LONG STANDING ANOREXIA NERVOSA

Case Study

Cindy was a 40 year old female with AN who I followed for 20 years, until her death. She had severe, unremitting, restrictive AN complicated by hyponatremia, hypokalemia, hypomagnesemia, an empyema of her lung, multiple bone fractures, renal failure, anaemia, and terminally, pneumonia and acute inferior myocardial infarction.

Cindy had been admitted repeatedly over the years to various eating disorder units. She had tried and given up on many psychiatrists and psychologists, she was on chronic disability leave from her work, and within the last few years of her life she moved to an apartment in a suburb where she would eat very small amounts of food and have intermittent infusions of saline, potassium, and magnesium at home.

Cindy had been emaciated for years, but she enjoyed helping others and always asked about my children and would send them birthday presents. Although she could hardly hobble around with the use of a cane, she dressed in vividly coloured glasses and maintained her dignity to the end.

It is never too late to recover. Prof C.L. Birmingham (Birmingham & Beumont 2004 p173)

Ongoing signs and symptoms of protein-calorie malnutrition

- Thinning hair
- Dry and yellow skin
- Decreased ability to focus eyes
- Shortness of breath on exertion
- Decreased exercise/activity capacity
- Repeated dysrhythmias
- Dizziness on standing
- Weakness
- Tiredness
- Hypothermia
- Muscle cramps
- Decreased memory
- Poor capacity for concentration
- Progressive osteopenia causing repeated fractures (initially stress fractures, later symptomatic fractures of spine and lower extremities)

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1 Birmingham & Beumont 2004 p173
Long-term anorexia nervosa is associated with:

- Social isolation
- Inability to work and learn
- Diminished functional activity (family, friends and at work)

May be reclusive or fully integrated into family, work and society despite weight (here the rehabilitation goal is to assist the client move from the former to the latter)

Overall goals of long-term management include:

- Prevent death – monitor depression, actively prevent suicide, build rapport, search for psychological comorbidity that may prevent improvement or diminish quality of life, help set rehabilitation goals, continue to celebrate life with the client every visit.
- Medically, frequency of follow-up varies, depending on the degree of illness, from weekly to every three months.

Ongoing assessment should include:

- Weight
- BP
- Pulse
- Inquiry regarding mood & plans
- Setting goals
- If client is losing or gaining weight, potassium, magnesium, and phosphate levels should be measured.

If there is significant deterioration in physical symptoms, then a systemic inquiry and physical examination with laboratory measures selected based on symptoms (often to include haemoglobin, electrolytes, creatinine, AST, alkaline phosphatase, magnesium phosphate, vitamin B12, and ferritin) should be performed.

Management Tips

Concentrate first on physical complaints. Clients with long-term illness often find it easier to talk about physical concerns. Treating physical problems is easily accepted and appreciated, and this increases rapport. Treatment of urinary incontinence (which commonly occurs in chronic AN), careful care of feet and toes, and prevention of osteopenia with calcium and vitamin D supplements should all be considered. Use of the oral contraceptive pill to continue menstruation and potentially to increase bone mass should be discussed – a potential double-edged sword, as medication treatment of osteopenia may be taken as a reason to focus less on nutrition.

Psychologically, focus on rehabilitation and quality of life. Any co-morbid condition, such as a history of sexual abuse, substance abuse, or depression, should be sought and may require long-term treatment before other psychological gains are possible. If motivational enhancement therapy is available, then clients should be encouraged to undertake it. The primary physician should use a narrative approach in most cases — focusing on discussing the client’s life not according to their daily miseries but in the context of how someone would want to retell their story. The narrative approach should focus in particular on how the client’s life could be improved to make the story more to their liking. Often, it is useful to refocus the client on their life by pretending it is a movie and changing the ending or episodes of the movie as they would if they were directing it.
One must be very careful regarding the involvement of the family in the treatment of clients who have long-term illness. Other family members often hold powerful feelings of guilt and anger toward the client, who may also be ostracized from the family. Therefore, any discussions with family members are best done at the client's request and with the client present. From the GP's perspective, this will often be in the form of family interventions. E.g. the client may wish to change their place of residence, apply for disability insurance, or discuss their position in the family. The GP can act as a mediator for the client and explain the client's disease in the context of a process for which rehabilitation is necessary. It is of immense importance that the client's privacy is respected – this is particularly difficult in the setting of a 'family doctor' who has treated the entire family for years. All clients who reach the age of majority should be treated as independent adults, regardless of their health or place of residence. If the client's confidentiality is breached, their trust will be lost forever.

Medically, there are no medications other than food that are of absolute necessity in long-term anorexia nervosa.

The use of exercise in long-term anorexia is controversial. However, yoga, graded exercise programs focusing on breathing, stretching and gradually incorporating exercise to try to increase lean body mass and maintain bony mass is gaining acceptance. Paradoxically, excessive exercise may decrease with a very gradual introduction of minimal activity in the clients with long-term illness.

### Indications for consultation in long-term anorexia nervosa

- Specific complaints such as osteoporosis, chronic pain, depression
- Need for improved quality of life: weakness or other complaints that reduce quality of life must receive the usual investigation and treatment. This may require a rehabilitation approach.
- Motivation to change: during the course of the disease, many clients with long-term illness will ask to engage in active therapy for the disorder. This should be regarded as a great opportunity to involve them in therapy.

### Nutrition and Long-term Anorexia Nervosa

The nutritional intervention for long-standing anorexia nervosa is less vigorous than for the mild, moderate and severe/acute stages of illness. The goals for treatment should be modified to allow for sub-optimal (but realistic) weight and eating behaviour.

The aim of nutritional intervention at this stage is to assist the patient to maintain a weight that allows these patients to be medically stable and to have a reasonable quality of life. Encourage nutritional adequacy, at least to the level of minimum requirements, using nutritional supplements where necessary.

It cannot be assumed that once a client reaches his/her minimum healthy weight range they will automatically know how, or even want, to eat to maintain weight. There are often continuing difficulties with recognition of and appropriate responses to hunger and satiety; also ongoing psychological issues relating to acceptance of normal weight (or even an abnormally low, but stable weight higher than what the client may consider "ideal").

Clients with long-term illness invariably require ongoing guidance and support from psychological and nutritional counsellors for successful weight maintenance and potentially, recovery.