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An Inquiry into the Prevention of Eating Disorder Deaths

This report is dedicated to the memory of Zara Taylor, and all those whose lives have been lost to eating disorders.

October 2025

This report was compiled by Dump the Scales CIC who provide the secretariat to the All-Party Parliamentary Group on Eating Disorders.

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Foreword

By Wera Hobhouse MP and Richard Quigley MP

After six years of sustained All-Party Parliamentary Group (APPG) activity, the reality remains stark: services for people with eating disorders are still failing in many areas. The system continues to be fragmented, chronically underfunded, and resistant to meaningful change. What we need now is not more reflection, but breakthroughs in both strategy and delivery.

Without urgent and decisive intervention, individuals with eating disorders will continue to face dangerously inconsistent and inadequate care. The consequences are profound: lives are being lost, and too many families are left to navigate this crisis alone. While some areas of the UK showcase pockets of good practice, our evidence gathering makes it clear that unsafe discharges are still far too common, and the system is failing to prevent avoidable deaths.

These failures reflect deeper structural issues: poor accountability, disjointed commissioning, insufficient training for professionals, and a lack of tailored support for both patients and carers. These are not isolated problems; they are symptoms of a system in crisis.

Sweden and Australia have embedded mandatory training and minimum staffing ratios, improving survival and outcomes. The UK must follow suit by mandating MEED implementation and multidisciplinary standards across all settings.

With timely, well-integrated, evidence-based treatment, recovery is not only possible, but also achievable, even in the most severe and longstanding cases. The belief that "everything has been tried" is a myth that too often ends in tragedy. Everyone

Case Study

I have had an eating disorder for 12 years, starting when I was 16 but it wasn't until 3 years ago that a friend encouraged me to get referred to services. I had a bad experience and was discharged within a few months without any progress towards recovery being made. However, last year my weight had dropped very low and I was re-referred again but I heard that a new ED team had been put together. The support of this team has been so wonderful and really encouraging, helping me to make real progress into recovery and being a "healthy" weight for the first time in 12 years. They understand how EDs are different in everybody, recognised my autism while I was waiting for a diagnosis, never blamed me and never got frustrated with me. They listened to me, understood me and saw my potential even when I didn't and had lost all hope.

deserves the chance to recover, no matter how long they have been unwell.

Time and again, we hear that all treatment options have been exhausted, that people are resistant to change. We know this is not true. Due to systemic failings, too often the patient and their family are blamed. People are discharged too soon and abandoned by a system that is struggling to cope.

We are seeing a rise in people being diagnosed with eating disorders. If these increases in admissions were linked to a condition like cancer, treatment methods would rightly be updated in response. Yet when it comes to mental health, particularly eating disorders, our methods remain static, outdated, and disturbingly resistant to change.

By listening to those with lived experience and acting on the lessons we've already learned, we can save lives. With well-integrated, adequately resourced, and evidence-based treatment, recovery is possible even in the most severe cases of eating disorders.

We cannot bring back those we have lost, but we can honour their memory by making sure no one else dies needlessly. Every life lost to an eating disorder is one too many, and every future death is preventable. By listening, learning, and acting with compassion, we can stop these tragedies from happening again.

Recovery is possible, even after many years of illness, when the right care is available, care that is personalised, intensive, and never gives up on people. That truth must guide every decision about how services are designed, funded, and delivered.

The prevention of eating disorder deaths must be a clear and urgent goal for both Government and the NHS. This report is a call to action to turn lessons learned from loss into lasting change, and to make preventable eating disorder deaths a thing of the past.

"I was admitted to inpatient treatment adamant that I didn't want to be there and petrified of letting go of my eating disorder. Now, 13 years later, I have such immense gratitude for the team who admitted me. Not only did they save my life physically, they gave me the tools to recover and lead a life worth living." (Anna)

Executive summary

Eating disorders are some of the most serious and life-threatening mental health conditions, yet they have long been overlooked and are severely underfunded in the NHS. As a result, they now represent one of the most significant treatment gaps in modern healthcare. Over the past decade, the prevalence of eating disorders has risen sharply, an already troubling trend that was further accelerated by the COVID-19 pandemic. What was once a fragile support system for those affected has now reached breaking point under the weight of growing demand and limited resources.

"This inquiry calls for eating disorders to be recognised as a national patient-safety priority and for concerted cross-government action."

Eating disorders are treatable mental health conditions. Yet when the cause of death is attributed to an eating disorder, it is often treated as an inevitable outcome rather than as an opportunity to proactively consider what could have been done differently to prevent similar tragedies in the future. We also know that in many cases, deaths from eating disorders are misrecorded or omitted from death certificates and instead attributed to organ failure or suicide. As a result, we do not have exact statistics for eating disorder deaths and therefore the true scale of the crisis remains unclear.

For too long, people with eating disorders have faced vast amounts of stigma. This is reinforced by poor understanding and the repetition of misinformation. For example, eating disorders are often described as "coping mechanisms" or "all about control". Both descriptions are overly simplistic.

Eating disorders are influenced by a range of factors, including biology. We now know that genetics can play a role in the development of an eating disorder. Environmental factors also contribute, and there is evidence that eating disorders can have a metabolic component. This means that for some people, when they are in an "energy deficit" and do not get enough nutrition, disordered eating habits can be triggered.

There are many ways people can fall into an energy deficit, including dieting, not having the right nutrition, illness, or an increase in physical activity levels without sufficient increase in calories. Over the longer term, eating disorders cause changes in brain function and structure which can lead to maladaptive behaviours. Maladaptive behaviours may include calorie counting, rumination, body image problems, and extreme dietary restriction. Due to the stigma and a lack of understanding, many

people affected by eating disorders often find it hard to reach out for support.

Preventing further loss of life requires urgent and sustained action. This report calls for eating disorders to be treated as a national patient safety priority.

The Eating Disorder Prevention of Deaths Strategy identifies key areas for improvement, where immediate action is needed, and outlines how we can work towards preventing deaths from eating disorders.

Recommendations

1. A confidential inquiry into all eating disorder deaths
2. Integration with suicide prevention strategies
3. Improve Data Collection and Learning Systems. This will include:

—The establishment of a national learning mechanism to review all deaths from eating disorders, including death by suicide, misadventure and medical complications (e.g. sepsis, cardiac arrest)

—Secure data governance arrangements to allow for cross-checking of provider-level data with national datasets

—Ensuring the systematic coding of eating disorder subtypes and comorbidities to improve the clinical value of surveillance data

4. The regulation of NHS and private eating disorder services, which will:

—Require NHS England and the Department of Health and Social Care to publish an annual report on eating-disorder deaths, relapse and recovery outcomes

—Establish a national advisory group bringing together clinicians, researchers, and people with lived experience to review progress and advise on safety improvements and update national clinical guidance to cover not only early intervention but also long-term management and relapse prevention.

5. A standalone, fully funded Eating Disorder National Strategy which will include:

In healthcare

—Mandatory training on eating disorders for all NHS staff

—Full implementation of Medical Emergency Eating Disorder (MEED) guidance

—A guarantee of equal access to medical and psychological treatment for adults as for younger patients

—The abandonment of policies or service models that exclude people considered “too complex” or “not motivated enough”

—Making all eating disorder information documents available in multiple languages

— Ensuring that services cannot withdraw active treatment on the grounds that a patient is unlikely to recover

—The provision of long-term treatment and relapse-prevention plans for anyone leaving specialist care

—The creation of multidisciplinary teams in all services, including as a minimum dieticians, psychologists, psychiatrists, psychotherapists and support at mealtimes

—Evidence-based pathways (specifying minimum duration of therapy) and broader, accessible treatment options in the NICE Guidelines. If someone is not responding to first-line treatment, give them the chance to try other treatments

—Funding of research into new service models.

Legal and safeguarding

—Making external second opinions available to all patients on request

—Mandatory training on eating disorders for Court of Protection judges and lawyers

—Auditing recent Court of Protection cases involving eating disorder treatment where services have argued that treatment should be refused

—The inclusion of suicide risk in best interests decisions.

Education and prevention

—A national public health campaign on eating disorders

—Ban routine weighing of children in schools

—Targeted early intervention in high-risk cohorts

—Address weight stigma and misinformation

—Pilot proven school-based prevention programmes such as the dissonance-based models developed by Professor Eric Stice, which have reduced eating-disorder symptoms by up to 70 per cent in trials

—Continue to evaluate Body Happy Schools and similar UK initiatives, linking them to national research partners before large-scale rollout

—Train GPs, school nurses and university wellbeing teams to recognise early signs of eating distress and refer quickly for specialist assessment

—Review all national health campaigns to remove unhelpful emphasis on weight or calorie control

—Replace “good” and “bad” food language with messages about nourishment, balance, and enjoyment of food

—Include eating-disorder experts and people with lived experience in the design of all NHS and Government health messaging

—Explicitly include eating disorders in national suicide-prevention planning.

Whole-Journey Prevention

Preventing deaths from eating disorders means acting at every stage of the journey, helping people earlier and keeping them safe once they are ill. It is not only about spotting problems in schools or families but about ensuring that those already in treatment receive consistent, joined-up, and compassionate medical care for as long as they need it. Most lives can be saved through timely diagnosis, evidence-based treatment, safe discharge, and ongoing support. Early intervention helps prevent suffering; sustained care prevents deaths. Both are essential.

Introduction

Eating disorders are among the most serious and life-threatening of all mental illnesses. Anorexia nervosa carries a standardised mortality ratio five to six times higher than that of the general population, while bulimia nervosa, binge eating disorder, other specified feeding or eating disorder (OSFED), and avoidant-restrictive food intake disorder (ARFID) carry approximately double the population risk (Arcelus et al., 2011; Hambleton et al., 2022). People with type 1 diabetes who also have an eating disorder (T1DE) face particularly high mortality due to poor blood-sugar control and associated medical complications (Gibbings et al., 2021; Nielsen, Emborg and Molbak, 2002)

Despite these well-established risks, official mortality figures greatly understate the true scale of the problem. Death certificates often omit eating disorders as a cause of death or contributory factor, recording instead immediate medical events such as cardiac arrest, organ failure or suicide. Suicide is the most common non-natural cause of death among people with anorexia nervosa, bulimia nervosa, binge eating disorder and OSFED (Smith, Zuromski and Dodd, 2018). Research indicates that suicide is the cause of death in approximately one in five people who die as a result of an eating disorder.

The *National Confidential Inquiry* report demonstrates that people who died of suicide with an eating disorder are more likely to be women of working age (c.33 years) and have multiple comorbidities (Hercus et al., 2024).

Despite the most recent NOMIS and Office for National Statistics (2024) mortality report having eating disorders as a separate category, we know there is still limited reliable data on the number of deaths. The absence of a clear reporting framework conceals the true impact, impedes prevention, and limits accountability within health and social care systems.

Reliable national data is urgently needed. Systematic recording of long-term treatment outcomes and causes of death is essential to inform policy, improve accountability and prevent further avoidable loss of life.

In recent years, more people have begun to speak openly about eating disorders. Although public awareness has increased and many individuals have shown courage in sharing their experiences, stigma remains deeply embedded within healthcare owing to inadequate training of staff. These attitudes continue to influence how patients are perceived and managed, leading at times to the minimisation of risk, delayed intervention and decisions that unintentionally perpetuate harm.

> “If someone hadn't intervened, I wouldn't be here now. I was so stuck in my eating disorder I couldn’t see a way out but when forced to face my biggest fear I could finally see that this horrible illness was no way of life. Being an inpatient was the last thing I wanted, and it was the worst experience of my life but it was the best thing that happened to me. I am finally able to live a life I would never have imagined when I was in the grips of anorexia.” (Alice)

People who do not recover within the first three years are often seen as less likely to benefit from further treatment and are placed on pathways where full recovery is no longer considered achievable. Yet recovery is possible even after many years of illness (Eddy et al., 2017; Eielsen et al., 2021). Under-resourced services frequently lack the capacity to provide evidence-based care and clinicians face pressure to discharge patients early, sometimes driven more by system pressures than by clinical need.

In these circumstances, the principle of autonomy can become a double bind. Respect for personal choice must be balanced with the duty to preserve life, act with compassion, and prevent foreseeable harm. When decisions to refuse treatment are shaped by the cognitive and emotional effects of starvation, they cannot be regarded as fully informed or autonomous (Jefferson, 2024; Atti et al., 2020). The concept of “terminal anorexia”, first proposed in the United States and later withdrawn after international criticism , has contributed to fatalism in parts of the clinical community, discouraging active treatment and diminishing the hope of recovery for those with long term illness (Guarda et al., 2022; Asaria, 2023).

Clinicians may also hesitate to use the Mental Health Act, fearing ethical or legal repercussions. At the same time, individuals with higher body weight may be perceived as less severely ill, leading to missed diagnoses and delayed interventions.

Eating disorders are treatable illnesses. Deaths are not inevitable. With the right care, people do recover. But too many are still being failed by a system that reacts too late or not at all. Most deaths could be prevented with timely, coordinated, and compassionate treatment.

In December 2017, in the wake of multiple avoidable deaths, including that of 19-year-old Averil Hart, the Parliamentary and Health Service Ombudsman (2017) published *Ignoring the Alarms: How NHS Eating Disorder Services Are Failing Patients*. Prior to this, there had been no formal policy recommendations for the prevention of eating disorder deaths.

The report made five major recommendations:

Training of doctors and other medical professionals; the General Medical Council (GMC) asked to review the training of junior doctors on recognising and managing eating disorders.

Achieving parity in the quality and availability of adult services, including better transition from child to adult eating disorder services; the Department of Health and NHS England were asked to review and address existing gaps.

Improving coordination between services for people accessing multiple providers; NICE were asked to include coordination in its Quality Standard.

Addressing workforce and specialist training gaps; Health Education England (HEE) to review capacity and training to increase the availability of eating disorder specialists.

Improving investigation, serious-incident learning, and data capture, especially to ensure that deaths are thoroughly investigated and learning widely disseminated.

Despite these recommendations, progress has been slow and inconsistent; major differences in care can be due to where a person lives and to individual staff teams. The Public Administration and Constitutional Affairs Committee (2019) reviewed implementation and found that commitments had yet to deliver meaningful change.

Rebecca Hilsenrath, Chief Executive, Parliamentary and Health Service Ombudsman (PHSO), gave evidence for the APPG. She told us; “Our thematic reports offer insight into systemic failings. A 2017 report, Ignoring the Alarms, identified poor awareness of eating disorders among clinicians, lack of specialist care, poor care transitions, and poor coordination between services. These failings contribute to inadequate treatment access, poor quality care, and long waiting times.” She explained that many people don’t complain due to several barriers: the complexity of navigating systems, fear of repercussions, and the belief that complaints will not lead to change. Beyond this, they highlighted issues of poor complaint handling, including a lack of honesty, inadequate investigation, poor communication, and failure to learn. While some progress has been made since the 2017 report, significant gaps remain. Patients continue to face fragmented care, delayed discharges, and transitions that are poorly managed.

Disparities between adult and child services persisted and training for doctors remained inadequate.

We have seen some positive action from NHS England, including the publication of Quality Standard QS175 (NICE, 2018), which contains explicit statements on the coordination of care, consistent with PHSO’s recommendation. However, we do not know whether this important standard is being monitored.

Progress has also been made in investment in specialist adult eating disorder services, but this has not met population-level needs and there are significant geographical variations (House of Commons, 2019).

Despite these developments, the Parliamentary and Health Service Ombudsman (2023) issued a further statement, warning that “little progress” had been made in implementing its recommendations, and that preventable deaths were still occurring as a result of failings in training, service access and coordination.

Despite the scale of the problem, eating disorders have not been treated with the same urgency or investment as other life-threatening conditions. Public understanding remains limited and systemic barriers within the NHS continue to prevent people from receiving effective treatment at the right time.

Over the past decades, prevalence rates have risen sharply, but service capacity has not kept pace (Viljoen et al., 2023; Ayton et al., 2021. Chronic underfunding, fragmented commissioning, and workforce shortages have resulted in inconsistent care and long

waiting times. National policies such as the Medical Emergencies in Eating Disorders (MEED) guidance from the Royal College of Psychiatrists (2022) represent important progress, but implementation has been uneven across regions (Brennan et al., 2025; Turner, 2023). As a result, too many individuals and families still experience preventable harm due to gaps in training and coordination. Comprehensive reform is both necessary and achievable. With sustained investment, national leadership and full implementation of existing guidance, lives can be saved and outcomes transformed.

Charities, clinicians, and bereaved families continue to raise concerns about persistent inequalities between child and adult services, long waiting times, inappropriate use of BMI thresholds for treatment access and inadequate transitions between levels of care. Many adults with severe eating disorders still struggle to access evidence-based, coordinated care in a timely manner. Those who have been ill for many years are sometimes seen as less likely to recover and placed on alternative pathways that are not always evidence-based and may amount to a withdrawal rather than a continuation or amping up of active treatment.

> “Our daughter became so unwell with dangerous blood levels that she was admitted to a general hospital. During this admission it became apparent how unwell she had become in the community. We very nearly lost her a few times. She stayed on the general ward for two months until she was medically stable to be transferred to an EDU where she is now” (Anon)

> “The only 117 aftercare our daughter received was one weekly 30-minute session/meet with her community MH nurse, weekly blood tests and weigh in. How on earth was she supposed to cope with her ED with no support in the community. She was set up to fail.” (Anon)

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Case Study

I first developed anorexia as a teenager living in Ireland where I had several unsuccessful admissions and outpatient treatments. During these treatment episodes, weight restoration was prioritised, with psychological support patchy or inadequate. As a result, any physical improvements were short-lived. This carried on throughout my teens and early 20s. When I graduated university, very physically compromised, I was adamant that I was moving to London. I was desperate to escape healthcare workers and concerned friends and family at home. At this stage I'd become resigned to my eating disorder. I'd been ill for over six years and anorexia had consumed my identity. My personality – my entire personhood – had been slowly stripped away. I was completely unwilling to engage with treatment at this time. All the evidence I've had to date was that it didn't work. It was pressure from those around me that pushed me to the GP. At this stage, I knew that I was close to death. I was terrified of this prospect but equally paralysed by the notion of challenging my eating disorder. Any time I tried, the pull to do the opposite was too strong.

I was urgently admitted to an NHS specialist eating disorder unit in London, in October 2012. I complied with treatment but was adamant I would not gain weight past a certain (still extremely low) BMI and would "recover" just enough to slip back into the half-life I was living. My treatment team could have accepted this request. They could have discharged me at an unhealthy weight, only for me to end up back needing urgent treatment in a matter of months (or years) time. Or worse. They did not do this. Nor did they do what I'd found so damaging during previous treatment episodes – restore my weight and discharge me with none of the surrounding supports in place. Instead, they worked intensively with me to gradually and carefully open up my mind to the possibility of recovery. They saw me as someone with potential hopes, goals and ambitions beyond the eating disorder. I didn't have any of these at the point of admission. They helped me to rediscover them. This was in both big ways, like advocating for me to go back and do a master's degree in a subject I was passionate about, and

seemingly small. For example, practical support with cooking or going for meals with friends.

I was fortunate to have access to a wide range of therapies and psychological approaches (including arts and drama-based treatments) and was given autonomy in selecting which worked for me. I won't say that every aspect of my treatment was perfect but on the whole I was treated with compassion and a high degree of competence. When I entered treatment, I felt terrified and hopeless.

When I left, I had a real future ahead of me. Recovery, for me, remains an ongoing process but the fulfilled, exciting (and at times mundane!) life I live now would not have been possible without the treatment I received. And for that I will always be grateful.

Preventing eating disorder deaths in health care

The evidence obtained highlighted that access to a multi-disciplinary team was often limited. Nutrition is not just supportive but essential to eating disorder recovery. Malnutrition is a direct and preventable cause of death. It leads to cardiac complications, multi-organ failure and exacerbation of disordered thinking and behaviours.

> "Many inpatient units operate with a skill mix of 70–80% unqualified staff. We urgently need more psychological and medical input." **Dr Agnes Ayton**

> "Dietitians are uniquely trained to manage refeeding risk, assess biochemical markers, and guide nutritional rehabilitation. Without their expertise, treatment is delayed or inadequate" **Beth Francois, Specialist Eating Disorder**

The Inquiry heard evidence that inpatient units, often seen as the highest level of care, vary significantly in quality, clinical leadership and integration with community teams. Some units provide short-term medical stabilisation without addressing the psychological and social dimensions of recovery, resulting in revolving-door admissions and severe deterioration post-discharge.

The post-discharge period is the single highest-risk window for suicide and medical relapse. Studies indicate that individuals are up to 191 times more likely to die by suicide within three months of discharge from mental health units (Musgrove et al., 2021). This finding is a stark warning that post

To improve safety and continuity, the Inquiry recommends:

- National inpatient quality standards, including integrated psychological, dietetic, and psychiatric input, with weekly multidisciplinary reviews.
- Transitional care protocols, ensuring seamless step down to intensive community treatment and co-produced discharge plans involving patients and families.
- Commissioning continuity, so that inpatient, day-patient and community services operate as one coordinated system, rather than as isolated providers.

discharge intensive support is essential and not an optional extra.

Evidence from integrated treatment systems shows that sustained treatment through transitions dramatically reduces relapse and re-admission rates. Investment in skilled step-down and outreach support is essential to saving lives.

In January 2025, the *Right to Health* Report (APPG, 2025), found through a Freedom of Information (FOI) request that people with eating disorders are being discharged at dangerously low BMIs. Almost a year later, we are still hearing many of the same stories. Even when individuals are discharged at a healthy BMI, they are often not fully recovered and have no continuity of care owing to pressure in services.

> "My daughter was discharged from inpatient care at a healthy weight, but without support. Within weeks she relapsed. There was no plan, no coordination, and no one to call."

Due to the long waiting lists, a high level of stigma for those affected by eating disorders and a lack of available treatment, there has been an undue reliance on private providers and palliative pathways.

Eating disorders and palliative care

In 2022, an article published in a Royal College of Psychiatrists Medical Psychotherapy newsletter prompted widespread concern among people with eating disorders, their families and clinicians. The piece, written by a consultant psychiatrist working in a community eating disorder service in the East of England, suggested that clinicians might "step back if there are no changes or if the patient's behaviours are getting worse," and that where illness persisted beyond five years, treatment could be withdrawn.

Members of the Faculty of Eating Disorders Executive Committee subsequently issued a counterstatement emphasising that eating disorders are treatable at all stages and that sustained, evidence-based care can lead to recovery even after many years of illness (Royal College of Psychiatrists, 2023). Their response highlighted significant disagreement among senior clinicians about how to manage long-standing illness and the ethics of "palliative" approaches in non-terminal mental disorders. This division has highlighted major variation in practice across the NHS.

Consequently, in 2022, draft guidance issued by NHS East of England referred to palliative care pathways for adults as young as 25 with so-called "Severe and Enduring Eating Disorders (SEED)". The term SEED is not a recognised diagnosis and is widely regarded by patients as stigmatising. The guidance proposed that clinicians could consider ending specialist treatment where recovery appeared unlikely and recommended palliative care training for all eating disorder staff working with this population. Although this document was later withdrawn, its language and underlying assumptions have raised serious ethical and clinical concerns (Asaria, 2023).

Evidence presented to the Inquiry suggests that similar terminologies and practices are emerging elsewhere. Withdrawal of treatment is sometimes described as a "treatment break" or "palliative approach." Whatever the label, the effect can be the same: withdrawal of care from individuals who remain severely ill and at risk of death. Whilst some clinicians justify this decision, withdrawal of treatment especially when not all treatment options have been tried is neglect.

Calling someone else's distress their normal when they are unwell is not understanding. It is neglect. (James Downs, Researcher)

Reports from patients and families indicate that some discharges have occurred without clear communication or informed consent. In one case shared with the Inquiry, a woman treated in an eating disorder service in the East of England was told verbally that her BMI made her unsuitable for continued care, while her discharge note recorded that she "did not wish to engage in eating disorder-specific work." She was extremely disappointed to see this, describing herself as "desperate for treatment." The same individual later made a good recovery following admission to a specialist inpatient unit in another part of the country.

It's just for the first time ever since a steady relapse last year, it's evident that my "options seem to have run out". My GP deflects any symptom I report to my ED service team who then say I should talk to my GP any time I'm struggling. So I'm trapped in a washing machine. I'm currently also just sat in a holding bay of medical monitoring whilst they "figure out what's best" but they won't explain anything at all about what's next because I assume they've reached the limit of what they can offer but feel they perhaps can't tell me that? (Anon)

A part of my eating disorder behaviour was to take an unsafe amount of a prescription medication that caused weight loss. I presented to A&E in 2023 and informed them that I had been overdosing on this medication to cause weight loss. At A&E the nurse I saw didn't appear to know what to say in response to me disclosing that I was struggling with eating disorder thoughts again. Instead, I believe that because I appeared 'well' and 'insightful' to my condition, many assumptions were made that led to me not receiving adequate care.

“When I was first sectioned and sent to an inpatient unit, I didn’t want help. I wanted to remain locked in an illness that represented predictability and safety. And critically, I didn’t believe that anyone could or would help me even if I dared to want it. Six years later and in recovery, I am so grateful to those people who intervened. Without inpatient help I truly believe I would remain trapped in anorexia to this very day. Ultimately, they saved my life and I now see a future for myself, an idea that I never dared to envision.” (Charley)

Preventing eating disorder deaths by ensuring adequate training is implemented

The Parliamentary and Health Service Ombudsman (PHSO) has repeatedly identified inadequate training among doctors and allied health professionals as a major factor contributing to preventable deaths from eating disorders. A lack of knowledge, combined with unhelpful or dismissive messages from clinicians, delays recovery, puts patients at risk and can reinforce eating-disorder cognitions.

Doctors still receive less than two hours of training on eating disorders in their whole medical degree and there is no mandatory training for frontline staff (Ayton and Ibrahim, 2018). This often results in a poor understanding of eating disorders and can lead to traumatic experiences in treatment. Trauma in the context of eating disorder treatment caused by services should not be happening. Reform is needed and lessons need to be learned, but this is not a reason to close services. Instead, we should be using this as an opportunity to learn and move forward.

In 2022, the Royal College of Psychiatrists introduced the Medical Emergencies in Eating Disorders (MEED) guidelines, setting a new national standard for the safe management of medical emergencies across all settings. However, implementation remains worryingly inconsistent, and this is in part due to a lack of training of staff and resource and capacity difficulties (Turner, 2023; Brennan et al., 2025). Although online training has been developed, this is not included in the general training of frontline staff.

Training for professionals working across the health services of the presentation of the less understood eating disorders, such as ARFID, would go a long way in supporting families. This includes increased awareness of how the environment and sensory overwhelm can affect someone with ARFID.

> Last year we had two hospital visits and not one professional, from ambulance staff to A&E assistants to doctors, knew what ARFID was. When your child's blood sugar is low, trying to get them to eat a KitKat is never going to work. There needs to be basic training so staff know how to approach people with ARFID and their families. It should be supportive and understanding, not pressurised or judgmental. The MEED guidance does have a section on ARFID, but from my experience (and from others I've spoken to) it's often not followed. Families are left to cope on their own until their loved one reaches crisis point, and then they're threatened with admission instead of being offered early help...

continued from previous page: Teenagers with ARFID are often assessed using anorexia guidelines, which just doesn't fit and can make things worse. Families are dismissed because staff don't understand how serious ARFID can be or that it's not as simple as "just eat this" or "take this medicine." ARFID needs a proper MDT approach and a shared understanding so parents aren't made to feel blamed or gaslit, and young people get the right care before things get to crisis.

Recognising these issues, NHS England and NHS Improvement (2019) introduced AED WTT (Adult Eating Disorder Whole Team Training for specialist eating disorder servives servicesin adult care.

NHS England also supported the Royal College of Psychiatrists' Eating Disorders Credentialing Programme, which was launched in 2022 to strengthen the medical workforce and develop consultant-level expertise in eating disorders. Together, the whole-team training initiative and the credentialing programme represent important progress in building capacity, improving safety and ensuring parity between adult and young people's services. However, the future of both programmes is now uncertain, following the reorganisation of NHS England and the loss of national funding.

Case Study

The link between eating disorders and self-harming behaviours, suicidal ideation and suicide are far too frequently overlooked, and often feared. This is something that came up time and time again for me during my time in inpatient treatment for my eating disorder. Despite well-established links and high rates among those with eating disorders, many medical professionals try to place them into separate boxes instead of treating them in conjunction.

With increased weight restoration came increased suicidal ideation; the emotions that were suppressed through malnutrition and eating disorder behaviours were flooding back at what felt like the speed of light. I was unable to access therapy for the first five months of impatient treatment until I was deemed ready. This meant that while I was supported by some wonderful HCAs and nurses, I was without therapeutic input while managing the emotions and bodily discomfort of weight restoration. By the time I was deemed ready to start therapy, I was already incredibly low, and at high risk.

This coincided with the start of EMDR (eye movement desensitisation and reprocessing) and resulted in an increase in self-harming behaviours, suicidal ideation and attempts, all while in a place designed to keep me safe. Yet when I was honest about this with my consultant in the hope of being supported I was met with threats to discharge me or transfer me to a general psychiatric unit without specialist support because “we can’t deal with that here.”

At the time, I internalised this as my own fault; that I was too much, I was beyond help and even the specialists couldn’t support me and simply wanted to pass me off to someone else. This was nothing new to me I was used to being passed around from team to team, professional to professional. I’d previously been discharged by a therapist in the community following a suicide attempt, because it was beyond their capacity, and while I appreciate a professional acknowledging when something is beyond their scope I wasn’t immediately provided with a different therapist and instead had to wait months to be seen.

Looking back however, I am fuelled by anger at how I was treated, when we know that of all eating disorder deaths one in five are by suicide. So why is it that so many people refuse to acknowledge this within eating disorder treatment? How do we begin to prevent suicides in those with eating disorders without acknowledging the link, or creating a safe enough space to talk about suicidal thoughts without being met with threats to be discharged, transferred, or, as I have also experienced, threats to be admitted to hospital at just the mention of suicide. Until professionals are provided with adequate education around suicide, and eating disorders, then individuals will likely be met with fear and decisions will be made out of panic. After all, no professional wants to lose a patient. This should always be because of care and compassion for human life and yet I have too often faced comments like “I don’t want to end up in court if you kill yourself.” It has made me feel utterly dehumanised, reduced my trust in the system and made me doubt past decisions. Were they made in my best interest or were they made out of the professionals fear of investigation if I died?

In my experience, the early stages of weight restoration or when actively resisting urges to engage in eating disorder behaviours – or physically prevented from engaging in them - is when my suicidal ideation is at its highest and I feel most unsafe. Or in periods of relapse when things feel like a relentless cycle. Yet from the outside I am often deemed to be doing “better” through the lens of eating disorder recovery because I have weight restored, but that does not necessarily mean the risk of death has reduced. I often say, especially with co-occurring conditions, that my brain is like a whack-a-mole: when one aspect is treated in isolation and symptoms reduce, others are exacerbated, which is why it is so vital that individuals are treated as a whole and the treatment lens is broad enough to not overlook risks. There have been many points throughout my eating disorder where I have been certain it would kill me, I have just never known whether it would be my body or my mind that was the final straw.

Having a therapist who allows for open and honest conversations around suicidal ideation without immediately hitting the panic button and instead providing a safe space to speak about it has been integral in my recovery journey and ultimately in preventing my death.

Preventing eating disorder deaths through ensuring treatment is available to all

A recent European modelling study by McDaid et al. (2024) evaluated the economic impact of improving care pathways for adults with anorexia nervosa across England, Germany and Spain. The analysis compared standard care with enhanced pathways designed to reduce waiting times, ensure access to specialist multidisciplinary service, and strengthen transitional and carer-focused support.

> "In other medical fields, when first-line treatment fails, services escalate care. Eating disorders should be no different." **Dr Agnes Ayton**

The model found that the enhanced pathway generated the highest net monetary benefits, demonstrating that early, specialist and coordinated treatment is not only clinically effective but also economically efficient. The findings indicate a strong economic case across diverse health systems for investment in timely diagnosis, specialist-led outpatient treatment, and structured transitions of care.

In summary, early and effective treatment can alter the trajectory of anorexia nervosa, reduce chronicity and prevent costly hospitalisations and deaths, while improving long-term recovery and quality of life outcomes.

Emma Davis, an integrated arts psychotherapist with an important role in developing the application of FIAP emphasised, "people shouldn't be written off just because NICE guideline treatments haven't worked. There is more that can and should be offered to people." The increasing practice of individuals being discharged or placed on palliative pathways is something we are hearing more and more. The benefits demonstrated by FIAP are a clear example of why services need to expand their range of therapeutic options if we are going to prevent eating disorder deaths. She continued, "I think the problem is there's a lot of clinicians and leaders of services that think, well, this is all that's available. This is what NICE guidelines say works and therefore people are so sick that we can't help them and that's not the case."

When asked about the potential harm caused by the barriers to FIAP and lack of treatment options outside the NICE guidelines, Emma said, "patients report feeling like they are 'beyond help', that they have "failed in therapy" or "will never get better" when they are not given a chance to try a different approach."

> Back in 2017 I got referred to the CAMHS eating disorder services. I was told by someone that I was too big to have an eating disorder and come back when I'm really sick. My mum made a complaint about this and we never heard anything after that. (Becky)

Deaths from eating disorders will continue unless early intervention failures, long waiting lists and the inappropriate use of Body Mass Index (BMI) as a barrier to care are addressed. A person's BMI should never be used as a threshold for access to care. It is not an accurate measure of either medical risk or psychological severity.

> When I first sought help through primary care in the UK, my distress around food was interpreted as a "dietary issue" rather than a mental health concern. I was offered weight management advice instead of psychological support – a common experience for many people with binge eating disorder, (Stella)

People with eating disorders are still too often told they are "not sick enough" for treatment and later "too sick" or "too complex" to be helped. This inconsistency leaves patients without support at both ends of the illness spectrum. Outpatient, day-patient, and inpatient services need to operate as part of a coherent care pathway that provides timely, continuous, and person-centred support. Malnutrition must always be treated alongside psychological and behavioural factors, as both are integral to recovery. This integrated approach is recognised as good clinical practice and is essential for safety.

Families providing care at home carry a significant burden. Most carers are not medically trained and should not be expected to manage life-threatening illness without professional support and supervision.

NICE (2017) currently recommends several psychological treatments, including Cognitive Behavioural Therapy for Eating Disorders (CBTE), the Maudsley Anorexia Nervosa Treatment for Adults (MANTRA), and Focal Psychodynamic Therapy (FPT). All are designed to be personalised to individual needs, but in practice a single weekly session is often insufficient for people with complex or long-standing illness.

A significant proportion of patients drop out of treatment. However, to date there is a lack of consistency in identifying causal factors as research has largely focused on patients' individual characteristics, with limited attention to broader, systemic or service-provision related factors such as treatment modality. It is well documented that patients with complex presentations frequently fall through the gaps in services – which significantly increases both the duration of illness and the risk of death.

In addition, we know from our evidence gathering that what works for one individual may not work for others, . what works for one individual may not work for another, which sometimes makes standardised treatment approaches less effective and highlighting the need to broaden treatment pathways. Evidence increasingly highlights the longer-lasting efficiency of personalised therapies in comparison to standardised treatments (Nye, Delgadillo and Barkham, 2023). One study highlighted challenges within the NHS, where patients have reported that their individual needs had not been adequately recognised or addressed. This was emphasised by a 49-yearold male patient who stated, “I felt like I was being tailored to the treatment, rather than the treatment being tailored to me”. This should never be the case and is a sign of systemic failure (Li et al., 2024).

Evidence shows that up to 50% of people with eating disorders do not respond positively to first-line treatment (Viljoen et al., 2024). This could be explained by the significant variation in individuals’ symptoms, severity, history and co-morbidities, as well as their responses to treatment. It is well documented that patients with complex presentations frequently fall through the gaps in services - which significantly increases both the duration of illness and the risk of death.

The clinical trials informing NICE guidance are based on highly selected patient populations that do not reflect NHS realities, where comorbidities and chronicity are common.

Cognitive Behavioural Therapy (CBT) has shown significant long-lasting effects (Hilbert et al., 2012) and has become the most commonly used treatment for eating disorders – with its structured, manualised format making it easier to research, evaluate and replicate (Russell et al., 2023; Lubieniecki, McGrath and Sharp, 2025). As a result of this, it has created a feedback loop of research, funding and treatment delivery – creating firmer beliefs that it is the best option, and effectively marginalising other forms of treatment that deviate from first-line, manualised treatment. If we want to save lives, we need to be exploring a variety of treatment options and ensure that funding goes to many different areas.

Almost half of patients disengage from outpatient treatment, often because support levels are too low or services lack flexibility. People with autism, depression, or personality disorder frequently fall through gaps in provision, prolonging illness and increasing mortality risk.

> “I lived with anorexia for 38 years. Initially I was placed in a general psychiatric unit with no eating disorder expertise. I cycled through medical admissions, short term interventions and in 2010 was placed on palliative care and admitted to a hospice. A letter from another survivor changed my perspective and eventually I accessed specialist treatment have been fully recovered for 15 years. (Michelle Wright)

Treatment intensity and continuity must match clinical need. Evidence shows that integrated, whole care pathway multidisciplinary approaches such as integrated CBTE, which combine psychological, nutritional and medical care within one coordinated team, improve recovery and reduce reliance on restrictive interventions. Expanding and evaluating these models nationally would ensure that

every patient receives appropriate care and that preventable deaths are reduced.

As we have highlighted, there are many individuals whose complex and individual needs have not been met by first-line treatment and so to improve outcomes, reduce illness duration and prevent deaths, there is an urgent need to broaden research and treatment to include a greater diversity of therapeutic approaches by addressing the complexities of eating disorders with the recognition that no single treatment will work for everyone

It is important to note, that in many areas treatment fails due to the culture within that service.

Case Study

I had been struggling with my eating disorder for many years and had reached a point where I'd lost hope that recovery was possible. I'd been through various forms of NHS outpatient treatment, but nothing had managed to get to the root of my difficulties or offer the intensity of support I needed. In August 2025 the NHS put me on end-of-life care. My family ended up paying for private treatment, I was physically and emotionally exhausted, but from the very first day, I felt truly seen, understood and supported. The meal support sessions were some of the hardest yet most transformative parts of my recovery. Having professionals guide and sit alongside me during meals, helping me to challenge fears in real time, was something I hadn't experienced before.

Treating life-threatening physical and mental health conditions

> “There is stigma, inadequate training and the unacceptable normalisation of deaths in eating disorders.” (Suzanne Baker, Carer)

Type 1 diabetes and eating disorders (T1DE)

The combination of T1DE and an eating disorder is one of the most dangerous and least recognised conditions in the NHS. It occurs when people deliberately restrict insulin to control their weight, leading to high blood sugar, repeated hospital admissions, and a sharply increased risk of death.

T1DE is complex and needs coordinated treatment from diabetes and mental health specialists. Yet such services are almost non-existent. Most patients receive fragmented care despite NICE guidance highlighting the risk. People with T1DE are up to 30 times more likely to die than others with type 1 diabetes, and admissions for diabetic ketoacidosis are longer and more frequent (Chrisp, Gordon and Nathan, 2024; Gibbings et al., 2021)

In 2019, NHS England funded pilot T1DE services in Wessex and London. The results showed major improvements in blood sugar control and a 58% reduction in hospital admissions for diabetic ketoacidosis, far exceeding the national average (Kings Health Partners, 2024). Patient satisfaction was high and quality of life improved. Five further pilot sites followed in 2022, including the Warwick Clinic for Eating Disorders and Diabetes, the UK’s first dedicated service (Chrisp, Gordon and Nathan, 2024; Gibbings et al., 2021).

Despite their success, funding for these pilots has now ceased, leaving patients at risk and services in jeopardy. Without national commissioning, people with T1DE face a return to fragmented care, delayed diagnosis, and preventable deaths.

T1DE is treatable and preventable. The pilot results prove that integrated, multidisciplinary care saves lives and reduces NHS costs. Continued investment and national rollout are urgently needed to protect this high-risk group.

Psychiatric comorbidities and fragmented care

Many people with eating disorders also live with other mental health conditions that increase the risk of serious harm or death. Common comorbidities include depression, anxiety, complex trauma, autism spectrum disorder, attention deficit hyperactivity disorder, obsessive compulsive disorder, emotionally unstable personality disorder (EUPD) and substance or alcohol misuse. These conditions can intensify eating-disorder symptoms, delay recovery and increase the likelihood of suicide, medical complications, and premature death.

Despite this elevated risk, services remain fragmented and poorly coordinated. Patients are frequently passed between eating-disorder, substance-misuse, and personality-disorder teams, none of which are commissioned or staffed to manage complex overlapping conditions. Adults with both autism and eating disorders often fall through service gaps entirely, while those with addiction or EUPD are sometimes excluded from eating-disorder services on

the grounds of “complexity” or “non-engagement.”

This lack of integrated provision means that the people at highest risk often receive the least effective care. Treatment pathways rarely include psychiatric or addiction expertise, and multidisciplinary communication between services is inconsistent. The result is repeated crisis presentations, preventable hospital admissions, and risk of avoidable mortality.

Eating-disorder services should therefore be commissioned as part of a joined-up mental health service, ensuring access to psychiatry, addiction, and autism specialists within one coordinated pathway. Without this integration, the NHS will continue to lose lives to conditions that are both identifiable and treatable.

Parents’ experiences of caring for a child with an eating disorder: the impact of financial challenges.

This research suggests financial barriers are impacting treatment access and adherence.

- Our research found, to lessen the negative impacts on families:
- Tailored care: Services should consider each family’s individual circumstances, including financial situation and family structure.
- Routine financial discussions: The cost of care should be addressed during assessment and treatment, with clear guidance on available support (e.g., benefits, transport reimbursements, foodbank vouchers, community resources).
- Additional support measures: Parents suggested options such as paid leave allowances, supermarket vouchers, energy bill discounts, and access to grants.

(Shaw, Ranceva and Langdon, 202

Preventing eating disorder deaths by suicide: the government should ensure suicide and eating disorder prevention campaigns are joined up

Suicide is a leading, preventable cause of death among people with eating disorders, yet national suicide prevention plans rarely address this group. Deaths are often misclassified, with causes such as organ failure or overdose recorded instead of the underlying eating disorder.

The *Lancet Psychiatry* (2024) analysis of the National Confidential Inquiry into Suicide and Safety in Mental Health examined all suicide deaths in England between 1997 and 2021. Among more than 30,000 people who had recently received mental health care, 382 had an eating disorder. They were mostly women, with a mean age of 33 years, and showed greater clinical complexity than any other diagnostic group. Common comorbidities included depression, anxiety, personality disorder and substance misuse, alongside high rates of self-harm and trauma exposure (Hercus et al., 2024). Despite these risks, three quarters were rated low-risk at their final contact, highlighting major gaps in recognition and follow-up.

The study found a gradual increase in suicides among people with eating disorders over two decades, though rates stabilised when adjusted for the rising number of patients entering services. It concluded that comprehensive, evidence-based treatment and trauma-informed care are essential to prevent these deaths.

Foye et al. (2025) found that people with eating disorders are at an increased risk of suicide for five main reasons:

"*I don't want to live like this*" – the burden and impact of having an eating disorder.

"*Eating disorders don't stand in isolation"* – comorbidity and complexity.

"*There's a dark side to recovery"* – recovery as a risk factor.

"*Suicide isn't talked about… I felt alone and weird*" – silence, isolation, and stigma.

"People are falling through the cracks" – the gaps in treatment provision and care.

These experiences can fluctuate across the course of the illness and recovery journey and require consistent, compassionate, and multidisciplinary care.

The weeks immediately after leaving hospital are the most dangerous time for people with eating disorders. Suicide risk is almost 200 times higher in the first three months after discharge (Musgrove et al., 2021). No one should be left to cope alone at this critical point.

Follow-up cannot be a single appointment. It must mean consistent, proactive support from a joined-up team who stay in contact until the person is stable. Every discharge should include a personalised safety and relapse prevention plan co-produced with the patient and their family, and clear routes back into specialist care if risk increases. With sustained follow-up and integrated services, suicide in eating

disorders is preventable. To reduce preventable deaths, suicide prevention and eating disorder strategies must be integrated across NHS and government planning.

Case Study

Megan was bright, articulate, witty, a much-loved family member and primary school teacher. Her death was felt by everyone who knew her – all family members, friends, her pupils, their families and her colleagues. But her absence will also affect the two nieces she never knew and all those pupils she will now never teach. Megan had T1DE but was not able to get the treatment she deserved. It is said that a death by suicide can affect 135 people, this doesn't begin to represent the true ripple effect of such a death. A second inquest held seven years after her suicide concluded that the system is still, tragically, just as unfit for purpose as it was for Megan. Until the system changes to provide accurate diagnosis and care that is fit for purpose, things are not going to change and preventable deaths are going to continue.

Preventing eating disorder deaths through the correct legal frameworks

Testimonies to the Inquiry revealed significant inconsistencies in the application of the Mental Health Act 1983 (MHA) and the Mental Capacity Act 2005 (MCA) to cases of eating disorder. These inconsistencies can determine whether an individual receives compulsory, life-saving treatment or are left without access to care.

Two comparable cases illustrate this disparity. Both involved young women with a ten-year history of anorexia nervosa and a diagnosis of autism, each having experienced repeated admissions and relapses. Both were described as having *severe and enduring* illness, yet their clinical and legal trajectories diverged sharply.

One 23-year-old woman, referred to here as Mollie, was treated in a region that operated an integrated, evidence-based model of care (Integrated CBT-E). Although her community team initially considered further compulsory treatment futile given her long history of revolving door admissions, the regional consultant psychiatrist reviewed the case and supported her re-admission under the MHA. Through a sustained, multidisciplinary treatment programme, she achieved nutritional and psychological recovery and has since rebuilt her life and completed a degree in psychology.

In contrast, another young woman of the same age, Patricia, living in a different region, was denied further compulsory treatment. Her treating clinician felt that additional intervention would be futile and sought a declaration from the Court of Protection under the MCA, arguing that active treatment was not in her best interests. In EWCOP/2023/70, the Court accepted that position and authorised the withdrawal of compulsory nasogastric feeding. The judge stated:

> "There is no doubt that Patricia suffers from anorexia nervosa. It has indeed made her extremely ill. I take the view that she is and has been perilously close to death. There is also no doubt whatsoever that, over ten years of treatment, it has simply not worked, including compulsory treatment in a number of different settings and at a number of different times over a prolonged period. I gave a significant judgment in which I decided that Patricia should not be treated by nasogastric feeding under compulsion, whether it be via restraint or sedation. I did so because Patricia was passionately opposed to such treatment."

Over the following two years, Patricia's condition further deteriorated. In 2025, her family, with pro bono legal assistance, applied to reopen the case. In EWCOP/2025/30, Her Honour Judge Arbuthnot set aside the previous order, finding that reliance on the MCA had wrongly displaced the MHA as the appropriate legal framework for treatment. The judgment observed that the earlier order had foreclosed potentially life-saving clinical options and placed an undue burden on the family to secure care. The Court accepted new expert evidence that malnutrition itself may impair decision-making, and that improvement remained possible with appropriate treatment.

These cases demonstrate how divergent interpretation of legal frameworks can directly affect survival. Where treatment refusal results from illness-related cognitive impairment, the MHA provides a lawful, safeguarded route to compulsory care with independent oversight. In contrast, reliance on the MCA to justify treatment withdrawal can preclude recovery and expose individuals to avoidable risk.

Capacity, consent and risk

Clinicians and legal experts giving evidence to the APPG Inquiry agreed that capacity assessments in eating disorder cases often fail to account for the cognitive and emotional effects of starvation. Individuals may appear articulate and rational while lacking genuine autonomy due to the disorder's compulsive nature. The Inquiry heard calls for mandatory training for judges, barristers, and expert witnesses on the medical and psychological features of eating disorders, including how impaired nutrition can affect insight, judgment, and decision-making.

Safeguarding and systemic implications

The APPG Inquiry also examined broader safeguarding failures in inpatient settings. The death of 14-year-old Ruth Szymankiewicz in 2022, following a lapse in required one-to-one observation at Huntercombe Hospital, exemplifies the systemic risk arising from inadequate staffing and supervision. Coroner's findings established that she had been left unattended by inexperienced agency staff for 15 minutes, despite a requirement for continuous observation.

Families told the Inquiry that children in mental health hospitals are often isolated from their parents and carers who could help detect early warning signs of deterioration. Standard visiting policies on paediatric medical wards permit open, daily visiting and overnight stays, yet equivalent access is not routinely available in mental health settings.

Our Inquiry therefore recommends that children in psychiatric inpatient units have the same rights to parental contact and advocacy as those in general hospitals. This should include daily visiting, regular communication with a nominated person, and involvement in care planning.

Preventing eating disorder deaths through the improvement of private and NHS inpatient services

Concerns about trauma have led some to argue that inpatient units should close in favour of community or day-patient care. Yet demand far exceeds existing capacity. NHS Benchmarking data show around 30,000 acute hospital admissions each year with potentially life-threatening admissions, of whom approximately 70% are adults, at a cost of roughly £220 million (NHS England, 2024; (APPG, 2025). In contrast, there are only 400–450 specialist eating-disorder (SEDU) beds in England. These units treat the most severe and complex patients; community provision alone could not meet this need.

Hospital care can be lifesaving, but national audits and our evidence sessions highlight serious concerns about quality. Hundreds of patients each year, including children and adults, received nasogastric feeding under physical restraint, most of whom had anorexia nervosa. In some hospitals these interventions involved security staff or other unqualified personnel, contrary to the MEED guidance.

Restrictive practices may sometimes be used to maintain safety but can also cause trauma, conflict and breakdown of trust if overused. High-risk methods such as face-down restraint, which can restrict breathing, should never be used. Their continued use reflects under-resourcing, limited training and the absence of meaningful outcome monitoring. NHS England (2025) identifies eight types of restrictive practice and calls on all services to minimise their use. Any such intervention must be a last resort, clinically justified, and conducted by trained multidisciplinary teams using trauma-informed and autism-informed approaches.

> I developed an eating disorder unexpectedly at 31. I tried some community meal support with support workers visiting my house to sit with me during difficult meals but I found I just restricted myself elsewhere in the day when alone to make up for the meal I'd have to eat with the support worker. By the new year it was suggested I may need to go to an inpatient unit. I did not want to go and was worried about the time off work. I now know I would never have been able to gain the necessary weight on my own particularly with the digestive issues that came with the increased food. There was also therapy which helped me face some difficult issues I had been avoiding. (Chloe)

Evidence from our inquiry shows that Integrated CBT-E given by a fully staffed multidisciplinary team greatly reduces the

need for restraint. Psychological interventions that address the underlying illness are essential to prevent crisis situations and reduce reliance on restrictive measures.

During our evidence sessions, and from our case studies, what became even more clear was the difference in treatment could be based on nothing more than an individual's postcode. In some parts of the country, in both inpatient and outpatient services, patients experienced trauma, huge amounts of neglect and had services withdrawn too soon.

> Inpatient treatment was hell at times. Gaining weight felt unbearable, and the strict rules were suffocating. But, in a strange way, the lack of choice helped me. When my eating disorder was screaming at me, I could tell myself it wasn't me choosing to eat or gain weight it was something I had to do. If I refused food, I was given a supplement drink; if I refused that, I'd be tube-fed. There was no way out, and I needed that level of containment. I wasn't strong enough to recover on my own then. …

There remains a significant gap between outpatient and inpatient care. Based on current hospital admission and community service numbers, day-hospital or intensive community services would need capacity for more than 20,000 patients each year across all age groups to meet demand. Delivering this would require substantial investment.

While expanding community provision may not remove the need for specialist inpatient units since most hospital admissions occur when patients are already in a life-threatening condition such investment would ease pressure on the acute sector, improve continuity of care, and help prevent crises before they require hospital admission.

We heard harrowing stories from carers in our evidence sessions of how they are often left to pick up the pieces where services aren't able to offer more support. This has led to breakdowns, other mental health issues, and family breakdown.

> …That hospital stay laid the foundations for my recovery. It gave me the stability I needed to start rebuilding. When I was eventually discharged, I had regained some weight and was determined never to go back. I followed my meal plan, not because I wanted to at first, but because I knew what the alternative looked like. Over time, I learned that I wasn't alone, and that talking – really talking – about what I was going through could help. In-patient treatment didn't fix me, but it gave me the start I needed. It taught me that recovery wasn't about compliance or control – it was about courage, connection and the decision, however small at first, to want more from life than an eating disorder could ever offer.

Across both NHS and private eating-disorder services there is no consistent system for measuring outcomes across the treatment pathway. Most NHS reporting focuses on process outcomes, such as waiting times and activity rather than whether a treatment is effective or safe. This makes it difficult to identify which services improve patients' chances of recovery and which are falling short.

> "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)

We are pleased to see that NHSE are working to ensure that all services commissioned to provide NHS care in England provide core metrics on how many patients are being seen, access criteria, waiting times and treatment provision. This is being carried out through the National Audit Programme running from August 2024 to July 2027. The overarching quality improvement objectives focus on key areas of care; namely that services are safe, effective, patient centred, timely, efficient, and equitable (NAED, 2024). By collecting, linking, analysing, and reporting data on access to and treatment of eating disorders there is a hope that treatment will be improved.

Preventing eating disorders deaths through innovation and research

It is well-documented that many individuals with eating disorders are being deemed "untreatable," labelled as too complex, or have their treatment withdrawn if they do not respond within expected timeframes. In contrast, those with other mental or physical health conditions are typically offered a range of treatment options to maximise their chances of recovery. This disparity highlights the urgent need for change. We are therefore calling on the Government to invest in research focused on service innovation, to ensure that people with eating disorders receive the comprehensive and sustained care they deserve.

The Eating Disorders Clinical Research Network (EDCRN) will complement the national audit by facilitating research collaboration across the UK. It will enable services to collect a shared set of biopsychosocial variables agreed by people with lived experience, as well as researchers and clinicians. This shared dataset will support the evaluation of real-world effectiveness of treatments, help assess innovative approaches, and promote continuous improvement in clinical practice. The EDCRN will also strengthen much-needed research capacity in the field, complementing the work of established academic centres and helping to translate research into measurable improvements in patient care.

Alongside the development of the Eating Disorders Clinical Research Network, it is vital to highlight and evaluate emerging models of care that are already demonstrating improved outcomes in real-world settings. Across the UK, innovative services are challenging the assumption that some individuals are beyond help by offering flexible, person-centred approaches tailored to complex needs. These models combine psychological, medical and social interventions in new ways, often integrating digital delivery and creative therapies to enhance engagement and continuity. The following examples illustrate how service innovation, rooted in collaboration between clinicians, researchers, and people with lived experience, can extend the boundaries of recovery and inform future national standards of care.

SPEAKS is a novel, evidence-based outpatient psychotherapy developed in Kent for people who failed to benefit from traditional first-line treatments, particularly individuals with complex, long-standing conditions, or neurodivergent needs. SPEAKS addresses the whole person, beyond weight or eating disorder symptoms. (Appendix 1).

Focal Integrative Arts Psychotherapy (FIAP) was developed in Hertfordshire. It is an emerging therapeutic approach that aims to integrate the creative and expressive methods of arts therapies an emphasis on looking back at the history and underlying causes of the Eating Disorder aligning with focal psychodynamic therapy – therefore bringing together the psychodynamic principles recognised in the NICE

guidelines with the added benefits of creative arts approaches to treating eating disorders. As such, it is increasingly being recognised as a valuable treatment option. (Appendix 2)

The Step Care programme, developed by the Thames Valley Provider Collaborative, is a leading example of service innovation designed to reduce the high risk of relapse and death after hospital discharge. It delivers intensive enhanced cognitive behavioural therapy (CBT-E) through a multidisciplinary team (MDT) working collaboratively with patients and families to support change at home. The virtual model enables continuity of care, allowing patients to consolidate recovery in their own environment. An early evaluation of more than 60 patients shows high completion rates, significant clinical improvement and a marked reduction in hospital re-admissions, demonstrating that intensive, home-based treatment can be both effective and safe (Summary in Appendix 3).

Case Study – Jodie

When I first began engaging with the services in CAMHS I had no understanding of mental health, illness, treatment options etc. All I had back then was my understanding through the lens of stigma. I was given CBT for the first time, something which became the go-to treatment, spanning a decade with countless different people. It never helped. Initially I put it down to being new at therapy, then maybe it was the rapport with the therapist, but by the 8th therapist and still feeling the same I believed that I must be the problem, that maybe therapy worked for other people but not for me… it didn't take much for self-blame to kick in.
(continued overleaf)

After a decade of struggling with various treatments that didn't seem to work, or even caused more harm, Focal Integrative Arts Psychotherapy (FIAP) was the first therapy that truly made a difference as it accounted for my comorbidities. I began this therapy following a year in inpatient treatment for my eating disorder, hesitant and exhausted from constant 'treatment'. I did not want to start therapy again – start from scratch, engage with a new person and a form of therapy that I naively believed at the time to be too 'outside the box' – but after years of being forced into boxes I did not belong in it was exactly what I needed. The use of creative arts meant I was able to break out of the rigid ways I thought I had to engage in therapy. I no longer went into the session on auto-pilot mode with prepared scripts. I no longer felt like I was starting from scratch with another person, but actually I was just starting therapy effectively for the first time.

I was incredibly apprehensive at the beginning of treatment. I had little to no trust in the services' ability to support me and it initially felt like I was forcing myself to play the role of an engaged service user without actually being engaged. It felt like a chore, and not something that I was willing to put my time into, purely based on previous experience. I avoided face-to-face therapy for a few months at the start as a form of barrier due to vulnerability, but eventually therapy felt like something I was choosing to do. I finally had agency. What stood out to me was the importance of the therapeutic relationship. Trust and consistency were essential for me, and FIAP allowed me to build a deep, meaningful connection with my therapist.

A crucial aspect was the use of creative expression. Initially, I was sceptical and incredibly dismissive about incorporating art into therapy, but I quickly saw its impact in helping me express emotions that were hard to

verbalise or identify (alexithymia) – something I've always struggled with, and which had been a barrier in past treatments. The first time I was actually asked to draw in a session I hated it. I felt so uncomfortable trying to do something I knew I was terrible at. I still remember what it looked like 4 years later, a basic stick person attempting to explain how I felt. However, the way in which the therapist responded made me realise it was never about the drawing, it was about what it represented. It allowed me to externalise the internal thoughts and feelings in a physical way.

For far too long I had been treated as a symptom, as a label or diagnosis and not as a human – to the point where in hospital I remember during medications frequently being called out by room numbers instead of our names. So much of my past treatment had been dehumanising. FIAP being a person-centred approach was such a contrast and enabled treatment to be tailored to my individual needs, allowing me to finally feel seen and understood as a whole person beyond a diagnosis.

This was after a decade of feeling like, and being told, I was too complex, too difficult, too disengaged, too resistant. It allowed me to realise I wasn't these things; I was simply being forced into specific boxes and treatment pathways that did not suit my individual needs.

When I finally received treatment that met those needs I became and remain engaged in therapy, I allowed myself to sit in the vulnerability and no longer resist the discomfort it can bring. I still often feel too complex and too difficult, after years of it being drummed into me by mental health professionals and much of society – but through the use of arts alongside talking I am able to bring this into the room and feel safe in the knowledge that in that space I am not too difficult or too complex. Even when I go non-verbal, I can still engage in therapy, whereas in the past that would mean being marked as disengaged.

I firmly believe that broader access to this form of therapy could offer hope to so many individuals who have also felt let down by a system too often not accessible to them.

Preventing eating disorder deaths through education and public health reform

> "Prevention requires investment across all levels from school education to prevention deterioration and death. A one-hour school lesson is not enough. All tiers must be funded appropriately."
> **Dr Agnes Ayton**

Although population-level prevention is not directly relevant to the prevention of deaths among those currently unwell, it remains vital for reducing future illness and protecting the next generation. Early risk factors such as negative body image, appearance-based teasing and weight stigma can appear as early as age five and are linked to later restrictive eating, bingeing, and depression.

International evidence, particularly from the dissonance-based programmes developed by Professor Eric Stice and colleagues, shows that prevention works. These interventions encourage young people to challenge unrealistic appearance ideals and have reduced the development of eating-disorder symptoms in individuals by up to 77% in controlled studies (Wisting et al., 2023).

The Body Project is the most widely evaluated, evidence-based prevention programme that has been modified to meet the needs of a number of underrepresented groups, including men and boys, people from LGBTQIA+ communities and different cultural groups (Lewis 2025).

Since 2017, national implementation has been inconsistent, with some regions (such as Gloucestershire) having received training from the national centralised training body – The Body Project – resulting in sustainable local implementation, but other NHS teams and MHSTs remain untrained or unaware of the programme. (Lewis, 2025).

> "UK-based evaluation indicates that students would benefit from prevention programmes including more diverse representations of appearance ideals and culturally specific risk factors to meet the needs of underrepresented groups in the field of eating disorders."
> **Dr Hannah Lewis**

As well as targeted interventions in schools, population-level interventions need to be considered. Public-health campaigns have often focused on weight or obesity, sometimes reinforcing stigma and unhealthy dieting behaviour.

> My son received no treatment. He was referred to the gym when he was severely unwell and delayed referrals were a barrier. He died without support. (Pam)

Effective prevention must go further, addressing commercial and social factors that drive body dissatisfaction, including the weight-loss and cosmetic industries and the impact of social media on young people.

The Labour Government's 10-Year NHS Plan provides an important opportunity to align prevention of eating disorders with its wider prevention agenda. This includes a stronger focus on mental health promotion, early intervention in schools and communities, and tackling the social determinants of ill health (Department of Health and Social Care, 2025). Embedding evidence-based eating disorder prevention within this framework would not only reduce the future burden on NHS services but also protect the wellbeing of children and young people before illness takes hold.

> Food language in schools needs to change. We should move away from "healthy" vs "unhealthy" food labels, and children with restrictive diets should be allowed access to their preferred foods without a fight with the education system.

Programmes such as *Body Happy Schools* show how positive, whole-school approaches can promote body respect and reduce bullying, though further evaluation is needed. Embedding body confidence, digital literacy and mental-health education across schools and communities and tackling harmful commercial influences would help reduce risk in the long term.

Witnesses highlighted the need to reform public-health communication around weight and food. Campaigns focusing on calorie control or weight loss may unintentionally reinforce body dissatisfaction and dieting behaviour, particularly among young people. Stakeholders urged a shift towards weight-inclusive, health-promoting approaches that emphasise mental wellbeing, joyful movement, and nutrition literacy rather than appearance or restriction.

> "We are still stuck in the stage where feeding difficulties are brushed off as "just fussy eating" or "let's wait and see." By the time professionals take it seriously, it's often too late.
>
> For younger children especially, support needs to start as soon as feeding difficulties begin. Early intervention should include sensory exposure work and occupational therapy input, helping a child grow in their eating abilities rather than leaving it all to the family to cope alone. Families also need to be taken seriously. Too many people struggle to get past the first GP appointment because of a lack of understanding and knowledge."

Across the UK, we know that schools, universities, and colleges are extremely stretched, evidence sessions from the APPG highlighted that there are things that can be implemented to help prevent people developing eating disorders and to support those affected by eating disorders. Such implementations include:

- *Evidence-based prevention:* Invest in piloting and adapting dissonance-based prevention programmes for UK schools and universities, with long-term evaluation of effectiveness.

- *Cautious innovation*: Continue evaluating promising approaches such as Body Happy Schools, ensuring robust research design before national scale-up.

- Curriculum integration: Embed body-image literacy, media-literacy, and stigma-reduction content within the PSHE curriculum and teacher-training frameworks.

- *Health messaging reform:* Reframe national public-health campaigns to avoid weight-centric language and promote inclusive, evidence-aligned wellbeing messages.

- *Safeguards:* Prohibit routine weighing of children outside clinical need and ensure early referral pathways for young people showing early signs of disordered eating.

> “Prevention must begin before illness onset - we have seen the success of seatbelt, safe-sex and smoking campaigns over the course of a generation. Societal messages glorifying thinness and weight loss need countering with science-based education and early detection.” (Suzanne Baker)

Conclusion

> “We cannot change the past, but we can change the future. Every life saved through better care and understanding is a measure of progress.”
>
> (**Wera Hobhouse MP and Richard Quigley MP**)

Eating disorders have been neglected for decades, with chronic underfunding, fragmented services and a workforce that is overstretched and insufficiently trained. These systemic failings have resulted in delayed or denied treatment, unsafe discharges and avoidable deaths.

Eating disorders are serious but treatable mental illnesses. When care is delayed or refused, malnutrition impairs thinking, engagement becomes impossible and physical deterioration can be rapid and fatal. Treatment should never depend on a person reaching a dangerously low weight. Early and evidence-based intervention saves lives and must be available at every level of severity.

The Inquiry heard consistent testimony from more than six hundred witnesses, written submissions, and expert hearings that most deaths from eating disorders in the United Kingdom are preventable. These are not isolated failures but symptoms of a system under pressure and lacking accountability.

Efforts to raise awareness are valuable but not enough. Most people who die from eating disorders are already known to services. Preventing future deaths depends not just on the earlier identification of new cases of eating disorder, but on ensuring continuous, high-quality treatment for those who are already severely ill. Current NHS policy and funding remain heavily weighted toward early intervention for young people, leaving adults with long-standing illness without sustained specialist care. This imbalance must be addressed.

International experience shows that where early, specialist and integrated care is properly funded, such as in Italy, Sweden and Australia, mortality and relapse rates fall. Economic modelling confirms that timely access, shorter waiting times and coordinated transitional support provide the greatest return on investment.

The misuse of terms such as Severe and Enduring Eating Disorder (SEED) and SE-AN to justify treatment withdrawal has contributed to fatalistic practice and loss of hope. These are not diagnostic categories and should never be used as reasons to end care. In any other illness, if a patient does not respond to first-line treatment, more intensive or alternative interventions are provided. Withdrawing treatment from people who remain seriously ill is not consistent with accepted medical ethics and would not be tolerated in any other area of healthcare. National guidance must make this clear and ensure that all patients continue to receive appropriate, evidence-based care for as long as it is clinically needed.

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

The Inquiry calls for decisive Government action to ensure timely, continuous, and evidence-based treatment for all, to strengthen training and accountability across services, and to end the systemic neglect that continues to cost lives.

Recovery should never depend on geography, weight, demographics or persistence. It should be the expected outcome of effective and compassionate care.

I wanted to share my positive experiences of ED services in Shropshire (and the mental health teams here too.) I was open to EDs between 2010 and 2023. My initial appointment in 2010- I was seen within 10 days! I had an amazing nurse therapist, Anna. The consultant in the team was the same one throughout my 13 years- , the whole staff team were consistent with the same members of staff all the way through, so if I ever needed help I could call up and knew the person on the other end. I had frequent dietician appointments, monthly consultant appointments and therapy twice a week, then moved to weekly. I was offered group therapy too. My nurse therapist also helped with a referral for an autism assessment. I was never 'allowed' to mess around, Anna was very firm but fair- e.g. she didn't allow me to refuse to be weighed, I was always updated with what would happen next such if I was discussed at their weekly meetings. I went to an inpatient unit voluntarily in 2015, again, I didn't have to wait for a bed, I was straight in within two days. The consultant on the ward was the same consultant for outpatients so I knew what to expect. Unfortunately I was sectioned a few weeks later for six months but this saved my life ultimately- I feel all decisions were made at the right time, if they let me go home and waited and didn't act I would have died. I was discharged briefly but when I relapsed I was again seen within a week. My partner was also constantly offered support with the partner and family group that they run. The EDs team also worked very closely with the CMHT, so sometimes my Dr from CMHT would join my appointments with Anna. Anna also arranged for me to have a separate therapy for OCD. I felt respected and cared for, never like "just another number". It took time to get to where I am today but it's all down to Shropshire ED team. (Carla)

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Methodology

Over the last six months, the All-Party Parliamentary Group (APPG) for Eating Disorders has conducted a comprehensive inquiry into the current state of eating disorder services across the UK, focusing on deaths.

This included:

- Five one-hour evidence sessions with ten people per session, featuring testimonies from clinicians, researchers, charities, carers and individuals with lived experience
- 685 case studies submitted by patients and families from every region and nation of the UK, detailing their experiences with NHS eating disorder services
- Written submissions from leading institutions and charities; including the Royal College of Psychiatrists, and The Body Project Org
- Data reviews of current provision for people with longstanding and severe eating disorders, including the implementation of ‘SEED Pathways’ in NHS Trusts
- Conversations with bereaved families who have lost loved ones to eating disorders.

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Appendices

Appendix 1. Specialist Psychotherapy with Emotion for Anorexia (SPEAKS)

SPEAKS is a novel, evidence-based outpatient psychotherapy developed for people who have not benefited from traditional first-line treatments, particularly individuals with complex, long-standing conditions or neurodivergent needs. SPEAKS addresses the *whole person*, beyond weight or eating disorder symptoms.

Developed from lived experience, SPEAKS was developed during a five-year NIHR-funded research programme, learning from lived experience of recovery. Integrating qualitative and quantitative research, and using theoretical modelling, key change processes were identified and an integrated psychotherapy developed, drawing primarily on Emotion-Focused Therapy and Schema Therapy.

SPEAKS is delivered over five phases in around 40 sessions. SPEAKS aims to authentically develop a resilient, emotionally integrated sense of self, identified in lived experience research as central to recovery and described as *"The Real Me".* Therapy includes mode mapping, experiential chair work and imagery tasks, enabling clients to access emotions and explore identity in ways that traditional talking therapies may not reach. Techniques are carefully tailored to individual tolerance for emotion and adapted for neurodivergent needs, increasing accessibility (Oldershaw and Startup, 2024; Emotion Speaks, n.d.).

Evidence and benefits

Research to date demonstrates support for SPEAKS and its underlying change processes. A feasibility trial in NHS specialist services carried out by Oldershaw and Colleagues (2022) tested SPEAKS with people living with long-term anorexia presentations (average illness duration nine years; 80% previously treated). Findings demonstrated:

- **Significant and large improvements** in eating disorder symptoms, anxiety, depression, and quality of life
- **Strong rates of remission including relative to NICE-recommended therapies**
- **Feasibility of delivery in NHS services**
- **Reduction in health service use** outside of the ED service during treatment
- **High engagement and strong acceptability** amongst both clients and therapists with therapeutic disengagement at 0%

The exceptionally high level of engagement is striking and reflected in feedback:

"SPEAKS trial results were impressive. No patients dropped out of therapy – that speaks volumes in terms of patient experience…. Where the eating disorder has become entrenched, treatment tends to focus on care coordination and symptom management rather than active recovery and change. People with lived experience say that this can

bring a sense of hopelessness. SPEAKS can fill the gap in service provision and offer recovery-focused integrated treatment." (SPEAKS clinician)

"When you've been living with an eating disorder for so long, it consumes your identity. With SPEAKS, it was the first time my emotions were really explored… and I felt like I was finally seen for who I truly was underneath the eating disorder. The chair work and imagery-based exercises were so powerful, they gave me a way to connect with and express emotions that had always felt out of reach and explore things that initially felt too uncomfortable. That's what made SPEAKS not just helpful, but truly life-changing." (SPEAKS client)

Why it matters

People with longstanding eating disorders often only receive non-therapeutic management focused on symptom monitoring. SPEAKS is a structured, evidence-based outpatient psychotherapy, grounded in lived experience of recovery and adapted for longstanding, complex or neurodivergent needs. SPEAKS demonstrates that active, recovery-focused psychotherapy is possible, even following enduring illness. It fills a critical gap and offers both choice and hope for those who remain unwell after standard treatments.

Appendix 2: Focal Integrative Arts Psychotherapy

Focal Integrative Arts Psychotherapy (FIAP) is a focused adaptation of integrative arts psychotherapy, grounded in evidence-based psychodynamic principles, developed specifically within the Hertfordshire Community Eating Disorders Service (CEDS). It represents a new, creative approach to eating disorder treatment, arising from the recognition that NICE guideline-led interventions such as CBTE, whilst demonstrated to have significant and long-lasting effects for those with non-complex presentations (Hilbert et al., 2012; Fairburn et al., 2009) might not suit all patients, especially those with complex presentations such as those with co-morbidities (Kaidesoja, Cooper and Fordham, 2022; Gioia, Ali and Reilly, 2024) like PTSD or C-PTSD which are shown to have co-occurring rates of 27% (Hambleton et al., 2022).

The service in Hertfordshire adopted FIAP when faced with very unwell patients who were not responding to first-line treatments and repeatedly presenting to the service realised it was time to take a different approach and utilise the specialised therapists they had available. With staff trained as integrative arts psychotherapists, managers were willing to support an approach outside of NICE (2017) guidance. This openness enabled the development of FIAP, which became embedded as a valued part of the service. Its delivery has highlighted the importance of flexibility, relational depth and creativity in treating complex presentations, including those involving trauma or neurodiversity (Anstee and Davis, 2025). Its development was only possible due to open-minded leadership and managers who were willing to think outside the box and support therapies beyond those recommended in the NICE guidelines.

FIAP combines psychodynamic and relational elements of psychotherapy with the use of creative arts to facilitate expression of thoughts and feelings related to eating disorder behaviours, offering individuals an alternative treatment and the possibility of deeper engagement with increased accessibility. It goes beyond a therapeutic model and has emphasis on co-creation and the therapeutic relationship as a tool for healing.

FIAP combines multiple therapeutic approaches within a trauma-informed, collaborative space, using a range of artistic tools to support the expression of thoughts and feelings related to eating disorder behaviours. It is a person-centred approach that meets individuals where they are rather than imposing rigid expectations, and it values resistance and ambivalence as part of the therapeutic process, exploring the eating disorder's role as both a survival strategy and a source of harm.

The therapist does not act as an authority but as a facilitator and companion, using creativity, trust, and safety to support clients in uncovering their own answers. Each journey is uniquely co-created, with no single framework fitting all, allowing space for exploration, challenge and healing. Because of this, FIAP is not diagnosis-specific; instead, it explores the underlying factors that may have contributed to the eating disorder, such as attachment or developmental trauma, difficult relationships, loss and grief, identity struggles, neurodiversity, and trauma or PTSD/C-PTSD (Anstee and Davis, 2025).

Clinical outcomes (Anstee and Davis, 2025)

The use of FIAP was recently evaluated in the Hertfordshire Community Eating Disorders Service, examining both quantitative outcomes and qualitative experiences. This paper was amongst the first to explore the potential benefits of using art therapy as an

alternative to standardised treatment options within the NICE guidelines for the treatment of eating disorders.

This service evaluation explored the outcomes of individual FIAP, an integrative form of art therapy, for service users with eating disorders, particularly those with complex or comorbid presentations where standard NICE-recommended treatments may be less effective.

The evaluation of 48 patients demonstrated significant improvement across key outcome measures, including eating-disorder symptoms (EDE-Q), functional impairment (CIA) and psychological distress (CORE), all with $p < .001$. Qualitative feedback described greater confidence, improved mood and enhanced quality of life, underscoring FIAP's potential as a safe and effective adjunct or alternative to standard therapies. The feedback emphasised the importance of a trusting therapeutic relationship, the holistic, adaptable and supportive nature of FIAP, and the role of the arts in uncovering unconscious feelings and providing a safe medium for expression. Participants in the study described improvements in confidence, self-esteem, life satisfaction and overall wellbeing, reinforcing the potential of FIAP to support individuals with eating disorders with complex presentations or comorbidities.

These findings align with previous research indicating that art therapy can improve mood, self-esteem, emotional awareness and psychosocial functioning, potentially through the engagement of brain networks related to emotional regulation and creative expression, as outlined previously.

Overall, this research suggests that FIAP may be a promising alternative treatment for individuals with eating disorders. It is vital that there is further research into the use of art therapy and FIAP to improve outcomes in individuals that may not fully benefit from existing NICE-recommended treatments and prevent deaths from eating disorders.

Mechanisms of benefit

Art therapy within FIAP promotes non-verbal emotional expression, reconnection with the body, and integration of self, supported by relational healing and emerging neurobiological evidence of improved stress regulation. The use of creative arts in therapeutic settings can bypass defence mechanisms such as rationalisation or intellectualisation of behaviours and emotions, which are commonly used by individuals with eating disorders. These defences can slow progress in traditional talk therapies, whereas creative approaches encourage individuals to move from explaining their emotions to experiencing them and thereby beginning to process them (Bucharová et al., 2020).

Barriers and system challenges

Despite positive results, FIAP faces barriers to wider adoption. Manualised therapies such as CBT are easier to evaluate and dominate NICE guidelines and funding models. FIAP requires longer treatment duration and specialist staff training, yet arts therapists represent only 1 per cent of the NHS mental-health workforce. Recruitment, pay-banding and role recognition remain significant obstacles. The sustainability of such innovative approaches often depends on local leadership willing to support flexible, patient-centred models.

Policy implications

- Expand funding for research and evaluation of evidence-based “NICE-plus” treatments such as FIAP.
- Recognise arts psychotherapies within national workforce planning and pay frameworks.
- Encourage local services to pilot and evaluate integrative approaches for people with complex or comorbid eating disorders.
- Protect clinical leadership capacity to support innovation and flexibility beyond first-line treatments.

Key message

Research suggests FIAP may be a promising alternative treatment for individuals with eating disorders. It demonstrates that recovery is possible even for those with long-standing or complex illness when services are resourced, creative and compassionate. Broadening therapeutic options and supporting workforce diversity are essential to reducing chronicity and preventable deaths from eating disorders. It is vital that there is further research into the use of art therapy and FIAP to improve outcomes in individuals that may not fully benefit from existing NICE-recommended treatments and prevent deaths from eating disorders.

Appendix 3. Lessons from the Integrated Step Care Innovation

The problem

The period after discharge from hospital is the most dangerous time for people with severe eating disorders. Many patients are discharged underweight, relapse quickly, and some die before they can be readmitted. This gap between inpatient and community care remains a major cause of preventable harm.

What Step Care offers

Step Care is an NHS service developed by the HOPE Provider Collaborative in the Thames Valley. It provides an intensive, structured alternative to hospital admission or early relapse after discharge (Oxford Health, 2022; 2024).

Treatment is based on enhanced cognitive behavioural therapy (CBT-E) and delivered by a multidisciplinary team (MDT)—including psychologists, nurses, dietitians, and therapists—working collaboratively with the patient and their family.

Care is provided virtually, allowing patients to practise change in their own home, supported daily by the team. This approach promotes recovery in the least restrictive environment while maintaining medical and psychological safety.

Why it works

Continuity of care: Step Care bridges the high-risk transition between hospital and home.

Intensive and personalised: Each patient receives daily structured input, guided by their own formulation and recovery goals.

Collaboration: Patients, carers, and clinicians work together to build confidence, autonomy, and sustainable routines.

Accessibility: Virtual delivery reduces barriers and allows care closer to home.

Safety and outcomes: Most patients avoid readmission, maintain weight, and sustain recovery.

Impact so far (Viljoen and Ayton, 2021)

Around two-thirds of patients have avoided hospital admission.

None required emergency medical care; only one had an unplanned readmission.

Patient and carer feedback describes Step Care as “life-saving,” “safe,” and “the first time recovery felt possible.”

The model delivers substantial cost savings by reducing inpatient bed use.

Why this matters for prevention

Step Care shows that intensive, home-based multidisciplinary treatment can keep people safe, reduce relapse, and prevent deaths after discharge. The model combines evidence-based therapy with digital innovation and compassionate teamwork—ensuring that patients remain connected, supported, and empowered at home.

In short

Continuity and collaboration save lives. Step Care demonstrates that intensive CBT-E delivered by an MDT in partnership with patients and families can transform recovery and prevent eating-disorder deaths.

Appendix 4: Case Study: The Body Happy Schools Programme

The Body Happy Schools Programme is the UK's first whole-school initiative to embed body respect across the school environment. Developed with support from the Fair Education Alliance Innovation Award, the programme was piloted in 2024–25 in three diverse schools (urban secondary, all-through academy, and rural primary).

The multi-strand approach includes:

Staff CPD on body image, stigma, and inclusive practice

Student workshops mapped to the PSHE curriculum

Peer advocacy programme (Body Happy Heroes and Peer Advocates)

Parent engagement and home resources

Classroom resources including individualised lesson plans and full schemes of work

The theory of change is grounded in whole-systems work: culture change at staff, student, policy, and curriculum levels to reduce stigma, build protective factors, and foster environments that support both prevention and recovery.

Pilot Findings (The Body Happy Organisation, 2025)

Staff knowledge and confidence
Staff confidence in identifying body image risk factors, recognising weight stigma, adapting the curriculum, and embedding prevention strategies increased by 33.4 percentage points - from 57.1% to 90.5% after CPD (Body Happy Schools Pilot CPD Dataset, 2025).

Whole-school culture
At All Saints Academy, Plymouth, student reports that *"we learn about body image in school"* increased by 37.2% (48.9% → 86.1%). Reports that *"appearance-based bullying is taken seriously"* and *"all bodies are respected in school"* both rose by 21.7%.

Student outcomes
Secondary pupils showed significant increases in body image literacy, resilience, and advocacy. For example, Year 8 students reporting "knowing how to look after my body image" rose from 3.75 to 4.19 (5-point scale). Primary pupils reported greater empathy, resilience, and willingness to challenge stigma.

Qualitative insights

"It's about whole-school culture. Everyone now understands what body image means." (Headteacher)

“Students are kinder, checking in on each other, and making amends.” (Pastoral lead)

“Even quieter staff are talking to students about this now.” (Teacher)

Research Alignment & Implications for Eating Disorder Prevention

Reducing weight stigma protects wellbeing
Weight stigma predicts eating disorder symptoms and worsens health behaviours (Puhl and Latner, 2007; Pont et al., 2017; Puhl et al., 2020). School-wide stigma reduction reduces a key risk factor.

Media literacy builds resilience
Interventions teaching students to critically assess media and appearance ideals significantly reduce body dissatisfaction and internalisation of thin ideals (Levine and Smolak, 2016).

Positive body image fosters protective behaviours
Positive body image predicts intuitive eating, joyful movement, and psychological wellbeing (Avalos, Tylka and Wood-Barcalow, 2005; Tylka and Wood-Barcalow, 2015; Linardon, 2021) Body dissatisfaction, by contrast, predicts unhealthy weight control behaviours (Neumark-Sztainer et al., 2006)

Systemic approaches aid recovery
School environments that celebrate body diversity, reduce appearance-based bullying, and model weight-inclusive approaches help reduce environmental triggers for students already in treatment (Halliwell et al., 2018).

Ongoing Evaluation and Research Partnerships

Alongside pilot evaluation, the programme is being studied through a formal partnership with the University of Lincoln. A fully funded PhD studentship through the South East Network for Social Sciences (SENSS) begins in September 2025, strengthening the evidence base and ensuring long-term, rigorous evaluation of the programme’s preventative and recovery-supportive impact.

Conclusion

Supported by the Fair Education Alliance, and underpinned by an evolving research partnership, the Body Happy Schools Programme demonstrates that embedding body respect in schools strengthens protective factors, reduces risk factors, and creates recovery-supportive environments. This systemic prevention model is evidence-aligned and offers a scalable way to address one of the most common – and modifiable – early risk factors for eating disorders.

Further information

Full findings are available in the Body Happy Schools Programme Pilot Impact Report and impact video found on www.bodyhappyorg.com

Case Study: What is the Body Project? (Lewis, 2024)

The Body Project is a cognitive dissonance-based intervention which covers a critique of the thin ideal – as proposed by the 2017 green paper – and is based on the dual-pathway model (Stice, 2001). Both the intervention and the model were established by US researcher Dr Eric Stice. The dual-pathway model identified that thin-ideal internalisation leads to body dissatisfaction which subsequently leads to disordered eating via the dual pathways of negative affect and dietary restraint, and that thin-ideal internalisation was the most modifiable risk factor to address in preventive interventions (Stice, 2001).

Cognitive dissonance theory argues that psychological discomfort is created when behaviours are inconsistent with cognitions, and so individuals are motivated to change their cognitions or behaviours to restore consistency. Our intervention involves cognitive dissonance-based activities such as role plays, letter writing and behavioural challenges. For example, participants engage in verbal, written and behavioural exercises in which they critique the thin-ideal, which consequently produces cognitive dissonance that motivates participants to reduce the pursuit of this ideal (Thompson et al., 1999).

In terms of the evolution of the evidence-base for The Body Project, Stice and colleagues have tested their approach in educational settings over the last 20 years. The most rigorous trial conducted to date found that the intervention prevented 60% of the cases of eating disorders that emerged in the control condition over a 3 year follow-up, suggesting that for every 100 young women who complete this program, there should be 9 fewer young girls who develop eating disorders over the subsequent 3 year period (Stice, Onipede, and Marti, 2021)

UK implementation of The Body Project

Despite the success of 'The Body Project' in the US, there is limited evidence to demonstrate the intervention's generalisability in the UK. Examples of 'The Body Project' being delivered and evaluated in a UK setting are limited and have exclusively taken place in the South-West and North-East of England (Halliwell and Diedrichs, 2014; Diedrichs, Halliwell and Paraskeva, 2014; Halliwell et al., 2015; Jankowski et al., 2017; Kant et al., 2019) – see also https://sites.glos.ac.uk/thebodyproject/.

These studies explored the effectiveness of *The Body Project* with 12 to13 year-old girls (Halliwell and Diedrichs, 2013), 14 to15 year-olds (Halliwell et al., 2015), and older teenagers (Mean age 19.6; Diedrichs, Halliwell and Paraskeva, 2014 and 19.4; Kant et al., 2019). Two of these four studies reported on the ethnicity of participants. However, the majority were reported as White (97%, Halliwell et al., 2015; and 70% with 12% Asian, Halliwell and Diedrichs, 2014).

Whilst these studies did show some positive effects in body appreciation and body satisfaction (Halliwell et al., 2015) and decreased body dissatisfaction and thin-ideal internalisation (Halliwell and Diedrichs, 2014), and pathological eating attitudes (Kant et al., 2019) a qualitative evaluation of 'The Body Project' revealed that participants experienced 'awkwardness' and found the intervention too scripted and 'artificial', as well as too 'static and still' (Jarman, Treneman-Evans and Halliwell, 2021). In addition, a small number of participants (5%) would have appreciated content that went beyond weight and

shape and covered different body parts and skin colour (Jarman, Treneman-Evans and Halliwell, 2021).

The suggestion to include skin colour as a factor in the appearance ideal is an important consideration when looking at UK implementation, as people from an Asian ethnic background – namely South Asian (Indian, Bangladeshi, Pakistani and Sri-Lankan) – make up the second largest group in the UK after White British people (Office for National Statistics, 2011), yet access to specialist services for problems related to body image disturbance are under-represented from this group, despite some studies indicating similar or higher prevalence rates in this group (Wales et al, 2017; Chowbey, Salway and Ismail, 2012). Therefore, it is important that preventive interventions are inclusive of the needs of South Asian adolescent girls in the UK, and that MHSTs are equipped to deliver these culturally appropriate interventions.

Considering the policy context in the UK, where there are national commitments to delivering interventions based on 'The Body Project', this thesis will contribute to the growing evidence-base of CDBI to alleviate body dissatisfaction, by conducting research to support its rollout in a diverse, UK context.

NIHR funded research into equitable implementation of The Body Project (Lewis, 2025)

To advance the equitable implementation of The Body Project in the UK, the National Institute of Health and Care Research (NIHR) has funded a two-year project supporting the pilot of a cultural adaptation of The Body Project for South Asian adolescent girls. Following a qualitative exploration of culturally specific risk factors in the development of body dissatisfaction and disordered eating in this population (Lewis et al., 2025), an adapted version of the intervention will be tested in East London schools. The findings from this feasibility and acceptability trial will form the basis of a larger, nationwide trial which will intentionally place a focus on intersectionality and diversity in experiences of body dissatisfaction and other risk factors for the development of eating disorders.