

Eating disorders matter



Beat's Welsh Manifesto for the 2019 General Election



Beat is calling for the following commitments:

- ⇒ Full implementation of the Welsh Eating Disorder Service Review's recommendations.
- ⇒ Ensuring that eating disorders are identified early and that people in Wales are supported to seek help
- ⇒ Eating disorders being appropriately taught and assessed at Welsh medical schools and all junior doctors undergoing Foundation training in Wales to benefit from specialist clinical experience of eating disorders.
- ⇒ Parity of esteem achieved for mental health research funding, including for eating disorder research in Wales.

This document has been produced to influence the Welsh 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 Welsh 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 disorder¹. The most common age of onset is 15-25 years old, during a developmentally sensitive time².

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 high³. 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 depression². Carers typically experience high levels of psychological distress⁴. Time spent caring for someone with severe anorexia nervosa is around twice as high as the average for other serious illnesses². Many people suffer in silence with only a minority accessing evidence-based treatment. However, access to the right treatment and support is life changing.

⇒ Full implementation of the Welsh Eating Disorder Service Review's recommendations

In the next Parliament Welsh MPs should campaign for full implementation of the Welsh Eating Disorder Service Review's recommendations, enabled by the allocation of sufficient funding, workforce and staff training.

The Welsh Eating Disorder Service Review

The Welsh Eating Disorders Service Review, led by Dr Jacinta Tan, Consultant Child and Adolescent Psychiatrist at Aneurin Bevan University Health Board, was developed with close engagement and input from patients and carers across the country in 2018⁵. This review was commissioned by the Welsh Government.

It found that the current system in Wales is based on reacting to patients who are already severely ill, rather than intervening early, and that there is a postcode lottery in the level and quality of treatment.

It has proposed an ambitious strategy for improvement, which prioritises early detection of eating disorders, rapid access to treatment, and equitable provision of evidence-based treatment nationwide. Its recommendations include the introduction of an ambitious four week waiting time target for patients of all ages, which would make a huge difference to eating disorder sufferers across Wales. The recommendations also include that patients and their carers are fully involved in the development of services, ensuring that families and other carers receive the information and support they need.

The Welsh Government has published the Executive summary of the review and asked Health boards to begin the process of implementing its recommendations⁶. However there are questions remaining as to whether sufficient funding, workforce and staff training will be provided to match the review's ambition of world-class treatment and support across the whole of Wales.

Beat's research findings

Access, waiting times and staffing levels

In 2019, Beat, submitted a Freedom of Information (FOI) request to all NHS health boards in Wales about eating disorder treatment for adults⁷. Under the current system introduced by the Eating Disorders Framework for Wales (2009) many patients with eating disorders are treated in primary care-based mental health services or in Community mental health teams (CMHTs)⁸. We requested data on access, waiting times and staffing levels for these patients, but almost none was available. Only one health board was able to report the mean average waiting time specifically for eating disorder treatment at their CMHT in 2017/2018 and this was 32 weeks⁷. Long waiting times at Welsh CMHTs was identified by regulators earlier this year as a key concern⁹.

The data obtained via this FOI shows that there is a postcode lottery when it comes to accessing Tier 3 specialist eating disorder services in Wales, and that the capacity of these services in terms of staffing levels varies widely between areas⁷. At 31 March 2018, after accounting for differences in population sizes, there was a 2-fold difference between the health board with the biggest caseload (number of patients) and the health board with the smallest⁷. At 31 March 2018 the health board with the most staff had 3 times more than the lowest after accounting for differences in population sizes. In proportion to the number of patients treated, the service with the most staff had 4 times more than the lowest⁷.

Self-referral

People with eating disorders often have difficulty securing the referral they need. The review recommends that services should accept referrals from all sources including self-referral⁵. In an FOI submitted by Beat in 2018 about eating disorder treatment for under 18s in Wales, only one of the seventeen health boards reported accepting self-referral at their Child and Adolescent mental health services (CAMHS)¹⁰.

Recovery in the community

A key principle of the review's vision for state of the art care in Wales is that services should be recovery-focused, helping those with severe eating disorders to recover, when possible, while living in the community and maintaining independence with appropriate support⁵.

Intensive day patient and intensive home-based treatments can be an important part of such an approach and in many cases are as effective as inpatient admission. They are also generally more acceptable to patients and their families, as well as being considerably less expensive¹¹. They can mean that patients are able to receive more support from family and other carers during their treatment and more easily implement the skills learnt as they progress through therapy¹¹.

They are an essential part of any ambition to reduce the distressing and costly practice of Welsh patients being sent hundreds of miles from home to access treatment in England. 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 readmission¹¹.

Despite these advantages, a separate Beat FOI submitted in 2019 found that just 1 of the 7 health boards in Wales provides an intensive day- or home-based eating disorder service which offers the levels of intensity indicated by the evidence as necessary to provide optimum outcomes¹¹.

Empowering families and other carers

Families and other carers often do not receive adequate support, as eating disorders can consume their own energy and wellbeing¹². They are often key to recovery; however the service review confirms that they are currently an under-used resource in Wales⁵. Empowering families and other carers will be essential to realising a world-class service for people with eating disorders in Wales¹².

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

In the next Parliament Welsh 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 Wales.

Early intervention provides the best chance for recovery¹³. Delays prolong the suffering and significantly increase the costs to the NHS, as hospital admission becomes more likely¹⁴. Despite this a 2017 Beat survey of 54 respondents who lived in Wales at the time of first being referred for eating disorder treatment, found a mean average of three years and one month between onset and the start of treatment. This was due to delays in identification, referral, and waiting times¹⁴. By far the longest component of this delay is the period of time before the person seeks help: an average of 2 years and 7 months¹⁴.

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 past¹⁵.

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 Wales.

⇒ **Eating disorders being appropriately taught and assessed at Welsh medical schools and all junior doctors undergoing foundation training in Wales 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 all¹⁶. Some that provide theoretical teaching do not offer any clinical skills training. Assessment drives learning, yet of the schools which responded to the relevant FOI question, only half included a question about eating disorders in their final exams¹⁶. Overall the data suggests that education and training on eating disorders is a low priority at UK medical schools.

The Parliamentary and Health Service Ombudsman's (PHSO) 2017 report 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 enough¹⁷. 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 management¹⁶.

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 recommendations¹⁸. In response to their report the UK Government said that the GMC will engage with medical schools on "*developing a common approach to changes*"¹⁹.

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 Welsh MPs should campaign for improved coverage of eating disorders at medical schools in Wales.

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 specialisms¹⁶. However opportunities to learn about their treatment in greater depth through specialist clinical placements are extremely limited¹⁶.

Foundation training is based around six four-month clinical placements. Currently only about half of UK junior doctors experience a psychiatry placement¹⁸. PACAC recommended that all junior doctors should complete a four-month psychiatry placement and that such placements should include exposure to patients with eating disorders¹⁸. 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 Welsh MPs should campaign for all junior doctors undergoing Foundation training in Wales to experience a psychiatry placement which includes exposure to patients with eating disorders.

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

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 Welsh MPs should campaign for the Welsh 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 Wales-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 research²⁰. As major funders of health research both the UK and Welsh Governments have important responsibilities to ensure that commitments to achieve parity of esteem for mental health extend to research funding.

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

An evidence-based estimate of the prevalence of eating disorders in Wales is needed to provide an understanding of the level of unmet need and the resources required to address it.

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