Information brochure for families and patients

Anorexia nervosa: management
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ASSOCIATION FRANÇAISE POUR LE DÉVELOPPEMENT DES APPORTS SPÉCIALISÉS AUX TROUBLES DU COMPORTEMENT ALIMENTAIRE
This document aims to provide a brief explanation about the nature of this disorder, its consequences, and above all what to do if you are yourself concerned, or if someone close to you is concerned. The purpose is to improve detection of anorexia so that appropriate care can be started earlier, and also to provide landmarks for finding the right kind of care.

**Eating Disorders (ED) in a few words**

- **By Eating Disorders (ED)** we mean eating behaviours that are different from those generally found among individuals living in the same nutritional, cultural and social environment, and that lead to bodily and mental disturbances. The most common eating disorders are anorexia nervosa and bulimia. In nine cases out of ten they affect girls and women.

- **To sum up anorexic behaviours**, we can say that it means that a person is refusing food although he or she is starving (anorexia nervosa) or refusing to gain weight although his or her body is emaciated (anorexia nervosa and anorexia with bulimic (binge-eating) episodes).

Anorexia occurs most frequently among girls, pre- or post-puberty, and young women. They may have had an apparently unproblematic childhood, and there is no particular somatic pathology.

Typically, the teenage girl or young woman is obsessed by the idea that she is too fat, or that she might become too fat, and she develops behaviours where food intake is severely restricted (restrictive anorexia nervosa), often accompanied by bouts of uncontrolled overeating (anorexia nervosa with episodes of bulimia). These behaviours may or may not be accompanied by compensating behaviours, i.e. aimed at avoiding weight gain, such as excessive physical activity self-induced vomiting, or excessive use of laxatives.

These obsessions will end up governing the person’s whole life. The person's self-esteem will become directly dependent on his or her weight.

In the first stages the person has a sort of honeymoon period with his/her anorexia, since the behaviour provides relief for an underlying state of distress. But very soon this adaptive strategy is overwhelmed, and the pain and distress return, alongside a sort of addiction towards controlling behaviours, deprivation and emptiness. This is when the situation spirals out of control.

The diagnosis of anorexia nervosa can be confirmed when the following are observed in pubertal girls: dietary restriction, sometimes explained by the subject as by lack of appetite, extreme thinness, and amenorrhoea (absence of monthly periods). In boys or pre-pubertal girls, the most characteristic features signalling a problem will be sudden loss of weight, a marked change in the growth curve, and disturbed eating habits.
What are the consequences?

- **Concerning bodily and physical aspects**, malnutrition leads to dietary deficiencies that are damaging for muscle function (which includes the heart), for bones (risk of brittle bones or even early osteoporosis), for hormone function and for brain function (certain neurobiological and cognitive functions can be affected).

- Amenorrhoea is often the first physiological consequence of excessive thinness, with its corollaries of fertility disorders and an increased risk of early osteoporosis in later life.

- If emaciation (extreme thinness) worsens and lasts over time, the risk of cardiac problems increases, and there is immediate risk of osteoporosis developing.

- Among anorexics with bulimic (binge-eating) behaviours, certain compensatory behaviours are also very damaging: dental enamel can be attacked by repeated vomiting and become brittle, and tooth decay can set in. In the longer term parodontal problems can arise, such as receding gums and irreversible wear on the teeth. Serious digestive damage can also occur. Metabolic disturbances as a result of vomiting, and in particular losses in potassium, can lead to kidney failure (in the longer term) and even heart attack.

- **Concerning mental state**, malnutrition and a distorted image of the body (seeing all or part of the body as being “too fat”) can contribute to a deterioration of the already damaged self-esteem. Other disturbances may occur, such as excessive emotion, impulsiveness (self-harm), mood swings, anxiety, obsessive thoughts and depression, and in the most serious cases suicidal thoughts.

- **In the social sphere**, lack of self-esteem and obsession with food and diet lead to isolation, withdrawal, and in some cases dropping out from educational programs or ceasing professional activity, and this will tend to aggravate the disordered eating behaviours, thus creating a vicious circle.

What are the things that are noticed by family and friends?

**Dietary restrictions**

Families may notice that their teenagers are gradually reducing the amounts they eat, and are being choosy about the food on the plate. They will eliminate certain categories of food, in particular the most calorie-rich (carbohydrates and fats). They will sigh that they aren't really hungry, or complain that certain foods are too filling or too sickly, while previously they ate the food without question. Mealtimes become a time of tension.

They also complain of various aches and pains, often in the abdomen. They drink large amounts of hot beverages, especially coffee and tea, or cold calorie-free drinks (water or “sugar free” soft drinks).

At meal times, when they have not found an excuse to leave the table, they will sort their food, cut it into tiny bits and classify it by size, they will hide it and eat as little as possible.
Weight loss

Teenagers in this situation are losing weight. They will then either hide the fact by wearing loose or baggy clothes, or they will proudly show off the fact by getting into clothes of smaller and smaller sizes. Weight loss can be significant and sudden. It can reach as much as 20 or 30% of the person's weight in a few months. They nevertheless think they are "too fat", either overall, or certain parts of their bodies. Reasoning gets you nowhere. It is pointless to try and lecture or make the person see reason, it is just a source of conflict. At this stage it is nothing but a vast waste of energy for the family, and for the person concerned it generates a feeling of being completely misunderstood.

Amenorrhoea

In girls the menstrual cycle is disturbed, and very soon her periods will cease. Amenorrhoea is a central element in realising of what is happening. It should however be noted that if the girl is taking oestrogen-progestin contraception, the periods will persist.

Other signs to look for

- The person gradually loses interest in all the activities that he or she enjoyed previously. He or she withdraws, stops going out, some shut themselves up to work and over-achieve in school, others lose interest in everything.

- Progressively all the person's mental and intellectual activity is absorbed by thoughts about weight and slimness, and inventing strategies to reduce hunger and refuse food, while at the same time thinking of nothing else, because he or she is effectively starving (for instance there can be endless shopping for food). Sometimes rituals will develop in relation to food, tidiness or washing.

- In the family environment the person will want to control everything that relates to food, making shopping lists, cooking for the rest of the family, but not eating.

- Some may also complain of sleeping badly, of feeling cold, of losing hair, which are all the direct consequences of malnutrition.

- In the case of anorexia with binging and purging, manifestations may be less readily noticed (there is weight loss, but it is less pronounced). Apart from the signs listed above, the family should notice the following:
  - excessive concerns about the body. This often concerns girls, but can also be observed in boys, in particular if they practise a sport where excessive value is attached to low weight and weight control (gymnastics, athletics for instance).
  - signs of "purging" behaviours (buying laxatives, vomiting in the toilet, excessive sport or exercise).
  - indirect signs: eating large quantities in a more or less concealed manner - the cupboard is emptied, the empty packaging is left on the shelf (bulimic episodes).
What should be done?

- In anorexia nervosa, early instatement of care is recommended to prevent it from evolving towards a chronic form, and also to avoid physical, mental, and social complications.

- One of the first difficulties that confront family and friends, once they have realised that their child or a person close to them is not well, is getting the person to agree to care and change. Indeed, the person has been involved in this method of coping with his or her difficulties and distress for weeks, months or years, for ever struggling against hunger, carefully organising the strategies, drowning in a frenzy of physical or intellectual activities, and deriving a form of pleasure from losing weight. For these reasons, the person is not ready to give it all up, because everything has been built up and organised around this disordered eating pattern, and the idea of abandoning it is highly distressing. This is all the more true because all forms of treatment will aim to obtain weight gain, which the person cannot countenance for the time being. This is what we refer to as denial.

- Yet rapid instatement of care avoids useless suffering, and also improves prognosis. Persuading the person to consult is a challenge for the family, and is in itself a very large step in the direction of recovery. The decision to consult may not be easy for the family or friends either, as they may be wary of doing what it entails. In this phase, patient and family organisations and support groups can be very useful.

Providing care for a person with an eating disorder is the job of a health professional. It is a good thing to seek help from a health professional who is familiar with eating disorders:
- a child psychiatrist or a paediatrician for children or adolescents;
- a GP, a psychiatrist or a medical doctor specialised in eating disorders for adults.

- This doctor can be the person who coordinates the care, by organising the way in which different specialists become involved, so as to treat psychological, nutritional and bodily issues at the same time (the care is multi-disciplinary, i.e. it involves numerous specialities). Global evaluations of the patient on these different aspects are regularly performed by the healthcare team to assess the patient's condition.

FNA-TCA (www.fna-tca.com) and AFDAS-TCA (www.anorexieboulimie-afdas.fr) can help you in seeking care.

- In anorexia nervosa in the strict sense (without binge-eating), the main objectives of care will be restoring a normal weight in relation to stature and age before anything else. Then, as soon as there is sufficient weight gain to allow it, appropriate psychotherapy (individual and/or family) is started up so as to ensure good-quality social rehabilitation as early as possible.

- When there are associated bulimic (binge-eating) behaviours, the aim will be to start psychotherapy in order to put a stop to the bulimic episodes and the compensation strategies that accompany them.
The weight target is discussed progressively with the doctor. However, stopping weight loss is the first objective for most patients, before considering weight gains.

Alongside nutritional and bodily care, psychotherapy is the choice therapy in eating disorders. However psychotherapy is only possible if the person has reached a certain weight, because otherwise the scope for evolution may be compromised, and the patient will derive no benefit from the psychotherapy. When weight is too low, consultations aiming to provide psycho-therapeutic support can accompany weight gain, and cater for the distress that the person is bound to experience (see the section: Finding out more).

**What about hospitalisation?**

Hospitalisation is no longer systematic. At the outset, preference is given to care in the patient's usual environment (so-called "ambulatory" consultations) wherever this is possible, i.e. without endangering the patient.

Hospitalisation has become fairly rare, but it is justified when the patient's condition is life-threatening, when the situation has not evolved sufficiently despite good-quality ambulatory care (i.e. it is becoming chronic, which seriously compromises outcome) or when the patient and/or the family are exhausted and need a break to disentangle the situation.

Hospitalisation enables urgent issues to be dealt with, that is to say halting the starvation process, helping the patient to contain his or her overwhelming distress and /or depression, and organising a tailored ambulatory care plan for afterwards.

Distancing from the usual living environment as a result of hospitalisation, with or without separation from the family, depending on healthcare teams and situations, enables some patients to escape from the terrible spiral of the illness and find incentive to recover, which may have hitherto not been possible in the family environment.

While a few years back, for certain families, hospitalisation was viewed as traumatic, things have changed a lot, in particular because specialised units have developed care procedures for these disorders that are effective and that contribute to establishing what is known as a "therapeutic alliance" with both the patient and his or her family (see the section: Finding out more).

In care for anorexia nervosa, the people who are closest to the patient are valuable allies on the way to recovery. Better still, families often have numerous skills to help the person in distress, and they contribute widely to recovery when they are systematically involved in the action of the healthcare teams.
Yes there is! But remember:

- **The sooner the person consults**, the greater the chances of preventing the disorder from taking over the person’s life and becoming chronic, and of avoiding the most serious physical complications.

- **The sooner the person consults**, the easier it will be to relieve the physical and mental distress of both patient and family

- **The sooner the person consults, the sooner he or she will recover and feel comfortable with him or herself in body and mind.**

### Finding out more

**About psychotherapies**

- Generally speaking, the therapies proposed are of the *psychodynamic* type, aiming to "get to the bottom of things", so as to enable patients to understand what brought them where they are today, and to enable them to replace their destructive behaviours by more appropriate solutions for the future. This process takes a long time, and can require several years.

- There are also *cognitive-behavioural* approaches, which act in several ways. They can firstly address nutritional education, so that the patient can fully understand what is at stake. Secondly a more behavioural approach will enable patients to develop skills in self-assertion, and help them feel more at ease with others. This will also enable anxiety to be tackled. This type of therapy can be very useful to resolve moments of particular tension or stagnation in the therapeutic process.

- Another type of therapy that is frequently offered is *family therapy*. These involve the child, one or both parents, and sometimes the siblings. These therapies are particularly indicated for children and adolescents, who are likely to spend several more years in the family environment. The family "system" must be able to accompany the process of recovery. While it is essential for the patients to have appropriate care, it is just as essential for the environment in which the patient lives to be accompanied and assisted. This is the particular value of these approaches.

- It is also possible to use the scope provided by *support groups*, where other people with the same illness are encountered. These groups enable each participant to express his or her feelings about the illness, and to understand that others are going through a similar experience, that they can share and exchange, and come to see things from a different angle. These groups have great potential and provide incentive.

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**Is there a cure for ED?**

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About the therapeutic alliance in case of hospitalisation

- Because hospitalisation without any agreement would be non-productive, it should be discussed with the patient and his or her family. Except in case of life-threatening emergency, it should be prepared for with patient and family by way of encounters to provide information, and discuss the care plan. This can also include a visit to the unit or ward.

- During hospitalisation in a specialised unit, the patient will be closely followed and accompanied by the healthcare team. He or she will be offered a tailored nutritional programme, therapeutic encounters, and group activities such as support groups, art therapy, sport, cultural activities etc. A therapy can be started up or pursued over the course of hospitalisation.

- Separation from the family and its functioning occurs de facto with hospitalisation. Depending on the healthcare team, this will be managed in different ways, which will be explained to you. The patterns will vary with the age of the patient. If you are not satisfied with the amount of contact allowed, do not hesitate to talk to the care team about it. In case of separation (which is however not isolation) parents can have news of their child on a daily basis, and visits are programmed.

- In all cases, the family and friends will be supported during the hospitalisation period, which is also a difficult time for them (parent support groups, family therapy, encounters with the healthcare providers, etc).

This document was developed by FNA-TCA (French federation of eating disorder associations).

The guidelines and the evidence report can be consulted in full at www.has-sante.fr and at www.anorexieboulimie-afdas.fr