

February 25, 2025

Dear Members of Parliament,

We are writing to you on behalf of people with eating disorders, who are at grave risk if the *Terminally Ill Adults (End of Life) Bill* is enacted in its current form. The bill does not contain any provisions to prevent individuals with eating disorders from being classified as “terminally ill” based on the physical consequences of their condition, should they decline or be unable to access treatment. We accept that it is not the intention of the sponsor of the legislation to include eating disorders, but we are concerned that the wording of the Bill is sufficiently vague for it to be interpreted in that way.

Meet Mollie and Patricia, both in their twenties and diagnosed with anorexia and autism. Both faced years of illness, hospitalisations, and were labelled as having severe and enduring anorexia. At times, both wanted to die — driven by severe malnutrition and crippling depression. Today, Mollie is at university rebuilding her life. Patricia remains critically unwell, and is unable to access services.

The difference? How doctors interpreted the law. Mollie was treated under the Mental Health Act by a team that fought for her recovery. Patricia was taken to the Court of Protection, where she was described as “untreatable” by her doctors. Despite having a near-identical history to Mollie, a consultant asserted she was in the “pre-death stage” of her illness. The court accepted this assessment and ruled that she could not be fed against her wishes. As a result, she was discharged from eating disorder services, with the judge stating: “I fear that this may well be a return home to die.” Eighteen months later, she has been repeatedly denied care and is still fighting for the treatment she desperately needs.

### **INCONSISTENT MEDICAL PRACTICE PUTS LIVES AT RISK**

Eating disorders are not terminal illnesses, yet some doctors increasingly frame them as such. Underfunding, rationed care, and stigma — compounded by narratives like “terminal anorexia” — have led to more cases where patients had been deemed untreatable and even terminal. This has been reflected in decisions in the Court of Protection, where treatment has been withdrawn from young people based on doctors' subjective opinions about their prognosis. Judges are often presented with a false dichotomy: the patient can be fed under restraint and sedation or sent home to die.

Care has been withdrawn from patients as young as 19 years old, despite the option of compulsory treatment under mental health legislation. There is little consistency in clinical practice, even among specialists in the field — some advocate for withdrawing treatment after three or five years, or once a patient turns 30 if the patient is not compliant with treatment. If people with treatable eating disorders are already being framed as terminal and denied care, what would stop doctors from providing them with lethal medication if this bill passes?

It is not uncommon for someone in the depths of an eating disorder to say they want to die and refuse life-saving treatment. Many feel hopeless, helpless, isolated, and like a burden to their families. Some have experienced trauma in treatment and struggle to trust services. These are not reasons to offer assisted death — they are signs of a person in need of support and a system failing to provide the care they need and deserve.

## LEARNING FROM INTERNATIONAL FAILURES

We urge the committee to consider how assisted dying laws in Oregon, California, and Colorado have been interpreted by doctors in ways lawmakers never intended — leading to the premature deaths of young women with eating disorders. The bill must be amended to prevent similar loopholes from being exploited in this country. Many important amendments have been tabled. In this letter, we call on the committee to support the following amendments in Clause 2:

- **Amendments 9 and 10:** Ensure that conditions manageable with treatment do not qualify as terminal illnesses.
- **Amendment 48:** Clarifies that a person is only considered terminally ill if their death is reasonably certain within six months, even with all recommended treatment.
- **Amendment 402:** Explicitly states that a person cannot be deemed terminally ill because they have stopped eating or drinking.
- **Amendment 11:** States that a person cannot be considered terminally ill due to a mental disorder (removes “for the avoidance of doubt” and “only”).

### We have concerns about the following amendments:

- **Amendment 247:** While this requires terminal illness to be physical, it does not go far enough, as it would still allow physical complications of an eating disorder (e.g., malnutrition) to qualify. So whilst this amendment is a step in the right direction, and is no doubt well intended, it is not sufficient to allay our concerns.
- **Amendment 181:** This amendment states that mental illness alone does not qualify as a terminal illness, but as the legal text (“Nothing in this subsection...”) makes clear it has no effect beyond restating that the condition must meet the requirements of clause 2(1). If a doctor holds that a mental illness meets the test in clause 2(1) for terminal illness, this amendment will do nothing to prevent that.

Eating disorders are treatable. They are life-threatening when left untreated or poorly treated, but this risk is preventable, and deaths from eating disorders are not inevitable. As campaigners, clinicians, charities, and organisations working with those affected, we urge the committee to take these concerns seriously and ensure this bill does not put people with eating disorders at risk of premature death under the guise of assisted dying.

Yours sincerely,

**Hope Virgo**, Founder of #DumpTheScales and Campaigner

**Chelsea Roff**, Founding Director of Eat Breathe Thrive

**James Downs**, Campaigner and Researcher

**Ellie Smith**, Campaigner and Lived Experience

**Gemma Oaten**, Actress, Presenter and CEO of SEED

**Nic Hart**, Averil’s Dad

**Suzanne Baker**, Carer representative

**Dr Agnes Ayton**, Vice Chair of the Faculty of Eating Disorders at RCPsych

**Rachel Egan**, lived experience campaigner

**Andrea Stroud**, Campaigner and Lived Experience

**Louisa Rose**, CEO of BEYOND

**Mandy Scott**, Founder of Personalised Eating Disorder Support (PEDS)

**Mollie Twitchell**, Lived Experience

**Nicky Smith**, Carer and Campaigner

**Dr Ali Ibrahim**, Eating Disorder Consultant

**Rev Graham Archer**, Taste of Life UK

**Tom Quinn**, Director of External Affairs, Beat

**Nerissa Shaw**, Clinical Lead, SWEDA

**Paula Blight**, CEO, SWEDA

**Sam Best**, COO, SWEDA

**Deborah Xavier**, Head of Fundraising, SWEDA

**Kerrie Jones**, CEO, Orri

**Dr Rebecca Ferris**, GP with the North Yorkshire

CAMHS eating disorder service, Trustee of PEDS

**Hannah Hickinbotham**, Eating Disorder Advocate and Research Associate, Orri

**Andrea Stroud**, Lived Experience Campaigner

**Claire Jackson**, CEO, Caraline

**Kelly Voller**, Practice Manager, Caraline

**Bryony Dought**, MQ: Transforming Mental Health

**Simon Brown**, Chairman, PEDS

**The Laurence Trust**, supporting male eating disorders

**Di Archer**, CEO TasteLife UK

**Jodie Goodacre**, Campaigner and Lived Experience

**Debs Taylor**, Campaigner and Parent

**Emma O’Brien**, Social Worker