British Journal of Hospital Medicine

Br. J. Hosp. Med. (Lond) **2026**; 87(1): 50390
https://doi.org/10.31083/BJHM50390

Editorial

Is There a Role for Palliative Care in the Treatment of Anorexia Nervosa?

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Academic Editor: John Alcolado
Submitted: 27 June 2025 Revised: 10 September 2025 Accepted: 31 October 2025 Published: 26 January 2026

1. Background/Current Controversies

It is frequently cited that anorexia nervosa has the highest mortality of any psychiatric illness other than addictions, with an estimated standardised mortality ratio of approximately 5.5 [1]. It is likely that indirect deaths [i.e., due to other physical health conditions that become more difficult to treat in the context of severe malnutrition] are a key driver behind the high standardised mortality ratio of anorexia nervosa. Deaths directly from anorexia nervosa are rare, with approximately 20 deaths per year in England and Wales [2]. Despite the small number of deaths involved, the framework for the provision of end-of-life care for people with anorexia nervosa remains a topic that has caused considerable controversy within the field of eating disorder professionals.

Attempts have been made to propose criteria to make a sub-diagnosis of 'terminal anorexia nervosa', in cases where death from the illness is accepted as an inevitability, however, such criteria has been criticised for lacking an evidence base, being arbitrary, and the reality that it is not possible for eating disorder psychiatrists to accurately predict future treatment futility [3]. It is also not necessary to have a confirmed terminal illness in order to provide palliative care; if certainty is demanded of the terminal nature of the illness for an individual, before addressing their palliative care needs, there is a risk of missing the window to provide a holistic assessment and support of those needs. The price of certainty is the risk of denying the opportunity for a good death when all treatment options fail.

There are also significant concerns with respect to the unintended harms that may arise from the introduction of new diagnostic categories, such as 'terminal anorexia nervosa', particularly with the concern that the classification of a new illness category can serve to create new illness behaviours, and not function only as a specific descriptor of an existing clinical condition. The nature of the psychopathology of anorexia nervosa can include a powerful drive to be the thinnest or the most malnourished patient, and there is concern that creating new categories for more severe malnutrition could function to further complicate the psychopathology of existing patients [4].

2. Limitations of Active Eating Disorder Treatment

Eating disorder treatment is change-orientated and collaborative. Psychological treatment models are largely based on supporting the individual with the eating disorder to find the motivation for change, agreeing on treatment goals, and supporting the individual to achieve them. Coercive treatment has been demonstrated to be a negative prognostic indicator for treatment success [5]. Treatment for severe anorexia nervosa, with severe malnutrition, which has not responded to first-line inpatient and outpatient treatments, is likely to involve interventions with significant harms. Such treatment can include highly restrictive practice, such as continuous one-to-one nursing supervision, including in bathrooms, and repeated forced nasogastric feeding under restraint [6]. Such treatment is frequently experienced as traumatic and recognised to cause psychological and physical injury [7]. While there is provision for such restrictive practices within mental health law in the UK (in both England/Wales and Scottish legal systems), there are also significant legal safeguards, and such treatment options cannot be continued indefinitely.

3. Mental Capacity

Assessing mental capacity in anorexia nervosa is often complex and at times contentious [8]. Cognitive distortions characteristic of the illness can significantly influence how individuals process information, weigh risks, and make decisions about food, weight, and treatment in general. While the Mental Capacity Act (2005) provides a clear legal framework, applying its criteria to individuals with severe anorexia requires specialist understanding.

Patients may present as articulate and consistent in their treatment refusals, yet anorexic thinking may impair their ability to use and weigh relevant information. There is now a legal precedent recognising that patients with anorexia may lack capacity even when their decisions appear superficially coherent [9]. However, a presumption of incapacity is both ethically and legally problematic. Capacity is decision-specific, can fluctuate, and must be assessed on an individual basis. Careful, multidisciplinary assessments are essential, involving those with expertise in eating

disorders and supported, where appropriate, by independent advocacy.

A best interest decision may support the use of compulsory treatment, but there are also circumstances where ongoing interventions are likely to cause more harm than benefit. In such cases, a decision may appropriately include the limitation or withdrawal of further coercive treatment, while continuing to offer care and support.

4. Palliative Care Needs

Current models of palliative care provision do not equate palliative care to terminal care only; active change-orientated treatment can continue to be provided and encouraged alongside palliative care [10]. There are precedents for this in other areas of medicine; for example, patients with end-stage renal disease may be provided with palliative care even while hope remains that a kidney transplant may be made available [11].

The nature of severe malnutrition is such that patients may have specific palliative care needs in relation to frailty, weakness, nausea, pain, and non-healing ulcers [12]. These needs may require the input of a specialist palliative care team. Where there is a significant risk of death, there is a responsibility for healthcare providers to offer the opportunity to explore with the patient (and their families) wishes, preferences and decisions in relation to advance care planning, including individualised end of life plans, funeral wishes, and to address existential/spiritual needs where possible.

Concerns from palliative care professions relate to there being no reliable criteria/staging for anorexia nervosa, limited evidence base for treatment of symptoms, and for models of care, and minimal professional experience; for many palliative care clinicians providing input in this area will feel uncomfortable and unfamiliar. There is little evidence base for the provision of palliative care in the context of anorexia nervosa; however, it is established that a small number of people with anorexia nervosa do die each year, their deaths can often be "expected", and they may have unmet needs in the days and weeks prior to their death. Like other clinical specialities, eating disorder teams lack the specialist knowledge, skills and experience to navigate end-of-life care, therefore palliative care support is required.

The question of which patients, and when, to provide palliative care input is challenging and controversial; decisions must be individualised and based on clinical needs. Together, we can navigate the challenges and risks of prognostic uncertainty with collaborative working. Communication with all involved is key; defining goals and intent of care, frequent reviews and an openness to changing decisions.

5. Conclusion

Deaths directly caused by malnutrition secondary to anorexia nervosa are rare, and therefore, in absolute terms, the role for palliative care in relation to treatment for anorexia nervosa is limited. This makes it challenging to build up experience, evidence and to develop robust guidelines in this ethically and legally complex area. There are significant concerns about the provision of palliative care pathways for patients with anorexia nervosa, particularly with regard to associated unintended harms. Coercive treatment under the Mental Health Act (or equivalent legal frameworks) cannot be provided indefinitely, and is not always successful. Therefore, there are rare cases where patients may experience persistent and severe malnutrition with associated health consequences. The provision of palliative care may be needed in such cases; without this, patients will be left in a state of unmet care need. It could be considered as discriminatory to withhold palliative care support when an individual may be experiencing end-of-life symptoms and a death could be considered to be 'expected', albeit not inevitable. There are existing models of care in other settings for the provision of palliative care in clinical circumstances where recovery can be hoped for.

A common feature of eating disorder psychopathology is a sense of shame and being undeserving of care. As such, patients may perceive any shift in focus from active recovery-based treatment to palliative input as 'giving in to the eating disorder' or 'letting anorexia win'. This risk can be mitigated when palliative care is framed not as a withdrawal of active treatment, but as an additional layer of support aimed at relieving symptoms and improving quality of life.

The view of the authors is that, in rare circumstances, there is a clear role for palliative care in the management of anorexia nervosa and, without this in place, patients risk being left in a state with unmet care needs.

Key Points

• Deaths directly due to malnutrition secondary to anorexia nervosa are rare.

• There can be significant care needs in the last months of life for an individual that dies from anorexia nervosa.

• Eating disorder services are not equipped to address end-of-life care needs without specialist support.

• Palliative care can be provided while still holding hope for recovery.

Availability of Data and Materials

Not applicable.

Author Contributions

RF, VSC and JB designed the work. All authors participated in the drafting of the manuscript and contributed to the important editorial changes in the manuscript. All authors read and approved the final manuscript. All authors have participated sufficiently in the work and agreed to be accountable for all aspects of the work.

Ethics Approval and Consent to Participate

Not applicable.

Acknowledgment

Not applicable.

Funding

This research received no external funding.

Conflict of Interest

The authors declare no conflict of interest.

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