



# **Delaying for years, denied for months**

**The impacts on sufferers of delaying  
treatment for eating disorders in  
Wales.**

# Introduction

An estimated 1.25 million people in the UK have an eating disorder, serious mental illnesses that are often poorly understood. They are not 'diets gone wrong', narcissistic, fads or phases but illnesses that cause devastating consequences for those suffering and the people that care for them.

Anorexia nervosa has the highest mortality rate of any mental illness, and when eating disorders are not fatal, they can still lead to severe long term physical health consequences, such as damage to organ systems, fertility issues, a higher risk of heart problems, type 2 diabetes and loss of bone density.

Despite the severity of these illnesses, those in need of treatment often don't find it quickly enough, resulting in unnecessary financial cost and emotional distress to sufferers, their families and the State in a cycle of relapse and recovery lasting, on average, six years.

As the UK's eating disorders charity, Beat exists to end the pain and suffering of eating disorders. Every day we speak to sufferers and their families who contact us for support through our Helpline or online support services, and we hear first-hand about the challenges people face in asking for help, the long delays they experience in receiving treatment once they seek it, and the frequent obstacles they must overcome to receive appropriate treatment.

In order to explore and quantify these issues, to demonstrate the impact of eating disorders on sufferers and their families, and to highlight where change is needed, we undertook a large research programme during 2017.

As a result, we are calling for action from Government, healthcare professionals and others. We have also identified a number of actions that we as a charity will take to build on our support for sufferers and their families.

This report focuses on the experiences of respondents who were resident in Wales when they were (first) referred to treatment. A comprehensive report of all the findings from this research project will follow next year.

We would like to thank consultant psychiatrist and academic Dr Paul Robinson, ably assisted by Emily Rothwell and Jonathan Kelly, for leading the research programme. Thank you also to the consortium of concerned business people who came together to fund this project. And most importantly, we would like to thank the brave individuals who shared their personal experiences through our surveys and interviews. It is to these people we dedicate this report, for whom, in many cases, the fight for recovery continues.

# 'Accessing treatment for an eating disorder' survey

We carried out an online survey in early 2017, which we promoted through the Beat website, email, and social media. Sixty seven people who accessed the survey lived in Wales when they were first referred to receive treatment for an eating disorder. For this report, we have analysed the data from the 54 respondents who had their (first) assessment appointment between 2007–2017. This is to ensure that the data reflects recent experiences. Some of the survey questions were only applicable to certain respondents and some others were optional.

This survey asked about experiences of accessing treatment for an eating disorder. It included questions about how quickly the respondents had been able to access treatment after the start of their illness, and the support and information provided between the referral and the start of treatment.

This survey was open to anyone with experience of accessing treatment for an eating disorder. As a result, there is the possibility of self-selection bias. This, combined with the small sample size, means that the group of sufferers who chose to respond to this survey may not be fully representative of all sufferers in Wales.

## People delay seeking help, and wait a long time for treatment

### Delays are experienced at every stage



Average time (weeks) spent waiting for eating disorders treatment

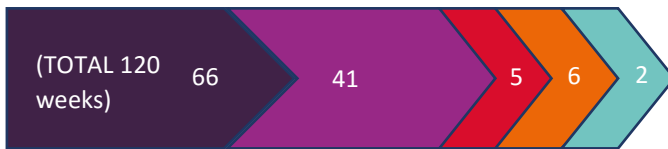


The average wait between someone's eating disorder symptoms emerging and them seeking help was 134 weeks – almost three years. This may be due to low awareness of the significance of the illness, denial of the problem, and/or resistance to seeking help for a mental illness. The delay in seeking help is followed by an average of 26 weeks between first GP visit and the start of treatment, meaning the average person with an eating disorder waited 160 weeks before treatment began.

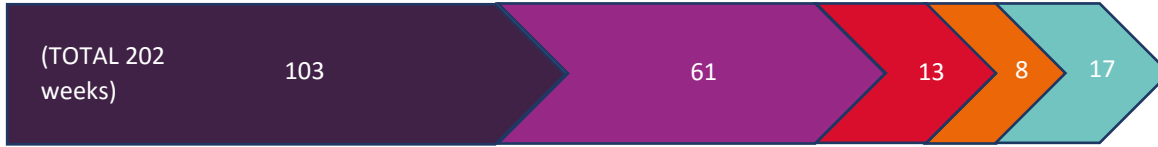
This is despite the fact that the earlier someone can access treatment, the better their chance of making a full and sustained recovery. Evidence suggests that treatment for anorexia nervosa in particular becomes more difficult, and the prognosis worsens after around three years of illness, with increased risk thereafter of the illness becoming severe and enduring, or even fatal<sup>1</sup>.

For the 17 respondents who were referred to treatment by a GP, on average, after discussing the eating disorder with that GP they had three appointments, over a nine-week period before securing the referral for treatment.

## Adults wait longer than children and adolescents at every stage for treatment



Average time (weeks) spent waiting by under 19s for eating disorders treatment



Average time (weeks) spent waiting by 19+ year olds for eating disorders treatment



In total under 19s experienced an average delay of 120 weeks, in comparison to 202 weeks for those aged 19 and over. Typically, the first symptoms of an eating disorder appear in adolescence. Since we have split the data by the age of the respondents at their (first) assessment, the difference between the age groups for the first three phases may reflect the fact that sufferers who experience a longer delay are adults by the time they are assessed, not that adults who develop an eating disorder wait longer before seeking help.

Nevertheless, it is concerning that adults may often have to wait longer for treatment after referral, given that they have in general been suffering for longer already. Adults had to wait on average 25 weeks from referral to start of treatment, which was 17 weeks longer than the wait for those who were under 19 years old at their (first) assessment.

### Government action is welcome, but is not nearly enough

The Welsh Government has set a four week waiting time target from referral to treatment for patients referred to local primary mental health support services<sup>2</sup>. Child and Adolescent Mental Health Services (CAMHS) in Wales have a waiting time target that patients should not wait longer than 16 weeks from referral to start of treatment<sup>3</sup>. In some other cases treatment is covered by a general 26-week waiting time target<sup>2</sup>. We support the recommendation of the 'We Need to Talk Wales' coalition that all people in Wales should be able to access psychological therapies within four weeks, whether they have been referred to primary or secondary care mental health services<sup>5</sup>.

In 'Together for Mental Health Delivery Plan: 2016-2019' the Welsh Government stated that it would aim to reduce waiting times to no longer than four weeks for 'routine' CAMHS referrals<sup>5</sup>. Recent waiting times targets set by NHS England for the treatment of under-19s with an eating disorder, specify that specialist treatment must be delivered within one week after referral for urgent cases and within four weeks for all other cases<sup>6</sup>.

Our research demonstrates the substantial delay that often occurs between symptoms emerging and the referral to treatment being made and highlights the importance of efforts directed at reducing these delays, as well as efforts to reduce waiting times between the referral and the start of treatment.

# People don't automatically get the information and treatment they need

## People are not given the information they need about their illness

**80%** of people (35 out of 44) answered **NO** when asked if they were told about sources of support that could help them between referral and the start of treatment.

**63%** of people (26 out of 41) answered **NO** when asked if they were told what treatment would be like. When respondents were given information about what to expect from treatment, **71%** (10 out of 14 people) found it helpful.

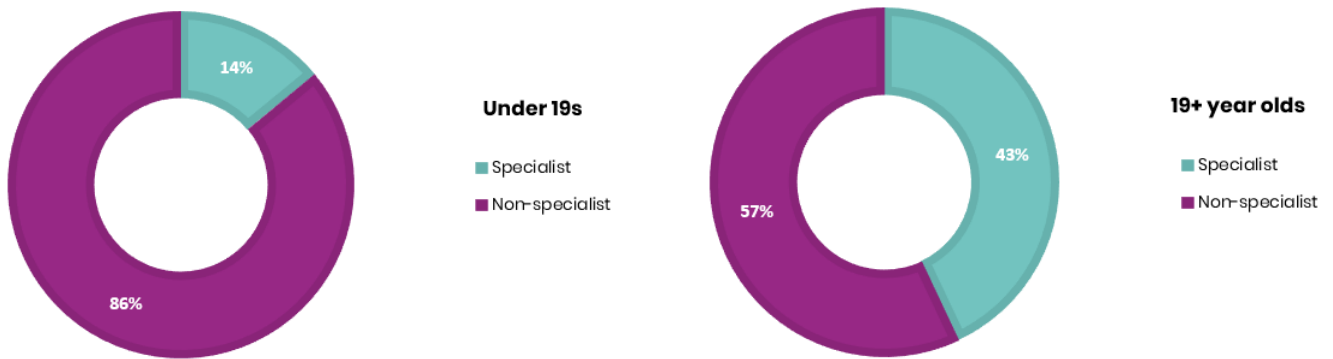
**47%** of people (21 out of 45) answered **NO** when asked if they were given information about eating disorders.

NICE recommends that people with eating disorders and their families or other carers are signposted to sources of support. For most of the respondents this did not happen during the time between their referral and the start of their treatment. Despite NICE guidance<sup>7</sup> stating that people with eating disorders and their families or other carers should be offered information about eating disorders and available treatments, many of these respondents did not receive this information.

Mental health services should be providing this kind of information, but this finding is also particularly important for Beat, so we will produce standard packs to ensure this information is provided, both for patients and their relatives and friends.

# Children and Adolescents are referred to services that don't specialise in the treatment of eating disorders

Proportion of respondents referred to a specialist eating disorders service vs. non-specialist:



Respondents who were under 19 years old when they had their (first) assessment appointment were far less likely to be referred to a mental health service that specialised in the treatment of eating disorders, with only 14% (4 out of 29) referred to a specialist eating disorders service. This finding is significant, given the evidence to support the value and cost-effectiveness of specialist treatment for children and adolescents with an eating disorder<sup>5</sup> and the recent investment in specialist eating disorders services for under 19s in England<sup>6</sup>.

More than half (13 out of 23 people) of those who were 19 years old or over when they had their (first) assessment, were also referred to a non-specialist service. This is concerning since often, general adult mental health services are not equipped to assess and treat patients with eating disorders.

## Recommendations

- 1) GPs should be well-informed of the early symptoms of eating disorders so that they are able to refer without delay. Increased eating disorder training at all medical schools is needed, with appropriate examination, to ensure that medical professionals are equipped to identify eating disorders as quickly as possible. It is vital that all medical professionals understand that eating disorders can affect all sectors of society and are equipped to identify the early signs in all cases.
- 2) The Welsh Government and the Local Health Boards in Wales must extend their focus on early intervention to include the earlier stages of the illness, ensuring attention and resources are applied to reducing the delay between onset of an eating disorder and the individual seeking help. We recommend introducing measures to increase awareness of the early signs and symptoms of eating disorders, and supporting initiatives that support and encourage individuals to seek professional help as soon as they suspect they have an eating disorder. These measures must sufficiently target all demographics to ensure everyone gets the help they need.

- 3) An access and waiting time standard for both children and young people and adults, with appropriate funding, should be introduced as soon as possible, consistent with existing waiting times targets (for children and young people) in England, so that all individuals presenting with an eating disorder for the first time receive treatment within four weeks, and urgent cases receive treatment within one week.
- 4) Beat is calling on the Welsh Government to increase the provision of specialist community eating disorders services, including its Tier 3 services, to ensure that sufferers are able to access the most appropriate treatment at the earliest opportunity. It is important for sufferers to be able to access the appropriate treatment as close to home as possible, and therefore Beat recommends that new services are commissioned to cover areas where currently no services exist.
- 5) All patients should receive written information about their assessment and care plan, and be directed to other available sources of support.

## References

1. Treasure, J., & Russell, G. (2011). The case for early intervention in anorexia nervosa: theoretical exploration of maintaining factors. *The British Journal of Psychiatry*, 199(1), 5-7.
2. NHS Direct Wales. (2017). Waiting times. Retrieved from <http://www.nhsdirect.wales.nhs.uk/encyclopaedia/w/article/waitingtimes/>.
3. Welsh Government. (2011). Waiting Times for NHS Services: Frequently Asked Questions (FAQs). Retrieved from <http://gov.wales/docs/statistics/2011/110609waitingtimesfaqen.pdf>.
4. We Need to Talk Wales. (2016). Improving Access to Psychological Therapies. Retrieved from <http://www.bps.org.uk/system/files/Public%20files/Comms-media/WNTT%20Wales%20report%20-%20ENG.pdf>.
5. Welsh Government. (2016). Together for Mental Health Delivery Plan 2016-2019. Retrieved from <http://gov.wales/docs/dhss/publications/161010deliveryen.pdf>.
6. NHS England. (2015). Access and Waiting Times Standards for Children and Young People with an Eating Disorder. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2015/07/cyp-eating-disorders-access-waiting-time-standard-comm-guid.pdf>.
7. National Institute for Health and Care Excellence. (2017). Eating Disorders: recognition and treatment. Retrieved from <https://www.nice.org.uk/guidance/ng69>.
8. Gowers, S. G., Clark, A.F., Roberts, C., Byford, S., Barrett, B., Griffiths, A.,...& Roots, P. (2010). A randomised controlled multicentre trial of treatments for anorexia nervosa including assessment of cost-effectiveness and patient acceptability—the TOUCAN trial. *Health Technology Assess*, 14(15), 1-98.