



Eating Disorders Awareness Week 2021: Key Policy Asks

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Our key policy ask for each of these areas is listed at the top of each section.

Policies and research evidence cited in this briefing are accessible via hyperlinks. Quotes are included throughout from people with lived experience of eating disorders, professionals, organisations and others. All names attributed to quotes are pseudonyms.

Summary of Key Policy Asks

This document outlines our key concerns and specific policy recommendations for the following priority areas:

Treatment for Adults

Introduction of a fully funded ‘Access and Waiting Time Standard’ for adults with an eating disorder in England.

This would enable much more rapid progress towards an NHS where all adults with an eating disorder can quickly access evidence-based treatment.

Treatment for Children and Young People

Achievement of the ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’ in every area of England.

While good progress has been made overall, there is still a postcode lottery. Some children and young people are unable to access an evidence-based service or are made to wait months to start treatment. Clinicians have raised concerns about promised extra funding not reaching frontline services.

Campaigns to address obesity

Public health campaigns to address obesity are informed by experts from the field of eating disorders, including experts by experience.

There is a risk that campaigns to address obesity can promote messages that are harmful to people with eating disorders and those at risk of developing one.

Research funding

Significant increase in the funding awarded for research into eating disorders.

Further research is key to improving our understanding of how best to treat and ideally prevent eating disorders. Eating disorders research receives less than 1% of mental health research funding in the UK. Far more investment is needed considering the prevalence and severity of these conditions and the economic and social costs of the status quo.

Medical training on eating disorders

Eating disorders are appropriately taught and assessed at all UK medical schools, and all junior doctors in the UK gain clinical experience during their foundation training.

Learning about eating disorders is generally overlooked in UK medical training, with severe consequences for the prognosis and safety of patients.

Introduction

About Eating Disorders

Eating disorders are serious mental illnesses. Around 1.25 million people in the UK have an eating disorder. Eating disorders affect people of any age, gender, ethnicity or background. They have major impacts on individuals, families, the NHS, social care and wider society.

Types of eating disorders include binge eating disorder, bulimia, anorexia, other specified feeding or eating disorder and avoidant/restrictive food intake disorder. Eating disorders have high mortality rates, with anorexia having the highest mortality rate of any mental illness, and the mortality rates of bulimia nervosa, binge eating disorder and other eating disorders also being high.

People with eating disorders typically develop severe physical health problems and overall quality of life has been estimated to be as low as in symptomatic coronary heart disease or severe depression. Without early intervention, many become unable to participate in education or employment.

However, recovery is possible. Access to the right treatment and support is life-changing, and early intervention provides the best chance for recovery. Delays prolong the suffering of the individual and those who care for them, as well as significantly increasing the costs to the NHS, as hospital admission becomes more likely. Despite this, those who are able to access treatment experience an average three-and-a-half-year gap between onset and start of treatment, due to delays in identification, referral, and waiting times.

Families and other carers can play an important role in recovery, yet they are often not empowered to provide this support.

The difference you can make as an MP or Peer

In recent years the support of MPs and Peers has helped increase the political profile of eating disorders. This support has been crucial in unlocking much needed investment for NHS eating disorders services for children and young people in England and also in lobbying for improved medical training on eating disorders.

However, there is much more work to do before we have a health system and society that enables everyone affected by eating disorders to get the help they need.

Tabling written or oral parliamentary questions and writing to Ministers are valuable actions that Members can take to support the cause. Members are also invited to join the All-Party Parliamentary Group for Eating Disorders.

Eating Disorders Awareness Week 2021: Binge Eating Disorder



This year the theme of Eating Disorders Awareness Week is binge eating disorder. Binge eating disorder will affect one in fifty of us in our lifetime. It is the most common but perhaps the least understood eating disorder. People with binge eating disorder regularly feel out of control when they eat and feel very distressed afterwards. It isn't about being greedy or lacking in willpower, but a serious mental illness. It can affect anyone of any age, gender, ethnicity or background.

In November 2020, **29% of contacts to Beat's Helpline were about binge eating disorder**. Our Helpline Advisors consistently hear that people with binge eating disorder experience significant shame and suffer alone, without seeking help due to the fear of how others might react. If we are to achieve our vision to end the pain and suffering of eating disorders, we need to change the conversation about binge eating disorder. We must challenge harmful stereotypes about the disorder so people living with this serious mental illness can find kindness and compassion when they bravely reach out for help.

In 2020 Beat submitted a Freedom of Information request to NHS Trusts that provide eating disorder services. The response rate was 83%. Of those providers that responded, **19% said that they do not offer any treatment for people with binge eating disorder**, while 28% said that they provide some treatment with exceptions depending on age or geographic area. A small number of the providers that offer treatment ration access to it by only accepting those who meet severity criteria.

The Government and NHS leaders should ensure that, in line with national guidance, all eating disorder services are commissioned to provide NICE-recommended treatments for people with binge eating disorder, without exceptions based on geography, age or severity.

Impact of COVID-19 on people affected by eating disorders

COVID-19 and the resulting lockdown restrictions are having profound, negative impacts on people affected by eating disorders. The disruption caused to routines, living arrangements, opportunities for physical activity and access to treatment make the pandemic especially challenging for people with eating disorders and those that support them.

In a Northumbria University survey of people with an eating disorder conducted during the first lockdown, nine out of ten respondents said that their symptoms had got worse as a result of the pandemic, with 30% reporting that their symptoms had got much worse.

The impacts of COVID-19 are also evident through the scale of demand for Beat's support services. **Demand for support services offered by Beat was 173% higher in January 2021 than it was in February 2020.** In December 2020 124 safeguarding concerns were reported by support services at Beat. This was a marked rise upon on the 24 such reports made in January 2020. Beat welcomes the 'Emergency Funding' package that the Government introduced to support the work of charities during the pandemic.

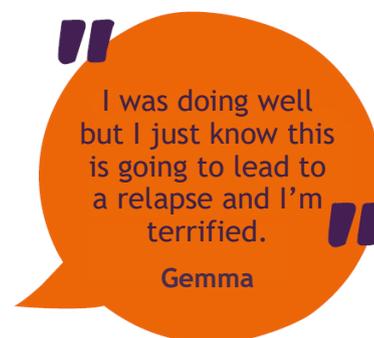
Referrals for children and young people to community eating disorder services in England were rising significantly before the pandemic**. Now they are rising even faster. The total number of people aged 18 or under referred to these services from March to October 2020 was 83% higher than across March - October 2019**. From July to September 2020 the proportion of children and young people starting treatment that were classified as urgent cases was 5% higher than during the same period in 2019.

In 2017 the Parliamentary and Health Service Ombudsman highlighted that lives were being put at risk due to the limited capacity of adult eating disorder services in England. Referrals for adults requiring treatment for an eating disorder in England were 9% higher in total over April - July 2020 than across the same period in 2019.

Clinicians across the country are reporting that far more patients are presenting at a stage where they are already severely ill or in crisis. They are also

expressing concerns about the strains on the current workforce and the need for plans to support staff and boost recruitment and retention. These concerns were echoed by Simon Stevens in evidence given to a joint select committee inquiry on 26 January, when he said: *"...in other areas, such as young people's mental health services and eating disorders, urgent referrals are going up very sharply. The second thing we need to do, over and above what we were going to be doing anyway, is to make sure we have taken account of those new needs."*

In the 2020 Spending review the Government pledged to provide an additional £500m of funding for mental health services in 2021/22. The Government and NHS England/Improvement should ensure that a fair share of this funding reaches eating disorder services, so that they are better equipped to cope with the rising demand.



** Data provided to Beat by the NHS Strategy Unit's analysis of Mental Health Services Data Set (v4), accessed via the NCDR service.

Treatment for adults

Our key policy ask:

- Introduction of a fully funded 'Access and Waiting Time Standard' for Adults with an Eating Disorder in England.

This would enable much greater progress towards an NHS where all adults with an eating disorder can quickly access evidence-based treatment.

There are no waiting time targets in place for adults with an eating disorder in England.

The current state of service provision for adults in England

Adult eating disorder services in England are severely under-resourced. They typically have either long waiting lists or referral criteria, which means that many adults are blocked from accessing the treatment they need until they have become even more seriously ill. This is despite evidence showing that the sooner a person with an eating disorder receives treatment, the better their chance of making a full and sustained recovery and the lower the costs to the NHS.



Adults with eating disorders face a postcode lottery in trying to access specialist treatment. Very little data is published on adult eating disorder services.

A Freedom of Information request submitted by Beat in 2018 found that, **in 2017/2018 the numbers of adults accessing specialist treatment varied sevenfold between different service providers**. In some areas, treatment is only granted to adults with anorexia based on whether their BMI is 'low enough'. Treatment for people with bulimia can be rationed by the frequency of bingeing and purging episodes. This contradicts guidance from the National Institute for Health and Care Excellence (NICE), which says that severity and risk can only be judged on the basis of a comprehensive clinical assessment. In many areas there is no

treatment provided for people with binge eating disorder, despite its severity and relatively high prevalence.

Only 26% of adult patients started treatment at a specialist service within four weeks of referral in 2017/2018. On average patients waited nine weeks, although this varied widely, with an average waiting time at one service provider of five-and-a-half months.



There was a ninefold difference in staff per patient ratios, illustrating variation in the capacity of services.

The lack of a mandatory care pathway has enabled some Clinical Commissioning Groups (CCGs) to require that adults are first referred to a non-specialist mental health service, or that referrals to specialist treatment must be approved by a panel. This creates unnecessary delays, which are potentially dangerous given the importance of rapid access to specialist treatment.

Some areas do not have a specialist service for adults. **From April to July 2020 1,375 people (21%) over 18 years of age (in England) were referred to non-specialist mental health services for eating disorder treatment**. This is concerning as these services often do not have the required capacity and expertise.

In recent years additional investment has been made into specialist treatment for those under the

age of 18 to support the implementation of an ambitious national 'Access and Waiting Time Standard'. This has led to significant improvements in timely access to evidence-based treatment for children and adolescents. However, many of the young people who will have benefited from these improvements will need to continue their treatment into adulthood.



In 2017 the Parliamentary and Health Service Ombudsman (PHSO) published a damning report into the failings that led to the deaths of 19-year old Averil Hart from anorexia and two other adults with an eating disorder. It expressed alarm at failures to coordinate care and the postcode lottery adults face when trying to access quality treatment. The Ombudsman explained that achieving parity in access and quality between adult eating disorder services and those for children and young people is essential to preventing further tragedies.



Progress but a need for greater urgency

In 2019/2020 and 2020/2021 eight areas have received extra funding to help develop understanding of the resources required for adult community eating disorder services to achieve a four-week waiting time target. NHS England/Improvement is yet to clarify how these pilots will be evaluated, and whether it intends to publish the lessons learned.

As part of the NHS Long Term Plan NHS England/Improvement has pledged to allocate additional investment to develop new models of care for adults with severe mental illness, including adults with eating disorders from 2021- 2024. As part of this work, NHS England/Improvement recently announced that from 2021/22 new early intervention services for young adults will be established in a further 18 areas of the country, building on a successful model developed in South London.

While these are important steps, we understand that the additional funding currently allocated for adult community mental health services will likely be insufficient to enable the introduction of a national access and waiting time standard for adults with an eating disorder before 2024.

The Government should increase the funding allocated for adult community mental health services so that NHS England/Improvement is able to introduce an Access and Waiting Time Standard for Adults with an Eating Disorder.



Treatment for young people

Our key policy ask:

- **Achievement of the ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’ in every area across England.**

While good progress has been made overall, there is still a postcode lottery. Some children and young people are unable to access an evidence-based service or are made to wait months to start treatment. Clinicians have raised concerns about promised extra funding not reaching frontline services.

The access and waiting time standard

The introduction in 2015 of the [‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’](#) set for the first time clear expectations regarding access to specialist treatment for under-18s. The standard says that by 2020/2021, 95% of children and young people will start NICE-approved treatment within one week of referral in urgent cases and within four weeks in all other cases. Crucially the Government and NHS England made extra funding available. [The NHS Long Term Plan](#) confirmed that the policy will continue to be applied beyond 2021 and will be supported by further additional funding.

Some areas of the country are being left behind

We warmly welcomed these developments and acknowledge that significant improvements have been made in the care available for children and young people. However, this progress has varied widely, with some areas being left behind.

Although NHS England/Improvement believes that it is on track to meet these targets by 2020/2021, the [national averages hide major variation](#) in waiting times both between and within regions. In 2019/2020, 94% of non-urgent cases in the North West NHS region started treatment within the target of four weeks, in contrast to 74% in the South East.

This [variation continued between Clinical Commissioning Groups \(CCGs\)](#). **In 2019/20, the percentage of CCGs with 15 urgent cases or more meeting the target varied from 22% to 100% and for CCGs with 40 or more routine cases, the percentages ranged from 55% to 100%.**

In 2015, [NHS England](#) stated that children and young people in every area should be able to refer themselves for a specialist assessment by 2020/2021, to help speed up access to treatment. This is not available in every area. In January 2020 **Beat found that only a third of services were advertising self-referral as an option on their website.**

It is crucial that services in every area receive enough funding and can recruit and retain the staff they need to enable them to meet local need as the number of referrals continues to rise. The additional funding allocated for these services by the Government and NHS England/Improvement has been provided to local CCGs. In 2019/20 and 2020/21, [CCGs were allocated significantly more funding](#) for these services. Clinicians have expressed concerns that this additional funding has not reached frontline services in many areas.

The Royal College of Psychiatrists has [highlighted shortages in psychiatric input](#) in eating disorders services. Health Education England’s [‘Stepping Forward to 2020/2021’](#) strategy for the mental health workforce included an objective to recruit an additional 30 consultant eating disorder psychiatrists by 2020/2021. We are not aware of a progress update having been published for this.

MPs and the Government should hold the NHS and other responsible stakeholders to account for comprehensive implementation of the ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’, in every area of England.

Campaigns to address obesity

Our key policy ask:

- **Public health campaigns to address obesity are informed by experts from the field of eating disorders, including experts by experience.**

There is a risk that campaigns to address obesity can promote messages that are harmful to people with eating disorders and those at risk of developing one.

Beat recognises the importance of addressing obesity. However, public health campaigns must be evidence-based and avoid causing harm to people with eating disorders.

Campaigns to address obesity must:

- Do no harm to people with eating disorders.
- Be informed by people with lived experience of eating disorders, and experts from the field of eating disorders.
- Avoid the use of reductionist and stigmatising language.
- Be evidence based and understand obesity as a complex interaction involving multiple factors, rather than an individual's choice or something to be ashamed of.

The Government's 'Tackling obesity' policy paper

In July 2020, the Government published 'Tackling obesity: empowering adults and children to live healthier lives'. **The Government and public health leaders should continue to consult with Beat and other eating disorders experts, including experts by experience, when implementing the policies outlined in the 'Tackling obesity' paper.**

It made me feel like a criminal for being overweight and I sat in tears.

Gemma

"During the week that the Government released the policy paper 'Tackling obesity: empowering adults and children to live healthier lives', contact with Beat's Support Services specifically mentioning obesity or similar increased by 165%."

Andrew Radford, Beat Chief Executive.

'Tackling obesity' outlines several policies, including mandatory calorie labelling, the promotion of a new weight-loss app and the expansion of weight management services.

Calorie labelling

The 'Tackling obesity' paper outlines plans to make calorie labelling mandatory on menus in food businesses with over 250 employees.

Research has found that when making hypothetical food choices, **if a menu includes a calorie count, individuals with anorexia and bulimia are more likely to order food with significantly fewer calories, whereas people with binge eating disorder are more likely to order food with significantly more calories.**

There is only a small body of low-quality evidence supporting the idea that calorie counts on menus will lead to a reduction in calories purchased by the general population. **The Government should not introduce mandatory calorie labelling on menus.**

Public Health England's weight loss app

Other measures included in the 'Tackling obesity' paper include a public campaign called 'Better Health', which includes promotion of a weight loss app. Beat welcomes the changes that Public

Health England has made to this app to discourage people with a low BMI from using it. Beat is working with Public Health England on further measures to reduce the risk of this app causing harm to people with eating disorders and those at heightened risk of developing one.

Attempts to embark on strict, restrictive diets without support and supervision from health professionals are associated with binge eating and further weight gain over time. Restrictive eating has also been found to trigger the onset of an eating disorder.

Expanding weight management services

Beat welcomes the Government's pledge within the 'Tackling obesity' paper to expand access to weight management services.

Many people with eating disorders also live with obesity. Various studies have shown that up to 30% of those who access weight management services would meet the diagnostic criteria for binge eating disorder. It is crucial that this group of people are identified and receive the most appropriate evidence-based support. Referring people with an eating disorder to a weight loss programme, without first addressing their binge eating, is likely to cause additional distress, but is unlikely to result in sustainable weight loss. NICE guidance states that health professionals should advise people with binge eating disorder against attempting to lose weight (for example, through dieting) given the likelihood of it triggering further binge eating.

The expansion of weight management services should be accompanied by measures to ensure that they can identify and refer those that require specialist eating disorder assessment.

Research funding

Our key policy ask:

- **Significant increase in the funding awarded for research into eating disorders.**

Further research is key to improving our understanding of how best to treat and ideally prevent eating disorders. Eating disorders research receives less than 1% of mental health research funding in the UK. Considering the prevalence and severity of these conditions and the economic and social costs of the status quo far more investment is needed .

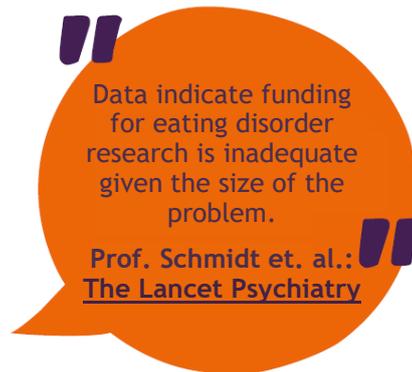
While some high-quality research is underway and effective therapies have been developed, we still don't have a full understanding of what causes eating disorders or how best to treat them.

This is not surprising when considering the way that research funding is allocated in the UK. Total UK research funding invested in mental health research fell steadily each year (in real terms) from 2015 - 2019. Analysis by the charity MQ found that just £9 per person affected was spent by UK-based funders on mental health research per year from 2014 - 2017. During this time, around £228 per person affected was 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.

A 2020 report by the International Alliance of Mental Health Research Funders showed that **although the UK plays a leading role in eating disorders research, it received on average less than 1% of the total grant funding awarded for UK mental health research per year from 2015 - 2019.**

The Government is a major funder of health research and has influence over other funders. It 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.

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.



Research into eating disorders should be seen as a prudent investment. Often chances for early intervention are missed. Treatments are not always effective. As a result, many patients are admitted to expensive hospital treatment. Hospital admissions in England for people with eating disorders have risen significantly in recent years. In 2015 PwC estimated that eating disorders result in lost income to the UK economy of £6.8 - £8 billion per year.

The Government should take steps to support a significant increase in funding for eating disorder research so that it reflects the number of people affected, the severity of these conditions, and the economic and social costs of the status quo.

Medical training on eating disorders

Our key policy ask:

- Eating disorders are appropriately taught and assessed at all UK medical schools, and all junior doctors in the UK gain clinical experience during their foundation training.

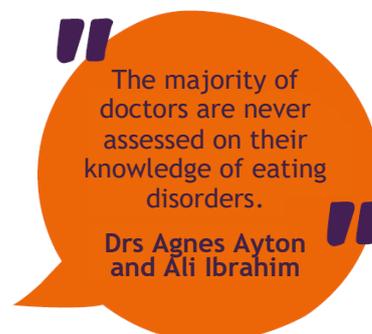
Learning about eating disorders is generally overlooked in UK medical training, with severe consequences for the prognosis and safety of patients.

Overlooked in medical training

- On average just 1.8 hours is spent on teaching about eating disorders in UK medical schools.
- One in five medical schools do not provide any teaching.
- Assessment drives learning, yet many medical schools do not include a question about eating disorders in their final exams.

A 2017 Beat survey of over 1,100 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'.**

There are many fantastic GPs delivering excellent care to people with eating disorders. Unfortunately, though we have heard many accounts of GPs failing to take people's disclosures seriously, where people with eating disorders have been told "it's just a phase", "just eat a bit of toast", "you're a nice size so you don't have anything to worry about" and even some cases where people have been encouraged to lose more weight in order for them to be taken seriously. These comments highlight the importance of training.



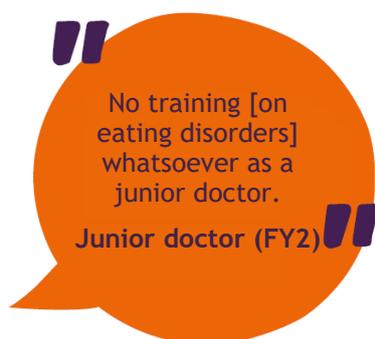
Research suggests that most non-specialist doctors lack confidence in and knowledge of how to help patients with eating disorders, and that this leads to delays in treatment and inappropriate management.



‘Ignoring the Alarms’

The Parliamentary and Health Service Ombudsman’s (PHSO) 2017 report found that low levels of knowledge among doctors and other health professionals was among several failings that led to the deaths of 19-year-old Averil Hart and two other people, and that there is not enough training on eating disorders for tomorrow’s doctors.

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 during foundation training 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.



The PHSO recommended that the General Medical Council (GMC) conduct a review of the coverage of eating disorders in medical training. In 2019 the

Parliamentary Administration and Constitutional Affairs Committee (PACAC) investigated the implementation of the PHSO’s recommendations. In response to PACAC’s report the Government said that the GMC will engage with medical schools on “developing a common approach to changes”.

Health Education England has funded Beat in collaboration with the Faculty of Eating Disorders at the Royal College of Psychiatrists to develop a training package for medical schools and foundation programmes. The feedback on the training pilot was very positive, and the package will be available to all medical schools and foundation programmes in the UK by next year. Beat are working productively with the GMC and Health Education England to promote the training.

MPs and the Government should continue to hold the GMC and medical schools to account for their responsibility to ensure that trainee doctors leave medical school with basic levels of knowledge and skills in the identification, safe management and referral of patients with eating disorders.

PACAC recommended that all junior doctors should complete a four-month psychiatry placement and that such placements should include exposure to patients with eating disorders.

The Government should ensure that all junior doctors obtain clinical experience in eating disorders during their foundation training.

Greater coverage of eating disorders in medical training and more opportunities to gain clinical experience would also be likely to encourage more trainee doctors to specialise in eating disorders, which is crucial considering existing workforce gaps.

About Beat

Beat is the UK's eating disorder charity. We exist to end the pain and suffering of eating disorders, and we are here to help anyone affected by these serious mental illnesses.

We provide information and support through Helplines, which people can call, text or email. We also run online support groups and HelpFinder, an online directory of support services.

We provide expert training, resources and consultancy to health and social care professionals and schools, and support and encourage research into eating disorders.

Beat's Helpline and other support services

Beat provides [Helplines](#) and [online services](#) for adults and young people offering support and information about eating disorders. Our services are confidential and free to use.

Individuals contacting our Helpline speak to trained advisors who are experienced in listening and talking to people affected by eating disorders. Anyone affected by an eating disorder can call, email or contact Beat's Helpline Advisors via one-to-one webchat.

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

Studentline: 0808 801 0811
studentline@beateatingdisorders.org.uk

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

Our Helplines are open 365 days a year from 9am - 8pm during the week, and 4pm - 8pm on weekends and bank holidays.

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