

# Eating disorders matter



## Beat's Scottish Manifesto for the 2019 General Election



### Beat is calling for the following commitments:

- ⇒ Commissioning and acting on the findings of an independent review into treatment and support for people affected by eating disorders in Scotland.
- ⇒ Ensuring that eating disorders are identified early and that people in Scotland are supported to seek help
- ⇒ Eating disorders being appropriately taught and assessed at Scottish medical schools and all junior doctors undergoing Foundation training in Scotland to benefit from specialist clinical experience of eating disorders.
- ⇒ Parity of esteem achieved for mental health research funding, including for eating disorder research in Scotland.

This document has been produced to influence the Scottish manifestos at the 2019 UK General Election. As health policy is devolved many of the commitments we are calling for could only be delivered by a Scottish Government. Therefore when addressing these issues in this manifesto we ask Parliamentary candidates to commit to using their influence through campaigning if elected as an MP.

### 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>. Carers 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>. Many people suffer in silence with only a minority accessing evidence-based treatment. However, access to the right treatment and support is life changing.

## ⇒ **Commissioning and acting on the findings of an independent review into treatment and support for people affected by eating disorders in Scotland**

**In the next Parliament Scottish MPs should campaign for the Scottish Government to commission and publish an independent review of treatment and support for people affected by eating disorders.**

**This review should include full consideration of the steps needed to:**

- **Reduce waiting times.**
- **Improve access to evidence-based treatment, including by implementing self-referral.**
- **Ensure equitable provision of intensive day- and home-based treatment, so that care is provided closer to home.**
- **Consistently provide the information and support families and other carers need.**
- **Ensure systematic collection and reporting of high quality data on the experiences of patients, carers and staff, to enhance accountability.**

### **Long waiting times**

The Scottish 10 year Mental Health Strategy details a commitment to delivering on the principle of '*ask once, get help fast*'<sup>5</sup>. Yet this is far from a reality for many people in Scotland with an eating disorder.

A 2017 Beat survey of 125 people who lived in Scotland when they were first referred to eating disorder treatment, found a mean average wait of 7 months from seeking help from their GP to starting treatment<sup>6</sup>. A 2019 Freedom of Information (FOI) request into adult eating disorder treatment in Scotland submitted by Beat found that only 3 of the 10 Health Boards which provide specialist treatment for adults held data on their waiting times from referral to start of treatment in 2017/2018. At two of these Health boards the median waiting times were 37 weeks and 14 weeks respectively<sup>7</sup>.

People with eating disorders often experience delays in securing a referral and in such cases the option of self-referral can be crucial. In an FOI submitted by Beat in 2018 only one of the seventeen Child and Adolescent mental health services in Scotland which responded reported accepting self-referral<sup>8</sup>.

### **Geographic variation in access to treatment**

Beat's 2019 FOI found that the provision of specialist treatment for adults in Scotland is highly variable between areas and is often only accessible to patients who are already severely unwell<sup>7</sup>. One NHS health board does not have an adult eating disorder service. One NHS health board only provides a day patient service and another NHS health board only provides an Intensive treatment team for people

with severe anorexia nervosa<sup>7</sup>.

In many cases intensive day patient and intensive home-based treatments can be as effective as inpatient admission. They are generally more acceptable to patients and their families, as well as being considerably less expensive<sup>9</sup>. They can mean that patients are more easily able to receive support from family and other carers and more easily implement the skills learnt as they progress through therapy<sup>9</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>9</sup>.

Despite these advantages, a separate Beat FOI request found that 3 of the 11 mainland Health Boards in Scotland do not provide intensive day- or home-based treatment which offers the levels of intensity indicated by the evidence as necessary to provide optimum outcomes<sup>9</sup>.

## Geographic variation in staffing levels and training

There is wide variation between health boards in staffing levels at adult eating disorder services. At 31 March 2018 the health board with the most staff had 3 times more than the lowest, after accounting for population sizes<sup>7</sup>.

The Psychology workforce in adult eating disorders in Scotland was lower at 31 December 2018 than it was at 31 December 2013 (19 WTE vs. 16 WTE)<sup>11</sup>. Some adult eating disorder services have no psychology input at all, despite this being highlighted as a 'core profession' of the multidisciplinary team by Healthcare Improvement Scotland in the clinical guideline they published in 2006<sup>11;12</sup>.

The Scottish mental health strategy also emphasises the importance of staff being trained to provide evidence-based treatments<sup>5</sup>. While the 2006 Healthcare Improvement Scotland clinical guideline on eating disorders is now in the process of being updated, there are significant training needs across Scotland, including in the delivery of family therapy for eating disorders, which is the internationally recognised first-line treatment for children and young people. In response to a BBC news FOI in 2018 into treatment for children and adolescents in Scotland<sup>10</sup>, a Consultant Psychiatrist from the Royal College of Psychiatrists in Scotland, said:

*"It's not only waiting times that are patchy. People tend to get very different treatments depending on where they go. I feel very guilty. I feel we should be able to offer our patients the best that is available. And very often its just an accident of the clinicians you have and the training they bring with them."*

## Lessons from England and Wales

### England

Children and young people with an eating disorder in England currently benefit from waiting time

targets which apply from referral to the start of evidence-based eating disorder treatment. Patients in urgent need must start treatment within 1 week, with all other patients seen within 4 weeks<sup>13</sup>. In Scotland there are no eating disorder-specific waiting time targets, instead the standard 18 week target applies (unless they are awaiting a planned inpatient admission or day care place, in which case a 12 week target applies). NHS England has also issued clear guidance to commissioners which has greatly improved access to evidence-based treatment for under 18s, while reducing waiting times<sup>13;14</sup>.

This year NHS England has published guidance setting out the service that patients and carers should receive from adult eating disorder services<sup>15</sup> and has announced plans to test the introduction of 4 week waiting time targets in pilot areas, followed by increased investment in these services as part of developing 'new models' of adult community mental health care<sup>16;17</sup>.

## **Wales**

In 2018 the Welsh Government commissioned Dr Jacinta Tan to lead a review of eating disorder care in Wales. This review was centred on the experiences of patients and carers. It provided a comprehensive analysis of the current state of service provision and the actions necessary to create a world-class service for Wales<sup>18</sup>. Earlier this year the Welsh Government welcomed the recommendations and asked Health Boards to begin implementation<sup>19</sup>. Considering the similarities between the health systems in Wales and Scotland this review and its recommendations should be carefully studied by the Scottish Government.

## **The need for a review**

When the Scottish mental health strategy was published, it was presented as a broad vision for the future<sup>5</sup>. The Scottish Government has said that its 40 actions will be revised and added to over time<sup>20</sup>. Of these initial actions, only one is specific to eating disorders. This relates to an important collaboration between Beat and NHS Lothian to provide peer-support for young people and their families and carers<sup>5</sup>.

We want to see a Scotland where eating disorders are consistently identified early, patients can quickly access evidence-based treatment close to home and where families and other carers get the information and support they need. There is a long way to go before this vision can be realised and it is clear that provision varies widely across Scotland. Our experience with FOIs and our communication with ISD Scotland has shown that little data is currently systematically collected. Therefore an independent review of treatment and support for people affected by eating disorders in Scotland must be commissioned. This is required to enable full understanding of the current state of service provision, to highlight areas of good practice and to make recommendations to the Scottish Government. This review should be co-produced with people with lived experience of eating disorders, the voluntary sector, clinical experts and representatives from other professions which are key to awareness, identification, referral and support.

## ⇒ **Ensuring that eating disorders are identified early and that people in Scotland are supported to seek help**

**In the next Parliament Scottish MPs should campaign for sufficient funding to enable the expansion of services and initiatives which support early identification of eating disorders and help-seeking in Scotland.**

Early intervention provides the best chance for recovery<sup>21</sup>. Delays prolong the suffering and significantly increase the costs to the NHS, as hospital admission becomes more likely<sup>22</sup>. Despite this a 2017 Beat survey of 125 respondents who lived in Scotland at the time of first being referred for eating disorder treatment, found a mean average of over three-and-a-half-years between onset and start of treatment. This was due to delays in identification, referral, and waiting times<sup>6</sup>. By far the longest component of this delay is the period of time before the person seeks help: an average of 3 years and 1 month<sup>6</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>23</sup>.

Eating disorder services, primary care, education and voluntary and community sector organisations (amongst others) can play key roles in ensuring early identification and supporting help-seeking. It is crucial that sufficient funding is made available to make this a reality in Scotland.

## ⇒ **Eating disorders being appropriately taught and assessed at Scottish medical schools and all junior doctors undergoing Foundation training in Scotland to benefit from clinical experience of eating disorders.**

### **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>24</sup>. Some that provide theoretical teaching do not offer any clinical skills training. Assessment drives learning, yet of the schools which responded to the FOI question, only half included a question about eating disorders in their final exams<sup>24</sup>. Overall the data suggests that education and training on eating disorders is a low priority at UK medical schools.

A Parliamentary and Health Service Ombudsman's (PHSO) report published in 2017 concluded that low levels of knowledge among doctors and other health professionals was amongst several failings which

led to the deaths of 19 year old Averil Hart and two other unnamed individuals, and that the current level of eating disorder training is not enough<sup>25</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>24</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>26</sup>. In response to their report the UK Government said that the GMC will engage with medical schools on "*developing a common approach to changes*"<sup>27</sup>.

**The next UK Government should hold the GMC and all medical schools to account over their responsibility to ensure that all trainee doctors leave medical school with basic levels of knowledge and skills in the identification, safe management and referral of patients with eating disorders.**

**In the next Parliament Scottish MPs should campaign for improved coverage of eating disorders at medical schools in Scotland.**

## **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>24</sup>. However opportunities to learn about their treatment in greater depth through specialist clinical placements are extremely limited<sup>24</sup>.

Foundation training is based around six four-month clinical placements. Currently only about half of UK junior doctors experience a psychiatry placement<sup>26</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>26</sup>. As well as improving knowledge and clinical skills in eating disorders this would also likely increase the number of junior doctors applying to specialise in eating disorders.

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

**In the next Parliament Scottish MPs should campaign for all junior doctors undergoing Foundation training in Scotland to experience a psychiatry placement which includes exposure to patients with eating disorders.**

## ⇒ Parity of esteem achieved for mental health research funding, including for eating disorder research in Scotland

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

**In the next Parliament Scottish MPs should campaign for the Scottish Government to increase the funding it provides for eating disorder research.**

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. An analysis of health research grants made by UK-based funders (unfortunately Scotland-specific data is not available) 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 disorder research<sup>28</sup>. As major funders of health research both the UK and Scottish Governments have important responsibilities to ensure that commitments to achieve parity of esteem for mental health extend to research funding.

**In the next Parliament Scottish MPs should campaign for a national population-based study of the prevalence of eating disorders in Scotland.**

A robust estimate of the prevalence of eating disorders in Scotland is needed to provide an understanding of the level of unmet need and the resources required to address it.

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