. It appears to improve their overall chances of recovery and survival.

How is nutrition restored?

Restoring nutrition by getting you to eat sufficiently again is a non-negotiable aspect of treatment. Every effort is made to help you do this yourself. A diet high in proteins, carbohydrates and fats is used and is best supervised by a dietician.

If food is refused, balanced food substitutes are used. But this is generally avoided because the key goal is to get you to eat normal foods again. Generally, re-feeding through a nasal tube is only used in an emergency and is not recommended. Instead, psychologists will design a behaviour program to help you overcome your fears about eating.

Restoring normal nutrition is essential for recovery, but on its own is not enough to prevent relapse. Psychological change is also needed. Figure 1 shows the goals of psychological treatment and the treatment process.



What psychological treatments are available?

Because there is no proof of any treatment being the best, it is important to discuss all options with your key health professional to see if they apply in your case. Different treatments have very specific roles and the appropriate treatment will depend on the severity of illness and your stage of treatment or recovery. These are the main psychological treatments that have been evaluated.

Supportive psychotherapy – this is counselling conducted by either a medical or non-medical professional. It is ‘supportive’ in that it discusses with you your experiences of anorexia 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. It is thought by available research and consumer feedback to be helpful.

Psychoeducation – this term really just means getting information and education about anorexia 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 take charge of your health through being fully informed.

Cognitive behavioural therapy – this psychological treatment can be done by medical or non-medical staff. It is usually performed by specially trained psychologists and involves looking at how you think and how thought shapes behaviour. It 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. CBT is also used for depression where the focus is to change negative perceptions about events in your life, which may contribute to lowered mood.

Interpersonal therapy – this short term therapy has a role to play if a person with anorexia has identified relationships as a problem. Relationships are often strained with anorexia. You are taught to approach relationship issues differently. While it is not proven to ‘treat’ anorexia specifically, it has been shown to reduce depression, which often exists with anorexia.

Psychodynamic oriented psychotherapy – this approach is similar to interpersonal therapy but is often long term, focuses on past patterns of emotion and relating. It is of unproven usefulness.

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

Family therapy – there are many different kinds of family therapy and it can be provided by social workers, psychologists, psychiatrists or nurses. Because anorexia can run in families and can impact on whole families, it tries to maintain relationships and support from the family for the person with anorexia. It helps the whole family in a group. It is considered very appropriate for children and adolescents with anorexia and there is research evidence to support its value for those under 19 years of age.

Motivational Enhancement Therapy - there is emerging interest in the application of motivational interviewing to the treatment of anorexia. 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 the stage of readiness to change that you are at, and tailors treatment advice to that stage. He or she and helps to motivate you along a process whereby you 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' and 'maintenance'. Each stage gradually becomes more active and brings with it gradual life style, eating, meal routine and other psychological, social and emotional changes.

Medication for anorexia and the treatment of co-morbidity

Unlike anti-depressants, or anti-psychotics, there is no anti-anorexia medication that is specifically designed to treat anorexia. However, medications have been found to be useful for treating some of the conditions that occur with anorexia. 'Comorbidity' means that one or more illnesses are present at once. For example, anxiety and depression are both common in anorexia. Although there is no firm evidence that antidepressants are effective against the depression of anorexia nervosa, if an antidepressant is used, SSRIs are a preferred type because they are safer for your heart.



Always discuss side effects with your doctor. A book called 'MIMS' will list all known side effects of medication.

Being prescribed *antipsychotic* medication need not mean that you have psychosis, or that you are going 'crazy'. They are sometimes used because they can also reduce anxiety without the risk of addiction, whereas many anti-anxiety medications risk addiction. Examples of antipsychotic medications include:

- chlorpromazine (Largactil)
- thioridazine (Aldazine and Melleril)
- olanzapine (Zyprexa)

Certain medications should be avoided because of physical deterioration or vulnerability. For example, tricyclic anti-depressants and cisapride (for the intestines) are potentially dangerous for the heart if you have anorexia nervosa.

Obsessional symptoms are often the focus of treatment. Recent reports suggest that some people benefit from a drug called *olanzapine* used to treat this symptom.

Treatment for womens health issues

Anovulation (not ovulating in women) should not be treated except by restoring nutrition. Hormone Replacement Therapy (HRT) or similar treatments are generally not advised for women with anorexia.

Women with anorexia are likely to have complicated pregnancies and can have premature and unhealthy babies. Parenting skills can also be complicated if the anorexia 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 very aggravated by anorexia nervosa. The only sure way to restore bone density is by nutritional restoration. Calcium supplements are harmless but of little use and HRT is of unproven use. Recently, bisphosphonates have been used in people with chronic anorexia, but their long-term effects are unknown.

Beyond symptom control to social adjustment

Coping with anorexia is discussed in detail in Section 2. However, it is important to note that once you start to gain weight again, the road to recovery is only just beginning and this is a 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 under control and manage the complications of weight loss, but thereafter, it helps you to rebuild a life which is as normal as possible, despite living with anorexia. This is called *maintenance* and *relapse prevention* stages of treatment and are critical to ultimate recovery. It involves ongoing contact with your key health professional in regular psychotherapy and medical monitoring as needed.

Are self help groups going to 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 them in anorexia nervosa.

Non-government organisations of people having recovered from anorexia and their families provide referral, information, telephone support and individual advice. Many also provide self help or support groups. Services vary from place to place with 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.

It is not known which type of self help or support group is the more effective. However, most agree that they may help in the following ways:

- to guard against total 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; and
- to provide free services to those awaiting access to treatment.

The organisations in Appendix 4 provide lists of where and when support groups are held along with other information.

SECTION 2: LIVING THROUGH ANOREXIA NERVOSA

4. Hospitalization, access to treatment and emergency situations

The lived 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, periods of relapse and loss of hope. Sometimes persisting with treatment can be difficult. Chapters 4-8 provide advice from people who have been through this experience and covers aspects of treatment, emergency situations, looking after yourself, and information for carers.

The treatment plan

A 'treatment plan' is your road map to recovery. Treatment planning is about seeing the person with anorexia as an individual. It should be flexible for changing needs and circumstances. It may also include or inform your family or partner, especially in the case of adolescents and young people.

Setbacks do occur and should be planned for.

Important aspects to consider are, where is treatment provided and are the people qualified so the right result will be likely?



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

Where are treatments provided and what does it cost?

Because it is a long-term illness for many people, a range of settings is usually considered for treating anorexia. The cost will be a major factor:

- hospital in-patient treatments;
- comprehensive day programs or other non-residential programs;
- outpatient treatments; and
- outpatient support programs.

Treatments provided in the private sector can be extremely expensive even if you have private medical insurance (Appendix 2). You can tell your GP or mental health service if you are unable to afford these costs. Some public hospitals, community mental health services and GPs with special training in eating disorders may offer more affordable treatment.

What qualifications do health professionals need to treat anorexia?

When you are just diagnosed, it is important to seek treatment from health professionals who are expert in anorexia nervosa, as well as having appropriate qualifications and registration for their profession. Treatments can only help if applied with skill.

Because of the physical consequences of the illness, it is also a condition where a doctor must supervise the treatment to monitor your physical health. In most cases, a psychiatrist will have a role in directly overseeing all aspects of treatment or giving advice to those involved in your care.



It is OK to ask health professionals about their qualifications and experience in treating anorexia nervosa.

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

If there is a waiting list, or if expert treatment for anorexia is not available in your area, or if you can't afford treatment being offered, you can ask for a referral to an alternative option. Country people regularly attend treatment centers 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 should coordinate these services for you.

Some medical procedures common in monitoring progress

Reduced eating can damage the whole body - nutritional status is monitored regularly. This is done by a measure called the body mass index (BMI). A BMI under 17.5 is the cut off for diagnosing anorexia nervosa. Measurement of body fat may also be done.

You may be assessed for raised urea, which indicates dehydration.

Your blood biochemistry may be tested for things such as potassium levels in the blood. Electrolyte disturbances are especially common in people who vomit a lot and lead to cardiac problems that may be fatal.

Heart failure is a serious potential complication in anorexia. An ECG, a test that checks your heart, is important to have done.

Bone density can be affected. Osteopenia (low bone density) leading to osteoporosis is a serious longer-term complication. It can result in stress fractures. Bone scans may be needed.

Endocrine disturbances are often investigated and oestrogen is checked.

The role of hospitalization

The primary purpose of hospitalization is to provide safety when a person's life has been severely compromised by starvation. However, admission to hospital can have several roles in treating anorexia nervosa. Some hospitals have developed psychological programs that encourage the patient to learn new ways of coping other than through food programs. Sometimes hospitalization is used to help the person to settle into a psychological treatment routine. This includes learning to eat again and to ensure access to medical staff to manage any health consequences of starvation.

Do I have to go to hospital?

The majority of people with anorexia nervosa are treated outside of hospital, and hospitalization is only one component of overall care. However, it is expensive. Yet, it can also be key to some peoples' recovery. To reduce costs and inconvenience, being treated without going into hospital is encouraged where possible. Day hospital programs are being used increasingly because they are less disruptive, cost less and can be equally effective.

Anorexia can be an illness of many years duration, but hospital treatment is usually offered on a short-term basis only.

What about after hospital?

Because most treatment will take place outside of hospital, it is important that all aspects of treatment are carefully coordinated with communication between the hospital staff, the GP and your community treatment team. '*Discharge planning*' is a term that refers to a meeting to organise post-hospital support to help you stick with your treatment plan. Carers may be invited to help at this stage and follow-up visits may be arranged in advance.

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



Research shows agreement amongst professionals and consumers that treating anorexia nervosa should involve a team, each member of the team expert in one or more aspects of your care.

What do I need to know about treatment programs?

People who have recovered from anorexia recommend you request an information package prior to or on admission of both inpatient (hospital) and outpatient (day treatment centers) services that includes the following: the treatment program/activities and its rationale; the treatment centre's ethos and philosophy, and the costs (including extras, hidden costs and rebates available).

It is also helpful to know the admissions procedure: eg explanations of the treatments and when they will be followed; any treatment alternatives available; the roles of the different health professionals; how the treatments work; rules and policies of the agency; information about legal orders if they apply to you and your rights.

What medical complications and emergencies happen?

Both medical and psychiatric emergencies 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 because lack of food over a fairly short period of time can result in any number of serious health consequences very rapidly.

Extreme emaciation, serious electrolyte disturbances, cardiac irregularities and delirium (from a starved brain) require urgent treatment in a medical intensive care unit.

When you have anorexia nervosa you may indeed appear more resistant to viral illness than are healthy persons. However, your body can't deal with severe bacterial infections, which must be treated without delay.

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, hospitalization is very likely. In relation to treating malnutrition, overhasty refeeding, particularly with a high carbohydrate diet or a dextrose drip, can lead to the development of the 'refeeding syndrome', a physiological response. If this should happen out of hospital, it requires hospitalization to correct.

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:

- refusal of medical treatment that is life saving;
- refusal of psychological treatment that may be life saving; and
- an immediate risk of suicide or self-harm.

Hospitalization is also 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 hospitalize you against your will under the Mental Health Act, 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 members in these situations. The goal should be to arrange the most safe, but agreeable arrangement and take into account your preferences wherever possible.

Legal considerations for you

More detailed legal information is contained in mental health legislation and guardianship legislation in your area.

It is best to prevent any crisis occurring that diminishes your control over making your own health care decisions. Some consumers like the idea of a written agreement in the form of an *Advance Care Directive*. This agreement is reached between you and the health professional and would spell 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 physical illnesses.

Legal considerations for family members 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 patient’s care and make decisions on their behalf to authorize 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 on the websites of Eating Disorder Associations and Foundations.

What about confidentiality?

In Australia, you can seek a confidential medical consultation at age 14, and in New Zealand, at age 16. Health information you agree to share with your family or carer can be shared by the health professional. If you are below the legal age, parents will usually be included in all discussions about your health and welfare. However, it is recommended that health professionals, you and where possible, those you nominate to be involved, work together jointly 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; and
- discuss in general terms, 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. What your worker discloses in a crisis situation will depend on your age and circumstances but may include:

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

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

What are my rights then?

You have both rights and responsibilities in treatment. For example, your rights include:

- a right to confidentiality wherever possible, including to know what is told to others and when and why;
- a right to 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;
- have your age taken into account and be treated accordingly; and
- be treated in a way that respects your growing knowledge of your health over time;
- a right to decline and refuse treatment in non-life threatening situations; and
- a right to complain if you are unhappy about your care.

5. Standards and other issues

It is reasonable for people experiencing a traumatic and life threatening illness such as anorexia nervosa to expect reasonable standards of care. Consumers generally agree that some things matter in particular to help them progress in treatment. These include, that health professionals should:

- 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;
- be flexible to the changing nature of your needs during treatment;
- provide prompt referral to other specialised health professionals so that all aspects of treatments are covered;
- (if they have a limited experience or expertise in anorexia nervosa either refer, or liaise closely with more expert colleagues;
- work out within the team that one of them coordinates and acts as your advocate through the treatment process;
- provide moral support;
- not refuse to help you without offering you an alternative; and
- extend help or referral to your family members.



Health Care Complaints Tribunals or systems exist in each jurisdiction. You can discuss your concerns with them in confidence, and you can also write to them to lodge a complaint formally.

Your complaint is then considered for mediation or investigation.

It is also recommended that you check the qualifications that health professionals hold. The following are possible qualifications that you would probably like to know about. There may be others.

For general practitioners:

- Are they a Fellow of the Royal Australian College of General Practitioners (FRACGP) or Royal New Zealand College?
- Are they a member of their local Division of General Practice?
- Do they have a Masters of Psychological Medicine from the Universities of New South Wales or Monash University?

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)?

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 New Zealand College of Clinical Psychologists or the Australian Psychological Society (MAPS) and of the Society's College of Clinical Psychology?
- Are they a member of the Australian Association for Cognitive Behavioural Therapy?

Being fully informed

Ensuring you are fully informed is often the best way to get the highest standard of treatment for any health problem. The same is true for anorexia nervosa. Questions you might wish to ask about your treatment are suggested in Appendix 3.

6. What carers and partners can do to help

Parental involvement with adolescents with anorexia is usually critical to the well-being of the young person with anorexia and the rest of the family.

Most people with anorexia 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’ rather like when someone supports a person to stop smoking just by being encouraging.

They can support a person with anorexia nervosa in some of the following ways:



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

- 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 center;
- encouraging the person to keep appointments;
- upgrading knowledge of the illness;
- contacting an eating disorder support association for information;
- being mindful of the illness and its impacts on the person; and
- trying not to diminish the person’s overall autonomy and independence.

How the illness may affect the family

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

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

At meal times in particular, siblings may feel ignored by parents and the normal social event of mealtimes is replaced by awkwardness. Everyone in the family sometimes worries that the person with anorexia will die. Isolation is the critical thing to avoid for all concerned.

Often there is unnecessary guilt, particularly felt by mothers, worried they are responsible for the condition. Fathers may feel frustrated, to blame, or on the other hand, uninvolved as if unable to help

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



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

Consumer perspective of carer concerns

People living through anorexia 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 for everyone is the goal.

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, the problem rarely gets better by itself and it is not made worse by talking about it.

Families frequently find that services and health professionals do not listen to their views about their relative. Professionals may not always give them any 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.

¹ Thanks to the Mental Health Foundation of New Zealand (2002) for passages used in this section.

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

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.

Continued care of chronic illness in the community

Some people with anorexia nervosa will have a chronic and long-term illness, which may not get better despite best efforts made. If this happens to the person you love with anorexia, it is important that all concerned maintain realistic goals, which aim to improve the quality of their life and yours. The goal is more to stabilize health as best as possible rather than to cure the anorexia.

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 informed 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 on www.ranzcp.org

Appendix 1: How this guide was developed

This guide was developed by consumers and carers. It was informed by a research process involving Eating Disorders Associations and Foundations whose members consulted widely to develop a list of 118 recommendations ('guidelines'). These were recorded in a background research document, *Australian and New Zealand Consumer Guidelines for Anorexia Nervosa* (Loveridge, 2001). The research gathered strategies from people with personal experience of anorexia nervosa, both consumers and family members, after their consideration of issues and problems experienced with this illness. This document can be viewed on websites or obtained from these organisations.

We then held an editorial workshop with the RANZCP editor and agreed to a prioritised list of questions of consumer and carers that would be answered by this guide. We answered those questions from the original list of consumer and carer recommendations to inform Section 2. We then applied the research from the expert guideline development team's literature searching on the epidemiology and treatment effectiveness research to develop Section 1.

We appreciated permission from the Mental Health Foundation of NZ to include content from their rigorously developed resource on anorexia (2002). We invited NZ eating disorders organisations to appraise our drafts.

Each draft of this guide was appraised against the National Health and Medical Research Council's (2000) guide for developing consumer CPGs and the DISCERN Instrument's (Charnock, 1998) quality criteria for developing consumer treatment guidelines. These appraisals were done by the co-writer and editor and by an independent group of 30 consumers and carers. Professionals working with people with anorexia nervosa also appraised and reviewed the guidelines. The committee especially thanks the following people for contributing to the research:

Pamela Stanley – Eating Disorders Association of NSW
Margaret Edgley – Eating Disorders Association of NSW
Marian Gill – Eating Disorders Association of NSW
Katherine Gill – Eating Disorders Association of NSW
Carmel Jones – Eating Disorders Association of NSW
Ursula Clare – Chairperson, Eating Disorders Association of SA
Janine Phillips – Executive Board Members Eating Disorders Association of SA
Cina Mastrantone – Eating Disorders Association of SA
Helen Jenkins – Project Officer, Eating Disorders Association of SA
Sophia Liddy – Eating Disorders Association of Victoria
Karen Elford – Executive Officer, Eating Disorder Association of Victoria
Jewel Pyne – Secretary, Eating Disorders Association NZ Inc
Carol Drew - Education Field Worker, Eating Disorders Association NZ Inc
Joane Blair – Eating Disorders Association QLD
Julia Arnold – Eating Disorders Association QLD Resource Centre

Appendix 2: Cost of treatments

The cost of mental health care varies place to place in Australia.

General practitioners

In Australia, many general practitioners bulk bill so that Medicare will cover the full cost. If they don't bulk bill, Medicare will refund you up to 85% of the cost if you visit the GP's surgery. Medicare will refund you 75% of the fee for GP care in a hospital or an aged care facility. In Australia, there are now ways that GPs can be paid to coordinate your care, which involves some of their time being spent working with other health professionals. Some of the newer payments enable them to offer you a longer consultation and an expert second opinion if needed. They can case conference with a psychiatrist and a dietician for example to coordinate your care.

Psychiatrists

When seeing a psychiatrist outside of hospital, Medicare will cover 85% of the scheduled fee and you pay the balance. Medicare will pay 75% of the cost if you are treated by the psychiatrist whilst a patient in hospital.

Hospital services

The care you receive in a hospital emergency department is provided without a charge to patients. By far the more expensive care for someone with anorexia nervosa is for time spent in hospital as an inpatient, particularly given that many tests are sometimes performed, especially if the admission is made in an emergency. It is important for a person with anorexia nervosa to have health care insurance to ensure adequate cover for hospitalisation.

Community health centers, crisis teams and public mental health services

Community mental health services are free clinics where you can see a psychiatrist, psychologist or social worker or other health professional by appointment. Usually you make several appointments, a week or more apart. They may also provide 24 hour free crisis assessment services staffed by mental health nurses and allied health professionals.

Allied health disciplines working as private practitioners

Medicare does not cover the cost of treatment if you see a psychologist, social worker or nurse practitioner privately. These visits usually cost between \$60 and \$120 for a one-hour session if these professionals were provider your psychological treatment.

Appendix 3: Questions to ask about your treatment

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 take longer to see 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 to someone who has been through this procedure with other therapists? _____

Questions to ask about medication

- ✓ Name of medicine: _____
- ✓ Dose / instructions: _____
- ✓ When and how often do I take the medicine? _____

- ✓ 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?

- ✓ 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:

- 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 the other if I need it?
- How long is a typical course of treatment?
- How frequent are treatment sessions? How long does each session last?
- What are your fees?
- Can you help me determine whether my health insurance will cover fees?

Appendix 4: Information and support

These are mostly voluntary non-government agencies. They do not replace the need for formal treatment but are an adjunct to it and can provide further information.

nsw

NSW Eating Disorders Foundation Inc
PO Box 532
Willoughby NSW 2068
Ph: 02 9412 4499
Website: www.edsn.asn.au
Support & Information Telephone Line Ph: 02 9412 4499

Eating Disorders Association of NSW Inc.
PO Box 811
Castle Hill NSW 2154
Ph: 02 9899 5344 Fax: 02 9899 5811
Website: www.edansw.org.au

vic

Eating Disorders Foundation of Victoria
1513 High Street, Glen Iris VIC 3146
Ph: 03 9885 0318 Fax: 03 9885 1153
Website: www.eatingdisorders.org.au
Email: edfv@eatingdisorders.org.au

qld

Queensland Eating Disorders Resource Centre
53 Railway Terrace
Milton QLD 4064
Ph: 07 3876 2500 Fax: 07 3511 6959
Website: www.uq.net.au/eda
Email: eda.inc@uq.net.au

ISIS - Centre for Women's Action of Eating Issues
88 O'Keefe Street Buranda QLD 4210
Ph: 07 3392 2233
Eating Disorders Support Group
C/- Women's Community Health Centre
PO Box 1128 Aitkenvale QLD 4814
Ph: 07 4728 2399

Gold Coast Eating Disorders Association
PO Box 391 Pacific Fair Broadbeach QLD 4218
Ph: 07 559 33010



Smaller states may not have the phones staffed at all times. You can also try the Mental Health Association or Foundation in your State, usually listed in the front pages of the phone book.

Public mental health services are usually listed in the front page of the phone book, including 24-hour crisis assessment teams.

sa Eating Disorders Association of South Australia Inc.
Woodards House
2nd Floor 47 - 49 Waymouth Street
Adelaide SA 5000
Ph: 08 8212 1644 Fax: 08 8212 7991
Email: mail@abnasa.asn.au

tas Tasmania - Community Nutrition Unit
3rd Floor Peacock Building
Repatriation Centre 90 Davey Street
Hobart TAS 7000
Ph: 03 6222 7222

Anorexia and Bulimia Support Group
2/9a Coolabah Road Lower Sandy Bay TAS 7005
Ph: (03) 6225 0131

nt Northern Territory Amity Community Services
GPO Box 3628 Darwin 0801
Ph: 08 8981 8030 Toll-free tel. (within NT: 1800 629 683)
Email: cdasweb@taunet.net.au

wa Eating Disorders Association of WA Inc.
PO Box 8015
Perth Business Centre Perth WA 6849
Ph: 08 9221 0488 Fax: 08 9221 0499

act Eating Disorder Association of NSW - ACT Branch
Ph: 02 6281 7511
Help Line: 02 9899 5344

nz Eating Disorders Association NZ Inc.
PO Box 80, 142 Green Bay, Auckland
Ph: 09 818 9561
Fax: 09 627 8493

Wellington Eating Disorder Services
Ph: 04 473 5900
Fax: 04 472 0779
Email: weds@xtra.co.nz



Support groups may not be run year-through. Contact a Mental Health Association or Foundation for alternative groups or supports, or for referral to professional treatment services.

EDEN (Eating Difficulties Education Network)

P O Box 78005

Grey Lynn Auckland

Ph: 09 378 9039

Fax: 09 378 9393

Email: info@eden.org.nz

North Shore Women's Centre

PO Box 40 106

Glenfield, Auckland

Ph 09 444 4618

Fax 09 444 4626

Email: women.ctr@ix.net.nz

Website: www.womyn-ctr.co.nz

Eating Awareness Team

PO Box 4520

Christchurch

Free phone 0800 690 233

Email: eat@chch.planet.org.nz