# Early-Onset Anorexia Nervosa:
# French National Diagnostic and Care Protocol

# APPENDIX

## **Appendix 1.** DSM 5, ICD 10 and ICD 11 diagnostic criteria

**• DSM 5 diagnostic criteria**

A. Restriction of energy intake relative to requirements leading to a significantly low weight in the context of age, sex, developmental trajectory, and physical health. *Significantly low weight* is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.
B. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.
C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

**Coding note:** The ICD-9-CM code for anorexia nervosa is 307.1, which is assigned regardless of subtype. The ICD-10-CM code depends on the subtype (see below).
*Specify whether*:
**(F50.01) Restrictive type**: During the last 3 months, the individual has not engaged in recurrent episodes of binge eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas). This subtype describes presentations in which weight loss is accomplished primarily through dieting, fasting, and/or excessive exercise.
**(F50.02) Binge-eating/purging type**: During the past 3 months, the individual has engaged in recurrent episodes of binge eating or purging behavior (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).
*Specify if*:
In partial remission: After full criteria for anorexia nervosa were previously met, Criterion A (low body weight) has not been met for a sustained period, but either Criterion B (intense fear of gaining weight or becoming fat or behavior that interferes with weight gain) or Criterion C (disturbances in self-perception of weight and shape) is still met.
In full remission: After full criteria for anorexia nervosa were previously met, none of the criteria have been met for sustained period of time.
*Specify current severity*:
The minimum level of severity is based, for adults, on current body mass index (BMI) or, for children and adolescents, on BMI percentile. The ranges below are derived from World Health Organization categories for thinness in adults; for children and adolescents, corresponding BMI percentiles should be used. The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision.
**Mild**: BMI >17 $kg/m^2$
**Moderate**: BMI 16-16.99 $kg/m^2$
**Severe**: BMI 15-15.99 $kg/m^2$
**Extreme**: BMI < 15 $kg/m^2$

- **ICD-10 criteria for anorexia nervosa F50.0**

For a definite diagnosis, all the following are required:

A. Body weight is maintained at least 15% below that expected (either lost or never achieved), or BMI is 17.5 or less. Prepubertal patients may show failure to make the expected weight gain during the period of growth.
B. The weight loss is self-induced by avoidance of "fattening foods" and one or more of the following: self-induced vomiting; self-induced purging; excessive exercise; use of appetitesuppressants and/or diuretics
C. There is body-image distortion in the form of a specific psychopathology whereby a dread of fatness persists as an intrusive, overvalued idea and the patient imposes a low weightthreshold on himself or herself.
D. A widespread endocrine disorder involving the hypothalamic-pituitary-gonadal axis is manifest in women as amenorrhoea and in men as a loss of sexual interest and potency. (An apparent exception is the persistence of vaginal bleeds in anorexic women who are receiving replacement hormonal therapy, most commonly taken as a contraceptive pill.) There may also be elevated levels of growth hormone, raised levels of cortisol, changes in the peripheral metabolism of the thyroid hormone, and abnormalities of insulin secretion.
E. If onset is prepubertal, the sequence of pubertal events is delayed or even arrested (growth ceases; in girls the breasts do not develop and there is a primary amenorrhoea; in boys the genitals remain juvenile). With recovery, puberty is often completed normally, but the menarche is late.

Differential Diagnosis: There may be associated depressive or obsessional symptoms, as well as features of a personality disorder, which may make differentiation difficult and/or require the use of more than one diagnostic code. Somatic causes of weight loss in young patients that must be distinguished include chronic debilitating diseases, brain tumors, and intestinal disorders such as Crohn's disease or a malabsorption syndrome.

- **ICD-11 criteria for anorexia nervosa 6B80**

Anorexia Nervosa is characterised by significantly low body weight for the individual’s height, age and developmental stage that is not due to another health condition or to the unavailability of food. A commonly used threshold is body mass index (BMI) less than 18.5 kg/m2 in adults and BMI-for-age under 5th percentile in children and adolescents. Rapid weight loss (e.g. more than 20% of total body weight within 6 months) may replace the low body weight guideline as long as other diagnostic requirements are met. Children and adolescents may exhibit failure to gain weight as expected based on the individual developmental trajectory rather than weight loss. Low body weight is accompanied by a persistent pattern of behaviours to prevent restoration of normal weight, which may include behaviours aimed at reducing energy intake (restricted eating), purging behaviours (e.g. self-induced vomiting, misuse of laxatives), and behaviours aimed at increasing energy expenditure (e.g. excessive exercise), typically associated with a fear of weight gain. Low body weight or shape is central to the person's self-evaluation or is inaccurately perceived to be normal or even excessive.

# Appendix 2. Biological and endocrine abnormalities in anorexia nervosa.

**Dre C. Blanchet - Maison de Solenn, AP-HP, Paris.**

| Adaptive changes to AN | Changes reflecting poor tolerance to AN | Changes reflecting poor tolerance to refeeding syndrome | Changes suggesting a differential diagnosis or comorbid disorder |
|---|---|---|---|
| ➢ Normocytic normochromic anemia (30%)<br>➢ Leukoneutropenia (30%)<br>➢ Hypokalemia (20 %)<br>➢ Hyponatremia (10 %)<br>➢ Urea and creatinine levels: functional kidney failure<br>➢ Low fasting blood glucose (<0.7 g/l)<br>➢ High total cholesterol<br>➢ Hyperferritinemia<br>➢ ALT, AST < 5N (45%)<br>➢ Vitamin D, B9, Folate: variable deficiency (38%)<br>➢ Low fT3 with normal TSH<br>➢ Low IgF1<br>➢ Low estradiol and testosterone levels with normal or low LH, FSH levels<br>➢ Increased 24-hour urinary excretion of cortisol<br>➢ Low pre-albuminemia | ➢ Pancytopenia (3%): hypoplasia to aplasia +/- gelatinous degeneration) of the bone marrow<br>➢ ALT, AST >10 N<br>➢ Fasting ketonuria<br>➢ Hepatic failure (low factor V, high PT, hypoalbuminemia): rarely<br>➢ Severe acute kidney failure (hyperkaliemia, acidosis, or anemia)<br>➢ Rhabdomyolysis (elevated creatine kinase) | ➢ Hypophosphoremia<br>➢ Hypomagnesemia<br>➢ Hypokaliemia<br>➢ Thiamine (B1) deficiency<br>➢ Hémolyis<br>➢ Thrombopenia<br>➢ Cytolytic hepatitis<br>➢ Hypo ou hyperglycemia<br>➢ Elevated creatine kinase | ➢ Inflammation (elevated CRP and/or elevated ESR, hyperleucocytosis)<br>➢ Severe anemia with or without iron deficiency<br>➢ Isolated thrombopenia<br>➢ Hyperkaliemia<br>➢ Hyperglycemia<br>➢ Hypoalbuminemia<br>➢ Decreased ACTH, low AM cortisol<br>➢ Low to high TSH levels |

# Appendix 3. Hospitalisation criteria of the HAS 2010 recommendations Anorexia nervosa and Pediatric criteria for severe undernutrition of the HAS 2019

Somatic criteria for hospitalisation

| | |
|---|---|
| **Children and adolescents** | |
| **History** | • Rapid loss of weight: more than 2kg/week<br>• Refusal to eat: total aphagia<br>• Refusal to drink<br>• Lipothymia or fainting appearing to be orthostatic<br>• Fatigue or exhaustion reported by the patient |
| **Clinical criteria** | • BMI <14kg/m$^2$ at 17 yrs or over, or BMI < 13.2kg/m$^2$ at ages 15 and 16, or BMI <12.7kg/m$^2$ at ages 13 and 14<br>• Slowness in ideation and speaking, confusion<br>• Occlusive syndrome<br>• Extreme bradycardia: pulse<40/min, irrespective of time of day<br>• Tachycardia<br>• Low systolic blood pressure (<80 mmHg)<br>• BP <80/50mmhg, orthostatic hypotension measured by an increase in heart rate >20/min or decrease in BP >10-20 mmHg<br>• Hypothermia <35.5°C<br>• Hyperthermia |
| **Paraclinical criteria** | • Acetonuria (urine test strip), hypoglycaemia <0.6g/L<br>• Severe hydroeletrolytic or metabolic disturbances, in particular: hypoalkalaemia, hyponatremia, hypo-phosphoremia, hypomagnesemia (threshold levels non-specified for children and adolescents).<br>• Creatinine elevation (>100 mol/L)<br>• Cytolysis (>4xN)<br>• Leuconeutropenia (<1000/mm$^3$)<br>• Thrombopenia (<60 000/mm$^3$) |
| **Adults** | |
| **History** | • Scale and speed of weight loss: loss of 30% of body weight in 3 months<br>• Fainting, falls and loss of consciousness<br>• Uncontrollable vomiting<br>• Failure of ambulatory refeeding |

| | |
|---|---|
| **Clinical criteria** | • Clinical signs of dehydration<br>• BMI<14kg/$m^2$<br>• Marked amyotrophy with axis hypotonia<br>• Hypothermia <35.5°C<br>• Hypotension <90/60mmHg<br>• Heart rate:<br>  ○ sinus bradycardia HR <40/min<br>  ○ tachycardia at rest >60/min if BMI <13kg/$m^2$ |
| **Paraclinical criteria** | • ECG anomalies other than heart rate<br>• Symptomatic hypoglycaemia <0.6g/L or asymptomatic if <0.3g/L<br>• Hepatic cytolysis >10xN<br>• Hypokalaemia <3mEq/L<br>• Hypophosphoremia <0.5 mmol/L<br>• Renal failure, creatinine clearance <40mL/min<br>• Natraemia:<br>  ○ <125mmol/L (excessive fluid intake, risk of convulsions),<br>  ○ >150mmol/l (dehydration)<br>• Leucopenia <1000/$mm^3$ (or neutrophiles <500/$mm^3$) |

## Psychiatric criteria for hospitalisation

| | |
|---|---|
| **Suicide risk** | • Suicide attempt or failed attempt<br>• Precise suicide plan<br>• Repeated self-injury |
| **Co-morbidity** | Any co-occurring psychiatric disturbance where severity warrants hospitalisation:<br>• Depression<br>• Substance abuse<br>• Anxiety<br>• Psychotic symptoms<br>• Obsessive-compulsive disorder |
| **Anorexia nervosa** | • Intrusive, constant, obsessive ideations, inability to control obsessive thoughts<br>• Refeeding – the need to refeed by nasogastric intubation or other feeding mode that is not possible in ambulatory care<br>• Physical activity: excessive, compulsive physical activity (in association with another indication for hospitalisation)<br>• Purging behaviours (vomiting, laxative and diuretic use): inability of the patient to control intense purging activities |
| **Motivation, cooperation** | • Previous failure of satisfactorily managed ambulatory care<br>• Uncooperative patient, or cooperating solely in highly structured care setting<br>• Insufficient motivation, hindering compliance with ambulatory care |

## Environmental criteria for hospitalisation

| | |
|---|---|
| **Availability of entourage** | • Family problems or absence of family to accompany ambulatory care<br>• Family exhaustion |
| **Environmental stress** | • Serious family conflict<br>• High levels of parental criticism<br>• Severe social isolation |
| **Availability of care facilities** | • No ambulatory care available for lack of facilities (distance may be an obstacle) |

| | |
|---|---|
| **Previous treatment** | • Failure of ambulatory care (aggravation or development of chronic illness) |

Pediatric criteria for severe undernutrition of the HAS (2019):

- BMI ≤ IOTF 17 curve.
- Weight loss >10% in 1 month or >15% in 6 months compared to the premorbid weight.
- Weight stagnation resulting in a weight at least 3 standard deviations below the usual trajectory.
- Decrease height velocity (with a loss of at least one standard deviation in relation to the usual height).

The observation of a single criterion of severe undernutrition is sufficient to qualify the undernutrition as severe.

# Appendix 4. Clinician's tool: Practical method to determine the individual EOAN target weight

Dr A. Ayrolles and Dr C. Stordeur, CRMR AMP, Child and Adolescent Psychiatry Department, Hôpital R. Debré, AP-HP, Paris

In patients with a diagnosis of early-onset anorexia nervosa and incomplete bone maturation, persistent weight loss negatively influences the prognosis for growth and puberty.

An individual weight restoration target must be defined based on the premorbid BMI trajectory for better height prognosis in children with EOAN. We provide a standardized protocol to determine the child's individual weight restoration target. Growth and BMI charts are needed for this.

**The individual weight restoration target is determined according to the patient's pre-morbid BMI trajectory.** The BMI target is first determined ($3^{rd}$, $10^{th}$, $25^{th}$, $50^{th}$ or $75^{th}$ percentile or sometimes an intermediate "mid-range" percentile) and then a cross product with the patient's height (at the time of admission to hospital) is performed to calculate the individual target weight:

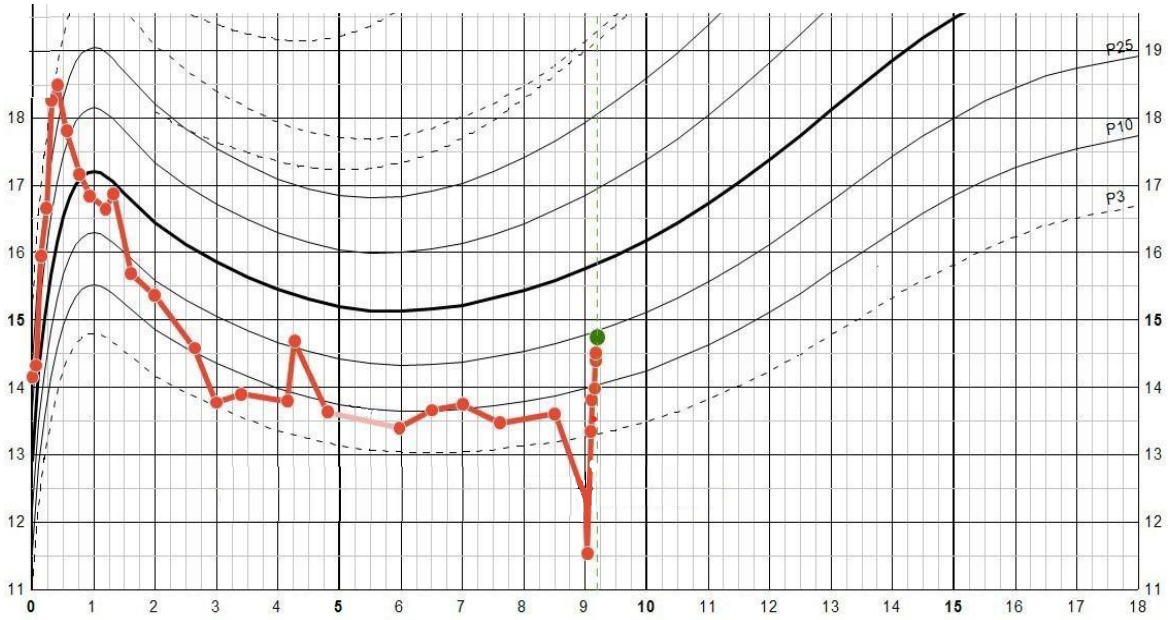
Individual target weight (kg) = Target BMI ($kg/m^2$) * Current height $(m)^2$

The result of this weight restoration target calculation is rounded up to the next 0.5 (examples: 22.1 to 22.5; 22.4 to 22.5; 22.6 to 23).

The individual weight restoration target can be determined collegially especially in case of a pathologic premorbid BMI curve (e.g., overweight).

| Examples of curves and choice of target BMI trajectory |
|---|

- Here is an example of a 9-year-old girl with a decrease in BMI. The BMI curve is labeled in percentiles.



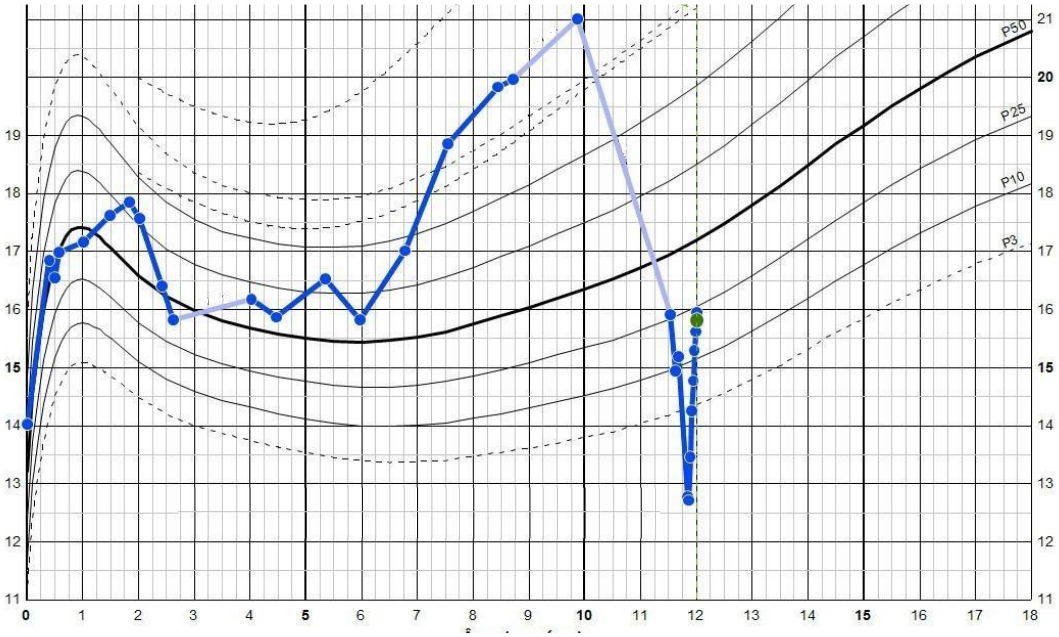

Thus, we observed a regular trajectory of premorbid BMI between the 3rd and 10th percentile from age 3 to age 8 and a half (with 1 point above the 10th).

Based on the percentile BMI curve, a BMI recovery target at the 10th percentile would correspond to a target BMI= 14 kg/m².

Individualized weight restoration target = target BMI * current height$^2$ = 14*1.31$^2$ = 24 kg.

- Some patients are overweight or obese prior to the anorexia nervosa episode. The goal of renutrition should then target the BMI trajectory before the patient became overweight or obese, often the 75th BMI percentile.

Here is the BMI curve of a 12-year-old patient.




The pre-morbid trajectory before the age of 6 years was between the 50$^{th}$ and 75$^{th}$ percentile with a point above the 75$^{th}$ percentile at 5 years 4 months.

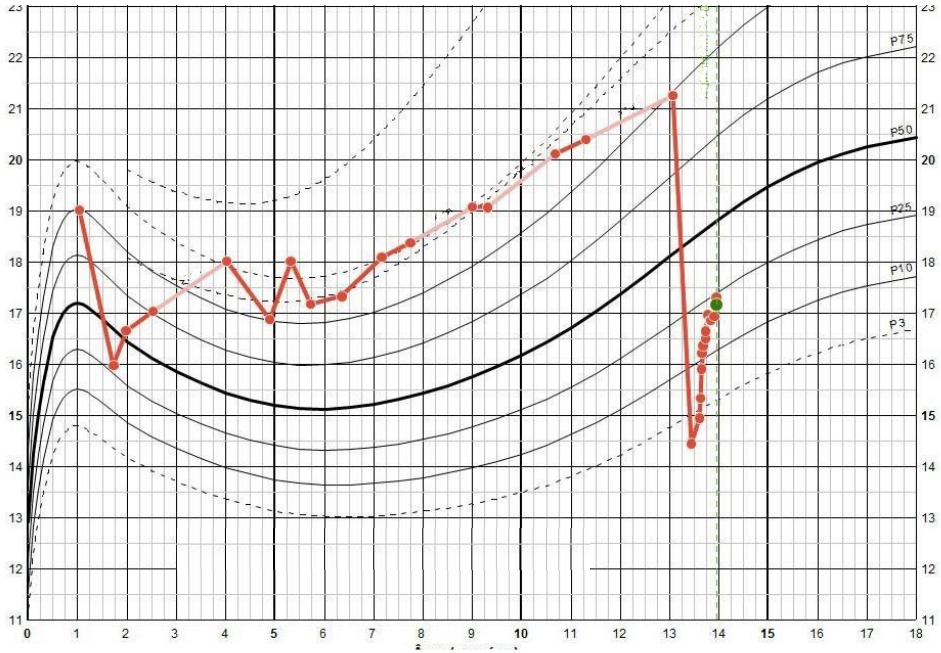
A target BMI at the 75$^{th}$ percentile would correspond to a BMI = 18.5 kg/m$^2$.

Individualized weight restoration target = target BMI * current height2 = 18.5*1.462= 39.43

So individualized weight restoration target = 39.5 kg.

- Some patients have had an overweight BMI trajectory since childhood. In this case, the aim is not to return to the overweight BMI, so a target BMI is set at the 75$^{th}$ percentile.

Here is the BMI curve of a 13-year-old patient.

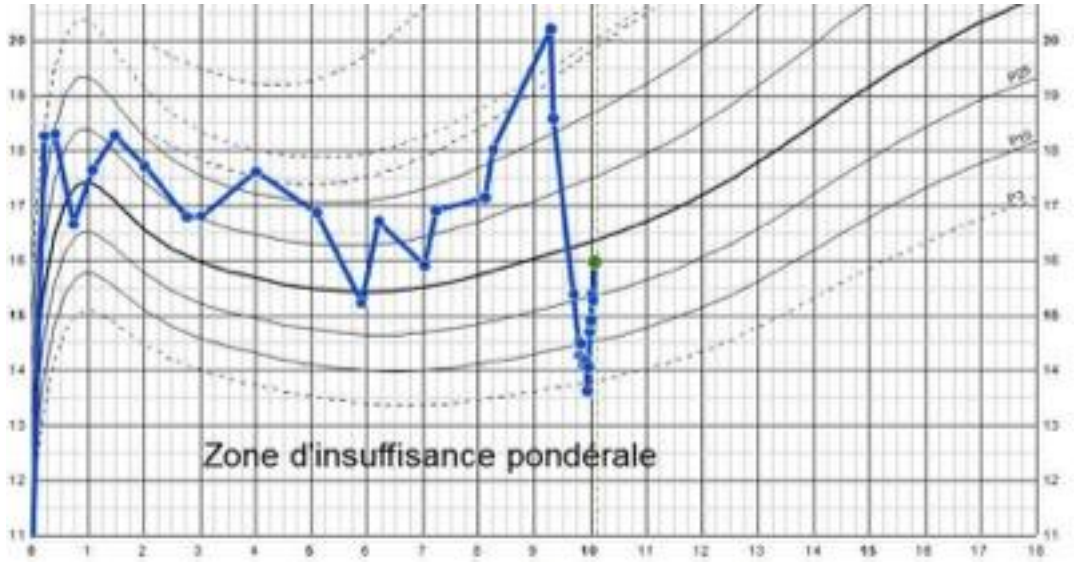



The BMI at the 75$^{th}$ percentile is 20.5 kg/m².

Individualized weight restoration target = target BMI * current height$^2$ = 20.5*1.682= 57.86
So individualized weight restoration target = 58kg.

- In others clinical situations the BMI trajectory shows many oscillations. It is more difficult to determine the individualized weight restoration target.

This is the curve of a 10-year-old patient.




The premorbid BMI ranged from the 50th to the 97th percentile. We also set the target BMI at the 75$^{th}$ percentile, i.e., 17.5 kg/m².

Individualized weight restoration target = target BMI * current height$^2$ = 17.5*1.372= 32.84
So individualized weight restoration target = 33kg

*Reference for BMI curves : Body mass index variations: centiles from birth to 87 years. Rolland-Cachra MF, Cole TJ, Sempé M, Tichet J, Rossignol C, Charraud A. Eur J Clin Nutr, 1991 ;45 :13-21*

## Appendix 5. Competence framework of the Therapeutic Patient Education Programme (TPE) with Early-Onset Anorexia Nervosa of the CRMR EOAN, Robert Debré University Hospital, AP-HP, Paris.

| **Competence framework** | |
|---|---|
| | |
| Understand, explain | |
| | |
| **Know the symptoms related to the disease** | Become aware that this disorder is a disease |
| | Know the disease |
| | Know the different symptoms |
| | Know the physiopathology of the disease (favouring factors, precipitating factors, maintenance factors) |
| | Know the small symptoms (anorexic behaviours such as hiding food, cutting small pieces, etc.) and their links with the disease ("vicious circle") |
| | Know alternative strategies to anorexic behaviour |
| | |
| **Know the principles of "normal" nutrition** | Define intuitive eating, orthorexia, cognitive restriction |
| | Know the benefits of eating, what the body needs to grow and develop, the benefits of renutrition |
| | Know the relevance and definition of the minimum healthy weight |
| | Name the different eating disorders |
| | Know the food families |
| | Know how to choose one item from each food family at each meal |

| | |
|---|---|
| | Know the dietary principles of diversification/various choices |
| | Note that diversification is self-evident |
| | |
| Identify, Analyse, Measure | |
| | |
| **Be aware of your normal eating behaviour** | Recognise the sensation of hunger, satiety, appetite, specific satiety |
| | Identify your "comfort foods" |
| | Identify what an adequate portion is |
| | |
| **Be aware of symptoms related to the disease** | Identify your own symptoms (including cognitions, anorexic behaviour) |
| | Identify 'easy', 'difficult' and 'impossible' foods |
| | Measuring the presence of the disease |
| | Being on the road to recovery |
| | |
| Practice, Do | |
| | |
| **Eat normally** | Gradually diversify |
| | Make a varied choice based on a balanced diet (food varieties) |
| | Eat calmly, paying attention to tastes, textures, flavours |
| | Eat in a community, under the gaze of others, possibly not sick |
| | Know how to maintain a convivial atmosphere around the meal (not being focused on your plate, listening to what is being said, keeping the conversation going, etc.) |
| | |

| | |
|---|---|
| **Apply techniques for managing emotions** | Know the techniques of solution finding (brainstorming, down arrow, decision balance, acceptance, value scale, etc.) |
| | Practice abdominal relaxation |
| | Apply the principles of mindfulness |
| | Apply the principles of downward arrow, alternative thinking |
| | Apply cognitive-behavioural self-soothing techniques |
| | |
| **Applying assertiveness techniques of oneself** | Implement the different modes of communication |
| | Describe what inhibition, aggression and assertiveness are |
| | |
| Coping, Deciding, Solving a problem | |
| | |
| **Put in practice the principles of "normal"nutrition** | Leave part of the portion |
| | Eat enough in any situation |
| | |
| Adapt, readjust | |
| | |
| | |
| Assert your rights | |
| | |

| | |
|---|---|
| | |
| Inform, educate those around you | |
| | |

| | |
|---|---|
| **Know how to communicate about your illness** | Explain your illness |
| | Identify what you want to share or not |
| | |
| Express needs, ask for help from those around you | |
| | |
| **Accept with the help of family** | Say when you are in trouble |
| | Accept to apply solution-finding techniques as a family |
| | |
| **Accept help from carers** | |
| | |
| | |
| Mobilise your resources | |
| | |
| -Identify your qualities and strengths | |
| -Identify what helps us in the fight against the disease | |
| -Identify what holds us back in the fight against the disease | |

# Appendix 6. Contacts

CRMERCD Network- French Reference (CRMR) and Competence Centres (CCMR)

- Reference Centre for Rare Disease - Early-Onset Anorexia Nervosa
  AP-HP - Paris Cité University - CHU Robert Debré - Child and Adolescent Psychiatry Department 48 bd Sérurier 75019 Paris

- Reference Centre for Endocrine Diseases of Growth and Development AP- HP - Paris Cité University - CHU Robert Debré - Pediatric Endocrinology Department 48 bd Sérurier 75019 Paris

- Centre of Competence for Rare Disease - Early-Onset Anorexia Nervosa AP-HM - Hôpital Salvator - Service de psychiatrie de l'enfant et de l'adolescent 249 bd de Sainte Marguerite, 13009 Marseille

- Centre of Competence for Rare Disease - Early-Onset Anorexia Nervosa
  Henri Laborit Hospital - Child and adolescent psychiatry department 370 avenue Jacques Coeur 86021 Poitiers

Patients' Associations

- FNA-TCA, President: Véronique Lion-Sanchette, 30, Charmilles de l'Aube 13100 Saint-Marc-Jaumegarde
- Fondation Sandrine Castelloti, President: Danielle Castelloti, 115 avenue Foch, 94100 Saint-Maur-des-Fossés

Other resources, General information:

French Rare Endocrine Diseases network: http://www.firendo.fr

Ressources on EOAN:

- https://www.clepsy.fr/category/troubles-des-conduites-alimentaires/
- http://crmerc.aphp.fr/pathologie/anorexie-mentale-enfant/
- http://www.orpha.net

Ressources on eating disorders:

- https://www.ffab.fr
- https://www.fna-tca.org/bienvenue
- https://www.has-sante.fr/upload/docs/application/pdf/2010-09/fs_anorexia_3_cdp_300910.pdf (criteria for inpatient treatment in the AN)
- https://www.hassante.fr/upload/docs/application/pdf/2019-09/fs_boulimie_urgences_v3.pdf (emergencies and eating disorders)
- http://tca-poitoucharentes.fr/anorexiclic/ (AN for general practitioners)