



Eating Disorders Matter: Manifesto for Wales

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Beat is calling for the next Welsh Government to:



Fully implement the Welsh Eating Disorder Service Review's recommendations



Ensure that eating disorders are identified early and that people in Wales are supported to seek help.



Ensure that eating disorders are appropriately taught and assessed at Welsh medical schools and ensure all junior doctors undergoing Foundation training in Wales benefit from specialist clinical experience of eating disorders.



Achieve parity of esteem for mental health research, including for eating disorder research in Wales.



Ensure that public health campaigns tackling obesity in Wales are informed by eating disorder experts by experience to ensure that messaging doesn't cause distress to people at risk of developing an eating disorder or exacerbate eating disorder behaviours in those already diagnosed.

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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.

About Beat

Beat is the UK's eating disorder charity.

- We are a champion, guide and friend to anyone affected by eating disorders.
- We provide information and support through Helplines that 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 Support Services

Beat provides Helplines and online services for adults and young people offering support and information about eating disorders. Our Helpline services are free to use.

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

0808 801 0677

help@beateatingdisorders.org.uk

beateatingdisorders.org.uk

Our Helplines are open 365 days a year from 12pm – 8pm during the week, and 4pm – 8pm on weekends and bank holidays.

The difference you can make as a Member of Senedd

In recent years the support of MSs has helped increase the political profile of eating disorders and unlock additional investment for NHS eating disorders services in Wales. However there is much more work to do before Wales has a healthcare system and society that enables everyone affected by eating disorders to get the help they need.

Tabling written or oral questions and writing to ministers are valuable actions that MSs can take to support the cause. MSs are also invited to join the Cross Party Group on Eating Disorders. Within their constituencies, MSs can also make a big difference by helping to hold local NHS leaders and others to account.

Eating Disorder Service Review

Our key policy ask:

- **Full implementation of the 2018 Welsh Eating Disorder Service Review's recommendations**

The next Welsh Government should fully implement the Welsh Eating Disorder Service Review's recommendations, by the allocation of sufficient funding, workforce and staff training.

The Welsh Government Eating Disorder Service Review 2018

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.

"Our family has had to turn to the private sector to gain sufficient treatment for my sibling."

Lucy

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 and ensuring that families and other carers receive the information and support they need.

The current Welsh Government has published the Executive summary of the review and asked Health boards to begin the process of implementing its

"There are too many hurdles to access the right service."

David

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.

"
A total of over four months of delays, during which I deteriorated further."
"

Sarah

"
The person I was supporting reached crisis during this period and lost faith in services."
"

Susan

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.

"
I think the minute you've got tiers [of treatment] it's creating barriers."
"

Eating disorder clinician

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 one of the seven health boards in Wales provides a suitably intensive day- or home-based eating disorder service¹¹.

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.

Early Intervention

Our key policy ask:

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

The next Welsh Government should commit 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.

Medical training

Our key policy ask:

- **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**

The topic of eating disorders is generally overlooked in medical training with severe consequences for the prognosis and safety of patients.

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.

" We have been told about eating disorders briefly...we weren't told who to refer these patients on to. "

Year 5 medical student

" [We] don't get any clinical skills experience. "

Year 4 medical student

" The majority of doctors are never assessed on their knowledge of eating disorders. "

Drs Agnes Ayton and Ali Ibrahim

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

Last 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 Welsh Government should hold Welsh 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.

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.

" I found that the teaching I received on eating disorders was out of date and misleading. "

Medical student

" No training [on eating disorders] whatsoever as a junior doctor. "

Junior doctor (FY2)

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 Welsh Government should ask Health Education and Improvement Wales (HEIW to ensure that ensure that all junior doctors undergoing Foundation training in Wales experience a Psychiatry placement which includes exposure to patients with eating disorders.

Research funding

Our key policy ask:

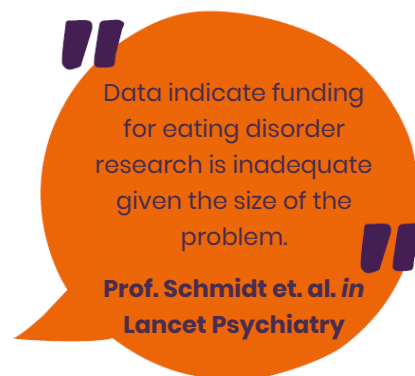
- **Parity of esteem for mental health research achieved, including for eating disorder research in Wales .**

The next Welsh Government should invest in and support eating disorder research in Wales.

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.

Analysis by the charity MQ found that just £9 per person affected is spent by UK-based funders on mental health research per year), with just 96p per person affected spent on eating disorder research²⁰. In contrast, around £228 per person affected is spent on vital cancer research each year²⁰ and this level of funding has led to major breakthroughs in diagnosis and treatment, with survival rates having doubled in the last forty years. **As a major funder of health research, the Welsh Government has important responsibility to ensure that commitments to achieve parity of esteem for mental health including greater investment in research.**

Mental health research should be seen as investment, as every £1 spent returns around 37p to the UK in health and GDP gains each year.²¹



In the next parliament Welsh MSs 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.

Obesity Prevention

Our key policy ask:

- **Ensure that public health campaigns tackling obesity in Wales use messaging that doesn't cause distress to people at risk of developing an eating disorder or exacerbate eating disorder behaviours in those already diagnosed.**

The 2007 Adult Psychiatric morbidity survey²² found that of people diagnosed with an eating disorder, particularly high numbers are also living with obesity (8% of men and 17% of women).

Beat recognises the importance of reducing obesity and the need for work in this area. However, we have concerns about the risk of anti-obesity campaigns leading to worsening health outcomes and potential loss of life among people with eating disorders. Beat's research²³ has found that poorly thought out anti-obesity campaigns have the potential to cause distress to people at risk of devel-

oping an eating disorder and have exacerbated eating disorder behaviours in those already diagnosed.

The next Welsh Government should ensure that public health campaigns emerging from the Healthy Weight Healthy Wales 10 year anti-obesity strategy use appropriate messaging and involve experts by experience in the design to ensure that people at risk of developing an eating disorder aren't caused distress and that it doesn't exacerbate eating disorder behaviours in those already diagnosed.

Our Hope

It is our hope that our policy asks will give the next Welsh Government concrete and achievable objectives to improve the lives of those affected by eating disorders.

If you're a Member of the Senedd/Aelod y Senedd, we can provide information to help with a range of issues including constituency issues, casework or parliamentary research.

For more information please contact:

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A charity registered in England and Wales (801343) and Scotland (SC039309)

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