



**Early intervention
on eating disorders.
The crucial role of GPs.**

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Summary

Eating disorders are serious mental illnesses that can have devastating long-term consequences and may even be fatal if not treated early. We estimate that at least 725,000 people in the UK of all ages, genders and backgrounds have an eating disorder, but due to misconceptions and lack of recognition among sufferers and those around them, the real number may be higher.

Early intervention is key for someone with an eating disorder if they are to have the greatest chance of recovery. But sufferers face barriers to early intervention, among them a lack of public awareness about early signs and symptoms, misconceptions among GPs, and limited funding for treatment. All these obstacles need to be addressed. This briefing focuses on the critical role of GPs.

Many GPs are not equipped to help sufferers of eating disorders into treatment. Without more training on eating disorders, many are not able to recognise these serious illnesses. From our survey of almost 1700 people with experience of eating disorders, either their own or that of someone they know, it's clear that getting help from a GP is a lottery for sufferers. When we asked respondents to our survey to focus on the first time they sought help from a GP about their eating disorder they told us:

- Only 34% of respondents believed their GP knew how to help them with their eating disorder.
- 3 out of 10 sufferers did not get a referral to a mental health service from their GP, despite guidance from NICE and NHS England that stresses the importance of immediate referral.
- While half of respondents rated the quality of care received from their GP as very good or good, half said it was poor or very poor.

Beat is focused on early intervention to ensure those that need help receive it as soon as possible.

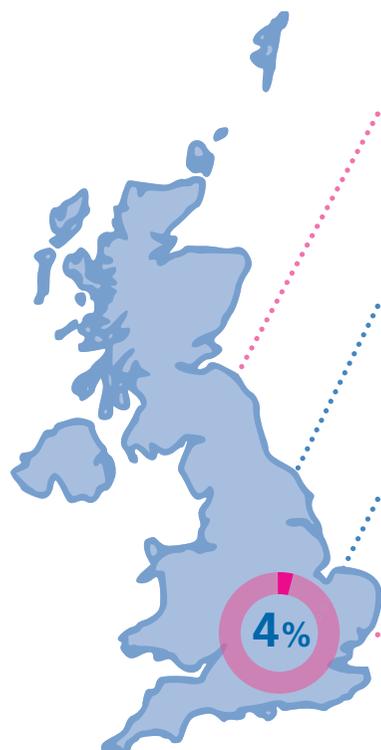
1. We're running a public awareness campaign and running awareness training in schools and workplaces to help everyone recognise the early signs of eating disorders and encourage those that need help to seek it early.
2. We're providing guidance and support through our national helpline and have produced new information guides so that sufferers are equipped for a successful appointment.
3. Creating new GP information guides to equip GPs to recognise the signs and symptoms of eating disorders and refer without delay.

But we can't do it alone.

Beat is calling for the following:

1. Increased eating disorder training for medical students specialising in general practice, so that all GPs are equipped to support eating disorder sufferers.
2. Sufficient eating disorder training at all medical schools, with appropriate examination.
3. Increased funding for eating disorder services to ensure everyone receives the treatment they need without delay.

About eating disorders – what's the problem?



We don't know the scale of the problem. We estimate at least 725,000 people in the UK suffer from an eating disorder but we do not know how many people haven't come forward or recognised their illness.

Eating disorders don't discriminate: any age, any gender, any background.



Around **15%** of calls to our Helpline last year were about someone **over the age of 40.**



62% of symptoms appeared **before the age of 16.**

Eating disorders don't only affect females. Up to **25%** diagnosed with anorexia or bulimia are male and **40%** for binge eating disorder.



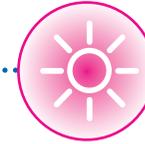
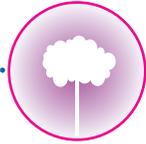
4% of the total population will suffer in their lifetime. Many more around them are affected – family, friends, colleagues and others involved in their daily lives.

 **Eating disorders are serious mental illnesses.**



Why? What causes them?

Eating disorders are complex and there is no one single cause. We're still learning more but their development is likely a combination of **genetic, biological, psychological, social and environmental factors**.



Eating disorders are not about food. Instead, eating disorder behaviours are a way of coping or feeling in control.

Why are we worried?



EATING DISORDERS COST THE ECONOMY £16.8bn PER YEAR

- £4.6bn treatment costs to the NHS
- £3.1bn costs to sufferers and carers
- £1.1bn private treatment costs
- £8bn lost income to the economy.



WE AREN'T INVESTING IN ENOUGH RESEARCH

15p on eating disorder research per adult affected vs £1,571 on cancer.

PEOPLE FACE STIGMA AND MISUNDERSTANDING EVERY DAY. 32% of people feel stigmatised or discriminated at work because of their eating disorder.

32%

IT'S HARD TO GET TREATMENT

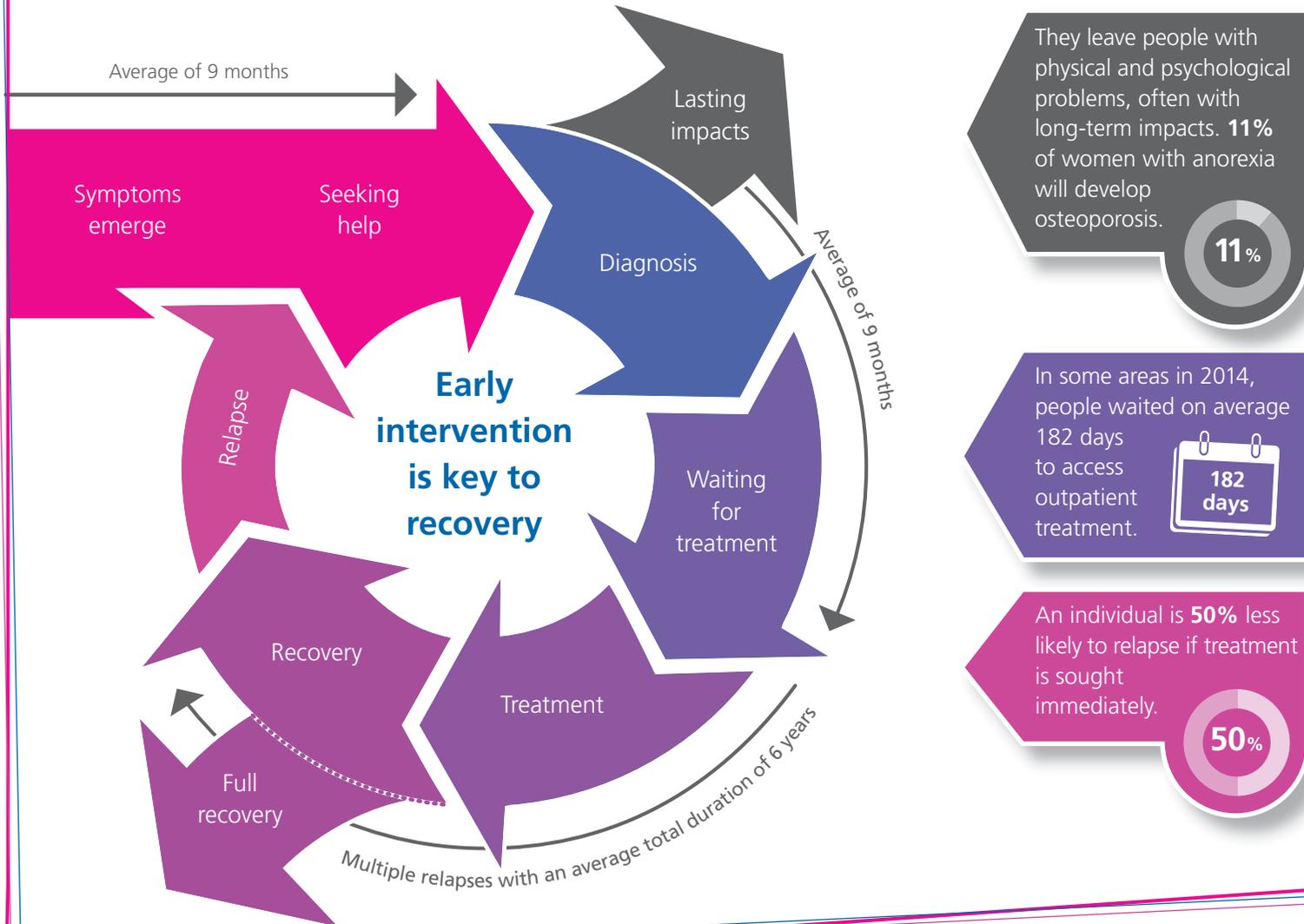
41% wait more than 6 months for diagnosis and treatment.

41%

Anorexia claims more lives than any other mental illness.

Delaying treatment damages recovery

Recovery is possible; the sooner someone gets the treatment they need the more likely they are to make a full recovery.



Why is early intervention so important?

The evidence is clear: treating people with eating disorders as quickly as possible gives them the best chance of a rapid, full, and sustained recovery. Recommended therapies are more effective at an early stage of an eating disorder's development, and individuals can better engage with treatment. But there are barriers to early treatment, and as it stands, we are letting people with eating disorders down.

What are the obstacles to early intervention for people with eating disorders?

Eating disorders are rarely talked about, widely misunderstood, and surrounded by stereotypes about who can be affected. People with eating disorders themselves might not realise or struggle to admit that they're ill. Those best positioned to spot early warning signs, such as family members, friends, and teachers, often don't have the knowledge to recognise eating disorders – an important first step towards helping sufferers. It's vital that there is increased public awareness to encourage people to seek help, and we're doing everything we can to support this.

If GPs refer a patient, the healthcare system in many cases does not have the capacity to provide appropriate treatment. Lack of funding means that often people with eating disorders face long waiting lists, or must travel long distances, sometimes having to go hundreds of miles away from family and friends to get the treatment they need. This must improve and will be a priority for Beat going forward.

But good quality treatment isn't enough if individuals aren't being referred early enough. Unfortunately, many GPs haven't had the training necessary to be able to recognise an eating disorder, especially in the absence of any physical signs. As a result, sufferers are often turned away when they desperately need help, with their GP deciding to "wait and see" what happens rather than referring the person to a specialist for assessment, in contrast to medical guidance¹.

As it stands, getting help from GPs is a lottery.

GPs are the first port of call for most patients. With their traditional role as the gatekeeper for specialist services, the part they play in identifying eating disorders is incredibly important.

To better understand the kinds of experiences that people with eating disorders have when seeking help from their GPs, we surveyed nearly 1700 people who have had personal experience of an eating disorder and/or cared for someone who has. 772 had had an eating disorder, 648 had both experienced an eating disorder and were also a family member/friend of a sufferer, while the remaining 273 were either a family member or a friend of the eating disorder sufferer. We invited responses from everyone, including those who have had positive, negative, or mixed experiences with their GPs.

The findings of the survey reveal that getting help from a GP for an eating disorder in the UK is a lottery. There are clearly some GPs that are well equipped and able to support people with eating disorders, but there are many who are not.

Eating disorder sufferers

Of the 1700 people who responded, 1420 had had an eating disorder themselves.

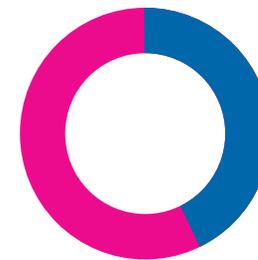
When asked about their first visit to a GP about their eating disorder, only 42% of these respondents felt their GP understood eating disorders, with only 34% believing that their GP knew how to help them with their eating disorder.

Of those respondents who have had an eating disorder themselves, **29% did not get a referral to a mental health service from the first GP they sought help from**, despite guidance from NHS England² and NICE that they should be referred as soon as symptoms emerge. This is fundamentally important to their recovery, and it is concerning that such a significant proportion of GPs are not taking this step.

We asked respondents to describe their experience with the first GP they sought help from using a set of statements:

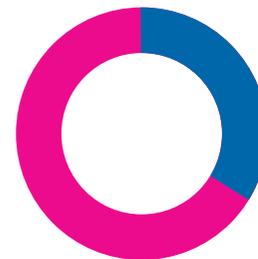
“ They need to pick up on and recognise early signs. If a young person says they are having issues they should listen. If I'd been taken seriously then I could have avoided becoming seriously ill during my GCSE year. ”

Survey participant



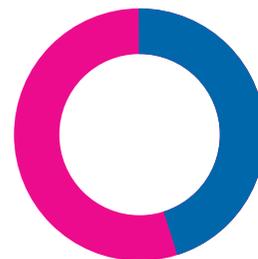
'I think that my GP understood/ understands eating disorders'

■ Agree
■ Disagree



'I think my GP knew/knows how to help me with my eating disorder'

■ Agree
■ Disagree



'My GP has emphasised the importance of getting help and treatment as soon as possible'

■ Agree
■ Disagree

How would you rate the quality of care you have received from your GP?



“ It's so important that GPs show understanding, knowledge and insight, as it is very hard for someone with an eating disorder to even ask for help. They will run away and be deterred from seeking help if they are not treated well to start with. ”

Vicki, 29, Kent



Only **1 in 5** were provided with information about eating disorders by this GP, as the NICE guideline recommends.



After seeking help from a GP for the first time about their eating disorder, almost **1 in 6 (189) of these participants decided to see a different GP.**



Of those who have received care from more than one GP since the onset of their eating disorder, **69% said that the quality of care they received had varied significantly.**

“ I was given a second chance when I saw a different GP. I do think that all GPs should be trained in how to handle an appointment where someone opens up about an eating disorder because they really don't know what they could do to a person if they simply dismiss them. ”

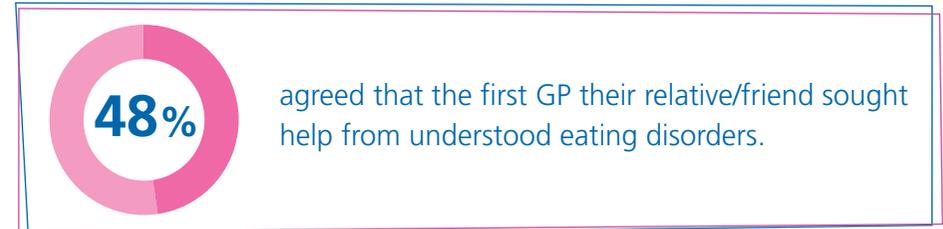
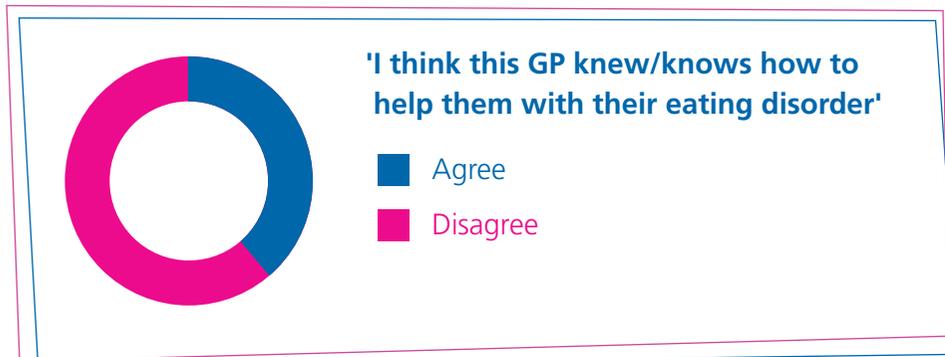
Survey participant

Carers

Of the 1700 people who responded, 921 people were a family member or friend of someone who had suffered with an eating disorder and told us about the experiences of their relative or friend.

In approximately 1 in 4 cases, the person they were supporting did not receive a referral to treatment from the first GP they sought help from.

The responses of these carers reinforce the sufferers' report of the wide variation in GPs' knowledge of eating disorders.



However, some highlighted positive care...

“ My daughter was sent away after the first appointment to come back in six months. She deteriorated. We returned after five months and were then sent away for another month...On the third appointment he realised how serious things had become and she saw a specialist in two days. But what price the delay? ”
Lorna, London

“ My daughter has not fully recovered but [if it wasn't] for GP care she might not be alive at all. The care shown by our GPs to the whole family has been exemplary. ”
Survey participant

Why the focus on GPs?

If someone is concerned about themselves or someone they know, the GP is often the first place they turn. When someone seeks help for an eating disorder, this is an important opportunity for both the patient and the health system. Unfortunately, the chance to get the patient into vital early treatment is often squandered, with the GP deciding to “wait and see” if the problem goes away.

This is despite NHS England’s 2015 Access and Waiting times standards for children and young people with an eating disorder, which include a new requirement for GPs to “contact the eating disorder service...as soon as an eating disorder is first identified.” Indeed the draft 2017 NICE guideline³ on eating disorders contains a passage calling on GPs to refer without delay when an eating disorder is suspected.

If they’re to be able to do this, GPs need to know the early signs and symptoms and be aware that certain consultation patterns could indicate that the patient may be suffering from an eating disorder^{4;5}. In fact, people with eating disorders often consult their GP frequently in the five years prior to their eating disorder being identified, often about physical health problems caused by the eating disorder. This is the best opportunity to help that person in need.

Not only do GPs play an essential role in the identification and referral of people with eating disorders, but a knowledgeable and compassionate GP can make a big contribution to recovery for these patients by coordinating their care and monitoring their physical health.

“ Given an appropriate education, they [GPs] can improve their detection and management and in collaboration with other health professionals, greatly improve the service given to these patients⁶. ”

Dr Alison James, a GP with expertise in eating disorders and over 20 years of experience

The need for more GP training

It is clear from our survey results that while many GPs are able to provide a good level of care to eating disorder sufferers, others are ill-equipped to identify and support those who need help. It is vital that training is increased so that all GPs are able to support eating disorder sufferers.

A King's College Institute of Psychiatry, Psychology and Neuroscience study found that many GPs felt dissatisfied with the care they were able to give to patients with eating disorders⁷. The NHS constitution (for England)⁸ states that all NHS staff must *"have the tools, training and support to deliver compassionate care"* and be provided with *"access to appropriate education and training for their jobs..."*. Similar promises have been made about the education and training of GPs by the Scottish Government⁹, Welsh Assembly¹⁰ and Northern Ireland Executive^{11; 12}.

"A GP's inexperience and lack of training in eating disorders can lead to a delay in diagnosis."
2004 NICE guideline on eating disorders.

"More training of health service staff is required, particularly for those in general practice including GPs. This would include training in the detection and the features of eating disorders and an understanding of how motivation and ambivalence can affect engagement in treatment."
2004 NICE guideline on eating disorders.

Training is a necessity for early identification and referral without delay.

What is Beat doing?

Through our focus on early intervention, we want to ensure people with eating disorders experience care and understanding, and can quickly access treatment that supports a rapid and sustained recovery.

We are:

- Creating new GP information guides to equip GPs to recognise the signs and symptoms of eating disorders and refer without delay.
- Raising awareness among the wider public about eating disorders, with a public campaign to enable people to recognise the signs and symptoms of eating disorders early on.
- Empowering those suffering from eating disorders and their loved ones to get support as quickly as possible, with new guidance for GP appointments and information booklets for carers.

We are offering awareness training in schools and workplaces to help people to recognise the early signs of eating disorders. We are ensuring our helpline is available to everyone that needs it by opening 365 days a year, and encouraging and supporting people to take the steps they need to access early treatment.

But we can't make early intervention a reality for eating disorder sufferers alone.

What Beat is calling for

We recognise the challenges faced by sufferers when initiating conversations about their eating disorders with professionals. Eating disorders are complex mental illnesses, which emerge from social, psychological, and/or biological factors. They cause a range of physical problems that can have severe consequences: anorexia has the highest mortality rate of all mental illnesses. It takes enormous courage for sufferers to approach the GP about their illness, and a delay in referral can cause huge and avoidable setbacks.

Our survey results make clear that many GPs are not aware of the signs and symptoms of eating disorders, meaning that crucial factors are missed when a patient first presents. Furthermore, the lack of awareness can lead to dismissive behaviour towards the patient's illness, treating it as not serious enough, thus fuelling the eating disorder further.

Beat is calling for the following:

1. Increased eating disorder training for medical students specialising in general practice, so that all GPs are equipped to support eating disorder sufferers.
2. Sufficient eating disorder training at all medical schools, with appropriate examination.
3. Increased funding for eating disorder services to ensure everyone receives the treatment they need without delay.

About Beat

Beat is the UK's eating disorder charity. We seek an end to the pain and suffering caused by eating disorders. Since our founding in 1989 as the Eating Disorders Association, we have been a champion, guide and friend to anyone affected by these serious mental illnesses, giving sufferers and their loved ones a place where they feel listened to, supported, and empowered.

A champion

Eating disorders are widely misunderstood and stigmatised illnesses, so we work to change this at every level. We campaign for positive change for people who are suffering so that they can get the help they need and deserve as quickly as possible, because we know that the faster they get treatment, the greater their chance of full recovery.

A guide

We translate the complex and technical into practical guidance for people affected by eating disorders, both sufferers and their friends and families. We offer awareness training in schools and workplaces, and a HelpFinder service to help people find treatment in their area. We help healthcare professionals to recognise the thoughts and feelings that cause these mental illnesses, rather than focusing on physical symptoms, so that they can provide the best possible care for their patients.

A friend

Eating disorders can be deeply isolating for the people affected by them. Our message boards, online support groups, and regional support services allow people to talk to others with similar experiences, helping them to feel less alone with their eating disorder. We run phone and email helplines 365 days a year for anyone who needs us. Often when people get in touch it's the first time they've voiced their concerns about themselves or a loved one.

To discuss this briefing or for more information about Beat's work and activities please contact Kat Pugh, Campaigns and Public Affairs Manager. Email: k.pugh@b-eat.co.uk phone: 01603 753321.

End notes

- ¹ National Collaborating Centre for Mental Health (2004) *Eating Disorders Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. NICE guideline (CG9)*. Leicester and London (UK): British Psychological Society and The Royal College of Psychiatrists.
- ² National Collaborating Centre for Mental Health (2015) *Access and Waiting Time Standard for Children and Young People with an Eating Disorder Commissioning Guide*. <https://www.england.nhs.uk/wp-content/uploads/2015/07/cyp-eating-disorders-access-waiting-time-standard-comm-guid.pdf>. Accessed: 31/01/2017.
- ³ National Collaborating Centre for Mental Health (2016) *Eating disorders: recognition and treatment; NICE guideline: short version; Draft for consultation*. <https://www.nice.org.uk/guidance/GID-CGWAVE0703/documents/short-version-of-draft-guideline>. Accessed: 09/12/2016.
- ⁴ Lask, B., Bryant-Waugh R., Wright F., Campbell M., Willoughby K., Waller G. (2005) Family physician consultation patterns indicate high risk for early onset anorexia nervosa. *International Journal of Eating Disorders*. Vol. 38(3), pp.269–270
- ⁵ Ogg, E. C., Millar H. R., Pusztai E. E., Thom A. S. (1997) General practice consultation patterns preceding diagnosis of eating disorders. *International Journal of Eating Disorders*. Vol. 22(1), pp.89–93.
- ⁶ Waller, G., Micali, N. and James, A. (2014) General Practitioners are poor at identifying the eating disorders. *Advances in Eating Disorders*, Vol. 2(2), pp.146-157.
- ⁷ Graham, J. (2005) GPs are dissatisfied with the care they are giving patients with eating disorders. *BMJ*, Vol.330(7496), p.866.
- ⁸ Department of Health (2015) *The NHS Constitution*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/480482/NHS_Constitution_WEB.pdf. Accessed: 31/01/2017.
- ⁹ Scottish Government (2013) *Everyone Matters: 2020 Workforce Vision*. <http://www.gov.scot/Resource/0042/00424225.pdf>. Accessed: 31/01/2017.
- ¹⁰ Welsh Government (2016) *A Planned Primary care workforce for Wales*. <http://gov.wales/docs/dhss/publications/151106plannedprimarycareen.pdf>. Accessed: 31/01/2017.
- ¹¹ Northern Ireland Executive (2016) *Health and Wellbeing 2026: Delivering Together*. <https://www.health-ni.gov.uk/sites/default/files/publications/health/health%20and%20wellbeing%202026-%20delivering%20together-october%202016%20.pdf>. Accessed: 31/01/2017.
- ¹² Northern Ireland Executive (2011) *Quality 2020*. <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/q2020-strategy.pdf>. Accessed: 31/01/2017.

Help for adults

Helpline: 0808 801 0677 • Email: help@b-eat.co.uk

Help for young people

Youthline: 0808 801 0711 • Email: fyp@b-eat.co.uk

Online support

Visit www.b-eat.co.uk for information about eating disorders, message boards and online support groups.

Use helpfinder.b-eat.co.uk to find services in your area.



beatED



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