

# Eating disorders matter

## Beat's manifesto for the 2019 General Election



### Beat is calling for the following commitments:

- ⇒ Achievement of the *Access and Waiting Time Standard for Children and Young People with an Eating Disorder*, in every region and community
- ⇒ Introduction of an Access and Waiting Time Standard for Adults with an Eating Disorder
- ⇒ Ensuring that eating disorders are identified early and that people of all ages are supported to seek help
- ⇒ Eating disorders are appropriately taught and assessed at all medical schools and all junior doctors gain specialist clinical experience during their foundation training
- ⇒ Equitable provision of intensive day and home-based treatment to ensure care is provided closer to home
- ⇒ Parity of esteem is achieved for mental health research funding, including for eating disorders research.

This has been produced to influence the UK manifestos of the political parties contesting the 2019 General Election. As health is a devolved issue this means that some of its content is only relevant to England. **Beat has also produced 2019 General election manifestos for Northern Ireland, Scotland and Wales** and these are available on request from [campaigning@beateatingdisorders.org.uk](mailto:campaigning@beateatingdisorders.org.uk).

### About eating disorders

Eating disorders are serious mental illnesses. An estimated 1.25 million people in the UK have an eating disorder<sup>1</sup>. The most common age of onset is 15–25 years old, during a developmentally sensitive time<sup>2</sup>.

Eating disorders have major impacts on individuals, families, society, the NHS and social care. Anorexia has the highest mortality rate of any mental illness, and the mortality rates of the other eating disorders are also high<sup>3</sup>. 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<sup>2</sup>. Caregivers typically experience high levels of psychological distress<sup>4</sup>. Time spent caring for someone with severe anorexia nervosa is around twice as high as the average for other serious illnesses<sup>2</sup>. Access to the right treatment and support is life changing.

## ⇒ **Achievement of the Access and Waiting Time Standard for Children and Young People with an Eating Disorder, in every region and community**

The introduction of an access and waiting time Standard for children and young people<sup>5</sup> – setting clear expectations around access to evidence-based treatment within maximum waiting times – and funding to support this has been a major step forward. However some areas of the country are being left behind.

**The next Government should hold the NHS to account for comprehensive implementation of the Access and Waiting Time Standard for Children and Young People with an Eating Disorder, in every region and community.**

### **Waiting times**

While NHS England expects to meet the waiting times targets at the national level, there are major inequalities both between and within regions. For example in 2018/19 92% of routine referrals in the London NHS region started treatment within the target of 4 weeks, in contrast to 76% in the South East<sup>6</sup>.

At the more local level the most recent 12 months of data (up to end of Q1 2019/2020) shows that just 34% of urgent referrals in one CCG started treatment within the expected 1 week. In another CCG the figure was only 57%. Just 29% of routine referrals in one CCG started treatment within 4 weeks and in another CCG this figure was only 43%<sup>6</sup>.

### **Self-referral**

NHS England has stated that children and young people in every area should be able to self-refer to specialist treatment by April 2020, as a key step to improving access to treatment<sup>5</sup>. Despite this imminent deadline few services are advertising the option of self-referral on their website<sup>7</sup>.

### **Spending and staffing**

It is crucial that services in every area receive sufficient funding and can recruit and retain the staff to enable them to meet local need as the number of referrals continues to rise.

In 2018/2019 per-capita spending varied widely between areas. Two CCGs spent just 17p per capita on community eating disorder services for children and young people, whereas one CCG spent £5.55 per capita<sup>8:9</sup>.

In 2018/2019 28% of CCGs spent less on these services than they had planned at the start of the year and some spent less than half<sup>8</sup>. One CCG planned to spend £455,000 but only spent £137,000, whilst another planned to spend £275,000 but actually spent £137,000<sup>8</sup>.

## ⇒ Introduction of an Access and Waiting Time Standard for Adults with an Eating Disorder

**The next Government should increase the funding allocated for adult community mental health services, to enable NHS England to introduce an Access and Waiting Time Standard for Adults with an Eating Disorder as soon as possible.**

### A “Cinderella service”

Adult eating disorder services did not receive additional funding under the *Five Year Forward View for Mental Health*<sup>10</sup>. In December 2017 the Parliamentary and Health Service Ombudsman (PHSO) published a damning report into the treatment of adults with eating disorders, expressing alarm at failures to coordinate care, low levels of knowledge among non-specialist doctors, and the postcode lottery people face when trying to access quality treatment. It demonstrated that these problems lead to lives being lost and stressed the importance of parity between adult eating disorder services and those for children and young people<sup>11</sup>.

In 2018/2019 Beat conducted research to investigate access to treatment, waiting times and staffing levels at adult eating disorder services in England<sup>12</sup>. The findings supported the PHSO’s conclusion that adults with eating disorders face a postcode lottery to access specialist treatment. In 2017/2018 the numbers of adults accessing treatment varied seven-fold between providers. Only 26% started treatment within 4 weeks. The average waiting time was 9 weeks, although this varied widely with one provider having an average wait of 5.5 months. The staff per patient ratio also varied widely, but the mean ratio was low compared to other community mental health services at 6.4 WTE per 100 patients<sup>12</sup>.

Some commissioners and services have rationed access to treatment purely on the basis of Body Mass Index (BMI), in contravention of NICE guidance. Some adult eating disorder services do not offer treatment for patients with Binge Eating Disorder, despite its relatively high prevalence and severity.

### Progress, but a need for greater urgency

As part of the Long Term Plan NHS England has allocated additional investment to develop ‘new models’ of integrated care for adults with severe mental illness, including adults with eating disorders, from 2021-2024<sup>13</sup>. In 2019/2020 and 2020/2021 8 STP/ICS regions will receive additional funding to help develop understanding about the resources required to achieve a four-week access standard for adult community eating disorder services<sup>14</sup>. 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 PHSO was clear that achieving parity with services for children and young people is essential to preventing further tragedies<sup>11</sup>, so there is need for greater urgency.

## ⇒ Ensuring that eating disorders are identified early and that people of all ages are supported to seek help

**The next Government should ensure that sufficient funding is provided to enable the expansion of services and initiatives which support early identification of eating disorders and help-seeking.**

Early intervention provides the best chance for recovery<sup>15</sup>. Delays prolong the suffering and significantly increase the costs to the NHS, as hospital admission becomes more likely<sup>16</sup>. Despite this, those who are able to access treatment experience an average three-and-a-half-year gap between onset and starting treatment<sup>16</sup>. By far the longest component of this delay is the period of time before the person seeks help: an average of 2 years and 10 months<sup>16</sup>.

Due to the complex nature of eating disorders, in some cases sufferers do not recognise that they are ill. People with eating disorders often feel ashamed or worried that they won't be understood or taken seriously, in some cases due to negative experiences of seeking help in the past<sup>17</sup>.

Both NHS England<sup>18</sup> and the Welsh Eating Disorder Service review<sup>19</sup> have highlighted the important role that eating disorder services, primary care, education and voluntary and community sector organisations (amongst others) can play in ensuring early identification and supporting help-seeking. It is crucial that sufficient funding is made available to make this a reality.

## ⇒ Eating disorders are appropriately taught and assessed at all medical schools and all junior doctors gain specialist clinical experience during their foundation training

### **Overlooked at medical school**

On average just 1.8 hours is spent on teaching about eating disorders in UK medical schools, with 1 in 5 schools providing no teaching at all<sup>20</sup>. Some that provide theoretical teaching do not offer any clinical skills training. Assessment drives learning, yet of the schools which responded to the question, only half included a question about eating disorders in their final exams<sup>20</sup>. Overall the data suggests that education and training on eating disorders is a low priority at many UK medical schools.

The PHSO's 2017 report concluded that low levels of knowledge among doctors and other health professionals was amongst several failings which led to the death of 19 year old Averil Hart and two other unnamed individuals and that the current level of eating disorder training is not enough<sup>11</sup>. Academic research suggests that most non-specialist doctors lack confidence and knowledge in how to help

patients with eating disorders and that this leads to delays in treatment or inappropriate management<sup>20</sup>.

Greater coverage of eating disorders at medical school would also likely help to address the shortage of doctors choosing to specialise in eating disorders.

Earlier this year the Parliamentary Administration and Constitutional Affairs Committee (PACAC) investigated the implementation of the PHSO's recommendations<sup>21</sup>. In response to their report the Government said that the GMC will engage with medical schools on "*developing a common approach to changes*"<sup>22</sup>.

**The next Government should hold the GMC and medical schools to account over 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.**

### **Specialist clinical experience at foundation stage**

Due to the severe impacts of eating disorders on physical health, they are relevant to a wide range of medical specialisms<sup>20</sup>. However opportunities to learn about their treatment in greater depth through specialist clinical placements are extremely limited<sup>20</sup>.

Foundation training is based around 4-month clinical placements, but currently only about half of junior doctors experience a psychiatry placement<sup>21</sup>. 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<sup>21</sup>. As well as improving knowledge and clinical skills this would also likely increase the number of junior doctors applying to specialise in eating disorders.

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

## **⇒ Equitable provision of intensive day and home-based treatment to ensure care is provided closer to home**

**The next Government should set an expectation that intensive day- and home-based eating disorder treatment is commissioned in every area in England and that this meets the levels of intensity indicated by the evidence as necessary to provide optimum outcomes.**

In many cases intensive day patient and intensive home-based treatments can be as effective as inpatient admission. They are also generally more acceptable to patients and their families, as well as being considerably less expensive<sup>23</sup>.

They are an essential part of any ambition to reduce the distressing and costly practice of patients

being sent hundreds of miles from home to access treatment. For example last year *The Guardian* reported that from April 2016 to August 2018 154 patients from England were admitted in Scotland<sup>24</sup>.

The provision of this tier of treatment can provide a step-down from inpatient care, preventing patients staying in hospital longer than necessary and helping to provide a smooth transition back into the community, potentially reducing the need for readmission<sup>23</sup>.

Despite these advantages, a Beat Freedom of Information request found that just one third of eating disorder services in England provide an intensive day- or home-based treatment which offers the levels of intensity indicated by the evidence as necessary to provide optimum outcomes<sup>23</sup>.

## ⇒ Parity of esteem achieved for mental health research funding, including for eating disorders research

**The next Government should significantly increase the funding it provides for eating disorders research so that it reflects the number of people affected and the severity of these conditions.**

While there are some excellent examples of treatment and some high quality research underway, 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.

An analysis by the charity MQ found that just £9 per person affected is spent on mental health research per year, in contrast to £228 per person spent on cancer research. They found that just 96p per person affected is spent on eating disorders research<sup>25</sup>. As a major funder of health research the Government has an important responsibility to ensure that commitments to achieve parity of esteem for mental health include the allocation of research funding.

**The next Government should commission a national population-based study of the prevalence of eating disorders.**

A robust estimate of the prevalence of eating disorders is needed to enable policy makers, commissioners, service-users and the public to understand the levels of unmet need and the resources required to address it.

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