Section 1: Anorexia nervosa - The facts

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 five to seven 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, socio-economic 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.

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 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 a 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 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.

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

Families do not 'cause' anorexia nervosa.

Assessment and diagnosis

What are the early clues to anorexia nervosa?

Anorexia may affect people in some occupational groups more than in others. Some occupations or sports which favour lower body weight (such as modelling, 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.

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
- 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
- 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:

- Starvation of the body which also starves the brain and alters thinking and concentration
- Depression and irritability
- Becoming moody and angry in relation to eating
- Some people having rituals around eating to avoid anxiety
- Body image becoming 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
- Fine body hair growing on the back, arms and face as the body tries to stay warm
- Metabolism slowing 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).

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.

Get help as soon as you suspect anorexia.

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.

The first assessment

Your General Practitioner (GP), 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.

GPs are often the first point of contact. They can provide a diagnosis, full physical check up, and organise 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
- 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
- Clarifying referral options (eg, waiting lists)
- The aims and duration of specific treatments
- The cost of treatment with different health professionals.

Initial consultation with another health professional

Other mental health workers such as youth health and women's health professionals 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 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.

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 no 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
- Support family or partner where needed.

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.

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

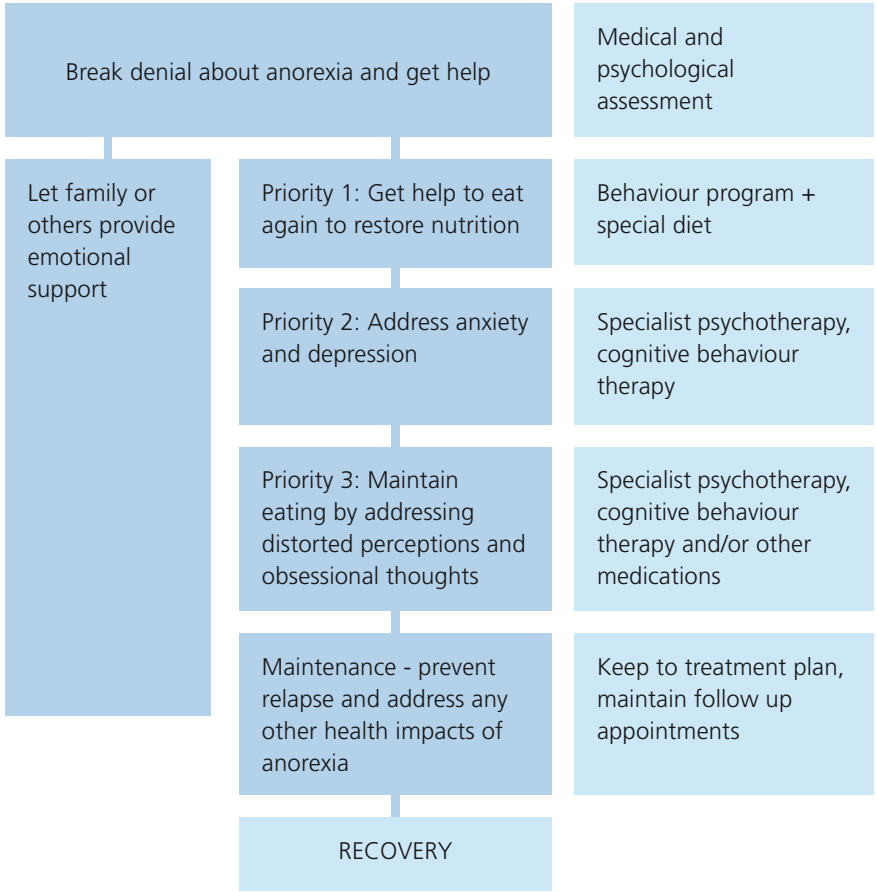
How is nutrition restored?

Restoring nutrition by getting you to eat sufficiently 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 eatin

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.

Figure 1: Some goals of psychological treatment and the treatment process



Research has not yet unearthed a cure.

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

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. Research and consumer feedback deem this treatment to be helpful.

Psycho-education – 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 (CBT) – 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, focussing 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 their 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 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 antidepressants, 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. 'Co-morbidity' 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, Selective Serotonin Reuptake Inhibitors (SSRIs) are a preferred type because they are safer for your heart.

Being prescribed anti-psychotic 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 anti-psychotic medications include:

- Chlorpromazine (Largactil)
- Thioridazine (Aldazine and Melleril)
- Olanzapine (Zyprexa).

Certain medications should be avoided because of physical deterioration or vulnerability. For example, tricyclic antidepressants 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.

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

Treatment for women's 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 severely 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, bisphosphanates 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
- To provide free services to those awaiting access to treatment.

The organisations listed in Appendix 3 can provide details of where and when support groups are held along with other information.