



An Inquiry into the Prevention of Eating Disorder Deaths

A Short Summary of the APPG Report



In October 2025, a report was released making recommendations to the Government for the prevention of eating disorder deaths.

The report was written by the All-Party Parliamentary Group (APPG) for Eating Disorders (). This zine is a short summary of the report, which I hope will help to make the findings more accessible and motivate action. It is not an official publication of the APPG or any other organisation. Rather, it is a representation of the findings, just like a newspaper or blog post. The summary is not comprehensive or objective, and likely reflects my own experiences as someone who struggled with an eating disorder for over 10 years before coming to terms with recovery (or rather, discovery) in 2023. If you feel the critical need for action, I encourage you to read the full report, share the campaign and write to your local MP demanding for change.



Summary

Eating disorders (EDs) have long been overlooked and severely underfunded in the NHS. This makes EDs one of the most significant treatment gaps in modern healthcare.

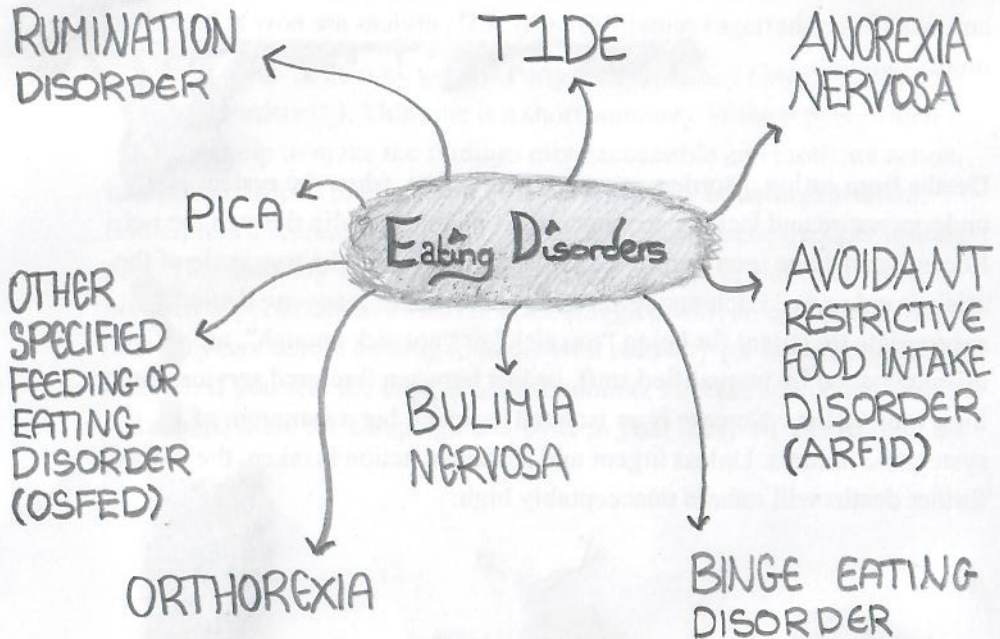
Though prevalence has seen a sharp rise in the last decade, service capacity has not kept pace. Chronic underfunding, fragmented services and workforce shortages remain a reality. ED services are now at breaking point.

Deaths from eating disorders are preventable. Yet, when the system is under pressure and lacking accountability, people can slip through the net. Recent years have seen multiple avoidable deaths, but the true scale of the crisis is unknown. Each one reflects a system where many are denied appropriate treatment for being “too sick” or “not sick enough”, are misunderstood by unqualified staff, or lost between fractured services and long waiting lists. No case is an isolated incident, but a symptom of systematic failures. Unless urgent and sustained action is taken, the risk of further deaths will remain unacceptably high.

To provide the foundations for change, the report calls for a National Strategy to address the eating disorder crisis, inclusion in national Suicide Prevention Plans, and a Confidential Inquiry into All Eating Disorder Deaths.

Background

EDs are some of the most serious and life-threatening mental health conditions. They are as diverse as they are numbered, and no two experiences are the same. The most recognised is anorexia nervosa, a restrictive disorder which brings a 5-6x higher mortality rate than the general population. Although, all EDs can have serious health implications, even when someone appears perfectly 'fine'.



Other EDs like bulimia nervosa, binge eating disorder, OSFED and ARFID have twice the mortality risk of the general population. People with Type 1 Diabetes and Eating disorders (T1DE) are especially at risk due to poor blood sugar control and associated complications. People with T1DE are 30x more likely to die than those experiencing Type 1 Diabetes alone, making it one of the most dangerous and least recognised conditions in the NHS.

Getting the Message Right...

Eating disorders are multi-factorial, caused by an interplay of genetic and environmental factors. Life events, stressors and existing health can play a role in maintaining an eating disorder. There is also increasing evidence of a metabolic component.

A Quick Guide: Why Nutrition is so Important

An 'energy deficit' occurs when someone does not receive adequate nutrition.

This may be for many different reasons, including illness, dieting, not receiving the right nutrients or doing more physical activity without a match in intake.

The energy deficit may trigger disordered eating habits.

Starvation can impact cognition and emotional regulation.

This can impair decision-making, wellbeing and relationships.

If the energy deficit persists, changes in brain function and structure may lead to maladaptive behaviours.

Maladaptive behaviours can include rumination, extreme dietary restriction and/or obsessive calorie counting, exercise or body image problems.

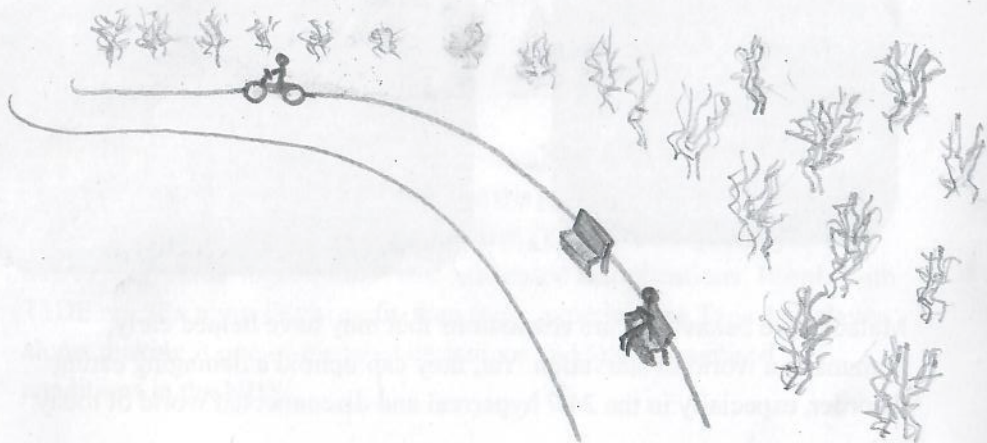
Maladaptive behaviours are adaptations that may have helped early humans in a world of starvation. Yet, they can uphold a damaging eating disorder, especially in the 24/7 hyperreal and disconnected world of today.

Since the energy deficit can trigger disordered eating, public health campaigns risk causing problems when they promote a skewed definition of 'healthy'. Extreme and sudden dieting, exercise and weight-loss can be extremely damaging in pushing vulnerable people into an eating disorder and possibly triggering patterns of bingeing, purging, further restriction and/or damaging thought patterns.

Many people with obesity actually have an underlying eating disorder. So when health experts stigmatise weight or encourage clients to count calories, they risk causing more harm than good. In fact, other investigations reveal cases of GPs referring people with unacknowledged eating disorders to programmes like Slimming World (Casserly, 2024).

Weight-loss programmes that encourage people to eat less and exercise more can be helpful for some. Yet their standardised approaches put many at risk, especially when they are not coupled with psychological support. A lack of understanding means that those vulnerable to eating disorders are not spotted, and can be pushed into a damaging relationship with food and body image.

What we really need are public health messages that emphasise mental wellbeing, joy, balanced exercise and nutrition literacy – not calorie counting, appearance or restriction.



...And Putting it into Practice

The energy deficit can compound inflexible thinking and distress. So when people are in recovery from an eating disorder, meeting their nutritional needs is essential. It is therefore worrying to hear that many eating disorder services operate without a qualified dietitian. At the launch event of the report, I spoke to several dietitians who revealed to me how few dietetic roles there are in NHS ED services.

For me, dietetic support was a baseline; a necessity that helped me develop trust, and realise the simple fact of what I needed to do to live the life I wanted. As my body was allowed to restore, there were moments where I suddenly realised that events didn't cause me as much anxiety. It was easier to make decisions and think things through logically. I could approach what was seemingly impossible just months earlier. Learning new skills and strategies also played a role, but I have no doubt that the guidance I received from dietitians and dietetic assistants was foundational to this change.



What laid the grounds for my recovery is sadly not a guaranteed in all services. I had won the postcode lottery. If I had not received qualified dietetic support, I honestly don't know where I would be now.

All services should be staffed by a multidisciplinary team, including psychologists, psychiatrists, psychotherapists, dieticians and mealtime support as a minimum.

Acknowledging Deaths and the Risk of Suicide

All EDs are treatable mental health conditions. This means that no-one should be dying of an ED. Every death is the result of a failure to provide someone with appropriate treatment, no matter how serious, enduring or complex their ED may be.

Despite this, people have died from EDs. The true scale of the crisis is unclear. Many deaths from EDs are mis-recorded or omitted from death certificates – organ failure, suicide or cardiac arrest may be written instead of the underlying ED. This gets in the way of holding our current system to account, allowing weaknesses to go unidentified and risk repeated deaths.

At the same time, if we simply label the cause of death as an ED, it may be perceived as inevitable. Like a terminal diagnosis, it focuses attention on biology and psychology, overlooking how the context failed to prevent someone's death. This diminishes the opportunity to look at what went wrong and learn from mistakes.



What Follows a Terminal Diagnosis

Most people who die from an ED are already known to services. Prevention of deaths is not only about intervening early when an ED starts developing, but providing continuous and high-quality treatment at all stages.

At the moment, NHS policy and funding is heavily weighted towards early intervention for young people. This means that adults and those with long-standing conditions struggle to receive specialist care. There are also gaps when people move across regional boundaries. Patients with co-morbidities frequently pass between separate services for EDs, substance-misuse and other mental health teams, none of which are prepared to manage overlapping conditions.

An ED does not exist in isolation. Joined-up mental health provisioning should be provided, commissioning ED services so that they can coordinate with other specialist teams.

Suicide is a leading cause of death among people with EDs. However, national suicide prevention plans rarely consider this group, allowing specific risk factors for people with EDs to go unaddressed.

The period after discharge is the single highest-risk window for suicide and medical relapse. Across all types of mental health units, the suicide risk is 191x higher in the first three months after discharge. Gaps between specialist inpatient, outpatient and other services exacerbate this risk, especially when people have to move across regions to receive care.

Transitions can be infused with anxiety, challenge and opportunity. It is vital that patients are not forgotten during these critical times. Support must be sustained, integrated and prepared for in advance with personalised relapse prevention plans for each individual.

Moving forward, treatment must be integrated with step-down services and outreach support. Designing care in this way has been shown to dramatically reduce relapse and re-admission, and instead help each person continue on their journey.

What Follows a Terminal Diagnosis

When the narrative surrounding an eating disorder ventures into the language of ‘terminal’, any motivation to try again can be extinguished. The label may encourage withdrawal from treatment instead of more active participation. It is not direct coercion, but language itself can close doors.



People who do not recover within the first 3 years are often considered less likely to benefit from further treatment. They may be put on pathways that assume full recovery is no longer achievable.

The concept of “terminal anorexia” was first proposed in the US and has received international criticism. Its effects have been documented as contributing to fatalism among some clinicians, discouraging active participation and diminishing the hope of recovery among those with long-standing illness.



There is disagreement among senior clinicians about how to manage long-standing EDs. In 2022, draft guidance was issued by NHS East of England referring to palliative care pathways for adults with so-called ‘Severe and Enduring Eating Disorders (SEED)’. It proposed that clinicians could consider ending specialist treatment where recovery appears unlikely.

SEED is not a recognised diagnosis and this document was later withdrawn.



When further treatment against one's will could cause trauma, withdrawing treatment is sometimes seen as respectful of autonomy. There is a deep ethical question here about a patient's right to withdraw from treatment and decide their own path. The principle of 'autonomy' can become a double bind – do you respect personal choice or the duty to preserve life, prevent harm and act compassionately to the person they can become?

It is a delicate subject, but when someone is in the midst of an eating disorder, decisions to refuse treatment are shaped by the cognitive and emotional effects of starvation. They cannot be regarded as fully informed or autonomous. Worryingly, the concept of "terminal anorexia" can validate the eating disorder voice and make it impossible to imagine a life without it. The Inquiry states that because of this, withdrawal of treatment is neglect;

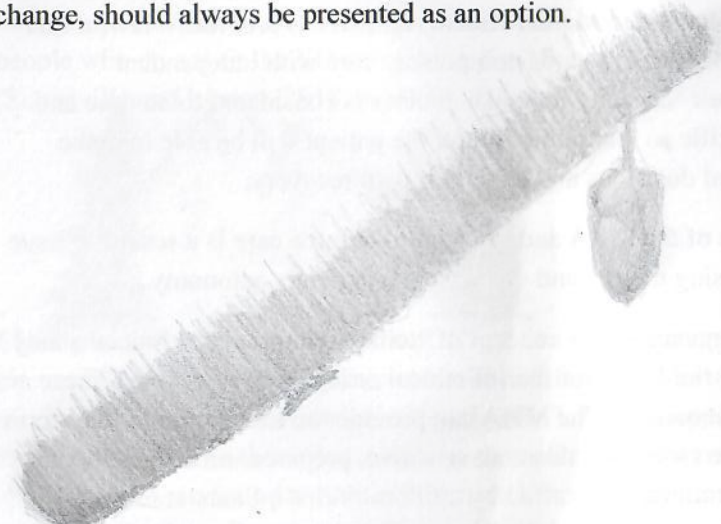


"If you are repeatedly told that recovery is unlikely, it becomes extremely difficult to imagine a different future" (Chelsea Roff, Researcher and Advocate)

Someone may outwardly refuse meal plans or to tackle behaviours, but that does not mean they are not desperate for change on the inside. Building a narrative that someone is unsuitable for treatment is a slippery slope – for the individual and services as a whole. By withdrawing, clinicians may discharge patients way too early, before treatment has even had a chance to break through. This reality could become all too common as system pressures mount and waiting lists grow.

I have no doubt that all clinicians intend the best for patients. However, an under-resourced service can undercut time for compassion. Facing mounting demand and workforce constraints, the risk of mistakenly labelling someone as 'terminal' is real, and should be mitigated at all costs.

We need to ensure services have time to listen and help each person realise their own values, meaning and potential. Regardless, clinicians should not have the choice of labelling an ED as ‘terminal’. Hope, and the prospect of change, should always be presented as an option.



After repeated admissions and exhausting all treatments available, patients with long-standing illness can feel like they are “beyond help” (p.22). However, national guidance provided by NICE offers only a few treatments. Many other evidence-based therapies exist and have been shown to help people recover when traditional treatments haven’t worked. Examples include forms of art therapy and outpatient psychotherapy that address the whole person. They can reframe recovery and account for co-morbidities and neurodivergence.

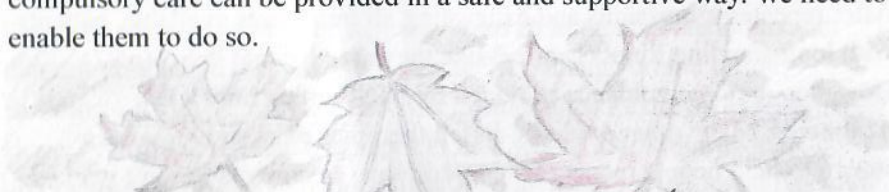
Recovery (or as a friend of mine prefers to call it, discovery) is possible even after many years. It is something I firmly believe in – choose to believe in – each and every day.

Using Legal Frameworks and Restraint with Care

When an ED is at its most extreme, people may refuse treatment. Sometimes, these decisions are impaired by ED thoughts and malnutrition, so that the individual struggles to make an informed decision about their care. In such cases, the Mental Health Act (MHA) provides a lawful and safeguarded pathway towards compulsory care with independent oversight. Their 'capacity' to make choices is considered to be time and decision-specific so that in the future, the patient will be able to make more informed decisions and lead their own recovery.

However, use of the MHA and restraint to enforce care is a sensitive issue that risks causing trauma and dismissing a patient's autonomy.

With the emergence of the concept of "terminal anorexia", clinicians may hesitate using the MHA for fear of ethical or legal repercussions. These are important concerns. Yet the MHA can provide the foundation to long-term recovery. If services are informed, sensitive, prepared, reflexive, accountable, trained and staffed by a full multidisciplinary team, compulsory care can be provided in a safe and supportive way. We need to enable them to do so.



Similarly, restraint should only be used as a last resort, conducted by a team trained in trauma and autism-informed approaches. In spite of this necessity, restraint is sometimes carried out by unqualified staff. There are even examples of face-down restraint, which should never occur.

These traumatic realities are what we see on the surface of systematic under-resourcing, limited training and inadequate monitoring. Without safety and trust, recovery is undermined and can become the site of further trauma. We wouldn't accept this for any other illness. How have we allowed this go on for so long?

Pervasive Stigma

Surrounding the systematic problems within ED services, stigma and a lack of understanding among the public feeds into a culture of misunderstanding. People with an ED may not even recognise their struggles, while others find it hard to reach out. This is especially true for people who do not fit the ED stereotype of a “skinny, White, affluent girl” (Sonneville and Lipson, 2018, p.518).

ED stigma extends into public policy. All of the NHS is struggling. However, previous analyses have revealed that funding allocated to ED services has been spent elsewhere (BEAT, 2017). The Royal College of Psychiatrists (2025) has raised concerns over planned spending cuts to children’s ED services. Doctors still receive less than 2 hours of training on EDs throughout the whole of their medical degree, and there is still no mandatory training for frontline staff. It is clear that EDs are not treated with the same urgency as other life-threatening conditions.

People are being told they are “not sick enough” to meet refuted BMI thresholds for treatment, and then later, “too sick”. Those with ARFID are often assessed under anorexia criteria, creating misunderstandings. Others are being discharged at dangerously low BMIs, without continuity of care.



In an under-resourced system, workforce shortages, early discharges and an unjust reliance on carers and private and palliative services are a daily reality. Capacity is stretched and unable to provide full training or evidence-based care. This can set patients up to relapse and amplify existing pressures. People with eating disorders are not the burden on the system, but alongside staff, carers and the wider public, we are all being injured by a violently under-funded service.

In this system, people can fall through the cracks;

“Community teams failed our daughter from before she was discharged home, during her short time home and are not accepting accountability for failing her. Our daughter nearly died because of them.” (Anon)

No-one is responsible for this failure, but the absence, the void, the gap, is.



Now with this knowledge, the importance of listening to those with lived experience, families, researchers and people on the frontline could not be more clear. Failing to take action will allow further harm and risks further deaths.

Going Back to Basics

Fractures in the system are growing, allowing more people with EDs to fall through. At the other end, unhelpful advice, social media bubbles and body-shaming messages create a culture ripe for EDs.

In schools, food is often labelled as 'healthy' vs 'unhealthy'; a demonising message reinforced by public health campaigns that focus on calories and weight-loss.

Entire cosmetics, weight-loss and fitness industries are built on unrealistic expectations that can foster dissatisfaction, disordered eating and excessive exercise. Social media amplifies this risk. Prevention requires awareness campaigns, greater regulation, and nutrition and digital literacy to enable people to critique and see past the myths.

Prevention goes right back; recognising that an ED does not develop in a void, but through an interaction of environmental and biological factors across a lifetime. There is a need to tackle the social determinants of ill health and change the messages being spread.

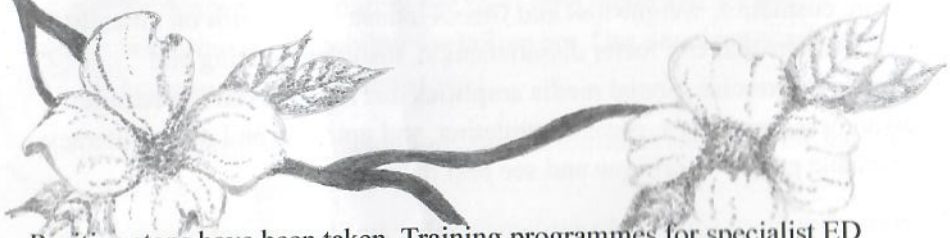
It may not be possible to stop EDs emerging, but we can reduce the chances. We can prevent them consuming a life and instead help build resilience, care and a road towards recovery.

Change is Possible


The Inquiry brings together cases of incredible – but not impossible – recovery journeys, alongside stories of people let down by the system.

If every individual is to be supported through recovery/discovery, there needs to be early and effective intervention, continuity of care and access to appropriate and evidence-based therapies all within a culture of understanding, accountability and support.

This requires sustained investment, national leadership and full implementation of existing guidance for treating people with EDs.

A decorative illustration featuring two large, stylized flowers with multiple petals and several leaves, connected by a thin, dark, winding vine that spans across the middle of the page.

Positive steps have been taken. Training programmes for specialist ED service teams have been supported by NHS England, for example. Yet the future of these programmes is uncertain due to funding cuts. Leading bodies have created clear standards and expectations for ED services, but implementation is inconsistent, partly due to difficulties with the resources and capacity to train staff. Meanwhile, there are stark inequalities between regions and child and adult services.

A decorative illustration of a thin, dark, winding vine with several small, pointed leaves and a small cluster of buds or tiny flowers, located in the bottom right corner of the page.

Recommendations

To provide the foundations for recovery and prevent further deaths, immediate action needs to be taken. The Inquiry makes the following recommendations;

- Create an Eating Disorder National Strategy.
The national strategy will recognise and respond to EDs as a health emergency. It will ensure mandatory training for all NHS staff, as well as judges and lawyers who may be involved in cases regarding ED treatment. Multidisciplinary teams will be created for all ED services and the messaging of public health campaigns reviewed.
- Integrate the risks for people with EDs in Suicide Prevention Plans.
- Undertake a Confidential Inquiry into all Eating Disorder Deaths.

Preventing deaths from EDs requires a holistic, whole-system approach. Further recommendations for how this can be achieved are outlined in the Inquiry, and I encourage you to read them.

Every single death from an ED is one too many. Zara Taylor, Averil Hart, Laurence Nugent. All their deaths were preventable.

So with renewed emphasis, we call on the Government to review the Inquiry and work with the APPG to address the crisis.

Everyone with an eating disorder deserves a life beyond it, but systems need to change.

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By Hannah
@myenviromind