



Delaying for years, denied for months

**The health, emotional and financial impact
on sufferers, families and the NHS of delaying
treatment for eating disorders in England**

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Introduction

An estimated 1.25 million people in the UK have an eating disorder⁽¹⁾, serious mental illnesses that are often poorly understood. They are not 'diets gone wrong', narcissistic, fads or phases, but illnesses that cause devastating consequences for those suffering and the people that care for them.

Anorexia nervosa has the highest mortality rate of any mental illness, and when eating disorders are not fatal, damage to organ systems, fertility issues, a higher risk of heart problems, type 2 diabetes and loss of bone density are just some of the severe long-term physical health consequences sufferers can be left with.

Despite the severity of these illnesses, those in need of treatment often don't find it quickly enough, resulting in an average cycle of relapse and recovery lasting six years, causing unnecessary financial cost and emotional distress to sufferers and their families and placing avoidable additional cost on the public purse.

As the UK's eating disorder charity, Beat exists to end the pain and suffering of eating disorders. Every day we speak to sufferers and their families who contact us for support through our Helpline or online support services, and we hear first-hand about the challenges people face in asking for help, the long delays they experience in receiving treatment once they seek it, and the frequent obstacles they must overcome to receive appropriate treatment.

In order to explore and quantify these issues, to demonstrate the impact of eating disorders on sufferers and their families, and to highlight where change is needed, we undertook a large research programme during 2017.

This report presents the key findings of this research, with a particular focus on the situation in England. A comprehensive report of all findings will follow next year.

As a result, we are calling for action from Government, healthcare professionals and others. We have also identified a number of actions that we as a charity will take to build on our support for sufferers and their families.

We would like to thank consultant psychiatrist and academic Dr Paul Robinson, ably assisted by Emily Rothwell and Jonathan Kelly, for leading the research programme. Thank you also to the consortium of concerned business people who came together to fund this project. And most importantly, we would like to thank the brave individuals who shared their personal experiences through our surveys and interviews. It is to these people we dedicate this report, for whom, in many cases, the fight for recovery continues.

Summary

Two large online surveys, a Freedom of Information request to inpatient units, and interrogation of NHS England spending data have been combined with in-depth qualitative interviews to present an assessment of the experiences of people suffering

from an eating disorder, as well as their families, as they seek and receive NHS treatment in England. Separate papers will present the situation in the rest of the UK.

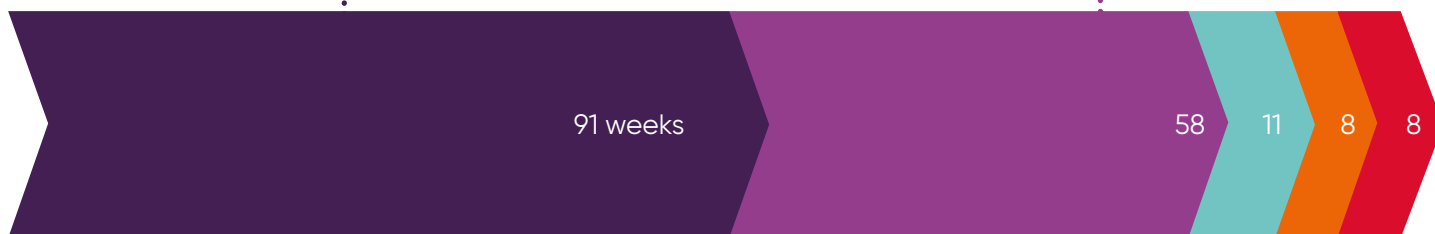
Before realising they had an eating disorder

- The longest delay to treatment is the period before recognising the signs and symptoms of an eating disorder.
- People wait on average three-and-a-half years between falling ill and starting treatment.

Between realising and seeking help

- On average, it takes people over a year to seek help after recognising the signs of an eating disorder.
- Adults wait twice as long as under 19s.

TOTAL 176 weeks



Average time (weeks) spent waiting for eating disorder treatment

Between first GP visit and referral

- Only 14% of people are referred within four weeks of their first GP visit.
- Men and boys wait 28 weeks for a referral compared to 10 weeks for women and girls.
- *We had been to the GP quite a lot of times. They just kept saying it is her age and she is going through puberty... Father*

Between referral and assessment

- *I got referred to CAMHS and, I guess, they diagnosed me and then they didn't actually call back for another year and a half... Sufferer*
- 25% of sufferers aged 19 and over were referred to non-specialist services.

Between assessment and start of treatment

- For 27% of people, treatment did not begin for over three years after their symptoms emerged.
- Less than 50% of patients received all the information they need about eating disorders, their treatment, and sources of extra support.

Impact on families

- On average, carers spent £32,672 as a result of their loved one's eating disorder.
- *It's just like it's destroying the whole family... our other two kids, they're older, and they can hardly come home. Mother*

People delay seeking help, and wait a long time for treatment

People spend, on average, 21 months between their eating disorder symptoms emerging and realising that they might have an eating disorder. They then wait another year before seeking help from the NHS. Another six months pass between their first GP visit and treatment starting. Adults wait for twice as long as children and adolescents before seeking and starting treatment. Boys and men have to wait over twice as long as girls and women before their GP refers them for treatment. Additional funding allocated for eating disorders appears to have been spent elsewhere by around half of Clinical Commissioning Groups.

Early intervention is vital if treatment for eating disorders is to be successful and sustained. People treated within about three years of falling ill are more likely to have a quick and sustained recovery. After that period, the risk of severe and enduring illness rises significantly ⁽²⁾. Respondents to our survey waited on average for three-and-a-half years. Many sufferers will therefore have sought help when their illness was highly treatable, but were then kept waiting until later, when likely outcomes were much less positive.

Government targets and funding aimed at accelerating treatment for children and young people are very welcome. They are however only focusing on a small part of the problem, and much greater attention is needed at the earliest stages of the illness. Similar action is also needed for adults, and funding needs to be ringfenced in order to ensure it is spent on eating disorders as intended.

People don't automatically get the information and treatment they need

People with eating disorders report that they are not given the information they need to understand their illness or the treatments they are given. Families are not sufficiently empowered to support their loved ones into and during their treatments.

Many people may not be receiving the most appropriate treatment for their illness. A third of adults report that they were referred to a general mental health service, which will not be equipped to assess or treat eating disorders. Recognised best practice treatments such as family-based therapy may in some services be ineffectively applied.

Our findings suggest that patients may be spending unnecessary time in hospital, at significant and unnecessary cost to the public purse. This is a result firstly of long waiting times, meaning more intensive treatments are needed, and secondly of NHS budgeting and structural arrangements dis-incentivising innovative approaches that could improve outcomes, reduce costs, and treat more people faster.

Illness and delays have huge impacts on families

Families report that waiting for treatment and trying to support their loved one through treatment exacerbates an already highly distressing experience. Many have struggled to get the treatment their loved ones need, yet they highlight how much they have valued their positive experiences of the healthcare system.

Families describe the devastating impact that eating disorders have had on their lives, their relationships, and their finances. On average, each family spent over £32,000 in travel costs, buying special food, and lost income. Families themselves call for more specialist eating disorder teams and better training for GPs.

Recommendations for change

Beat has made recommendations for the Government and the NHS as a result of this research, notably calling for action to encourage people to seek help sooner, to reduce waiting times and to increase the provision of specialist and intensive community treatment options.

Beat itself will change as a result of this work. We will develop, promote and distribute the information that sufferers and families need to understand their illness and treatment, seeking partnerships with professional organisations and the NHS to achieve this. We will develop new services to support people to get the treatment needed and to empower families better in engaging with their loved ones' care. And we will seek funding to explore further the research needs highlighted by the current study.

This document is a summary of the key findings and recommendations from the research project. Full findings will be published shortly.

People delay seeking help, and wait a long time for treatment

Key findings:

- On average, people wait almost three-and-a-half years to get treatment for their eating disorder.
- They visit their GP three times before they get a referral for a specialist assessment, and have to wait more than six months for treatment to start.
- Adults wait for twice as long as children and adolescents before seeking and starting treatment.
- Boys and men with eating disorders have to wait longer than girls and women.

Delays are experienced at every stage

TOTAL 176 weeks



Average time (weeks) spent waiting for eating disorder treatment

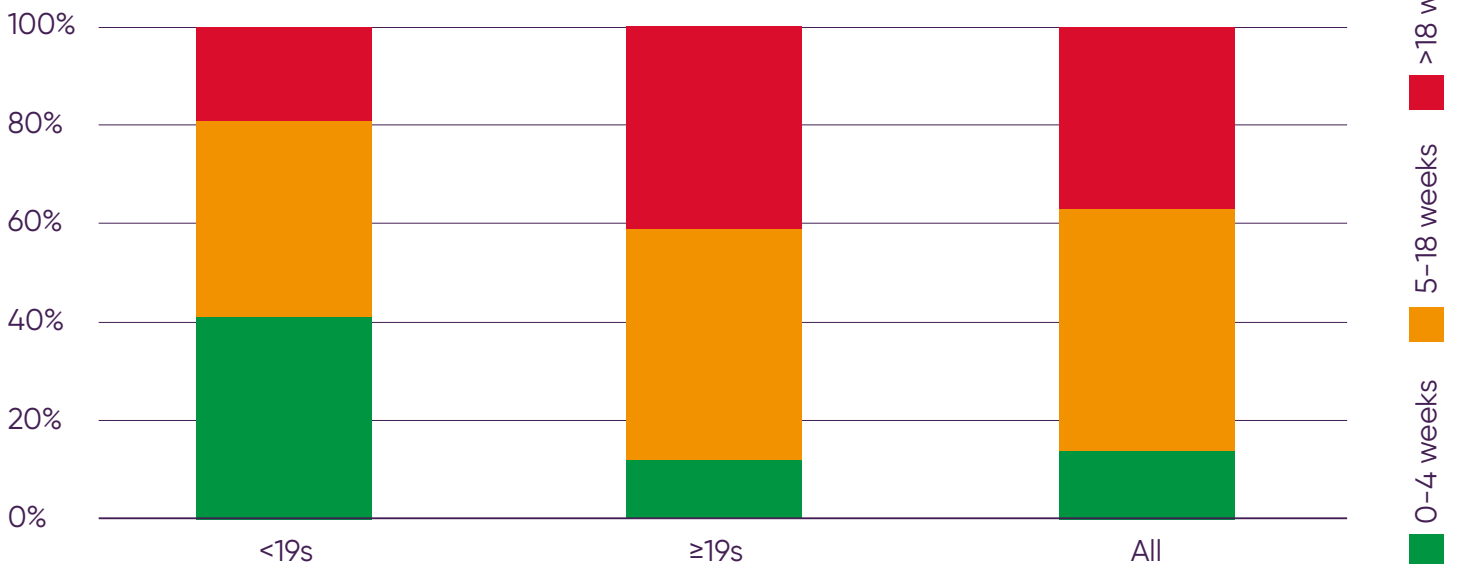
- Before realising they had an eating disorder
- Between realising and seeking help from GP
- Between first GP visit and referral
- Between referral and assessment
- Between assessment and start of treatment

The average wait between someone's eating disorder symptoms emerging and them seeking help is 149 weeks – almost three years. This may be due to low awareness of the significance of the illness, denial of the problem, and/or resistance to seeking help for a mental illness. The delay in seeking help is followed by an average of 27 weeks between first GP visit and the start of treatment, meaning the average person with an eating disorder waits 176 weeks before treatment begins.

This is despite the finding that the earlier someone can access treatment, the better their chance of making a full and sustained recovery. Evidence suggests that treatment for anorexia nervosa in particular becomes more difficult, and the prognosis worsens after around three years of illness, with increased risk thereafter of the illness becoming severe and enduring, or even fatal ⁽²⁾.

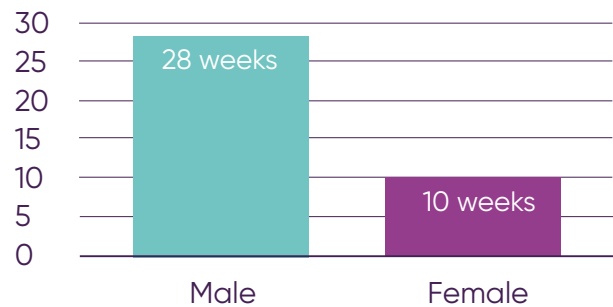
In fact, our survey found that for 27% of people, their treatment did not begin until over three years after their symptoms emerged. The timescales also suggest that many people first sought help at a time when their illness was still highly treatable, but did not receive it until later, when the likely outcome was much more negative.

Immediate referrals from primary care are uncommon



Proportion of people waiting different lengths of time between the first discussion with their GP and treatment starting.

The 2017 NICE (National Institute for Health and Care Excellence) guideline for eating disorders states that GPs should refer someone for specialist assessment immediately "if an eating disorder is suspected after an initial assessment" ⁽³⁾. Our survey finds that only 14% of people are referred within four weeks of their first GP visit. The average wait for referral is more than 11 weeks, while over a third of people wait more than 18 weeks. Those aged 19 and over wait significantly longer than under 19s.



Average waiting time between first GP visit and referral for assessment

The situation is worse for men and boys, who make up between 10% and 20% of people with anorexia or bulimia nervosa ⁽⁴⁾, with an average wait of 28 weeks before their GP makes a referral for specialist assessment, compared with 10 weeks for female sufferers.

The reasons for the longer delays faced by male sufferers are not clear, but it may be that a misplaced perception that men rarely get eating disorders means it takes longer for some GPs to make a diagnosis. This would tally with previous research in which some male respondents reported their eating disorder symptoms were dismissed by their GP explicitly due to their gender ⁽⁵⁾. Excessive exercising is also a common symptom of eating disorders in men, and this could be mistaken for a sign of a healthy lifestyle rather than cause for concern.

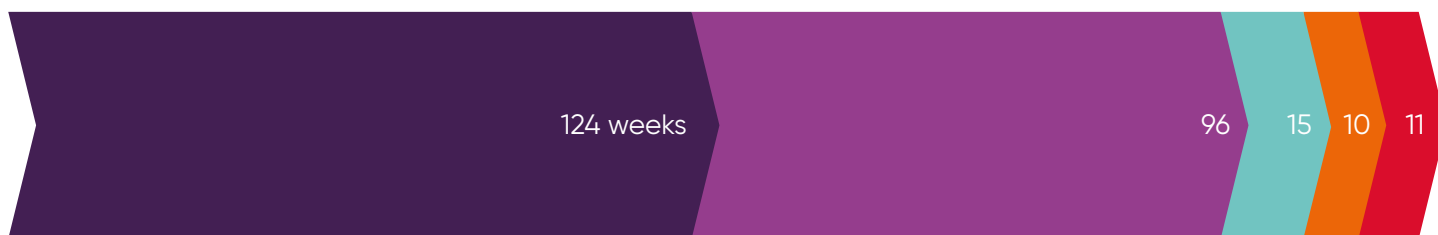
Adults wait longer than children and adolescents at every stage for treatment

TOTAL 130 weeks



Average time (weeks) spent waiting by under 19s for eating disorder treatment

TOTAL 256 weeks



Average time (weeks) spent waiting by 19 and overs for eating disorder treatment

- Before realising they had an eating disorder
- Between realising and seeking help from GP
- Between first GP visit and referral
- Between referral and assessment
- Between assessment and start of treatment

People who were aged 19 or over when they were assessed for an eating disorder waited significantly longer than under 19s at every stage, resulting in a total average delay of almost five years, compared with two-and-a-half years for the under 19s.

Government action is welcome, but is not nearly enough

Since the period covered by our survey data, the Government has taken steps towards reducing the time people under the age of 19 must spend waiting for treatment. New access and waiting times targets state that people should wait no more than a week after referral to begin treatment in urgent cases, and no more than four weeks in all other cases⁽⁶⁾. Our research found an average wait of 15 weeks for children and adolescents. Additional funding has been provided to Clinical Commissioning Groups (CCGs) to support this change.

This action is welcome, and a necessary first step. However, our research demonstrates that the time between symptoms emerging and a person beginning treatment is made up of a number of phases and much more is needed to fully address the problem.

For example, even if the new access and waiting times directive for under 19s is fully achieved, the time period between symptoms emerging and treatment starting will only reduce from 130 weeks to 119 weeks, which means that most young people will still not start treatment until well over two years after the time they fell ill.

No government action has been taken to address delays in treatment among the 19 and overs.

Carers struggle to get the right treatment for their loved one

Our analysis of the in-depth interviews shows that sufferers and carers often feel let down by the healthcare system, and that sufferers' health worsens while they wait for treatment.

Four carers described having to make suggestions to or challenge the decisions of a professional involved with treatment in order to further the care provided to their loved one. The steps they took included making suggestions to the professional directly, phoning eating disorder services to push for a referral, and arranging for other professionals to assess the sufferer.

[I asked] "Don't you think you ought to be putting a referral in... for a hospital appointment?"... to which she turned around and said, "Oh, yes, well, I was thinking about it."

Mother who pushed for further treatment

Eight interviewees described the GP as unhelpful, or felt that they lacked understanding of eating disorders.

We had been to the GP quite a lot of times. They just kept saying it is her age and she is going through puberty...

Father

My GP just turned around and said to me "Oh, just look in the mirror and tell yourself you're beautiful every day and you'll be fine."

Sufferer

In other cases, however, interviewees felt more positively about their experience with the GP, and their interviews illustrated the important role GPs can play in helping someone to recover.

[The most helpful aspect of treatment was] having regular contact with the GP...

Sufferer

Where interviewees had got a referral for themselves or their loved one, they often still encountered issues in the form of long waits for assessment – in some cases, this meant waiting for so long that they were no longer eligible to use the service to which they had been referred.

I got referred to CAMHS and, I guess, they diagnosed me and then they didn't actually call back for another year and a half... They called about a week before my 18th birthday and sort of said, "Well, we can't help you now."

Sufferer

So, it was almost a year after being diagnosed that I'd actually got through their system to receive treatment, and that's where we are today.

Sufferer

In the period that they're left waiting for treatment, sufferers' health can deteriorate considerably. This was the experience of nine interviewees, with four sufferers having to go to hospital during the wait.

But we had to wait another four weeks again. And that four weeks was just terrible. We were so scared that we were going to lose her... Her behaviour was shocking at that point. And she was screaming and ripping at her arms. And it was just horrendous.

Mother

So we went back [to the GP] the next day again and they referred her to hospital... And [the doctor] phoned [CAMHS] up and said, "If you don't see her she will be dead in two weeks."

Sister

But we had to wait another four weeks again. And that four weeks was just terrible. We were so scared that we were going to lose her... Her behaviour was shocking at that point. And she was screaming and ripping at her arms. And it was just horrendous.

Mother

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Sufferer

Allocated funding for eating disorders is being spent elsewhere

As our survey was being completed, NHS England published data ⁽⁷⁾ which suggested that at least 44% of CCGs spent less than or equal to the amount of 'additional' funding they received for eating disorders in 2016–17 ⁽⁸⁾. Action from government and NHS England is clearly needed to ensure that CCGs spend their additional funding for eating disorders on the purpose for which it is intended, and that it is supporting rather than supplanting existing spending.

Recommendations

Our findings demonstrate that much more needs to be done to improve understanding of eating disorders and the importance of seeking medical help quickly if we are to ensure that everyone receives treatment at a time when it can be most effective, and that particular attention is needed on reducing the delays faced by adult sufferers, and by male sufferers of all ages.

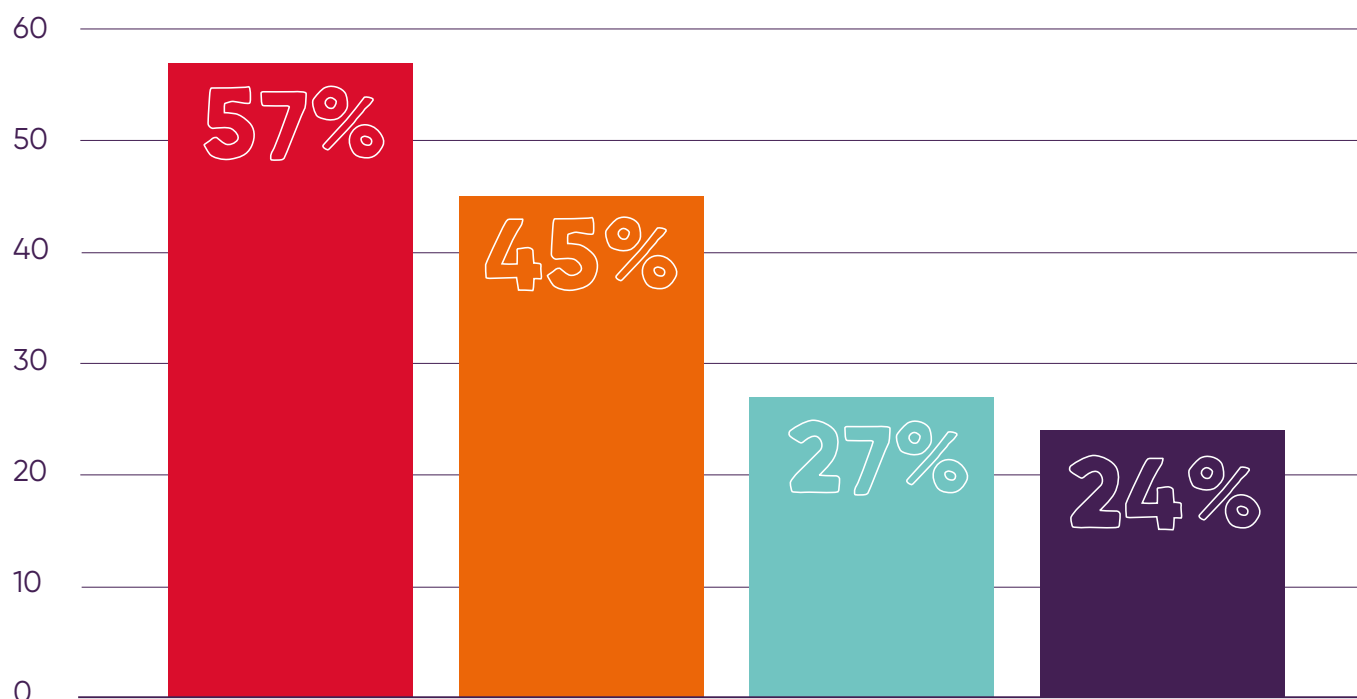
- The Government and CCGs must extend their focus on early intervention to include the earlier stages of the illness, ensuring attention and resources are applied to reducing the delay between onset of an eating disorder and the individual seeking help. We recommend introducing measures to increase awareness of the early signs and symptoms of eating disorders, and supporting initiatives that support and encourage individuals to seek professional help as soon as they suspect they have an eating disorder. These measures must sufficiently target all demographics to ensure everyone gets the help they need.
- The Government and local decision makers must ensure eating disorder services are sufficiently funded so that all providers can meet waiting time targets for children and young people, with particular attention on ensuring funding allocated for eating disorder treatment is actually used for this purpose.
- An access and waiting time standard for adults, with appropriate funding, should be introduced as soon as possible, so that all individuals presenting with an eating disorder for the first time receive treatment within four weeks, and urgent cases receive treatment within one week.
- GPs should be well-informed of the NICE guideline and the early symptoms of eating disorders so that they are able to refer without delay. Increased eating disorder training at all medical schools is needed, with appropriate examination, to ensure that medical professionals are equipped to identify eating disorders as quickly as possible. It is vital that all medical professionals understand that eating disorders can affect all sectors of society and are equipped to identify the early signs in all cases, including understanding how eating disorders might manifest in male sufferers.
- All treatment providers must ensure they are equipped to accept self-referrals and referrals from schools and colleges, as recommended by the access and waiting time standard, so that individuals can receive treatment for their eating disorder as soon as possible.

People don't automatically get the information and treatment they need

Key findings:

- Less than 50% of patients receive all the information they need about eating disorders, their treatment and sources of extra support.
- A quarter of adults are referred to services that do not specialise in eating disorders.
- Inpatient hospital care appears to be overused at a high price to the public purse.

People are not given the information they need about their illness



Percentage of people answering 'no' to the following questions when asked in our survey.

- Were you told about sources of support?
- Were you told what treatment would be like?
- Were you given information about eating disorders?
- Were you given an eating disorder diagnosis?

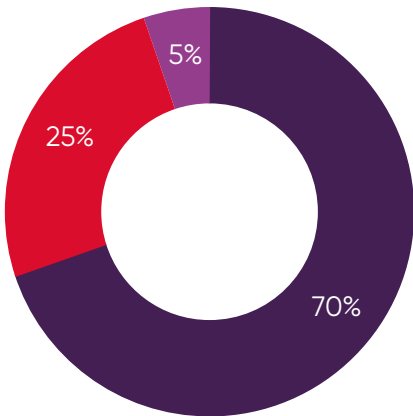
Despite NICE guidance stating that people with eating disorders and their family or carers should be offered information about eating disorders, their affects and available treatments⁽³⁾, our survey shows that people are insufficiently informed about their illness as their treatment starts. We do not have explanations for why relatively high numbers of patients were not given a diagnosis or useful information. However, it is reasonable to expect that they should be given full information about their

illness, its treatment and the support available from other sources before, during and after their treatment.

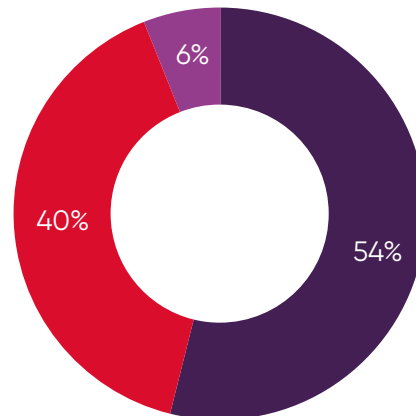
The mental health services have the responsibility of providing this information and should be doing so. However, this finding is also particularly important for Beat, as we can – and therefore should – produce standard packs to ensure that this information is available and provided, both for patients and for their relatives and friends.

Adults are referred to services that aren't equipped to treat them

Proportion of respondents referred to a specialist eating disorder service vs non-specialist:



19 and over
 Specialist 70%
 Non-specialist 25%
 Don't know 5%

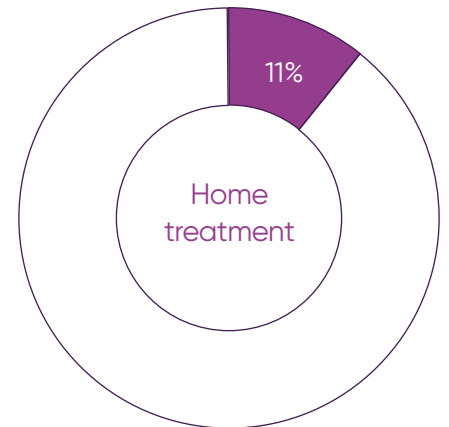
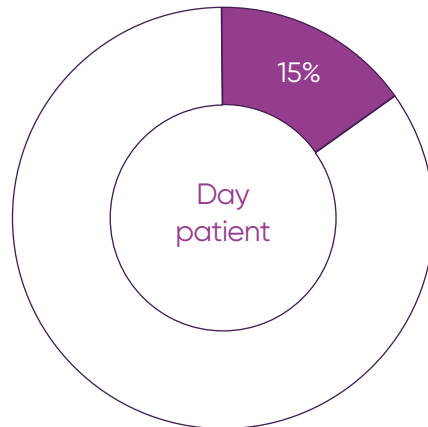
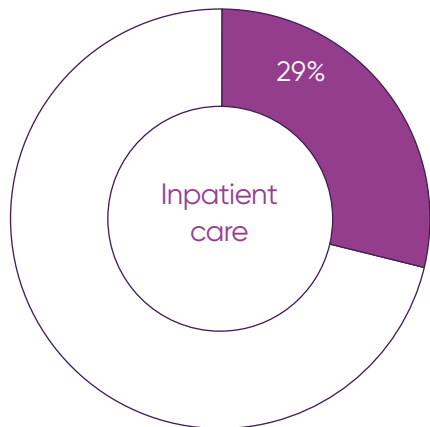


Under 19s
 Specialist 54%
 Non-specialist 40%
 Don't know 6%

The finding that 25% of those aged 19 and over were referred to non-specialist services is disturbing since general adult mental health services are not set up to assess and treat any eating disorder. The equivalent figure for under 19s was 40%, although this is less

concerning since general CAMHS services see large numbers of eating disorder cases and many therefore have good expertise. However, even for children and adolescents, research suggests that specialist treatment is more cost-effective⁽⁹⁾.

Patients may be spending time in hospital unnecessarily



Proportion of respondents accessing inpatient care, day patient care and home treatment.

29% of our survey respondents had experienced inpatient care, compared with 15% having day patient and 11% home treatment. We acknowledge that the self-selecting nature of our survey respondents mean that this is not a reliable measure of the proportion of patients seen in each setting across England. Furthermore, inpatient care has an important role

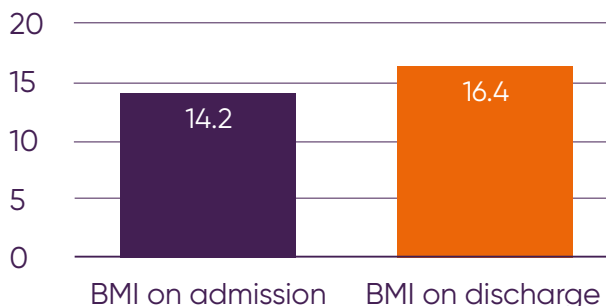
to play and is always required if the situation is life threatening. Nevertheless, our findings, combined with anecdotal reports from eating disorder services themselves, suggest that patients may be admitted to hospital unnecessarily, and that hospital stays may be longer than necessary.

Inpatient treatment is also expensive. Between 2011 and 2016, on average, 798 adults were admitted to hospital each year, staying 114 days at a cost per day of £405. The annual cost of adult inpatient care provided by the NHS therefore totals over £36 million.



Totals over: £36m

The cost of NHS treatment by private providers has not been assessed, but would increase this sum considerably. Average body mass index rose by 2.2 (from 14.2 to 16.4) between admission and discharge, and 22% of patients were re-admitted within 12 months of discharge. We were not able to obtain equivalent data for child and adolescent inpatient stays.



Average body mass index of respondents on admission and discharge to inpatient treatment

There is substantial evidence, at least for adolescents, that intensive community care for severe anorexia nervosa (day care and home treatment) produces outcomes just as good as those achieved from inpatient care⁽¹⁰⁾. Community care also causes less disruption to day-to-day life, allows patients to live at home, avoids potential long and expensive journeys, and supports empowerment of families in their loved ones' treatment.

Part of the reason for overuse of inpatient care is the way that it is funded. Outpatient treatment is funded from CCG budgets, while NHS England pays for inpatient care. Providing more intensive community-based care would increase CCG expenditure and reduce costs for NHS England, but the savings would not be transferred to pay CCGs to treat more people. Meanwhile, inpatient providers are paid for occupied beds. So despite the potential for improved overall clinical and financial outcomes, the system dis-incentivises providers from exploring different treatment models.

There were concerns about the treatment sufferers received

Our analysis of the in-depth interviews shows that sufferers and carers also felt concerned that care and treatment were often not provided in a timely or appropriate manner.

The NICE guideline is clear that: "Professionals who assess and treat people with an eating disorder should be competent to do this for the age groups they care for."⁽³⁾

It's essential that anyone involved in the treatment of someone with an eating disorder is properly equipped to do so, and that care units are appropriately staffed.



I actually complained to the head of the service. How has my daughter not been flagged up? She's clearly disappearing in front of our eyes.

Mother

Nine interviewees felt that during the treatment, professionals had run afoul of the common misconception that eating disorders are mainly about weight, and that their treatment had therefore only addressed the physical aspects of the illness. In four cases, the sufferer had explicitly been told their weight was not low enough for treatment – something that can actively harm the sufferer, driving them deeper into their eating disorder behaviour.

And the doctor said, in front of [my daughter]... once she drops to [a BMI of] 15, that's the point you should be re-referring her to the inpatient team.

Mother

...The consultant turned around to me and said, "Oh well, you haven't got the lowest BMI I've seen so we'll just discharge you."

Sufferer

The NICE guideline for eating disorders states: "Do not use single measures such as BMI or duration of illness to determine whether to offer treatment for an eating disorder."⁽³⁾ The guideline lists a range of psychological as well as physical factors that healthcare professionals should consider when deciding whether to offer treatment.

Sufferers sought support outside the treatment they had been offered

Speaking about their own experience or that of someone they were caring for, five interviewees described external support sought by sufferers for an eating disorder, beyond the treatment they were offered or currently receiving. Both private therapy and help from charitable organisations were avenues of support that people turned to.

...I have a Beat card in my purse with the phone number... When I moved here I phoned the Helpline and they listened to me.

Sufferer

I would say definitely the Hope through Horses [charity]. It was a safe space, it was somewhere that she could go and she found somebody that she could actually talk to and feel comfortable talking to.

Sister

...I have a Beat card in my purse with the phone number... When I moved here I phoned the Helpline and they listened to me.

Sufferer

I would say definitely the Hope through Horses [charity]. It was a safe space, it was somewhere that she could go and she found somebody that she could actually talk to and feel comfortable talking to.

Sister

Recommendations

- Specialist treatment must be available for all, with particular focus given to ensuring adults are not treated in general mental health services, since these do not have the expertise to treat eating disorders.
- It is vital that medical professionals are familiar with, and follow, the NICE guideline on eating disorders. We particularly highlight its guidance that single measures such as BMI or duration of illness should not be used to determine whether to offer treatment.
- All children and adolescents with eating disorders should be offered intensive community care when appropriate, and research should be commissioned to investigate the effectiveness of intensive community care in adults, moving to rapid implementation if warranted by the evidence.
- All funding for eating disorder treatment (including inpatient) should be held locally by the same budget holder to create incentives to develop improved community treatment and reduce costly inpatient care.
- All patients should receive written information about their assessment and care plan, and be directed to other sources of support available.

Illness and delays have huge impacts on families

Key findings:

- Families are not given the support they need, either to help them provide the best care or to protect their own wellbeing.
- Family members widely report being very badly affected in all aspects of their lives by their loved one's illness.
- On average, an eating disorder costs a family over £32,000 in increased spending and lost income.

The NICE guideline for eating disorders repeatedly recommends the appropriate involvement of family members in the treatment of someone with an eating disorder⁽³⁾. The family can form a vital part of someone's support network as they go through recovery, and it is essential that they are empowered to give their loved one the support they need. However, our research suggests that often this does not happen.

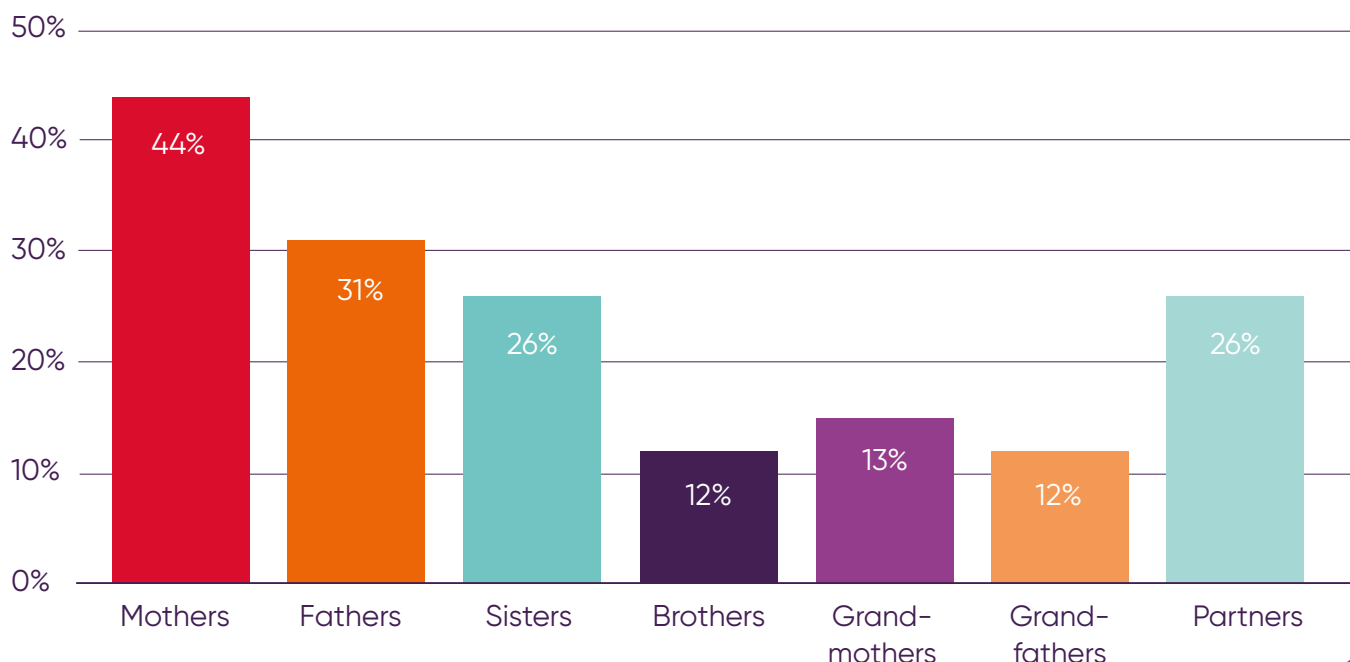
Furthermore, eating disorders can also have a huge effect on the mental wellbeing of carers, their finances, and their day-to-day lives. Our research highlights the effects that these illnesses have beyond the direct impact on the person suffering.

Being a carer is something I had never thought I would have to do at 12 years old, not only for my sister but for my struggling parents as well.

Carer respondent to survey

In our survey of carers of people with eating disorders, we asked about the impact of the wait for assessment and treatment. The impact was greatest on mothers, with 44% describing themselves as being affected "extremely badly". This was followed by fathers (31%), sisters (26%), brothers (12%), grandmothers (15%), and grandfathers (12%). 26% of partners were also reported as being "extremely badly" affected.

Our analysis of the in-depth interviews with sufferers and carers exposed numerous ways in which eating disorders devastate family lives. We can be confident that the experiences described here are typical of the wider community of people affected by eating disorders or supporting a loved one with an eating disorder.



Percentage of family members describing themselves as "extremely badly" affected by the wait for assessment and treatment.

Carers did not receive adequate support during their loved one's treatment

Carers commonly described feeling alone and as though there was a lack of support for them. Five sought external support for themselves, through charity support groups, support groups run by individuals who have recovered from eating disorders, and private counsellors. It was clear that this was necessary to both the wellbeing of the carer and their ongoing ability to support those around them.

I just felt like I hadn't got the strength to support the rest of my family.

Mother who sought private counselling

...The biggest thing that helped me was [that] I found a charitable organisation... I used to go to their carers groups once a week and that was the thing that saved me, if you like... being able to actually talk to other mothers.

Mother who attended a support group for carers

[I] wanted to talk to somebody about it... there's never really anything for siblings of people with eating disorders

Sister

I just felt like I hadn't got the strength to support the rest of my family.

Mother who sought private counselling

[I] wanted to talk to somebody about it... there's never really anything for siblings of people with eating disorders...

Sister

Five carers did receive support through the treatment centre their loved one was attending. Their experiences demonstrate how further support might be given to carers, with support including talking therapies, group meetings that carers could attend, and contact via text with the clinician treating their loved one. The value of this support was evident.

They did have a carers' meeting that we went to every month... and that opened our eyes a little bit, because we thought we were the only ones who that was happening to, and we found out that that was the norm.

Mother provided with support through treatment centre

Eight carers spoke about their involvement with treatment, including in family-based therapy, which is recommended by NICE for treating anorexia nervosa and bulimia nervosa in adolescents⁽³⁾. The experiences of families suggest that the therapy provided in practice does not always meet the standard assumed in theory.

[Our parents] had family sessions sometimes, [but] that was more to ask how my parents were getting along with her eating plans. They were literally given a list of food and [told], "Go away and make her eat it".

Sister

[Our parents] had family sessions sometimes, [but] that was more to ask how my parents were getting along with her eating plans. They were literally given a list of food and [told], "Go away and make her eat it".

Sister

The eating disorder severely disrupted daily life

For all carers interviewed, the eating disorder had caused disruptions to daily life – as may perhaps be expected, mealtimes in particular became a major source of conflict.

The table started to become a battlefield. It was horrendous.

Mother

... A lot of our time... was just sat around the dinner table with [my sister] shouting and crying for hours before she would actually touch any of the food.

Sister

Every single mealtime was a trauma for us, but more so him.

Father

For some interviewees, the impact the illness had on daily life had a domino effect on the ability of carers to access support for themselves, and therefore their ability to support their loved one.

[My parents] went [to the support groups] separately because one of them had to be with [my sister].

Sister

We have had no respite from [the illness], whatsoever and there's nothing. There's nothing anyone can do because she's too sick to go... You can't send someone who is potentially suicidal and not going to eat anything to stay with a relative... It just doesn't work like that. It's dangerous and it's not fair on other people.

Mother

School was another area in which sufferers were seriously impacted, with several interviewees having to take time out of school or attending inpatient treatment while of school age.

When they're at school, you just can't [help them eat]... I never knew if she's eaten lunch or not or what had happened.

Mother who took her daughter out of school

However, schools can also play a positive role – three interviewees described how the school gave the sufferer someone to talk to and somewhere they could go if they felt anxious. There are clear benefits both of sufferers being able to stay in school and of schools being equipped to recognise eating disorders and to support those suffering from them.

There's a therapist [at school] and one of the teachers reached out a couple of times... That was actually really nice.

Sufferer

The school were really good, they had almost like a welfare officer I suppose or somebody that she could just go and see at lunchtime, if she was feeling anxious and that was brilliant, and that was all she needed.

Mother

There's a therapist [at school] and one of the teachers reached out a couple of times... That was actually really nice.

Sufferer

The eating disorder had a serious impact on the family's time and finances

Lost working hours, as well as treatment and travel costs and other expenses, can impact heavily on family finances. It was necessary for some carers to take time out from work in order to look after their loved one, or even give up work altogether.

I was meant to be starting a new job and I was meant to be on a training course that day and [my daughter] just flat refused to go into school... I had to phone and say to the company I was going to be employed by, "I can't start this job because we've got a family crisis."

Mother

I've had to really drop [work] right back, and we are trying to sell [the business] because I can't really do both anymore.

Mother

[My daughter has not] been able to work for the last five or six years now [due to the illness].

Mother

[I feel I have to say that my] treatment's nearly done [because] work are not very happy about it...

Sufferer

Travelling long distances for treatment also takes up considerable time, and several of those we interviewed described the effect this had.

[City where daughter is an inpatient] is 250 miles away, so it is a 500-mile-round trip. And we go every weekend to see her. It has been hard, financially, mentally, and physically.

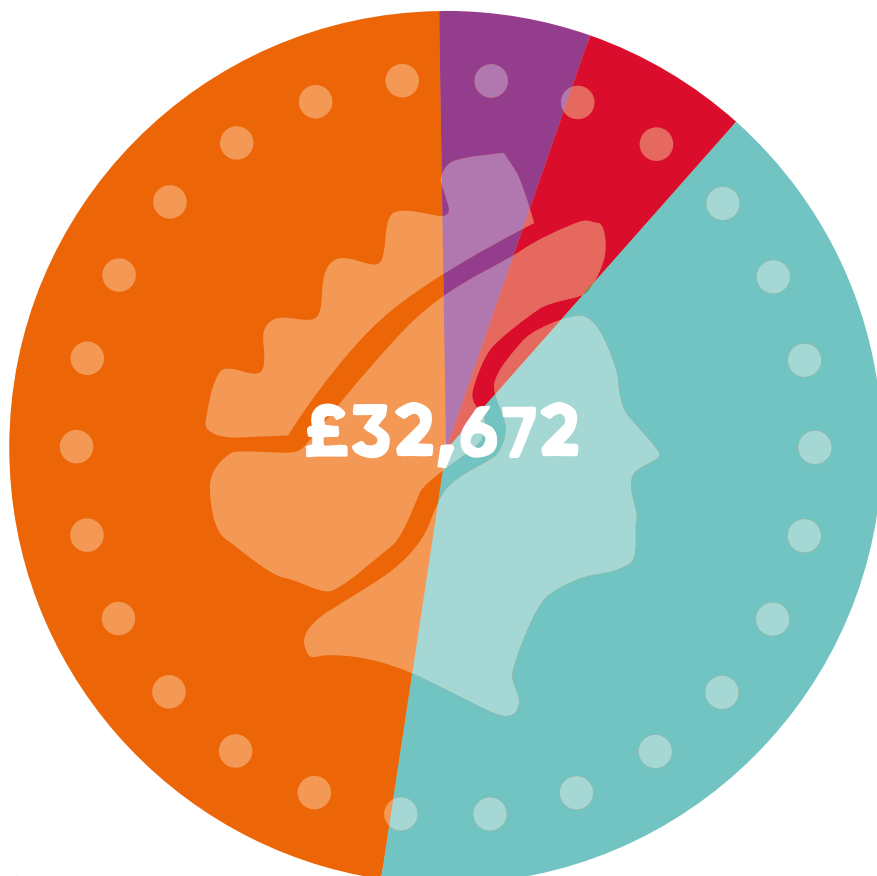
Father

" [My daughter has not] been able to work for the last five or six years now [due to the illness]. "

Mother

" [City where daughter is an inpatient] is 250 miles away, so it is a 500-mile-round trip. And we go every weekend to see her. It has been hard, financially, mentally, and physically. "

Father



Respondents to our online carers' survey were asked to quantify the financial impact of their loved one's illness. On average, they spent £32,672 as a result of the eating disorder, including on travel, special food and lost income.

- Travel to clinics (£1,726)
- Special food (£2,075)
- Lost work time (£13,348)
- Other expenses (£15,500)

The eating disorder affected family relationships

It was clear from the interviews that the eating disorder had affected relationships between the person suffering and members of the family.

At that time, he wouldn't speak to us hardly at all, because he blamed us, then, for him being in there... we were getting horrendous texts saying, "You're not my mother. If you were my mother, you wouldn't have done this to me."

Mother

I can see how terrifying it is for my parents at the moment, because they know that when she comes home they have to be with her 24/7... And the amount of stress and strain that put on all the relationships in the house last time was ridiculous. So it's a very tense atmosphere most of the time.

Sister, regarding her sister coming home from an inpatient unit

It was evident that the eating disorder had had a serious impact on siblings of the person suffering, even in cases where they weren't directly involved in the sufferer's care.

It's just like it's destroying the whole family... our other two kids, they're older, and they can hardly come home...

Mother

The other children have had to just knuckle down and get on with things really and it's been very hard.

Mother

Families also recognise that the person suffering is aware of the impact of their illness, and may attempt to mitigate it.

...There was a long time... where [my sister] just didn't talk to me at all because she felt like it was putting too much pressure on me or it would be too upsetting.

Sister

I can see how terrifying it is for my parents at the moment, because they know that when she comes home they have to be with her 24/7... And the amount of stress and strain that put on all the relationships in the house last time was ridiculous. So it's a very tense atmosphere most of the time.

Sister, regarding her sister coming home from an inpatient unit

The eating disorder caused danger to the sufferer or person caring for them

Some of the carers interviewed described incidents where the eating disorder caused behaviour that put other people at risk of harm, emphasising how the thoughts caused by the eating disorder overwhelm the sufferer's judgment, and the urgent need for better support for those caring for them in order to ensure their safety and that of the people around them.

She [became very distressed] in the car on the way back. Fighting to get out of the car. I was driving down the four-lane carriageway. We nearly had an accident. It was really, really dangerous.

Mother

The eating disorder caused enormous emotional distress

It is hardly surprising, given the experiences they described, that all interviewees spoke of the emotional distress that the eating disorder had caused.

But it's just like we're feeling really worried about her coming home [from inpatient]. Because, obviously, we want her home. But there's just this fear of, "Oh my God, if it happens again."

Mother

I have to say, signing those papers for her to go into a clinic was one of the hardest things I think we've ever done... It's been a journey, and hell.

Mother

We get no respite, whatsoever... I've been on pretty much 24/7 duty looking after her for the last four or five years.

Mother

At first it was the eating disorder voice... it feeds it, it makes you think: "Oh, well, I'm not getting the treatment, I can feel like this for longer."... But at the same time it's so tiring. You just think: "I just want to get rid of it." And the only way I can get rid of it is through help and it just becomes so frustrating and so tiring...

Sufferer, describing the wait for treatment

I have to say, signing those papers for her to go into a clinic was one of the hardest things I think we've ever done... It's been a journey, and hell.

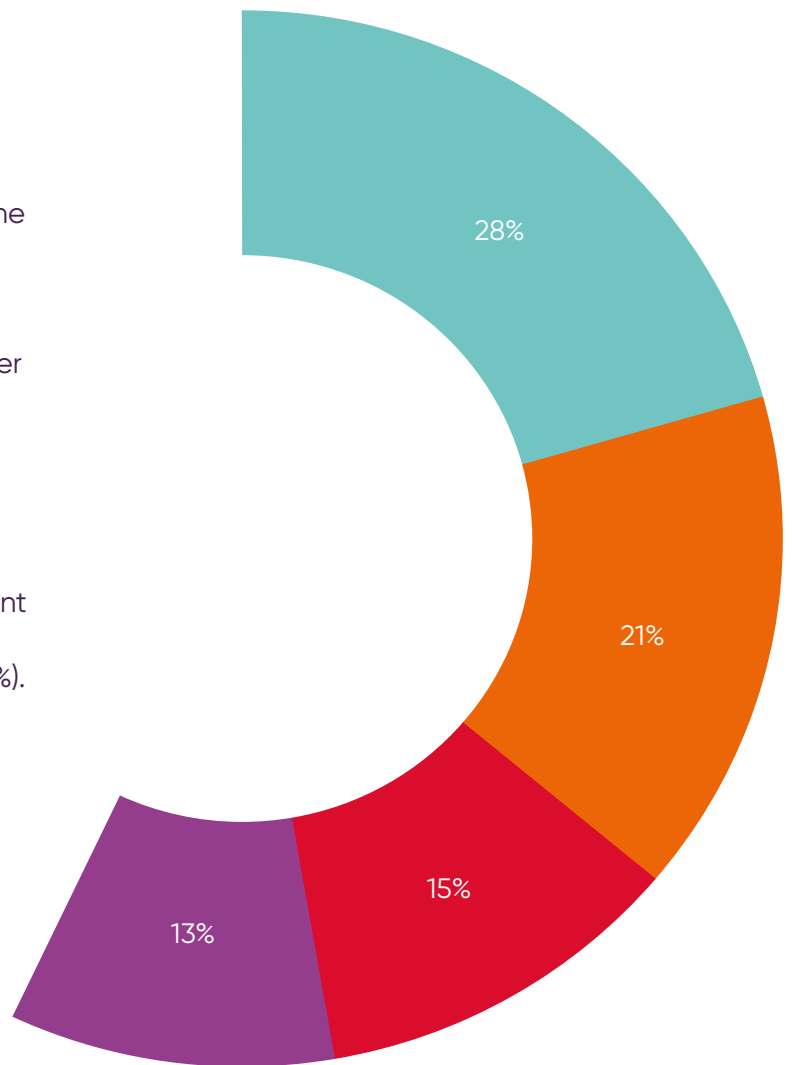
Mother

What carers would like to see change

We also asked the 1,645 carers who responded to our online survey to prioritise the actions and changes they thought most necessary to make the greatest difference. They were asked to prioritise from a list of possible changes: better training for GPs or other health professionals, more specialist eating disorder teams, more inpatient beds, better health monitoring in schools, more online or self-help and community support resources.

They clearly prioritised the need for more specialist eating disorder teams for children and adolescents (28% ranking this as their number one priority) and better GP training (21%). Also considered as important were more inpatient eating disorder beds (15%) and more specialist eating disorder teams for adults (13%).

- prioritised the need for more specialist eating disorder teams for children and adolescents
- prioritised the need for more specialist eating disorder teams for adults
- prioritised the need for better GP training
- prioritised the need for more inpatient eating disorder beds



Recommendations

Eating disorders devastate family lives and destroy relationships. Having a loved one suffer from an eating disorder will always be a time of immense pressure for families, but this is only worsened when treatment is delayed, denied, or inadequate, when they can't visit someone in hospital, when they don't know how to support their treatment, and when they don't understand their loved one's illness.

Carers, if empowered to do so, can play an important role in helping their loved one along the path to recovery. But they can only do this if they have full understanding, are fully supported and engaged, and if their own wellbeing is protected. We must do more to make sure that carers have the support they need.

- Family members must be supported to be optimally involved in the treatment of someone with an eating disorder. Family-based therapy can be very effective in treating eating disorders, but must be provided in line with evidence-based treatment protocols.
- The family of an eating disorder sufferer should be provided with more information about the illness, their loved one's treatment and care plan, and other support available, both for the sufferer and for themselves.
- More focus must be placed, both nationally and locally, on supporting the wider family of someone with an eating disorder. This will have significant benefit to the family members involved, and to the sufferer as their family is better able to support them.
- All employers should be understanding of the impact on their staff of having a family member with an eating disorder, and allow appropriate concessions, such as time off work, wherever possible.
 - More specialist eating disorder services are needed throughout the country so that no one has to travel for more than an hour to their nearest specialist service, and so that family members (and the sufferer themselves) are able to more easily engage with the service.

Impact on NHS budgets

This research has highlighted the potential for shorter treatment times and reduced inpatient stays, which would be achieved were more people to be treated as soon as possible after their eating disorder emerges. As well as the benefits to the individual patients and their families, this also implies that significant cost savings to the NHS could be achieved.

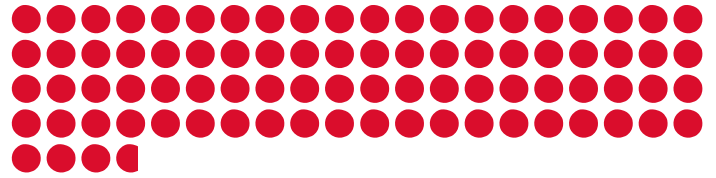
In 2015, research for Beat by PwC found that eating disorders cost the UK economy over £15 billion per year, including £4.6 billion in costs to the NHS⁽¹⁾. It did not quantify how to reduce those costs.

While the current study was not set up to assess how to save the NHS money, it does indicate that this should be a subject for future research. In the meantime, we have calculated the treatment costs of two different patients. They are both 19 years old and both represent typical patient pathways.

The first consults their GP and in three months is referred to hospital. The hospital sees them for assessment in four months' time, and at assessment they are found to have moderately severe anorexia nervosa, are placed on a waiting list for individual therapy, and are followed up by the doctor and dietitian every month. After six months, their name comes up for therapy and, 13 months after presenting to the GP, they start treatment. Unfortunately, their illness had started two years before the first GP consultation, and their length of history is therefore over three years when they start treatment. By the time they get to see their therapist, their weight has fallen dramatically, and after four sessions of therapy, they are so ill that they need to go into hospital, where they stay for six months, reaching a low but survivable weight. They are discharged at a BMI of 17. Individual and family therapy begin, and after five months their weight is better and stable, but it is still below normal and they still show signs of long-term physical damage.

Using the PwC figures⁽¹⁾, we have calculated the approximate cost of the first year of treatment:

Assessment and five weeks of multidisciplinary outpatient treatment: 5 x £351
Inpatient care for 24 weeks: £72,912
Multidisciplinary outpatient care weekly: 20 x £351
Family-based treatment 20 sessions: 20 x £106



Total: £83,807

The second patient has also had anorexia nervosa for two years. However, at their first consultation they are referred immediately to a unit set up to deliver rapid care. They have intensive outpatient and then day care, avoid hospital admission, and after a year their BMI is normal and they are well on the road to recovery:

Assessment and four weeks of intensive multidisciplinary outpatient treatment (bi-weekly): 8 x £351
Day care five days a week for four months: £28,080
Following discharge from day care, individual and family therapy weekly for seven months: £9,828



Total: £40,716

In the first case, treatment is delayed so hospitalisation is required and the outcome, at least at one year, is rather poor. In the second case, treatment is provided early enough to avoid hospitalisation and achieve a good outcome. The cost of the latter treatment is less than half of the former. Neither of the scenarios represents an extreme – there are longer and more expensive examples as well as shorter and less costly ones.

While outcomes cannot be guaranteed, early intervention will always have a better chance of achieving a positive outcome than delayed intervention, and always at lower cost to the NHS.

Beat's responses to the research

Our commitment to existing work

This research has highlighted a number of key issues for Beat to consider. It has confirmed the importance of much of our existing work, highlighted other areas that we will now prioritise, and demonstrated the need for programmes that we will seek funding for in order to deliver.

This research has highlighted the importance of much of our existing work that is focused on promoting early intervention and supporting families. As a result of our findings, we will:



1. Ensure that our Helpline and online support services continue to be focused on early intervention, with trained advisers available 365 days a year to support individuals and their families into getting help as quickly as possible.



2. Prioritise the early signs of eating disorders in our training for education professionals, and provide access to a dedicated helpline to assist them in identifying and supporting young people with eating disorders into appropriate treatment.



3. Step up our awareness raising of the early signs of eating disorders, highlighting the importance of seeking early treatment.



4. Engage families in shaping our work, and continue to provide tailored support for them, including online peer support groups, collaborative care skills workshops, and dedicated information materials.

New priorities in response to our findings

Having identified the challenges individuals face in seeking help and the frequent disempowerment of sufferers and their families, we will:



1. Ensure that our messages and information materials reflect the diversity of individuals affected by eating disorders, and encourage everyone who may have an eating disorder, irrespective of their gender, age, sexuality or background, to seek help as soon as possible. We will make this a central theme of our Eating Disorders Awareness Week in February 2018.



2. Collaborate with relevant professional organisations to identify, develop and distribute information materials, to help sufferers and their families to understand eating disorders, treatment pathways, and additional sources of support. We will collaborate to produce guidance that will help healthcare professionals empower family members to support their loved ones. And we will promote the importance of family engagement to all services providing care for eating disorder sufferers.



3. Create a weekly online peer support group for siblings and friends to complement existing offerings for parents.

Programmes we will undertake with sufficient funding

Our research has demonstrated the significant impact of eating disorders on the whole family. We have identified two significant programmes that we will introduce to support families to help their loved ones if we are able to secure the funding to do so. These are:



1. Introducing a volunteer-led telephone peer support programme for families, involving a weekly phone call to provide support, encouragement, reassurance and a listening ear from family members of someone who has recovered from an eating disorder.



2. Establishing an advocacy service and providing printed information and telephone and email support to empower family members to assert their loved one's right to best practice treatment, and their own right to information and involvement when this is being denied.

Further research

Our findings have also highlighted the need for further research in a number of areas. We will seek funding to undertake this research, or support others to perform it:



1. We have found that families often feel disempowered when it comes to their loved one's eating disorder treatment. There is a need to collate evidence of the benefits of optimal involvement of families in the treatment of their loved ones, and to establish the degree to which best practice is experienced by families.



2. There is strong evidence that intensive community treatment can be as effective as inpatient care in promoting recovery in children and young people. However, research is needed to establish whether adults can be as readily treated by an intensive community approach.



3. There is a need to quantify the benefits to sufferers, their families and the public purse of a shift from inpatient to intensive community treatment for children and adolescents, and to highlight the benefit of transferring savings from inpatient care to allow more people to be treated sooner.

We will also publish a comprehensive report of the research undertaken for this report, and make the data set available for others to examine and carry out their own analysis. This report has only highlighted the key findings from this research, and there are further lessons and conclusions that will emerge as we complete our full analysis and as others bring a fresh perspective.

This report has focused on healthcare in England, and we will include an analysis of the situation in the rest of the UK in our full report.

Campaigning

We have identified a number of recommendations for Government and other policymakers resulting from our findings, which are listed elsewhere in this report. We will continue to make the case for these changes and empower those affected by eating disorders to make their voice heard, both locally and at a national level.

Methodology

For this research we carried out two online surveys, submitted Freedom of Information requests, interrogated government spending data, and conducted qualitative telephone interviews.

'Accessing treatment for an eating disorder' survey

We carried out an online survey in early 2017, which we promoted through the Beat website, email, and social media.

3,158 individuals accessed the survey. For this report, we have analysed the data from the 1,478 respondents who were sufferers from England, and who were referred to treatment between 2007-2017. This is to ensure that the data reflects recent experiences. Some of the survey questions were only applicable to certain respondents and others were optional.

This survey asked about experiences of accessing treatment for an eating disorder. It included questions about how quickly the respondents had been able to access treatment after the start of their illness, and the support and information provided between referral and the start of treatment.

The survey was open to anyone with experience of accessing treatment for an eating disorder. As a result, there is the possibility of self-selection bias. This means that the group of sufferers who chose to respond to this survey may not be fully representative of all sufferers in the UK. However, given the lack of community-based epidemiological research into eating disorders in the UK, any attempt to stratify the sample would have been based on uncertain assumptions.

'Carers experience of eating disorders' survey

We carried out a second online survey in September 2017, which we promoted through the Beat website, email and social media.

1,645 carers accessed the survey. Some of the questions were only applicable to certain respondents, and some were optional.

This survey asked carers about their experiences of caring for someone with an eating disorder. It asked questions about how quickly the relative or friend they cared for had been able to access treatment after the start of the illness and the impacts of these delays. It asked about the overall impact of the eating disorder on the carers' quality of life, the expenses they have incurred, and their priorities for improvements to care.

This survey was open to anyone who had ever considered themselves to be a 'carer' of someone with an eating disorder. As a result, there is the possibility of self-selection bias. This means that the group of carers who chose to respond to this survey may not be fully representative of all carers of someone with an eating disorder in the UK. However, given the lack of data available on the demographics and experiences of carers of people with an eating disorder in the UK, any attempt to stratify the sample would have been based on uncertain assumptions.

Freedom of Information (FOI) requests

In March 2017, Beat sent Freedom of Information (FOI) requests to all NHS Mental Health Trusts in England.

The aim was to obtain data about specialist inpatient eating disorders services in England that is not already publicly available. The FOI included questions about BMI on admission and discharge, duration of admissions, cost of treatment, number of incidents and proportion of patients readmitted within 12 months.

We received data covering 22 NHS inpatient eating disorders services in England. In this report we have reported the data from the 18 Adult (or all-age) services.

CCG spending

We extracted data for CCG spending on Children and Young People's eating disorders services in 2016/2017 from NHS England's 'Mental Health Five Year Forward View Dashboard Q4 2016/2017' publication ⁽⁷⁾. We contrasted this with data provided by the Department of Health in answer to Parliamentary Question 50911 ⁽⁸⁾. This Parliamentary question asked how the 'additional funding' had been allocated to each CCG for 2016/2017.

Estimating different costs of different patient pathways

We used the unit costs of different forms of treatment, which had been cited previously by PwC, to generate indicative costs of two alternative (fictional) patient pathways ⁽¹¹⁾. The aim of this calculation was to illustrate the significant cost savings which can be made for the NHS through investment in early intervention.

Qualitative interviews with carers

We carried out in-depth interviews with 20 individuals: 11 carers of people who have or have had anorexia nervosa (eight mothers, two fathers and one sister), and nine people who have or have had anorexia nervosa.

The interview was designed to be no longer than 40 minutes. All interview questions were designed to be neutral and open-ended, and the interviewer was permitted to be flexible in their phrasing of questions.

The interviews were recorded and transcribed, before being analysed using thematic analysis as described by Braun & Clarke (2006) ⁽¹²⁾.

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Helpline: 0808 801 0677
help@beateatingdisorders.org.uk

Youthline: 0808 801 0711
fyp@beateatingdisorders.org.uk

 @BeatEDSupport

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Online support

Visit beateatingdisorders.org.uk for message boards, online support groups, one-to-one chat and more information about eating disorders and recovery.

Use helpfinder.beateatingdisorders.org.uk to find services in your area.

 @beatED

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