All-Party Parliamentary Group on Eating Disorders

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The Right to Health:

People with Eating Disorders are being failed

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The Right to Health: People with Eating Disorders are being failed

Foreword by Wera Hobhouse MP

Eating disorders are among the most serious and life-threatening mental illnesses and have been overlooked and underfunded for far too long. Because of this, eating disorders have one of the largest treatment gaps in modern healthcare. The question must be asked: “Why, in the face of overwhelming need, are we still ignoring this crisis?”

In the past decade, we have seen an alarming rise in eating disorders, a trend that only worsened during the COVID-19 pandemic. What was already a struggling support system for those affected by eating disorders has collapsed under pressure. Too many people are waiting; too many are being failed and neglected by the system. This was a problem before the pandemic, and we can no longer hide behind COVID19 as an excuse for historically grossly underfunded treatment services. The public perception of eating disorders remains narrow, but eating disorders don't discriminate and affect people of all ages, genders and ethnic backgrounds.

They manifest themselves in many different forms. Binge eating disorder (BED) is now five times more common than anorexia nervosa and does not have dedicated NHS services.

Yet, the services and treatment pathways available do not reflect this growing reality. In the past six months, the All-Party Parliamentary Group on Eating Disorders has met with patients, families, clinicians, and researchers who have shared harrowing, deeply personal accounts of the failure of our mental health services. We heard stories of children as young as four being diagnosed with avoidant/restrictive food intake disorder (ARFID), who were unable to access any specialist support. We heard of families losing loved ones due to systemic neglect and inadequate care, and we heard from dedicated professionals struggling to provide life-saving treatment in an environment that is underfunded, under-resourced, and overwhelmed.

Lives are at stake, and swift, decisive action must be taken.

Historically, the NHS has been reactive, putting out the flames of crisis rather than addressing the root causes. The devastating impact of eating disorders is now so widespread that we cannot continue in this way. The demand for services has reached a tipping point. Lives are being lost, families are being torn apart, and the toll on the NHS is unsustainable.

The stories we have heard are heart-breaking. The statistics are staggering. But still, eating disorders are not being treated with the urgency they deserve. This must change. Eating disorders must be treated as the emergency they are. It is time to act.

Executive Summary

This report highlights the urgent need for a national strategy to address the growing eating disorder crisis in the UK. NHS admissions for eating disorders exceeded 30,000 admissions for the first time in 2023/24. Evidence was gathered through oral and written submissions from people with lived experience, carers, clinicians, managers, and academics, combined with Freedom of Information requests and data analysis. Key findings reveal significant barriers to accessing treatment, including insufficient training for healthcare providers, fragmented care pathways, and a lack of standardised data for research. The report also emphasizes the postcode lottery in service provision and the alarming practice of discharging patients at dangerously low BMIs.

The All Party Parliamentary Group for Eating Disorders recommends:

1. Development of a National Strategy for Eating Disorders. This strategy will encompass adults and young people, with sufficient funding to reform all services. The goal is to provide timely, evidence-based treatment for every individual with an eating disorder. The national Strategy will include:

a. Mandatory eating disorder training for all Front-Line Workers (including GPs, Dentists, Teachers and Nurses)
b. Investment in a public health campaign to clarify messaging around obesity and eating disorders
c. Funding for the implementation and integration of evidence-based treatment practices including collaboration between services.
d. Mandatory health screening for high-risk groups
e. Training for Carers

2. Additional Funding for Eating Disorder Services This funding should address the demand for both adult and children's services.

3. Confidential Inquiry into All Eating Disorder Deaths.

4. Increased Research Funding for Eating Disorders The aim is to enhance treatment outcomes and ultimately discover a cure for eating disorders.

5. Non-Executive Director Oversight for both adult and children Eating Disorder Services. This oversight and accountability should be implemented in all NHS Trusts and Health Boards in the UK.

The current state of Eating Disorders

Purpose of the Inquiry

Eating disorders have faced decades of neglect, characterised by underfunding that has resulted in an under-resourced and often poorly trained workforce. This has resulted in substandard care and prolonged suffering for individuals with eating disorders and their carers and has hindered crucial research.

In 2017, the Parliamentary Health Service Ombudsman raised the alarm about avoidable deaths and the NHS eating disorder services failing patients. They called for increased training, improved funding and quality of adult services, more effective coordination, and cross-organisational learning from incidents. However, despite a follow-up by the Public Administration and Constitutional Affairs Committee, progress has been limited, and in recent years, we have seen an increasing number of people with eating disorders deemed untreatable, with some as young as 17 being placed on palliative care pathways.

This report documents the experiences of those failed by the system and highlights the gaps in services, the pervasive stigma surrounding eating disorders, and the lack of accountability within the NHS. This includes clinicians who have reached breaking point trying to get support for those in their care. There are compelling examples of effective interventions, including FREED's[1] early intervention programme, the Integrated Cognitive Behavioural Therapy for Eating Disorders (I-CBTE)[2] helping individuals with severe anorexia requiring hospital treatment, the Waterlily initiative, and innovative pathways implemented within the Independent Sector (see Appendix). However, while these examples showcase good practice, the burden of care often falls disproportionately on charities and carers.

Due to insufficient access to treatment, many individuals manage these conditions independently for years, enduring chronic malnutrition that leads to preventable physical and mental health complications. Improving access to treatment would not only alleviate individual suffering but also deliver significant benefits to the wider economy.

[1] Richards et al., "National Roll-out of Early Intervention for Eating Disorders: Process and Clinical Outcomes from First Episode Rapid Early Intervention for Eating Disorders."
[2] Ibrahim et al., "Integrated Enhanced Cognitive Behavioural (I-CBTE) Therapy Significantly Improves Effectiveness of Inpatient Treatment of Anorexia Nervosa in Real Life Settings."

Given this context, there is a clear and urgent need for an appropriately funded national strategy for eating disorders. This strategy should aim to address current service gaps and develop achievable standards of care that properly support patients, families, and healthcare professionals.

During our evidence sessions we spoke to people with lived experiences, patients and carers, clinicians (psychiatrists, psychologists, nurses), researchers and academics, managers, RCPsych, and medical students. Combining this with Freedom of Information (FOI) requests and data, we have obtained an accurate picture of what is happening on the ground.

What are Eating Disorders?

Eating disorders are often misunderstood as a lifestyle choice affecting only white, affluent, underweight teenage girls. In reality, they are serious mental illnesses caused by a combination of biological, psychological, and social factors. These conditions affect individuals of all sizes, religion, wealth, ages, genders, sexualities, abilities, races, and ethnicities.

Despite their complexity, eating disorders are fully treatable with a comprehensive approach that is accessible and inclusive to meet individual needs includes nutritional, medical, and therapeutic support.

The pressures of modern society, the normalisation of eating disorder culture on social media, and pervasive diet messaging are significant contributors to the rise in eating disorders. Research highlights that repeated exposure to images of lower-weight bodies shifts perceptions of average body size, fostering smaller ‘ideal’ body standards. This disproportionately impacts individuals with genetic and other predisposing risk factors for eating disorders, further exacerbating the problem.[3] Addressing these misconceptions and societal pressures in an ever-growing digital world is essential to improve prevention, treatment, and recovery outcomes for those affected by eating disorders.

[3]Bould et al., “Does Repeatedly Viewing Overweight versus Underweight Images Change Perception of and Satisfaction with Own Body Size?”

Overview of types of Eating Disorders

- **Anorexia Nervosa (AN):** Characterised by severe restriction of food intake, intense fear of gaining weight despite being underweight, and a distorted body image. Sex ratio is 9:1 female. This is the least common but has the highest mortality rate out of all eating disorders. Standardised mortality ratio (SMR) is 5-6,[4] Prevalence rate: 0.5-08%%
- **Bulimia Nervosa (BN):** Involves cycles of binge eating followed by compensatory behaviours such as vomiting, excessive exercise, or laxative use to prevent weight gain. The sex ratio is 2-3:1 female. SMR: 2-3
- **Binge Eating Disorder (BED):** Marked by episodes of uncontrollable eating without subsequent compensatory behaviours, often leading to feelings of shame or distress and metabolic disorders. The sex ratio is 2-3:1 female. SMR: 1-2
- **Avoidant/Restrictive Food Intake Disorder (ARFID):** Characterised by limited food intake due to lack of interest in eating, sensory sensitivity, or fear of consequences such as choking, without concerns about body weight or shape. Often linked with neurodevelopmental disorders. Sex ratio is 1:1. The prevalence rate is 2% in children[5]
- **Other Specified Feeding and Eating Disorder (OSFED):** Includes atypical forms of eating disorders that do not meet the full criteria for AN, BN, or BED but still cause significant distress or impairment. Less common presentations include purging disorder and night eating disorder.
- **Pica:** Involves the persistent eating of non-nutritive substances (e.g., dirt, clay, or chalk) that are not culturally or developmentally appropriate. There is not enough research to know if this is higher in one gender over another.
- **Rumination Disorder:** Involves repeated regurgitation of food, which may be re-chewed, re-swallowed, or spit out, not associated with a medical condition.

[4] Solmi et al., "Outcomes in People with Eating Disorders: A Transdiagnostic and Disorder-Specific Systematic Review, Meta-Analysis and Multivariable Meta-Regression Analysis."
[5] Dinkler et al., "Etiology of the Broad Avoidant Restrictive Food Intake Disorder Phenotype in Swedish Twins Aged 6 to 12 Years."

How Common are Eating Disorders Among People Living in The UK?

Eating disorders are a growing public health concern in the UK, with the eating disorder charity, BEAT, estimating over 1.25 million affected individuals in 2015[6,7]. However, this estimate relies on now outdated data and does not reflect the full range of conditions - particularly binge eating disorder and ARFID. Recent screening data shows a significant increase in eating disorder prevalence in the UK, although most of the data is from studies carried out in England using the SCOFF (Sick-Control-One stone-Fat-Food) eating disorder screening tool[8]. In England, the proportion of adults with a likely eating disorder rose from 6.4% in 2007 to 16.0% in 2019, with 4% reporting significant impairment[9,10]. Lifetime prevalence is estimated at 6%, affecting 2–3 million individuals in the UK[11], comparable to rates seen in other high-income countries[12] and similar to other conditions such as diabetes.

COVID-19 accelerated this upward trend. By 2023, 12.5% of 17- to 19-year-olds had an eating disorder, with higher rates in young women (20.8%). 75% of young women and 50% of young men aged 16–25 reported symptoms[13]. While these figures reflect screening results rather than confirmed diagnoses, they indicate a large, often hidden population-level epidemic. Eating disorders primarily affect young people and working-age adults, with higher prevalence among females. However, cases are rising among working-age men, especially those with higher body weight, a group often overlooked by health services. Individuals with conditions like Type 1 diabetes, obesity, or from historically marginalised groups also face higher risks. Eating disorders range from severe, life-threatening conditions to less visible but harmful disordered eating behaviours. Without timely intervention, they result in serious health complications, reduced quality of life, and limited social and economic participation[14]. Many premature

[6] "How Many People Have an Eating Disorder in the UK?"
[7] Ayton et al., "From Awareness to Action: An Urgent Call to Reduce Mortality and Improve Outcomes in Eating Disorders."
[8] Luck et al., "The SCOFF Questionnaire and Clinical Interview for Eating Disorders in General Practice: Comparative Study."
[9] "Health Survey for England, 2019: Data Tables."
[10] Mcmanus et al., *Adult Psychiatric Morbidity in England, 2007: Results of a Household Survey*.
[11] *Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care Guidance for Commissioners and Providers*.
[12] Hay et al., "Epidemiology of Eating Disorders: Population, Prevalence, Disease Burden and Quality of Life Informing Public Policy in Australia-a Rapid Review."
[13] "Mental Health of Children and Young People in England, 2023 - Wave 4 Follow up to the 2017 Survey."
[14] Santomauro et al., "The Hidden Burden of Eating Disorders: An Extension of Estimates from the Global Burden of Disease Study 2019."

deaths from suicide or medical complications from eating disorders could be avoided with early and appropriate treatment[1].

Figure 1: Whether feelings about food had a significant negative impact in the past year, by weight group and possible eating disorder status. (Adapted from NHS Digital) [15].

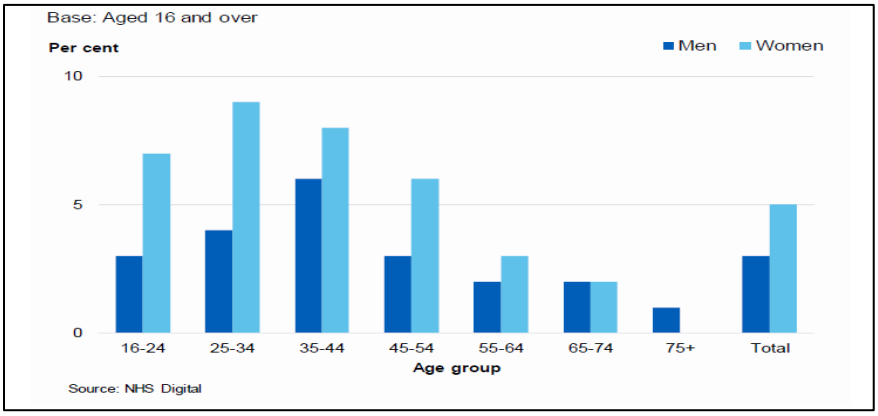
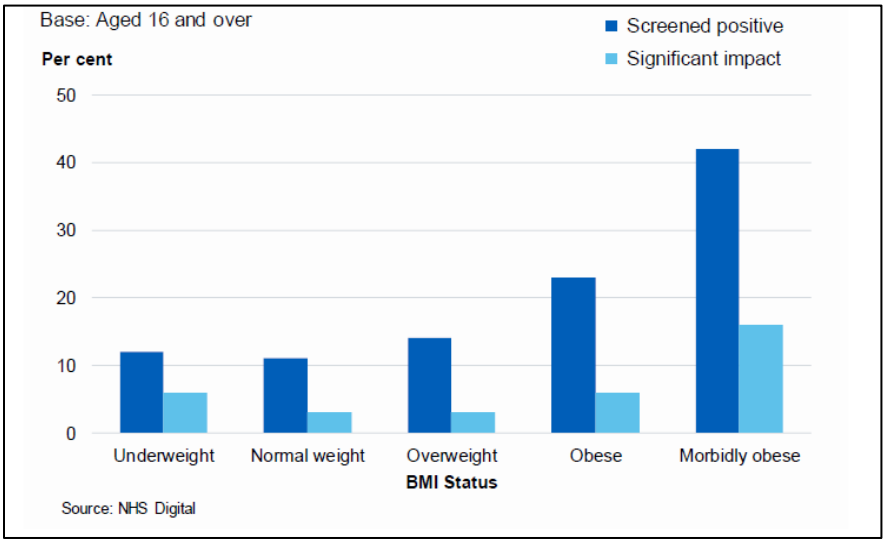


Figure 2: Whether feelings about food had a significant negative impact in the past year, by weight group and possible eating disorder status. (Adapted from NHS Digital) [16].



[15] "Mental Health of Children and Young People in England, 2023 - Wave 4 Follow up to the 2017 Survey."
[16] "Mental Health of Children and Young People in England, 2023 - Wave 4 Follow up to the 2017 Survey."

Key Data

Children and Young People

In England, an estimated 360,000 children and young people (7.5%) are affected by an eating disorder. However, only 55,000 were identified by GPs in 2020[17], and just 19,500 accessed NHS specialist services in 2022–23, the vast majority being females with anorexia nervosa[18]. That year, there were 8,434 hospital admissions for severe cases[19].

The significant gap between prevalence and diagnosis suggests many children and young people, particularly those with less visible or higher-weight disorders or who come from marginalised backgrounds, remain undiagnosed and untreated. Proactive school-based prevention programmes and accessible adolescent services are urgently needed to address this unmet need.

Adults

The 2019 Health Survey for England (HSE) estimated that 1.7 million adults in England were affected by eating disorders[20]. Despite 87% consulting their GPs, only 282,000 received a formal diagnosis in 2020, highlighting a major gap in recognition. This may be due to self-stigma, shame, or insufficient GP training on the full spectrum of eating disorders.

In 2022–23, just 19,200 adults accessed NHS Community Eating Disorder Services, 92% being females with anorexia nervosa (17,664). Acute hospitalisations further reflect the severity of cases, with 18,199 admissions for females and 1,421 for males. With only 450 specialist eating disorder beds available, annual admissions to these units remain limited to 1,200–1,500 and are normally limited to females.

A national pre-pandemic survey compared demand and capacity of adult community eating disorder services (ACEDS) with NHS England (NHSE) commissioning guidance. Thirteen services in England and Scotland responded (covering 10.7 million population). Between 2016-2017 and 2019-2020, mean referral rates increased by 18.8%, from 378 to 449 per million population. Only 3.7% of referrals were from child and adolescent eating disorder services (CEDS-CYP), but 46% of patients were aged 18–25 and 54%

[17] Cooper et al., “Prevalence and Demographic Variation of Cardiovascular, Renal, Metabolic, and Mental Health Conditions in 12 Million English Primary Care Records.”
[18] “NHS Benchmarking Network.”
[19]“Hospital Admissions for Eating Disorders.”
[20] “Health Survey for England, 2019: Data Tables.”

were aged >25, highlighting that the onset of eating disorders affects more adults than teenagers. Most ACEDS had waiting lists and rationed access. Many could not provide full medical monitoring, adapt treatment for comorbidities, offer assertive outreach, or provide seamless transitions. The ACEDS workforce budget accounted for only 15% of the level recommended by the NHSE workforce calculator for CEDS-CYP. This indicates that the services were operating with an 85% shortfall in resources relative to the recommended staffing levels. This study highlights the severe pressure in ACEDS, which has increased since the COVID-19 pandemic. Substantial investment is required to ensure NHS ACEDS meet national guidance, offer evidence-based treatment, reduce risk and preventable deaths, and achieve parity with CEDS-CYP.[21]

These findings highlight a major gap in recognition and treatment of eating disorders in England. Comparable data from the devolved nations is unavailable, limiting understanding of the broader UK context.

Economic Impact

In 2020, the social and economic costs of eating disorders in the UK were estimated at £9.4 billion (range: £7.5–11.2 billion) by Ernst & Young and the Hearts, Minds, and Genes Coalition[22]. This figure is likely to have increased since. The economic and social impact would be reduced by prevention and timely access to treatment.

Eating disorder	***Cost (£)***
● Anorexia and bulimia.	● £1.6 billion in healthcare costs. ● Emergency healthcare (A&E) costs were not included. ● £0.9 billion in carer costs
● Anorexia and bulimia.	● £0.7 billion in personal financial costs
● Anorexia and bulimia.	● £3.9 billion in productivity losses
● Associated with other specified feeding or eating disorders (OSFED) and binge eating disorder (BED).	● £2.3 billion in social costs

[21] Viljoen et al., “The Alarms Should No Longer Be Ignored: Survey of the Demand, Capacity and Provision of Adult Community Eating Disorder Services in England and Scotland before COVID-19.”
[22] Virgo et al., “The Cost of Eating Disorders in the UK 2019 and 2020.”

Current Funding Context

In 2023/24, £95.8 million was allocated to CYP eating disorder services in England. This reflects an 82.5% real-terms increase since 2016/17. However, this only accounts for 8.1% of total spending on children and young people's mental health services. It is also only 0.6% of Integrated Care Board (ICB) mental health budgets. On average, CYP services receive £817,000 per 100,000 population. This is compared to just £250,000 per 100,000 population for adult services, despite the new onset of eating disorders occurring in adults in ~50% of cases[23].

The cost of specialist inpatient treatment, including the independent sector, is estimated to be approximately £150 million annually. Acute hospital admissions for eating disorders add an additional £220 million per year.

These figures highlight the urgent need for proportionate investment across age groups and improved care models. This is necessary to prevent severe deterioration that can lead to costly inpatient and acute care services. It is important to note that, over the last decade, there has been some progress. This includes the publication of Adult Eating Disorders guidance in 2019 and the national implementation of First Episode Rapid Early Intervention for Eating Disorders (FREED). However, Child and Young People (CYP) services remain the best funded.

However, there are concerns about whether the frontlines have received the allocated funding.

> We must urgently address the systemic issues and lack of accountability within the NHS that result in funding intended for eating disorder services not reaching those who need it most. A stark example is the £29.5 million allocated for Children and Young People's Eating Disorder services (CYP-ED) in 2023-2024, which has not reached the front lines. This follows an audit by BEAT revealing that a previous £19.5 million uplift in 2019-2020 failed to reach over 60% of CYP-ED services. Cumulatively, £120 million of funding in England has not reached the frontline, depriving vulnerable patients of essential care and exacerbating the crisis in eating disorder treatment.
>
> Dr Kumar

[23] "Eating Disorders Are Just as Likely to Start in Adulthood as Childhood, EDGI Report Finds."

Workforce

Half of NHS specialist community eating disorder teams lack a consultant psychiatrist. In 2022–23, CEDS-CYP had 10.5 WTE staff per 100,000 population, while ACEDS had only 3.8 WTE. Consultant psychiatrists are scarce: 33 in CEDS-CYP and 57 in ACEDS nationally, with even fewer in Northern Ireland, Wales, and Scotland[24].

Community teams have a broader skill mix, while inpatient teams rely heavily on nursing staff, impacting care quality. Limited consultant psychiatrists in ACEDS lead to unmanageable workloads and delays.

A national plan is needed to expand the workforce, improve training, and ensure equitable access to evidence-based care.

Access to timely evidence-based psychological treatment

The 2019 Health Survey for England showed only 23% of individuals with eating disorders received psychological treatment, with just 4% accessing evidence-based models like CBT. In contrast, 1.2 million adults with anxiety and depression accessed NHS psychological therapy services in 2023, underscoring a stark disparity in access for individuals with eating disorders. Expanding NHS Talking Therapies to include non-underweight eating disorders could address this gap, with safeguards for patient safety.

[24] "NHS Benchmarking Network."

Findings (identification of the problems and best practice solutions)

The APPG had 4 oral evidence sessions, involving people with lived experience, carers, clinicians, managers, and academics. Further written evidence was submitted by clinicians working across the United Kingdom from both private eating disorder hospitals and the NHS.

Summary of themes:

Theme	**Similarities**	**Differences**
Training and Knowledge	All groups highlight insufficient training for healthcare providers. Emphasis on improving education to enhance care quality.	Clinicians focus on professional education (e.g., UCL psychiatry course). Carers stress carer-specific education (e.g., FEAST Toolkit).
Fragmented Care Pathways	Agreement on disjointed care pathways causing poor transitions and recovery issues. Need for integrated, all-age services. Much improved patient outcomes were demonstrated by integrating evidence-based psychological treatment across the care pathway	Carers highlight early independence in recovery as a risk factor. Lived experience focuses on the lack of long-term treatment plans.
Inclusion and Communication	Both carers and lived experience groups call for greater family inclusion in care. Combined evidence values family insights in recovery.	Clinicians focus on systemic barriers like confidentiality. Carers criticise the exclusion of their voices and patient-blaming culture.
Resource Allocation	Consensus on the urgent need for more inpatient beds. - Agreement on regional disparities in resources (e.g., binge ED services).	Clinicians emphasise broader funding issues and ring-fenced budgets. Carers and lived experience groups critique unregulated private services.

Increasing research	Universal agreement that research in eating disorders lags behind other fields. Consensus to focus on consistent investment in biopsychosocial research for all eating disorders is necessary to generate new treatments.	
Early Intervention and Prevention	Universal agreement on the importance of early detection and prevention strategies. Support for school-based interventions like the Body Project.	Clinicians focus on systemic incorporation of prevention in healthcare. Lived experience advocates stress-reducing BMI reliance in diagnosis to avoid treatment delays.
Hope and Recovery	Shared emphasis on fostering hope and transparent, recovery-focused care. Support for follow-up care post-discharge as part of long-term recovery.	Carers advocate for a "you said, we did" cultural shift in healthcare. Combined evidence emphasises reducing reliance on palliative care and increasing investment in chronic cases.
Preventable Deaths	Universal agreement that preventable deaths highlight systemic failures. strong need for accountability to address preventable harm.	Clinicians focus on systemic reforms and the implementation of recommendations (e.g., Ombudsman’s reports). Carers and lived experience groups emphasise the emotional impact of ignored warnings and advocate for early intervention.

1. Eating Disorder prevention requires a systematic framework and funding

Eating disorders, while often stigmatised and neglected, can have serious complications and increase the risk of avoidable death. With proper support and treatment, recovery is achievable.

Witnesses emphasised the importance of early detection and prevention strategies, including school-based interventions. A systemic incorporation of prevention is needed in health care.

> Just as increased awareness and research transformed our understanding of other illnesses such as HIV, we need the government to lead similar evidence-based public health campaigns
>
> Suzanne Baker

> Too many people still view eating disorders as only affecting skinny, white, affluent girls, what we call SWAG, instead of seeing it as a mental illness.
>
> Kerrie Jones, Orri

The impact of obesity messaging on individuals with eating disorders and the broader population cannot be ignored. While poor body image doesn't directly cause eating disorders, societal ideals and social media's portrayal of "health" can be detrimental. The Body Project, implemented in Gloucester, challenges these ideals and has shown a 60% reduction in eating disorder cases compared to a control group.[25,26]

High-risk groups, such as perinatal women, require particularly proactive support[27]. Research indicates high relapse rates during and after pregnancy, yet coordinated care often overlooks individual needs, focusing on the baby and weight. A collaborative approach across healthcare, education, and community support is essential to addressing eating disorders effectively. Yet, the coordinated care around perinatal support and eating disorders often fails to take into account how individuals feel, and beyond that, the messaging is often very much fixated on the baby and a person's weight. In order to tackle eating disorders, we need to be working across health care, education, midwives, GPs, dentists, and online groups such as MumsNet.

[25] Stice et al., "Effectiveness of the Body Project Eating Disorder Prevention Program for Different Racial and Ethnic Groups and an Evaluation of the Potential Benefits of Ethnic Matching."
[26] Stice et al.
[27] Ward, "Eating Disorders in Pregnancy."

With eating disorder services massively overstretched, we need to look at how we can roll out training across the country, whether that's to school nurses or midwives. It has been good to see so many more conversations about mental health in schools over the past decade, but too often these initiatives lack specialist eating disorder training. A workable national strategy for eating disorders is achievable. There are many precedents within the NHS where funded national plans have transformed access to care; this includes services for people experiencing first-episode psychosis, perinatal mental health, and psychological therapy via IAPT.

2. Inclusion of Eating Disorder Prevention into Public Health Policy

Within a National Strategy, it is essential to align Public Health obesity and eating disorder prevention policies. Recent reports on ultra-processed foods and the previous government's obesity strategy, with its emphasis on calorie counting, have inadvertently heightened anxiety in those with eating disorders. This "common-sense" approach contradicts the stance of eating disorder clinicians, who aim to avoid focusing on weight, calories, and BMI, as these can be psychologically damaging.

Obesity prevention and eating disorder management have often been treated as trade-offs, halting progress on both sides. Aligning these efforts is essential, with a strong focus on including lived experience in policy-making. At the Obesity Health Alliance (OHA), this could involve creating opportunities for individuals to contribute to consultations, early policy development, and impact assessments that consider both obesity and EDs. Food labelling policies should balance benefits and risks, recognising that while helpful for some, they may increase ED risks for vulnerable groups. Policies must undergo continual monitoring and evaluation to remain evidence-based, with terms like "obesity pandemic" offering a balanced yet urgent framing. Integration should also include collaborative research, campaigns, and funding to address shared risk factors effectively.

True empowerment comes from providing information that enables informed choices. A better approach is to allow customers to request a menu with calorie and nutritional information, similar to those with food allergies. This provides agency while safeguarding those vulnerable to eating disorders. Evidence shows that 25% of those

restricting food intake develop eating disorders, highlighting the need for a cautious approach to public health messaging.

Calorie counting alone does not ensure healthy outcomes. The focus should shift towards broader health messages, moving away from previous policies that encouraged calorie counting and potentially exacerbated disordered eating. Calorie labels neglect the nutritional value and enjoyment of food, promoting guilt and an unhealthy fixation on numbers. Research also shows that calorie counting does not consistently impact food choices in relation to obesity[28].

In a society where disordered eating is normalised, adding calories to menus can worsen this "culture"

> Running sessions for young people in the classroom and integrating them into the PE curriculum can help challenge the thin ideal.
>
> Lucy Stupple

The government has an opportunity to reshape Public Health Policy, aligning eating disorder and obesity messaging whilst educating and empowering individuals on food, nutrition, and healthy exercise, and that health cannot be determined solely on an individual's body shape.

3. Eating Disorder Treatment Requires a Whole-System Approach

Historically, access to eating disorder treatment has been inconsistent and inequitable, with patients often denied care based on weight or perceived complexity. NHS commissioning changes over time have further fragmented care, creating a "cliff edge" as patients transition from child to adult services. Acute hospitals, specialist units, primary care, and talking therapies operate in silos, hindering coordinated care.

[28] Sinclair, Cooper, and Mansfield, “The Influence of Menu Labeling on Calories Selected or Consumed: A Systematic Review and Meta-Analysis.”

Witnesses agreed that disjointed care pathways contributed to poor transitions and hampered recovery. There is a need for integrated, all-age services. Integrating evidence-based psychological treatment across the care pathway is also associated with improved outcomes[29].

While Integrated Care Boards (ICBs) present an opportunity for a whole-system approach, targeted funding is crucial. Current ICB plans prioritise children's services, neglecting the substantial need for adult care due to the lack of a national strategy. Provider Collaboratives can bridge these gaps by fostering integrated care pathways and service alignment. A comprehensive national policy, with adequate funding and coordinated commissioning, is urgently needed to prioritise both child and adult eating disorder services.

Hospital Admissions and Shortage of Specialist Psychiatric Beds

Hospital admissions for eating disorders in England have been steadily increasing since 2000 and further surged since the COVID-19 pandemic, with 28,533 admissions in 2022–23,[30] and new figures for 2023–2024 indicate 31,751 admissions[31]. Most patients are critically ill, reflecting insufficient community-based care. Unplanned admissions to general medical wards, due to preventable physical deterioration, cost an estimated £220 million annually across the UK[32].

The shortage of specialist eating disorder units (SEDUs) exacerbates this, with only 251 NHS adult beds and 198 in the independent sector, and none in Wales or Northern Ireland. This leads to treatment in general mental health wards or transfers to Scotland, with poor outcomes and high relapse rates[33,34,35]. Urgent action is needed to expand SEDUs, improve community care, and reduce reliance on costly acute hospital admissions. At the same time, it is essential to improve outcomes and reduce restrictive practices. Service developments should include all stakeholders, including patients and carers.

[29] Ayton et al., “Risk, Demand, Capacity and Outcomes in Adult Specialist Eating Disorder Services in South-East of England before and since COVID-19.”
[30] “Hospital Admissions for Eating Disorders by Patient Age.”
[31] “Hospital Admissions for Eating Disorders.”
[32] “NHS Benchmarking Network.”
[33] Goddard et al., “A Multi-Centre Cohort Study of Short Term Outcomes of Hospital Treatment for Anorexia Nervosa in the UK.”
[34] Morris, Simpson, and Voy, “Length of Stay of Inpatients with Eating Disorders.”
[35] Ibrahim et al., “Integrated Enhanced Cognitive Behavioural (I-CBTE) Therapy Significantly Improves Effectiveness of Inpatient Treatment of Anorexia Nervosa in Real Life Settings.”

4. Freedom of Information for Children and Adult Eating Disorder Services

Following evidence that individuals with eating disorders are being discharged at dangerously low BMIs, we submitted Freedom of Information (FOI) requests to hospital trusts across the country. This was first undertaken in 2023 and repeated in 2024, covering data from January to October. The findings are deeply alarming, revealing instances of patients discharged with BMIs as low as 13, often justified by claims that individuals "did not want to get well."

According to DSM-5 criteria, a BMI under 15 signifies extreme severity, while ICD-11 highlights that a BMI below 14 in anorexia nervosa is associated with severe underweight, high risk of physical complications, and substantially increased mortality. The Medical Emergencies in Eating Disorders Guidance (MEED) states that a BMI below 13 indicates a high impending risk to life. Discharging patients at such low BMIs places them at grave risk, as evidenced by deaths from physical complications and suicide. These practices reflect a worrying pattern of neglect in some regions.

One of the most alarming things that we discovered via the FOI was that services where patients are discharged at a low BMI tend to be services led by teams that do not believe in ongoing treatment for long-term recovery for patients with long-standing illness[36]. This is a significant area of controversy. Some experts have proposed the concept of severe and enduring eating disorder (SEED) and advocate for “quality of life” intervention instead of active treatment[37,38].. However, empirical research shows that recovery rates improve over time[39] and that recovery is possible for patients irrespective of duration or severity of the illness.[40] People with lived experience therefore advocate for active treatment at any stage, in line with NICE and NHSE guidelines[41,42].

[36] Viljoen et al., “Applying Integrated Enhanced Cognitive Behaviour Therapy (I-CBTE) to Severe and Longstanding Eating Disorders (SEED) Paper 2: An in-Depth Case Study for Clinicians.”
[37] Birch, Downs, and Ayton, “Harm Reduction in Severe and Long-Standing Anorexia Nervosa: Part of the Journey but Not the Destination-a Narrative Review with Lived Experience.”
[38] Marcolini et al., “Severe Enduring Anorexia Nervosa (SE-AN) Treatment Options and Their Effectiveness: A Review of Literature.”
[39] Solmi et al., “Outcomes in People with Eating Disorders: A Transdiagnostic and Disorder-Specific Systematic Review, Meta-Analysis and Multivariable Meta-Regression Analysis.”
[40] Ibrahim et al., “Integrated Enhanced Cognitive Behavioural (I-CBTE) Therapy Significantly Improves Effectiveness of Inpatient Treatment of Anorexia Nervosa in Real Life Settings.”
[41] Downs, “Care Pathways for Longstanding Eating Disorders Must Offer Paths to Recovery, Not Managed Decline.”
[42] Downs et al., “Untreatable or Unable to Treat? Creating More Effective and Accessible Treatment for Long-Standing and Severe Eating Disorders.”

Postcode Lottery in Eating Disorder Services

Our FOI requests were sent to all trusts across the UK, asking for the BMI of inpatients and community patients with eating disorders at the time of discharge. Only nine trusts were able to provide this data, as most do not record BMI at discharge in a central database.

The data we obtained shows significant regional disparities in discharge practices:

- In some areas, multiple patients with BMIs under 15 were discharged, including cases with BMIs as low as 11.
- A notable number of patients with BMIs of 15–20 were discharged from both inpatient and community settings, indicating inconsistencies in care thresholds.

This data expose a postcode lottery in the availability and quality of eating disorder services, with some regions exhibiting particularly high discharge rates at dangerously low BMIs. The alarming findings from this FOI exercise underscore the urgent need for national oversight and standardisation of eating disorder services.

To ensure patient safety for all ages and equitable access to care in both inpatient and outpatient units, it is vital that:

1. Trusts are required to record BMI at discharge in a central database.
2. Patients are not to be discharged under a BMI of 15
3. Discharge decisions are guided by clinical need and the potential for long-term recovery, rather than resource constraints or philosophical biases within teams.
4. National monitoring of standards to address the significant regional disparities in care.

Without urgent action, individuals with eating disorders will continue to face inconsistent and inadequate care, with devastating consequences for their health and wellbeing.[43] Despite pockets of good practice across the UK such as FREED, ICBTE, Ellern Mede's Autism ED Pathway, and Innovative Services such as the WaterLily Project, throughout our evidence gathering, dangerous discharges emerged as a recurring issue, highlighting systemic failures in accountability, inconsistent commissioning, inadequate training across services, and a glaring lack of support for both patients and carers, each contributing to the deepening crisis in eating disorder care.

[43] Viljoen et al., "The Alarms Should No Longer Be Ignored: Survey of the Demand, Capacity and Provision of Adult Community Eating Disorder Services in England and Scotland before COVID-19."

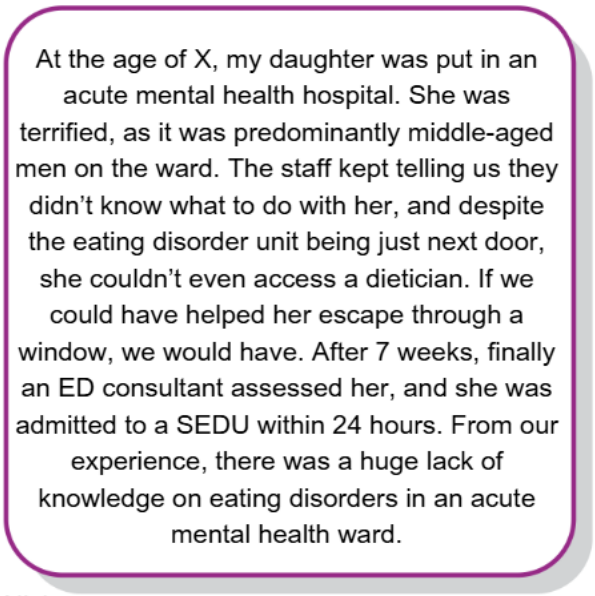
Carer Inclusion

Both carers and lived experience groups called for greater family inclusion in the care of patients with eating disorders. Carers criticised the exclusion of their voices in treatment and a ‘patient-blaming culture’. Families can provide valuable insights and are important resources for recovery.

> With only 1 hour of treatment a week, carers spend 167 hours supporting loved ones—include, educate, and empower us to be more effective caregivers outside the therapy room.
>
> Suzanne Baker

5. The Need for Improving Interdisciplinary Training in Eating Disorders

All of the groups who gave evidence highlighted insufficient training for healthcare providers, with the emphasis on improving education to enhance care quality. When we look at who comes into contact with those affected by eating disorders, we see a huge range of healthcare professionals, from GPs to consultants to dieticians to A&E staff; the list is endless. However, despite a few NHSE initiatives to expand the training for professionals within eating disorders, this only reaches a proportion of staff working in specialist services and not the wider workforce.



The lack of both undergraduate and postgraduate training in eating disorders leaves many healthcare professionals, including general practitioners, ill-equipped to address the complex physical and mental health needs of these patients, particularly those with complex co-occurring conditions like autism spectrum disorder or diabetes. Multiple national bodies have highlighted the urgent need for improved medical training since 2017[44,45], but progress remains limited[46]. This failure has been repeatedly emphasised in Coroner's Regulation 28 reports and the recent London Assembly Health Committee report Eating Disorders in London.

Patients requiring hospitalisation for severe medical complications are often admitted to acute hospitals, where staff are frequently unfamiliar with eating disorders or the *Management of Really Sick Patients with Anorexia Nervosa* (MEED) guidelines[47]. This lack of awareness contributes to negative patient experiences, reliance on restrictive practices, and poor outcomes[48]. Addressing these gaps in training and awareness is critical to improving care for this vulnerable population.

[44] Ayton and Ibrahim, "Does UK Medical Education Provide Doctors with Sufficient Skills and Knowledge to Manage Patients with Eating Disorders Safely?"
[45] RCPsych, "PS04/20: Improving Core Skills and Competence in Risk Assessment and Management of People with Eating Disorders."
[46] GMC, "Eating Disorders Briefing 2020."
[47] "Medical Emergencies in Eating Disorders (MEED)."
[48] Fuller et al., "Nasogastric Tube Feeding under Physical Restraint of Children and Young People with Mental Disorders: A Comprehensive Audit and Case Series across Paediatric Wards in England."

Training is a key part of all healthcare, upskilling staff that are working on the ground. Student nurses get 1-2 hours of training on eating disorders. It is staggering that there is such little training in eating disorders.

The lack of training was not just seen within healthcare but also with the increasing number of cases being referred to the Court of Protection. Judges and lawyers with no training in eating disorders are marking individuals as untreatable and allowing NHS Trusts to withdraw care when the individual has not necessarily been offered a variety of treatment. It is essential that lawyers and judges undergo training in eating disorders if they are going to continue to review these cases.

6. Patient Safety

The pre-pandemic survey of adult community eating disorder services highlighted significant shortcomings in community services' capacity to manage risk. Only around 40% of services provided complete medical monitoring and/or had good links with acute hospitals. Unfortunately, as the severity of a patient's illness increases, the likelihood of seeking and accepting help decreases significantly. The inability of 50% of services to provide follow-ups or assertive outreach to patients who did not engage further increased the risk of deterioration.[49]

Out-of-area Hospitalisations

Due to the increase in people requiring hospitalisation and a lack of beds, we have seen an increase of people with eating disorders being moved out of their area to treat.[50] We heard that for some this can take more than 10 months from date of referral, to moving.

Out-of-area referrals have a negative impact on patient outcomes and are associated with inconsistencies and interruptions in continuity of care. Communication gaps between services often result in insufficient support during critical transitions. Being admitted far away from home, increases stress and implies long-distance travel for families, with the risk of the patient losing contact with their local community, services, and support systems.

[49] Viljoen et al., "The Alarms Should No Longer Be Ignored: Survey of the Demand, Capacity and Provision of Adult Community Eating Disorder Services in England and Scotland before COVID-19."
[50] "'Harmful Practice' of Sending Mental Health Patients far from Home for Care Must End, Says RCPsych."

Patients who urgently need a bed found that their care is being delayed because of disputes about funding. In this regard, there should not be any delay to treatment decisions and hospitalisation while the funding/commissioning responsibilities are being resolved.

Preventing Eating Disorder Deaths

> There is no clear pathway for long-term patients, and they are often abandoned. In the past year, three people we know have died after being discharged, including one who was sent home with an NG tube and left unsupported due to disagreements between services about funding.
>
> Lucy Cooper

People with eating disorders face a significantly reduced life expectancy, with a Standardised Mortality Ratio (SMR) of 5 for anorexia nervosa (AN) and around 2 for bulimia nervosa (BN), binge eating disorder (BED), and other specified feeding and eating disorders (OSFED). [51,52,53] These are among the highest SMRs for mental disorders, particularly for patients requiring hospitalisation[54] or those with co-occurring physical conditions such as Type 1 Diabetes with Eating Disorders (T1DE)[55].

The Parliamentary and Health Service Ombudsman (PHSO) has highlighted systemic failings contributing to avoidable deaths, including inadequate funding of adult services, insufficient professional training, poor care coordination, and a lack of cross-organisational learning from incidents[56]. Despite repeated calls for action, progress has been minimal[57].

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[51] Arcelus et al., "Mortality Rates in Patients with Anorexia Nervosa and Other Eating Disorders. A Meta-Analysis of 36 Studies."
[52] Søeby et al., "Overall and Cause-Specific Mortality in Anorexia Nervosa; Impact of Psychiatric Comorbidity and Sex in a 40-Year Follow-up Study."
[53] Solmi et al., "Outcomes in People with Eating Disorders: A Transdiagnostic and Disorder-Specific Systematic Review, Meta-Analysis and Multivariable Meta-Regression Analysis."
[54] Hoang, Goldacre, and James, "Mortality Following Hospital Discharge with a Diagnosis of Eating Disorder: National Record Linkage Study, England, 2001-2009."
[55] Gibbings et al., "Diabetic Ketoacidosis and Mortality in People with Type 1 Diabetes and Eating Disorders."
[56] Parliamentary and Health Service Ombudsman, "Ignoring the Alarms: How NHS Eating Disorder Services Are Failing Patients."
[57] "Urgent Action Needed to Prevent Eating Disorder Deaths."

In AN, deaths are often caused by physical complications such as malnutrition, gastrointestinal issues, metabolic disturbances, cardiovascular events, or infections. T1DE significantly increases the risk of premature mortality. These risks are preventable with improved services and targeted medical training. Co-occurring psychiatric conditions, including substance misuse, personality disorders, and self-harm, further heighten mortality risk[58], necessitating integrated care to bridge gaps between eating disorders and mental health services.

Office for National Statistics (ONS) records report much lower mortality figures, likely due to inaccuracies in recording practices. However, international studies have shown that integrated, timely services can improve outcomes and prevent deaths.[59] Eating disorders are treatable illnesses. They are dangerous and life-threatening when untreated, undertreated, or poorly treated. But this risk to life is preventable, and deaths from eating disorders are not inevitable.

With integrated, well-resourced, and evidence-based treatment, recovery is possible, even in the most severe cases and after many years of suffering. Despite this, coroners, families, and communities continue to see too many lives needlessly lost. This should not be happening. It doesn't need to be this way. A national confidential inquiry is urgently needed to identify modifiable factors contributing to preventable deaths, enabling targeted interventions, service improvements, and enhanced professional training to address gaps in care delivery.

[58] Amiri and Khan, "Prevalence of Non-Suicidal Self-Injury, Suicidal Ideation, Suicide Attempts, Suicide Mortality in Eating Disorders: A Systematic Review and Meta-Analysis."
[59] Castellini et al., "Mortality and Care of Eating Disorders."

Zara's story

My beautiful daughter, Zara—intelligent, sassy, kind, and compassionate—took her own life on 22nd September 2021 after struggling with an eating disorder for nearly 10 years. Zara was diagnosed with Anorexia Nervosa in May 2013 and was admitted to an eating disorder unit almost immediately. Instead of being good news for her recovery, this is when the nightmare began. From May 2013 to June 2021, Zara endured 13 inpatient admissions across seven different units, including three years as a continuous inpatient—nearly two of which she spent without ever leaving one of the units or going outside. With each admission, her eating disorder and mental health deteriorated further. During this time, she was restrained daily, often by a minimum of six people holding her down. She received very little therapy, and instead, there was a culture of patient blaming and shaming. In the last two years of her life, Zara was crying out for help, but no one would listen. The Eating Disorder Unit discharged her completely, handing her over to the community mental health team. I spent nearly every day taking ligatures off her, lifting her down from her wardrobe when I found her near unconscious, and performing CPR when I found her in the shower. There was little to no support from our community psychiatrist; we were left to cope alone. No matter how much we pleaded for help, it was a constant battle, and we never received the support Zara so desperately needed.

Zara's story is just one of many, a story that is unfolding for countless others across the country. Behind these tragedies are systemic failures, often overlooked and hidden behind a lack of national data, questionable legal decision-making, and cost-saving agendas.

> When we meet people with the right level of treatment, people get well
>
> Kerrie Jones, Orri

7. Commitment to Research

Research Deficiencies and the Need for Enhanced Funding
Witnesses have testified that research in the field of eating disorders lags behind other medical disciplines due to consistently inadequate funding, hindering progress and innovation. Although there has been an increase in studies focused on anorexia nervosa and bulimia nervosa, research on other eating disorders remains limited. Compounding this issue is the absence of standardised data essential for advancing research and improving clinical services. The NIHR BioResource UK Eating Disorders Genetics Initiative (EDGI)[60], the UK's largest research project dedicated to eating disorders, aims to collect comprehensive data from 10,000 individuals with experience of any eating disorder. Preliminary findings have revealed significant interactions between genetic factors and environmental influences, underscoring the complexity of eating disorder aetiology.

The Importance of a Biopsychosocial Approach and Challenges in Data Standardization

A biopsychosocial approach, which considers the multifaceted factors influencing eating disorders, is essential for effective treatment. Research initiatives like EDGI have highlighted the role of metabolism in the trajectories of eating disorders. Additionally, important research avenues include examining the impact of local environments and evaluating various treatment modalities across different populations.

The field's capacity to address critical questions is hindered by the lack of standardised data. Significant heterogeneity exists across the UK regarding measurement tools, treatments, and data collection and storage, posing a substantial barrier to conducting high-quality research. Clinicians often lack the training, time, and data to evaluate their interventions effectively.

The Role of Collaborative Networks and the Necessity for Long-Term Investment
Initiatives like the MRC and MRF-funded £4M investment in Eating Disorders research infrastructure programmes represent crucial steps toward addressing these challenges, including the Eating Disorders Clinical Research Network[61]. These networks strive to collect standardised data in collaboration with eating disorder services across the UK and aim to make this data available for future clinical and research benefits. It is

[60] Monssen et al., "The United Kingdom Eating Disorders Genetics Initiative."
[61] "Medical Research Foundation."

imperative that such initiatives receive secure and sustained funding to enable the broader research community to benefit from their efforts.

Likewise, the Eating Disorders: Delineating illness and recovery trajectories to inform personalised prevention and early intervention in young people (EDIFY) UKRI funded project is enabling large scale PPI informed design of early intervention and prevention of eating disorders[62].

To foster meaningful advancements, long-term investment exceeding three or five-year funding cycles is essential. Building foundational infrastructure through sustained financial support will facilitate ongoing research, enhance data standardisation, and ultimately lead to improved outcomes for individuals affected by eating disorders.

All Party Parliamentary Group Recommendations

1. Development of a National Strategy for Eating Disorders This strategy will encompass adults and young people, with sufficient funding to reform all services. The goal is to provide timely, evidence-based treatment for every individual with an eating disorder. The national Strategy will include:

a. Mandatory eating disorder training for all Frontline Workers (including GPs, Dentists, Teachers and Nurses)
b. Investment in a public health campaign to clarify messaging around obesity and eating disorders
c. Funding for the implementation and integration of evidence-based treatment practices, including collaboration between services.
d. Mandatory health screening for high-risk groups
e. Training for Carers

2. Additional Funding for Eating Disorder Services This funding should address the demand for both adult and children's services.

3. Confidential Inquiry into All Eating Disorder Deaths.

4. Increased Research Funding for Eating Disorders The aim is to enhance treatment outcomes and ultimately discover a cure for eating disorders.

[62] “EDIFY - Shaping a Fresh Approach to Eating Disorders.”

5. Non-Executive Director Oversight for adult and children Eating Disorder Services. This oversight and accountability should be implemented in all NHS Trusts and Health Boards in the UK.

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Appendix 1:

Ensuring Effective Implementation of Eating Disorder Guidelines

Key guidelines for eating disorder care include the NHS AED Guidance[1], the Medical Emergencies in Eating Disorders (MEED) guidelines[2], NICE NG69[3] and NICE NG43[4], the SIGN164[5].

NHS Autism Strategy[6], and standards set by the Mental Health Act[7], Autism Act[8], Care Act 2014[9], and the DHSC 2022 Care Standards[10].

To ensure consistent application of these guidelines across the UK, NICE[11] should conduct a cost estimate to inform adequate funding allocation. This would enable effective implementation by all providers, reduce regional disparities in care, and improve outcomes for all patients with eating disorders.

[1] N. H. S. England, "NHS England » Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care – Guidance for Commissioners and Providers," accessed January 15, 2025, https://www.england.nhs.uk/publication/adult-eating-disorders-community-inpatient-and-intensive-day-patient-care-guidance-for-commissioners-and-providers/.
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[3] "Overview | Eating Disorders: Recognition and Treatment | Guidance | NICE," accessed January 16, 2025, https://www.nice.org.uk/guidance/ng69.
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[5] accessed January 15, 2025, https://www.sign.ac.uk/media/1987/sign-164-eating-disorders-v2.pdf.
[6] "Five-Year NHS Autism Research Strategy for England," accessed January 16, 2025, https://www.england.nhs.uk/wp-content/uploads/2022/03/B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf.
[7] Expert Participation, "Mental Health Act 1983," May 9, 1983, https://www.legislation.gov.uk/ukpga/1983/20/contents.
[8] Expert Participation, "Autism Act 2009," accessed January 16, 2025, https://www.legislation.gov.uk/ukpga/2009/15/contents.
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[11] "Homepage," NICE website: The National Institute for Health and Care Excellence (NICE), accessed January 16, 2025, https://www.nice.org.uk/.

Appendix 2 First Episode Rapid Early Intervention for Eating Disorders (FREED)

FREED[1] is an evidence-based early intervention model that provides rapid access to developmentally informed, person-centred care for young people aged 16-25 within 3 years of eating disorder onset. It was developed and first evaluated by South London and Maudsley NHS Foundation Trust and King's College London, and has since scaled nationally around England. Between 2018 – 2024, approximately 4,000 patients started evidence-based treatment under FREED across 54 NHS Trusts. FREED operates as a 'service within a service' and is a way of tailoring existing evidence-based treatments (e.g., CBT-ED, MANTRA) to the age and stage of emerging adults with a recent-onset eating disorder. This starts at the point of referral, where a FREED Champion manages all referrals for possible FREED patients and contacts people for an 'engagement call' within 48 hours of their referral being received. FREED waiting time targets facilitate rapid access to care: 2 weeks from referral to assessment, and 4 weeks from referral to start of evidence-based treatment. Treatment adaptations include an even greater emphasis than usual on engagement and early change; a greater emphasis on involving families / significant others; and attending to use of social media/apps, transitions (e.g., out of school or home, into university or work), and 'emerging adulthood' and identity formation.

Evaluations of FREED show a range of positive outcomes compared to treatment-as-usual, including:

- Duration of an Untreated Eating Disorder (DUED) reduced by 4-6 months and waiting times reducing by 32-41%[2].
- 70% of FREED patients (across all diagnoses) having symptom scores below clinical cut-offs within 12-months of starting treatment, vs. 50% in most published studies[3].
- 53-59% of FREED patients with anorexia nervosa reaching a minimally healthy weight (BMI>18.5) within 12-months, compared to 17% of non-FREED treatment-as-usual patients.

[1] "First Episode Rapid Early Intervention for Eating Disorders," accessed January 17, 2025, https://freedfromed.co.uk/.
[2] Amy Brown et al., "The FREED Project (first Episode and Rapid Early Intervention in Eating Disorders): Service Model, Feasibility and Acceptability," *Early Intervention in Psychiatry* 12, no. 2 (April 2018): 250–57, https://doi.org/10.1111/eip.12382.
[3] Katie L. Richards et al., "National Roll-out of Early Intervention for Eating Disorders: Process and Clinical Outcomes from First Episode Rapid Early Intervention for Eating Disorders," *Early Intervention in Psychiatry* 17, no. 2 (February 2023): 202–11, https://doi.org/10.1111/eip.13317.

This difference is maintained to 24-months[4] [5] [6](Austin et al., 2021; Fukotomi et al., 2019; McClelland et al., 2018)

- Improved treatment uptake: 90-100% with FREED vs. 71% with treatment-as-usual (Richards et al., 2023).
- Day and inpatient admissions reducing by 35%.[7]

Reductions in the need for intensive treatment are estimated to result in an average cost savings of £4,472 per patient treated with FREED. Additionally, this reduction in intensive treatment is estimated to have saved 110,000 days of workforce time in 2021/2022 and a total of £10.9 million to the NHS between 2020-2023[8]. Patients, carers, clinicians and service leads have all provided positive qualitative feedback on FREED. For example:

"There was such a risk with it that I would live a life that wasn't mine, that was anorexia's, and I've got it back. I completely feel like myself again... You enter such a risky place, and I think early intervention is so important. […] I'm fully recovered and I'm in such an incredible place in life, and I really, really wish and hope that everyone else who struggles will end up in that place, because it is possible." (FREED patient)

"FREED gave [the treatment team] freedom to personalise treatment and adapt it to exactly what [was] needed at that time" (parent of FREED patient)

"A highlight for our service is the value of family, carers and friends' involvement in supporting the treatment of young people / emerging adults" (service manager)

"If we can help these people, get them well sooner and reduce the risk that they might relapse, that eventually is [going to] mean we do have more resources for people who might need a higher level of care" (FREED clinician)

Additional quotes and findings are summarised in the Early Intervention Eating Disorders final learning report from the Academic Health Science Network, who facilitated the national scaling of FREED between 2020-2023. The report also summarises challenges to the continued implementation of FREED, in terms of increasing referrals after COVID-19 and eating disorder services reporting a lack of resources to meet demand.

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[4] Amelia Austin et al., "The First Episode Rapid Early Intervention for Eating Disorders - Upscaled Study: Clinical Outcomes," *Early Intervention in Psychiatry* 16, no. 1 (January 2022): 97–105, https://doi.org/10.1111/eip.13139.

[5] Akira Fukutomi et al., "First Episode Rapid Early Intervention for Eating Disorders: A Two-Year Follow-Up," *Early Intervention in Psychiatry* 14, no. 1 (February 2020): 137–41, https://doi.org/10.1111/eip.12881.

[6] Jessica McClelland et al., "A Pilot Evaluation of a Novel First Episode and Rapid Early Intervention Service for Eating Disorders (FREED)," *European Eating Disorders Review: The Journal of the Eating Disorders Association* 26, no. 2 (March 2018): 129–40, https://doi.org/10.1002/erv.2579.

[7] McClelland et al.

[8] Sundeep Sehijpal, "Early Intervention Eating Disorders: Final Report," The Health Innovation Network, September 8, 2023, https://thehealthinnovationnetwork.co.uk/news/early-intervention-eating-disorders-final-report/.

Appendix 3: Integrated Cognitive Behavioural Therapy for Eating Disorders (I-CBTE) for Treatment of Severe Eating Disorders

Dr Agnes Ayton, FRCPsych Oxford Health NHS Foundation Trust

As we have shown, hospital admissions for severe eating disorders have steadily increased since 2000, despite policies promoting community-based treatment. Treatment As Usual (TAU) often results in fragmented care, partial weight restoration, high relapse rates, and frequent hospitalisations, leading to chronic illness and inefficient use of NHS resources.

The Evidence-Based Solution

Integrated Cognitive Behavioural Therapy for Eating Disorders (I-CBTE)[1] offers a structured, evidence-based alternative tailored for patients with severe and complex difficulties who do not respond to outpatient treatment. Adapted from Enhanced CBT (CBT-E)[2] and integrated into the NHS, I-CBTE creates seamless pathways that combine inpatient, day-patient, and outpatient care.

Evidence from the UK and Italy shows significantly better outcomes compared to TAU, with 70% of patients sustaining recovery one year post-discharge[3], compared to less than 5% with TAU. Readmission rates are also much lower (14% vs. ~50%)[4], while faster weight restoration reduces hospital stays and costs.

Core Features of I-CBTE

1. I-CBTE is a whole system approach that combines inpatient, day-patient, and outpatient therapy into a seamless programme delivered by a multidisciplinary team. This approach uses evidence-based techniques to address harmful thoughts, promote behavioural change, and support long-term recovery.
2. The team works collaboratively with the patient to develop a personalised formulation that addresses both physical and mental health needs, focusing on overcoming

[1] Riccardo Dalle Grave, Massimiliano Sartirana, and Simona Calugi, *Complex Cases and Comorbidity in Eating Disorders: Assessment and Management*, 1st ed. (Cham, Switzerland: Springer Nature, 2021), https://doi.org/10.1007/978-3-030-69341-1.

[2] Christopher Fairburn, *Cognitive Behavior Therapy and Eating Disorders* (New York, NY: Guilford Publications, 2008), https://www.guilford.com/books/Cognitive-Behavior-Therapy-and-Eating-Disorders/Christopher-Fairburn/9781593857097?srsltid=AfmBOoobBn7n3NWMjEiEWNoRoBgMYH2cgiFlFp44A36JvFEnFL9WaV6L.

[3] Ali Ibrahim et al., "Integrated Enhanced Cognitive Behavioural (I-CBTE) Therapy Significantly Improves Effectiveness of Inpatient Treatment of Anorexia Nervosa in Real Life Settings," *Journal of Eating Disorders* 10, no. 1 (July 8, 2022): 98, https://doi.org/10.1186/s40337-022-00620-y.

[4] David Viljoen et al., "Applying Integrated Enhanced Cognitive Behaviour Therapy (I-CBTE) to Severe and Longstanding Eating Disorders (SEED) Paper 2: An in-Depth Case Study for Clinicians," *Journal of Eating Disorders* 12, no. 1 (October 31, 2024): 172, https://doi.org/10.1186/s40337-024-01116-7.

restrictive eating and achieving a healthy weight. This active involvement promotes autonomy and supports sustainable recovery.

3. The programme includes 13 weeks of inpatient care, 7 weeks of day-patient support (including remote options), and 20 weeks of outpatient therapy, designed to fit alongside work, school, or other commitments.

Benefits for Patients, Staff, and the NHS

I-CBTE not only delivers superior outcomes for patients but also benefits staff by providing clear frameworks, enhancing training, and fostering teamwork, which reduces reliance on crisis care and restrictive practices. For the NHS, it is cost-efficient, lowering readmissions and saving significant resources, such as over £360,000[5] in a single case, by avoiding re-hospitalisation. Another patient achieved full remission after more than 40 admissions, spanning 25 years[6].I-CBTE offers a scalable, evidence-based solution that improves patient recovery, supports staff, and reduces the long-term financial burden on the healthcare system. It represents a critical step forward in addressing the growing challenge of severe and complex eating disorders and has shown that recovery is possible irrespective of illness duration or severity[7].

[5] Lorna Collins, "Applying Integrated Enhanced Cognitive Behaviour Therapy (I-CBTE) to Severe and Longstanding Eating Disorders (SEED) Paper 1: I Am No Longer a SEED Patient," *Journal of Eating Disorders* 12, no. 1 (September 12, 2024): 139, https://doi.org/10.1186/s40337-024-01089-7.
[6] Viljoen et al., "Applying Integrated Enhanced Cognitive Behaviour Therapy (I-CBTE) to Severe and Longstanding Eating Disorders (SEED) Paper 2: An in-Depth Case Study for Clinicians."
[7] "CBT-E - Enhanced Cognitive Behaviour Therapy," CBT-E, accessed January 16, 2025, https://www.cbte.co/.

Appendix 4: Autism Pathway, Ellern Mede Group

The general population is around 1% autistic, but in the Ellern Mede Moorgate unit we had 50% of our patients with autism. This is consistent with recent research What's more, we were not progressing significantly with their treatment due to a clear focus on the Anorexia Nervosa and not taking much into account of autism. Without trusting relationships, we realised that autistic patients would not be able to engage fully with their team; in addition to this, they would require more integration into the decision-making process, as not understanding the why around a decision would result in them not engaging with the decision. We now have Autism Champions who work in each hospital to build those trusting relationships that begin with sitting on the patient's floor with them for prolonged periods of time to show that you are there and in it for the duration. By physically showing the patient that you are on their level and ready to hear their story brings trust and allows for them to reduce their anxiety and open up. The Autism Champions work with the patients to develop hospital passports to support any attendance at general hospitals. There is a development of sensory understanding and communication styles so that the HCA's and nurses can be supported to communicate in an effective way with the patients. All of this work ensures that ultimately the patients will open up and discuss with the Autism Team their views, feelings, thoughts, and wishes regarding their treatment, which can be advocated for in the MDT meetings.

As time moves on, there become specific pieces of work that commonly result in success. One of the most memorable pieces of work was with a patient who, when they arrived at Ellern Mede, had been unwell with Anorexia Nervosa for 12 years and had spent most of that time in the hospital. They were almost 25 years old, so for half of their lives they had struggled and were so resigned to the fact they would never recover that they had damaged and mistrusting relationships with almost all professionals in the hospital they were in. I met with them and spent time on their floor listening to their story. Over time, I used unconditional positive regard (Rodgers) and the SOLAR listening techniques (Egan), which resulted in the development of a trusting relationship where the patient began to express challenges in moving forward due to being ill for so long. We agreed to do a piece of work where we discussed each "behaviour" in turn and categorised it in terms of it being autism or anorexia. Once we had separated the "behaviours" that allowed the patient to see which elements of their life were always there, they would always be there, and we should work towards keeping and working with them. It also gave the patient a clear list of anorexia-related thoughts, beliefs, and behaviours, which allowed her to focus on fighting against them. Within 6 months of this intervention, the patient was discharged, and a year later I was in conversation with a friend who I had introduced to the patient for a peer support project in their local area. They spoke of that very conversation, and the patient cited it as being instrumental in their recovery, saying that without it they felt they would still be in the hospital.

Appendix 5: Service Innovation

Waterlily Inpatient Prevention Programme

The Waterlily Inpatient Prevention Programme is a pioneering new online service that has been set up by the East Midlands NHS Provider Collaborative for adults with Anorexia Nervosa. The service delivers practical and psychoeducational groups and therapeutic interventions for patients, with the aim of restoring weight and preventing potential inpatient admission. Examples of groups that the programme comprises: cognitive behavioural therapy, bodywise, anxiety management, neuroscience, diet and nutrition, mindfulness, and goal setting. Currently, the service provides supervision for 2 meals and 2 snacks a day online. Those attending are provided with a prescriptive meal plan to follow outside of programme times.

The service will be available for those under the care of one of the 5 regional community eating disorder teams in the East Midlands, Monday to Friday, with the main course lasting 16 weeks. Each person attending can also meet face-to-face with their allocated keyworker and participate in individualised community work with our support workers. The programme can be extended a further 4 weeks for a 'step-down', where support and interventions are reduced to promote independence and taking back the responsibility for their eating and well-being. After they complete the programme, they will return to the sole care of their community team.

We have been running for 16 months now, initially as a pilot, which provided us with data that demonstrated significant improvements in people's weight, psychological well-being, and eating disordered behaviours. Receiving treatment at home enabled sufferers to remain involved in aspects of their lives that lengthy hospital admissions would prevent, such as continuing hobbies and social activities and it significantly reduced the disruption to their family life. All loved ones are offered regular support calls and a Skills Group to equip them with skills and understanding to effectively support their loved one. All these important factors not only provide a better quality of life whilst they receive treatment; it has also been viewed as a motivating factor to recovery. Some people who have attended Waterlily have fed back that Waterlily has "saved my life," and the vast majority of the feedback received has been overwhelmingly positive, referring to the content of the programme and the staff delivering it. Although Waterlily is for patients who are needing to restore weight, most patients who agree to join the programme are reluctant to follow the prescribed diet and restore weight.

As a result of routine outcome measures collected via questionnaires and documented weights, we are able to provide the following figures for those we have paired data for who have completed the programme:

- 95% demonstrated improvements in Eating Disorder Examination Questionnaire (EDEQ)
- 6/10 further improved their EDEQ scores, 3 months following the end of the programme
- 12 /21 gained more than 1.5 BMI points
- 8 of them increased their BMI by 2 or more points.

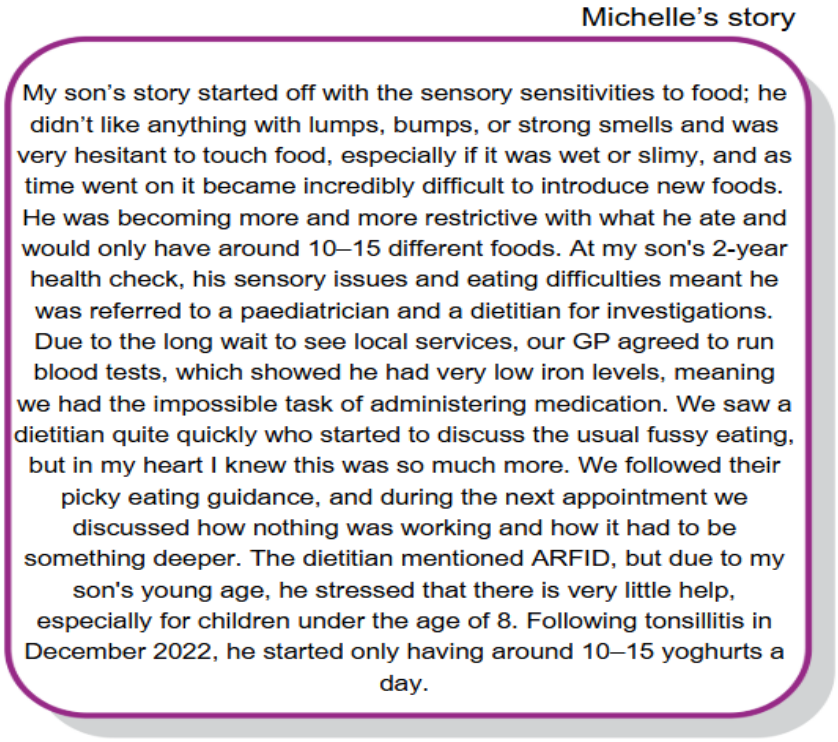
Further evaluation is under way.

Appendix 6 Testimonies of witnesses

Avoidant Restrictive Food Intake Disorder (ARFID)

ARFID was added to the DSM5 criteria back in 2013, and it is not related to body image or weight. Currently, it is extremely difficult for people under the age of 8 and over the age of 18 to be diagnosed with ARFID unless a person seeks private healthcare, and beyond that, there is very limited treatment available.

Michelle is the Mum to a 5-year-old who has ARFID, but because of his age, they are unable to get any support apart from a dietician who weighs him. Michelle told us that the times she had been to the GP to get support, her son was labelled a fussy eater.



Michelle's story highlights the stigma and huge lack of understanding and training around ARFID.

Despite ARFID often being labelled as fussy eating, it can be extremely dangerous. In 2021, a 7-year-old boy died suddenly. He was taken straight to the hospital, but they were unable to resuscitate him. The coroner's report highlighted the lack of support, training, understanding,

and treatment for those affected by ARFID and emphasised that more deaths would happen if no action was taken[1].

> Recovery starts with the right treatment, but it continues with self-compassion and the determination to thrive.
>
> Kate Majid

Anorexia Nervosa:

Anorexia nervosa (AN) is a severe mental illness characterised by dangerously low body weight due to restrictive eating, an intense fear of weight gain, and distorted body image. It often begins in adolescence, disproportionately affecting females.

Around 70% of individuals achieve remission within 10 years, but 20–30% develop chronic illness. Severe cases requiring hospitalisation face high relapse and mortality rates, with deaths often linked to malnutrition and suicide. Many of these fatalities are preventable with timely, intensive, and evidence-based treatment. Urgent action is needed to improve access and outcomes.

> In 2014, my 14-year-old daughter, now 26, was diagnosed with Anorexia nervosa. We had no idea how this cruel illness would shape our family for years, as it's unbearably hard to watch her fade away.
>
> Nicky Smith

There is still a huge stigma put on parents and carers of those who have eating disorders, and despite many years of campaigning and sharing the scientific research, too often carers are still blamed for their loved ones having an eating disorder. Beyond this, a carer's view is often dismissed as being 'too concerned' or 'making a fuss out of nothing'.

[1] "Alfie Nicholls: Prevention of Future Deaths Report," Courts and Tribunals Judiciary, February 22, 2024, https://www.judiciary.uk/prevention-of-future-death-reports/alfie-nicholls-prevention-of-future-deaths-report/.

Helen Missen, a carer representative at F.E.A.S.T., shared with us how 'carers are still often seen as the problem.' She told us how carers face huge barriers, from no support or training to being cut out of treatment plans to teams giving up on patients too quickly.

Severe and enduring illness

In recent years, there has been a worrying trend towards diagnosing people with eating disorders as having a "Severe and Enduring Eating Disorder" (SEED). This label is often applied to individuals who have had an eating disorder for a long time and have not responded to traditional treatments. However, this practice contradicts research that clearly shows that recovery is possible regardless of the duration or severity of the illness[2]. Despite this evidence, the SEED diagnosis is being used to justify the development of palliative care pathways in many areas, which implies that these individuals are untreatable and should only receive care to manage their symptoms and improve their quality of life. This approach is harmful and denies patients the opportunity to recover.

> My message is simple: recovery is possible, no matter how long or severe the illness.
>
> Lorna

Bulimia Nervosa

Bulimia nervosa (BN) is an eating disorder marked by episodes of binge eating, followed by harmful behaviours to prevent weight gain, such as vomiting, laxative misuse, excessive exercise, or fasting. Unlike anorexia, individuals with BN are often of normal or above-average weight.

BN affects 1–3% of people globally, including both males and females, but many males and individuals from ethnic minorities face stigma and barriers to accessing treatment. This highlights the urgent need for better outreach and more inclusive services.

[2] Bronwyn C. Raykos et al., "Severe and Enduring Anorexia Nervosa? Illness Severity and Duration Are Unrelated to Outcomes from Cognitive Behaviour Therapy," *Journal of Consulting and Clinical Psychology* 86, no. 8 (August 2018): 702–9, https://doi.org/10.1037/ccp0000319.

BN can cause severe emotional distress, serious physical health problems, and even increased mortality. Raising awareness and improving access to effective treatments are essential to support those affected.

James Downs told us 'It might be easy to say this with relative hindsight, but I do not believe that I had the capacity to make decisions about my care. One example is how I have had profound, refractory hypokalaemia (low potassium). This most recently happened over many months during a period of treatment which was not focussed on eating disorder symptoms, but on my quality of life and relationships.

Low potassium levels have in themselves made me feel suicidal, dysregulated, and unable to think properly - all of which have resolved rapidly with the replenishment of this vital nutrient. I have really struggled with medical admissions for this, which I have found particularly distressing as I've had past experiences where I have had my care mismanaged, not had my co-occurring conditions and neurodivergence considered, and experienced the stigma that so many patients with eating disorders are persistently met with.

Even when I have told staff straight away that I will want to discharge myself, will need support to stay, and do not want to be allowed to discharge myself, when the time comes that I feel too distressed to stay in the hospital for treatment, I have always been told that I have capacity to make that decision. I may be able to eloquently explain my cardiovascular risk even when I have life-threateningly low potassium. I may, in part, want to refuse treatment.

But this is not because it is what I really want. I want staff to support me in making it bearable, to reduce the harmfulness of the experience, but only so that I can get the treatment.

Looking back, I know that I have been allowed to make decisions based on what are actually features of my illness, rather than by engaging the part of me - often obscured - that has wanted to be well. Sometimes, I resent this. I am grateful for the times when I have been met with a firmer approach from staff, who have not deferred to my 'rights' and my 'patient choice' when I have been cognitively impaired by my physiology. Just because I have rights does not mean that I always have been right. Just because staff have been forceful with me at times doesn't mean that they've done so without also showing me that they are ultimately on my side. Ultimately, I am grateful for having my life saved when, in those moments, I did not want it to be - even if it was an incredibly difficult experience at the time."

Binge Eating Disorder (BED)

Binge eating disorder (BED) resembles bulimia nervosa (BN) but without compensatory behaviours. BED involves recurrent episodes of binge eating characterised by eating unusually large amounts of food within a short time, a sense of loss of control during the episode, and marked distress. Episodes are associated with behaviours such as eating rapidly, eating when not hungry, eating alone due to embarrassment, or feeling guilty or disgusted afterward. For diagnosis, episodes must occur at least once a week for three months and not overlap with BN or anorexia nervosa (AN).

> I didn't fit the stereotype of someone with an eating disorder, as I've always been on the bigger side. When discharged, I wasn't in recovery, yet I had received everything available. This is a common story I hear in the community.
>
> Sharon

People with BED often live with obesity and face related complications, with depression being a common comorbidity. Population-based studies show BED is increasing. An Australian study reported a rise in obesity from 19% to 33% and binge eating from 3% to 11% between 1995 and 2015. The most significant increases were in obesity with comorbid binge eating, which rose 7.3-fold (da Luz et al., 2017). These trends highlight the growing impact of BED and the need for targeted interventions.

Sharon, 52, developed Binge Eating Disorder (BED) in primary school. She has never been underweight and never met the BMI or other diagnostic criteria for anorexia nervosa, but for most of her life she met the diagnostic criteria for an Other Specified Feeding or Eating Disorder in DSM-5 (OSFED) (previously Eating Disorder Not Otherwise Specified in DSM-IV), and for several years in her 20s she met the criteria for bulimia nervosa and as a result was not able to access evidence-based treatment. Sharon did group therapy (plus 1:1 therapy) and a mindfulness course, but when this finished, she was still not in recovery. She noted that along the way, the barriers that so many people face with BED.

Evidence-based treatment for BED is cognitive behavioural therapy, delivered as guided self-help or in group or individual therapy, but here in the UK, this is extremely limited, with no treatment in Northern Ireland, and BED is excluded from talking therapies in the NHS. Eating disorder services in England vary in whether they provide treatment for BED, and if so, in what form. For many, the treatment on offer is woefully inadequate. NHS TT could offer scalable implementation of evidence-based treatment. It is important to look at the impact on society more broadly. When visiting the GP, people with BED shared with us that they are often given diet advice and weight loss instead of looking at what treatment they could be offered to help. Society and healthcare settings are contributing to eating disorders with too big a focus on obesity and not nuancing messaging.

Within the development of a National Strategy for Eating Disorders, it is essential that people with BED are given access to timely evidence-based treatment. One way of doing this would be including BED within eating disorder services or IAPT if agreed and with appropriate training and supervision support.

Type 1 Diabetes with Eating Disorders

A recent Parliamentary Inquiry highlighted the serious impact of Type 1 Diabetes with Eating Disorders (T1DE), where individuals, particularly young women, engage in disordered behaviours like insulin restriction for weight control. An estimated 144,000 people in the UK may be affected, facing severe complications such as diabetic ketoacidosis and increased mortality rates (Chrisp et al., 2024; Gibbings et al., 2021). Key challenges identified include the absence of internationally recognised diagnostic criteria, lack of integration in NICE guidelines, fragmented services, stigma, and insufficient interdisciplinary training, leaving many patients feeling dismissed by healthcare providers.

During 2019, a year where I got married, went travelling to the other side of the world, was offered weight loss surgery by my health care team as I was 'obese' and got a promotion at work that demanded I work all hours of the day without much reward. I began to deal with the ever-building whirlwind that was my life by missing meals, missing insulin doses, running before work, during my lunch break, and weighing myself every day. I started to see the numbers fall, and I felt pleased with myself one more day—another drop in weight. It became a little competition I was having with myself, and one I was winning. However, it didn't take long before I was in trouble, but I hid my struggles from my wife, my work colleagues, and my health care team, as I believed that no one would think I was struggling with an eating disorder because I was in a bigger body. My

As the eating disorder started to wrap its tight hold around me, I started to take less and less insulin. "I can't do this anymore," I screamed as I threw my insulin pump at the wall. I knew the risks, but at that moment, I didn't care. Within three days, my wife was rushing me to A&E in the back of an Uber due to Diabetic Ketoacidosis (DKA). This was my first DKA admission ever. I was not only in physical pain; my heart trying to break out of my chest, unable to breathe, my mouth like sandpaper, and my stomach feeling like it had been punched repeatedly—but also mentally disoriented.

Over the coming months I began to realise the more weight I lost, the better I felt; nothing felt as good as being skinnier did. I wanted to lose more, faster, but the longer this went on, the more hospital admissions followed, and the more my mind started to question what else I could do to lose more weight. I believed that what I was doing was what I needed to do to survive. In my own journey, I've experienced the isolation and pain of living with an eating disorder in a larger body. I've felt the sting of judgement and the frustration of not being taken seriously. I reached out to the Eating Disorder Community and those who have struggled with T1DE, and one common theme I kept hearing over and over again as I collected stories from others was how a lot of people with Eating Disorder are trying their absolute hardest to recover while feeling like there is no place for them to belong or no appropriate treatment available. One of my main struggles has been that being in a bigger body makes you feel invisible. I am still on my recovery journey. Managing Type 1 diabetes adds another layer of complexity to recovery.
During my journey seeking help, I have been repeatedly told that my BMI does not fall within the "critical" range, and thus I was not "sick enough" to receive treatment.

We do not have a comprehensive diagnosis for T1DE; we need a diagnosis that covers all Eating Disorder behaviours not just this focus and fascination on insulin omission. While insulin omission is of course serious and can make you seriously ill very quickly, it is not and should not be the only focus when someone cries out for help. We need a wider diagnostic criterion. We need leaders to come to the table and be prepared to listen and understand that when people move into T1DE recovery, whether they take their insulin should not be the main consideration anymore. Questions should reach broader subjects such as behaviours, Mental Health struggles and whether your quality of life is being impacted.

"Recently, people in the Type 1 Diabetes (T1D) community have been receiving devastating news: many are being discharged from T1DE (Type 1 Diabetes with Disordered Eating) services due to a lack of funding, and in some

cases, the services are closing altogether. This is a shocking and harsh reminder that healthcare is too often dictated by budgets and bottom lines rather than the needs of the people it's supposed to serve.

There's an uncomfortable truth that many of us feel but rarely say aloud: ***to the system, we cost too much money.*** *I recently read a quote from a diabetes consultant: "Those of us who battle T1DE cost the NHS too much money through DKA admissions, complications, and the sheer time it takes to treat us. It feels like in the eyes of the system, our lives just aren't worth the expense." As harsh as this sounds, this is how thousands of people feel every single day."*

While NHS England pilot projects have shown promise[3], long-term funding and research remain absent. The inquiry recommended establishing diagnostic consensus, integrated care pathways, expanding pilot programmes, enhancing professional training, and launching public awareness campaigns to reduce stigma. However, without dedicated funding, these initiatives remain in the planning stage, limiting their ability to improve care and outcomes.

Our 27-year-old daughter took her own life in 2017. She was diagnosed with Type 1 Diabetes in 2006, and for a decade prior to her first suicide attempt, she had been struggling with a condition called T1DE (formerly diabulimia). This disease is a toxic mix of insulin restriction and disordered eating and was dubbed the world's most dangerous E.D. in a BBC documentary broadcast the same year that Megan died. It falls into the recognised NHS gap between mental and physical health treatment resources, and T1DE complications are life-threatening.

In July 2024, a thorough second inquest was conducted, and Preventing Future Deaths recommendations were made primarily to address the lack of service integration evidenced by those providing testimony. It was apparent to the Coroner that T1DE care pathways were practically nonexistent, and there was little to no accommodation of the MEED guidelines issued in May 2022 in existing policy and treatment protocols

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[3] Natalie Zaremba et al., "Developing a Novel Intervention for Type 1 Diabetes and Disordered Eating Using a Participatory Action Design Process: Safe Management of People with Type 1 Diabetes and EAting Disorders studY (STEADY)," *Diabetic Medicine: A Journal of the British Diabetic Association* 39, no. 4 (April 2022): e14749, https://doi.org/10.1111/dme.14749.