Severe and Enduring Anorexia Nervosa

Individuals with severe and enduring Anorexia Nervosa (SE-AN) have one of the most challenging disorders in mental health care[1]. SE-AN has the highest mortality rate of any mental illness with a marked reduction in life expectancy[2,3].

There are a variety of consequences resulting from the severity and chronicity of SE-AN. This includes impaired physical and psychiatric health, as well as implications on the individual's families, occupation and social life. Individuals with SE-AN are often under or unemployed, supported by government benefits, have high levels of disability and pose a significant burden both financially and emotionally on their family and carers.

Individuals with SE-AN have often experienced multiple treatment failures with numerous admissions to both general and specialist medical facilities. They often require frequent hospitalisation due to medical instability and imminent health consequences (including death).

Providing treatment in line with best practice guidelines for AN, which aims for 'full recovery' can be traumatic for individuals with SE-AN as this is often not in line with their level of motivation and goals. This misalignment between the treating team's treatment plan and the individual's goals, further entrenches the individuals lack of hope for recovery and exacerbates their lack of trust in the health care system. A specific treatment paradigm that takes a global approach to treatment and where goals of therapy are reconceptualised is required for individuals with SE-AN.

What is SE-AN?

There is currently no consensus on the definition and criteria for SE-AN. There are 3 domains, which are important to consider in defining an individual with SE-AN[4], including:

1. Clinical severity
2. Treatment failure or resistance
3. Chronicity

However specific details of these domains are unclear[4]. At this time more research on the duration of illness, number of treatment failures, medical instability, ability to maintain function and quality of life, weight and other specifics are required for a clear definition of SE-AN to be determined.

The average illness duration for AN is 2-5 years, therefore SE-AN extends beyond this in terms of duration of illness.

Understanding individuals with SE-AN

Many individuals with SE-AN[4]:

- Are motivated to improve their quality of life
- Cannot comprehend the concept of making a full 'recovery' from AN
- Do not wish to die, and will agree to hospitalisation and treatment to ensure medical stability

- Have experienced many different treatment options and treatment teams and have lost hope in their effectiveness
- Are open to developing a supportive and therapeutic relationship with clinicians that are able to work outside of the standardised treatment paradigm
- Are capable of making small incremental changes towards improving their health and wellbeing

Principles for treating individuals with SE-AN

Individuals with SE-AN require a specific treatment paradigm that takes a global approach to treatment and that is matched to the individuals needs and level of motivation.

The foundation of standard treatment for AN (i.e. an outcome of making a 'full recovery') must be set aside when treating individuals with SE-AN.

To increase the individual's level of motivation and increase the possibility for further improvements in symptom and functioning[4], treatment for individuals with SE-AN should be centred on:

- crises intervention
- harm minimisation
- improving engagement with an overall focus on improving quality of life

The principles for treating SE-AN include the following (see summary of recommendations in Appendix 1) as outlined in the Royal Australian and New Zealand college of Psychiatrists clinical practice guidelines for the treatment of eating disorders[1]:

1. 'Maintain realistic hope and expectations for improvement'[1]

Making a full 'recovery' may not be the objective of treatment, however it is vital that the clinician still maintains a hopeful stance for improvement. Maintaining 'hope' for improvement, especially when the individual or the family/carer has lost hope, is crucial to instilling motivation to change and is crucial to effective treatment.

Any indication from the clinician that the individual will 'never recover' or are 'untreatable' will be severely damaging to the individual's motivation to make change and will impact the individual seeking further support or treatment.

It is important that clinicians adjust their expectations from those for standardised AN treatment where 'full weight restoration' is an expectation. This will not be a realistic expectation for individuals with SE-AN, and if pursued (especially against the individuals will) the outcome will result in the individual feeling traumatised, disempowered and will reduced engagement in future treatment.

2. 'Take a harm minimisation approach to nutrition, medical complications and weight control behaviours.'[1]

Treatment should focus on minimising eating disorder symptoms, rather than ceasing eating disorder behaviours. Ceasing the individual's engagement with eating disorder behaviours is likely to be unrealistic and traumatic for the individual and will further alienate the individual, resulting in avoidance of treatment.

Treatment in a hospital setting for individuals with SE-AN may involve:

- Time limited admissions to restore medical stability
- Less frequent weigh-ins, as weight may not necessarily be a primary outcome measure
- Flexible supervision options such as possible supervision around eating & behaviours dependent on the individuals needs and goals
- Flexible 'leave' arrangements, to maintain a sense of quality of life and normality, which will enhance engagement in treatment
- Flexible meal plan requirements according to the goals of treatment and tailored to what is safer and easier for the individual to eat
- Clear requirements for medical stability and medical monitoring

Treatment in an outpatient setting may involve working on improving quality of life whilst stabilising medical markers. There may be very little or no focus on weight.

3. 'Focus on supporting functions, relationships and quality of life.'[1]

Individuals with SE-AN are usually willing to make small and incremental changes towards improving quality of life and maintaining their health status. Improvements in quality of life can increase the individual's motivation to address eating disorder symptoms and further improve quality of life, health and wellbeing.

The focus of treatment will therefore be centred around improving the individual's engagement in hobbies, work or education, working on their relationships and social networks, improving self-care and independence and engaging in other activities that improve the individual's quality of life and future prospects.

4. 'Collaboratively set achievable eating and health-related goals and be clear with the individual and family what the goals of treatment are.'[1]

It is essential that treatment for individuals with SE-AN be centred on meeting the individual where they are at, and collaboratively setting achievable goals. This should occur within the context of having clear limits around requirements for medical stability and medical monitoring.

The clinician should be warm, curious, non-judgemental, compassionate, patient, respectful, empathic and should validate the individual's experiences. The clinician should always avoid punitive interventions and power struggles.

In working collaboratively with the individual with SE-AN it is important that the clinician does not have any preconceived treatment goals such as minimum weight/BMI targets or program non-negotiables other than medical safety. Each treatment setting should explore how they are best able to meet the needs of the individual, rather than the individual fitting into a predetermined treatment program.

It is important that there is always a sense of 'taking a step forward' in collaborative goal setting, rather than just 'monitoring' or 'maintaining'. However, these goals must be collaboratively set, be realistic and achievable.

Goals may be focused around a range of areas including; respite from the eating disorder or symptom interruption, medical stability, improving cognitive capacity, improvement in quality of life and small weight gain goals.

A treatment plan with clear treatment goals should be devised by the individual with SE-AN and the treating team. There should be regular communication around the treatment plan with the individual, their family and the treatment team.

5. 'Reserve hospitalisation for medical rescue, management of psychiatric risk.'[1]

Individuals with SE-AN should be treated as per the continuum of care, whereby each individual is treated in the least restrictive environment according to their needs.

Hospitalisation for individuals with SE-AN should only occur due to medical instability and psychiatric risk, or urgent need for nutritional rehabilitation.

It is important that health professionals do not advocate for a hospital admission with the promise that the inpatient team will be able to cater for the needs of individuals with SE-AN, unless a flexible and 'SE-AN' tailored admission has been agreed upon by the inpatient treating team. It is important that inpatient hospital staff are prepared to negotiate flexible and tailored admissions for individuals with SE-AN with the individual, their family and carers and with the individual's community team.

6. 'Communicate regularly with all team members.'[1]

A multidisciplinary treatment approach is required for individuals with SE-AN. At a minimum, this should include a medical expert, psychiatrist, psychologist and dietitian. There should be regular communication between team members to ensure that all team members agree with the treatment plan.

If an individual is receiving treatment in a hospital setting, there should be regular communication with the individual's outpatient team.

7. 'Meet with family members and relevant others on an 'as-needs' basis.'[1]

Hospitalisation for medical instability and/or psychiatric risk of a loved one is very distressing for family/carers. Incorporation of the family/carers in treatment planning will depend on the individual and the family and carers particular situation.

It is essential to note that individuals with SE-AN require a comprehensive support network, and that the family/carers are a vital resource in assisting the individual to remain stable and to take steps forward.

Additionally families and carers may require a greater level of support from the health professional team as they are often exhausted and suffer high rates of 'burnout' from the demands placed on them to care for their loved one.

If the individual with SE-AN has an existing community team it is pivotal that they are included in the treatment process to ensure a good outcome for the individual.

Involuntary Admissions

Unfortunately, many individuals with SE-AN may deteriorate to the point of requiring an involuntary hospital admission. Involuntary admissions for individuals with SE-AN should be of short duration with a specific focus on medical stability and or urgent nutritional rehabilitation.

It is important that a collaborative and transparent discussion around the individual's treatment options are facilitated. Most individuals with SE-AN do not wish to die, and therefore if they can comprehend the seriousness of their medical risk (or risk of death) then they may agree to a short duration admission for medical stability.

More information

For more information on severe and enduring AN:

- Hay, P., Chin, D., Forbes, D., Madden, S., Newton, R., Surgenor, L., Touyz, S. & Ward, W. (2014). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders. Australian and New Zealand Journal of Psychiatry, 48(11), 977-1008.
- Touyz, S., Le Grange, D., Hubert Lacey, J., Hay, P. (2016) Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide.

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References

1. Hay, P., Chin, D., Forbes, D., Madden, S., Newton, R., Surgenor, L., Touyz, S. & Ward, W. (2014). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders. Australian and New Zealand Journal of Psychiatry, 48(11), 977-1008.
2. Steinhausen H-C. (2002). The Outcome of Anorexia Nervosa in the 20th Century. American Journal of Psychiatry 159: 1284-1293.
3. Arcelus, J., Mitchel, AJ., Wales, J. et al (2011). Mortality Rates in Patients with Anorexia Nervosa and other Eating Disorders: A Meta-analysis of 36 studies. Archives of General Psychiatry 68: 724-731.
4. Touyz, S., Le Grange, D., Hubert Lacey, J., Hay, P. (2016) Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide.