

Eating disorders matter

Beat's Northern Ireland Manifesto for the 2019 General Election



Beat is calling for the following commitments:

- ⇒ Full implementation of the Regulation and Quality Improvement Authority (RQIA) 2015 'Review of Eating Disorder Services in Northern Ireland' recommendations, enabled by sufficient additional funding, workforce and staff training.
- ⇒ Funding to enable countrywide implementation of the 'Regional care pathway for the treatment of eating disorders'.
- ⇒ Ensuring that eating disorders are identified early and that people in Northern Ireland are supported to seek help
- ⇒ Eating disorders being appropriately taught and assessed for Medical students in Northern Ireland and all junior doctors undergoing Foundation training in Northern Ireland to benefit from specialist clinical experience of eating disorders.
- ⇒ Parity of esteem achieved for mental health research funding, including for eating disorder research in Northern Ireland.

This document has been produced to influence the Northern Ireland 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 Northern Ireland Assembly 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 RQIA Review of Eating Disorder Services in Northern Ireland recommendations**

Decisions about health and social care policy and funding are devolved to the Northern Ireland Executive (the devolved Government of Northern Ireland). The Executive collapsed in January 2017 and there has been no functioning government since.

In the next Parliament newly elected MPs in Northern Ireland should campaign for:

- **Full implementation of the RQIA's 2015 'Review of Eating Disorder Services in Northern Ireland' recommendations, enabled by sufficient additional funding, workforce and staff training.**
- **Funding to enable countrywide implementation of the 'Regional care pathway for the treatment of eating disorders'.**

In the years leading up to the collapse of the Northern Irish Executive, significant progress had been made in reviewing eating disorder service provision and a care pathway was published setting out what should be provided for patients.

The RQIA Review of Eating Disorder Services in Northern Ireland'

In 2015 a Government-commissioned independent review of Eating Disorder Services was published⁵. This review was informed by the views of service-users, parents and other carers as well as voluntary sector organisations, clinicians and commissioners.

Limited and variable capacity of specialist treatment

The review found that due to insufficient funding the capacity of adult eating disorder services and specialist provision within CAMHS is "*considerably less than required*" across Northern Ireland⁵.

With investment having varied significantly between Trusts the number of eating disorder specialists working in CAMHS varies significantly between Trusts, as does the mix of professional backgrounds/skills. This situation is mirrored at adult eating disorder services. They found that none of the adult eating disorder services employ a Clinical Psychologist and the provision of Occupational Therapy and Social work input is very low⁵. Overall, relative to the populations served, specialist eating disorder staffing levels vary from 2.32 WTE per 100,000 people in the Trust with the most staff to 1.52WTE per 100,000 in the Trust with the least⁶.

Most adult patients are treated within their local community mental health teams, meaning that treatment from a specialist service is usually reserved for the more severely ill patients⁵.

In some areas patients have to travel long distances to attend appointments and the review reported that services only operate from 9am to 5pm⁵.

Staff training and outcome measurement

The review raised concerns about patients being unable to access the full range of evidence-based psychological therapies due to gaps in therapeutic skills across the workforce. They also found that the measurement and audit of treatment outcomes was limited, due to unmet staff training needs and the limited capacity of services⁵.

Failures to safely monitor physical health

The review found that often monitoring of patients physical health, including the completion and analysis of blood tests is not carried out. This poses a serious risk to their safety. Many GPs refuse to carry out blood tests and some of those who do are unable to access the specialist advice necessary⁵.

Inpatient admission and referrals for treatment outside Northern Ireland

The review concluded that the limited capacity of many services to provide early intervention and treatment in the community has led to high rates of medical and inpatient admission with long lengths of stay, including cases of patients needing to be referred out of Northern Ireland⁵. It reported that there are around 100 admissions to acute hospitals for eating disorders annually. From 1 April 2013 to 31 March 2015, 67 young people were admitted to medical wards with symptoms of an eating disorder. They noted that admissions to Beechcroft Hospital – the regional inpatient CAMHS service – had more than doubled from 12 patients in 2011/2012 to 26 in 2014/2015. Between 1 July 2012 and 30 September 2015, 52 patients were referred to hospitals in Great Britain or the Republic of Ireland at a cost of over £5.7million⁵.

A review of published literature by Beat has found that in many cases intensive day patient and intensive home-based treatments can be as effective as inpatient admission. These forms of treatment are generally more acceptable to patients and their families, as well as being considerably less expensive⁷. 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. 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 readmission⁷.

Despite these advantages, a Beat Freedom of Information request found that none of the Trusts in Northern Ireland provide intensive day- or home-based treatment which offers the levels of intensity indicated by the evidence as necessary to provide optimum outcomes⁷.

Information and support for parents and carers

Some parents told the review team that information and advice is not consistently provided about available sources of support⁵.

The review's recommendations

The review made lots of important recommendations for the NHS in Northern Ireland⁵.

This included that the Health and Social Care Commissioning Board (HSC Board) – which plans and allocates funding for services across Northern Ireland – should review the services provided by primary care “*given the need for early intervention and prompt referral to appropriate eating disorder services.*” It recommended that the HSC Board should review the need for eating disorder services against the current capacity and level of funding to “*ensure that trusts can offer early intervention and further develop their community based teams*”. It recommended that the HSC should also review the therapeutic knowledge and skills of the staff working in eating disorder services. It highlighted the need for all therapists to be able to access training in evidence-based psychological treatments. It also asked the HSC board to review arrangements for physical health monitoring and said that it should explore with all Trusts how Intensive day patient treatment can best be provided⁵.

It recommended that Health and social care Trusts should consistently consider the welfare of family members as part of the treatment of children and adolescents, including by ensuring they are provided with advice on behavioural management and communication. It also asks trusts to monitor whether the established protocol is being adhered to when managing transitions from CAMHS to adult eating disorder services⁵.

Stalemate

Many of the key recommendations made by the eating disorder service review have yet to be implemented. Full implementation of these recommendations, enabled by sufficient additional funding, is critical to ensure that patients can benefit from early intervention and access to evidence-based treatment as close to home as possible, and that parents and other carers get the information and support they need.

The recommendation to develop and publish a regional care pathway for eating disorders has been completed⁸, but the investment required to enable countrywide implementation has not been delivered. The second phase of the feasibility study into establishing a specialist inpatient service, which had been due for publication in December 2016, has still not been published.

The political stalemate has left Northern Ireland without a mental health strategy. In 2016 the Mental Health Minister had committed to appointing an independent Mental Health Champion for Northern Ireland, but this has still not happened. It has also impeded the implementation of the new mental capacity Act⁹. Progress in these areas is also key to advancing early intervention, improving patient care and ensuring sufficient support for carers in Northern Ireland.

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

In the next Parliament Northern Irish 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 Northern Ireland.

Early intervention provides the best chance for recovery¹⁰. Delays prolong the suffering and significantly increase the costs to the NHS, as hospital admission becomes more likely¹¹. Despite this a 2017 Beat survey of 18 respondents who lived in Northern Ireland 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 times¹¹. By far the longest component of this delay is the period of time before the person seeks help: an average of 2 years and 8 months¹¹.

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 past¹².

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 Northern Ireland.

⇒ **Eating disorders being appropriately taught and assessed at medical school and all junior doctors undergoing foundation training in Northern Ireland 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 all¹³. 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 exams¹³. 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 enough¹⁴. 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 management¹³.

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 recommendations¹⁵. In response to their report the UK Government said that the GMC will engage with medical schools on "*developing a common approach to changes*"¹⁶.

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 Northern Irish MPs should campaign for improved coverage of eating disorders for medical students in Northern Ireland.

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 specialisms¹³. However opportunities to learn about their treatment in greater depth through specialist clinical placements are extremely limited¹³.

Foundation training is based around six four-month clinical placements. Currently only about half of UK junior doctors experience a psychiatry placement¹⁵. PACAC recommended that all junior doctors should complete a four-month psychiatry placement and that such placements should include exposure to patients with eating disorders¹⁵. 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 Northern Irish MPs should campaign for all junior doctors undergoing Foundation training in Northern Ireland 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 Northern Ireland

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 Northern Irish MPs should campaign for the Northern Ireland Assembly 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 Northern Ireland-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 research¹⁷. Both the UK and Northern Ireland Governments have important responsibilities to ensure that commitments to achieve parity of esteem for mental health extend to research funding.

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

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

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