SECTION 2

Section 2: Living through anorexia nervosa

Hospitalisation, access to treatment and emergency situations

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, 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.

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.

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

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
- Outpatient support programs.

Treatments provided in the private sector can be extremely expensive even if you have private medical 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.

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 experts 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.

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 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 should co-ordinate 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 one of the criteria 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 can lead to cardiac problems that may be fatal.

Heart failure is a serious potential complication in anorexia. An Echo Cardiogram (ECG), a test that checks your heart, may be required.

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 therefore be needed.

Endocrine disturbances are often investigated and oestrogen is checked.

The role of hospitalisation

The primary purpose of hospitalisation 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 hospitalisation is used to help the person settle into a psychological treatment routine. This includes learning to eat again and ensuring 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 hospitalisation is only one component of overall care. However, it is expensive. Yet, it can also be key to some people's 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 a hospital, it is important that all aspects of treatment are carefully co-ordinated 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.

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 to both inpatient (hospital) and outpatient (day treatment centres) 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, for example:

- 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 can 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, hospitalisation 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 hospitalisation 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
- An immediate risk of suicide or self-harm.

Hospitalisation 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 hospitalise 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 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 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 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 on the websites of Eating Disorder Associations and Foundations (see Appendix 4).

What about confidentiality?

In Australia you can seek a confidential medical consultation at age 14. 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
- 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
- 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 knowing 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
- 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
- A right to decline and refuse treatment in non-life threatening situations
- A right to complain if you are unhappy about your care.

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
- Liaise closely with their expert colleagues if they have limited experience or expertise in anorexia nervosa
- Work out within the team that one of them co-ordinates and acts 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 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)?
- Are they a member of their local Division of General Practice?
- Do they have a masters of Psychological Medicine from the University 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) 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 (MAPS) and of the Society's College of Clinical Psychology?
- Are they a member of the Australian Association for Cognitive Behavioural Therapy?

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.

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 2.

What carers and partners can do to help

Parental involvement with adolescents with anorexia is usually critical to the wellbeing 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:

- 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
- 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.

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

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.

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 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 meal times 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.

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.

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, or who to blame during periods when the condition worsens.

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

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 is everyone's 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.

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 stabilise health as best as possible rather than to cure the anorexia.