



The changes we are  
campaigning for in England

## About eating disorders

- Approximately 1.25 million people in the UK of all ages, genders and backgrounds have an eating disorder.
- These serious mental illnesses can be fatal - anorexia has the highest mortality rate of all mental illnesses. The mortality rates for other eating disorders are also high.
- However, they are treatable, and full recovery is possible. The sooner someone gets the treatment they need, the more likely they are to make a full and sustained recovery, and the lower the cost to the NHS.
- Research by Beat shows that, on average, three-and-a-half years pass between the symptoms of an eating disorder emerging and treatment starting.

## About Beat

Beat is the UK's eating disorder charity. We exist to end the pain and suffering caused by eating disorders. We do this by working directly with sufferers and their families, highlighting the challenges they face, and campaigning for change.

We want to see a society where people with eating disorders experience care and understanding, and health systems where they can quickly access effective treatment. To achieve this, we are calling for changes to be made by Government, the NHS and others in several key areas.

Our campaigning focusses on the urgent need for major improvement in access to evidence-based treatment for adults, and achievement of national standards for children and young people's eating disorder services in every area. We are calling for all medical students and junior doctors to be properly trained on eating disorders, asking the NHS to invest in intensive day-patient and intensive home-based treatments and campaigning for eating disorder research to be properly funded. Below is an outline of each campaign.

## Treatment for Adults

### **We want to see:** The Introduction of a fully funded 'Access and Waiting Time Standard for Adults with an Eating Disorder'

There are currently no national waiting time targets for adults requiring eating disorder treatment, despite the introduction of an Access and Waiting Time Standard for Children and Young People in 2016.

- Adults with eating disorders face a postcode lottery in trying to access specialist treatment. In 2017/2018 the numbers of adults accessing specialist treatment varied 7-fold between different service providers. In some areas access to treatment is restricted on the basis of Body Mass Index (BMI) or other single measures, in contradiction to the clinical guidance published by NICE. Some adult eating disorder services do not offer treatment for patients with Binge Eating Disorder, despite its relatively high prevalence and severity. Only 26% of adult patients started treatment at a specialist service within 4 weeks in 2017/2018. On average patients waited 9 weeks, although this varied widely, with an average wait at one service provider of 5.5 months.
- Access to specialist treatment for children and adolescents has significantly improved since 2016. However, under the current mental health system, many of these patients will be required to transfer to an adult service when they reach the age of 18. The limited capacity of adult services can mean that these patients face long delays or are denied treatment altogether. This risks squandering progress made in their recovery.
- Some areas do not have a specialist eating disorder service for adults. In 2016/2017, 2682 people over 19 years of age (in England) were referred to non-specialist mental health services for eating disorder treatment. These services often do not have the capacity and expertise to assess and treat eating disorders.
- The Parliamentary and Health Service Ombudsman (PHSO) - the final arbiter of NHS complaints in England - has expressed alarm at failures to coordinate care and the postcode lottery adults with eating disorders face when trying to access quality treatment. The PHSO has demonstrated that these problems lead to lives being lost and that achieving parity with services for children and young people is essential in order to prevent further tragedies.

## Treatment for Children and Young People

**We want to see:** Achievement of the Access and Waiting Time Standard for Children and Young People with an Eating Disorder, in every area.

An access and waiting time standard for children and young people was published in 2015, with implementation beginning the following year. This set, for the first time, clear expectations around access to evidence-based treatment within maximum waiting times - of either 1 week in urgent cases or 4 weeks in all other cases. Crucially the Government and NHS England are continuing to provide significant additional funding. As a result, there has been a major improvement in service provision for children and young people. However, progress has not been even, with some areas of the country being left behind.

- Major differences remain in waiting times both between and within regions. In 2018/2019 92% of non-urgent ('routine') referrals in the London NHS region started treatment within the target of 4 weeks, in contrast to 75% in the South East. At the more local level, the most recent 12 months of data available (up to end of Quarter 3 2019/2020) shows that some Clinical Commissioning Group (CCG) areas have a lot of work to do to begin meeting the targets. Amongst those CCGs with over 15 urgent referrals the proportions who began treatment within the target ranged from 22%-100%. Amongst those CCGs with over 40 routine referrals the proportions who began treatment within the four week target ranged from 47%-100%.
- NHS England has stated that children and young people in every area should be able to self-refer to specialist treatment by 2020/2021, as a key step to improving access to treatment. Despite this imminent deadline few services are advertising the option of self-referral on their website.
- For each of the last three years NHS England has allocated significant additional funding for the treatment of children and young people with an eating disorder to CCGs. Despite this there are concerns about the level of funding reaching frontline services and the ability of these services to recruit and retain the staff they need, as the number of referrals continues to rise. In 2018/2019 spending varied widely between areas. Two CCGs spent just 17p per person on community eating disorder services for children and young people, whereas one CCG spent £5.55 per person. In 2018/2019 28% of CCGs spent less on these services than they had planned to at the start of the year and some spent less than half. One CCG planned to spend £455,000 but only spent £137,000, whilst another planned to spend £275,000 but actually spent £137,000.

## Medical training

**We want:** Eating disorders to be appropriately taught and assessed at all medical schools and for all junior doctors gain to clinical experience during their Foundation training

Doctors of the future must have a good understanding of eating disorders so they can help patients to access treatment at the earliest opportunity and manage their care safely. All trainee doctors should leave Medical school with basic levels of knowledge and skills in the identification, safe management and referral of patients with eating disorders. All junior doctors should obtain clinical experience in eating disorders through their Foundation training.

Improved teaching, assessment and clinical experience in eating disorders during medical training would also be likely to increase the number of trainees choosing to specialise in eating disorders.

- The Parliamentary and Health Service Ombudsman's (PHSO) 2017 report found that low levels of knowledge among doctors and other health professionals was amongst several failings which led to the death of 19 year old Averil Hart and two others and that there is not enough training for tomorrow's doctors on eating disorders.
- On average just 1.8 hours is spent on teaching about eating disorders in UK medical schools, with 1 in 5 medical schools providing no teaching at all. Some that provide theoretical teaching do not offer any clinical skills training. Assessment drives learning, yet many medical schools do not include a question about eating disorders in their final exams. Overall the data suggests that education and training on eating disorders is a low priority at many UK medical schools.
- A 2017 Beat survey of over 1100 people found that three out of ten did not receive a referral to a mental health service from the first GP they sought help from, despite clinical guidance that stresses the importance of immediate referral. Only 45% felt that their GP emphasised the importance of accessing treatment as soon as possible and when asked to rate the quality of care they received from this GP 48% rated it either 'good' or 'very good', with 52% rating it 'poor' or 'very poor'.
- Academic research suggests that most non-specialist doctors lack confidence and knowledge in how to help patients with eating disorders and that this leads to delays in

treatment and inappropriate management.

- The severe impacts of eating disorders on physical health, mean that they are relevant to a wide range of medical specialisms. However, opportunities to learn about their treatment in greater depth through specialist clinical placements are extremely limited. Only around half of UK junior doctors experience a psychiatry placement during their Foundation training, and not all of these include exposure to patients with eating disorders.

## Research and innovation

**We want to see:** [A significant increase in funding for research into eating disorders](#)

While some high quality research is underway and effective therapies have been developed, we still don't have a full understanding of what causes eating disorders or how best to treat them. This is not surprising when considering the way that research funding is allocated in the UK.

The UK Government is a major funder of health research and has significant influence over other research funders. The UK Government has committed to ensuring that mental health conditions are treated with the same level of importance as physical health conditions. This principle must be applied to the allocation of research funding. A significant increase in the funding provided for eating disorder research is required to reflect the number of people affected and the severity of these conditions.

- Analysis by the mental health research charity MQ found that just £9 per person affected is spent by UK-based funders on mental health research per year, with just 96p per person affected spent on eating disorder research. Around £228 per person affected is spent on vital cancer research each year and this level of funding has led to major breakthroughs in diagnosis and treatment, with survival rates having doubled in the last forty years.
- Mental ill health accounts for 23% of NHS activity, yet the National Institute for Health Research (NIHR) - through which the Department of Health and Social Care funds health and care research - awarded just 10% of its funding to mental health research in 2018/2019. Just 0.09% of its health research budget went to eating disorders.