
The costs of eating disorders

Social, health and
economic impacts

*Assessing the impact of
eating disorders across the
UK on behalf of BEAT.*

February 2015



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Foreword

Beat has worked for 25 years to raise awareness about eating disorders; to support those individuals who are affected and their families; and to campaign for improved treatment. We are therefore fully aware of what the true cost is to the lives that are damaged and lost.

Eating disorders are a serious mental illness and have the highest mortality rate of any mental illness claiming precious, promising lives every year. Families get overwhelmed, desperate and broken by the challenge of beating an eating disorder.

We also know that they are treatable conditions and that full recovery is possible if intervention is early enough. No-one need die of an eating disorder. Sufferers can recover and lead healthy, happy lives again – ready to fulfil their potential – able to shine.

Our Young Ambassadors, all under 25 years old, have all recovered from their eating disorder and are outstanding examples of this. As they speak out about their recovery, others feel more able to take up that long path to recovery too. Families who hear them gain encouragement and hope for their own loved ones, and decision makers are reminded why the services they plan and fund are so important.

Much has changed for the better during our 25 year history.

- There is more accurate and compassionate reporting of eating disorders in the media. It is no longer just seen as silly girls on sillier diets.

- There is world class research underway into causes and the effective treatments, with the UK being in the lead in many cases.
- There are dedicated clinicians, therapists, doctors and nurses, psychiatrists, dieticians and others who bring their skills to this specialist field.

And yet, this report shows so powerfully that eating disorders remain complex, costly and challenging illnesses. Treatment is patchy at best, inadequate at worst and that unacceptable variability nationally is putting lives at risk every day.

Beat commissioned PwC to produce this report, and gratefully acknowledge the donation from N Brown Group PLC that funded it. The report assesses the incidence and cost to society of this debilitating condition including treatment and wider social costs too.

In addition to bringing their unparalleled analytical skills to bear, PwC also conducted a substantial interview programme in which people contributed their personal experience, both as sufferers and carers. This survey has provided such rich data with which to illustrate the issues involved.

The identified cost to society of eating disorders is shocking. It also indicates that early intervention could avoid much of this cost and the associated pain to sufferers and carers – the sooner someone gets the help and treatment they need, the better their chances of making a full recovery.

This early intervention is difficult given the pernicious nature of the disorder. Once a sufferer believes there is a problem they do not naturally reach for help. Shame, fear and concern for others can prevent them from seeking the help they need.

“I couldn’t tell my parents, I knew how much it would worry them if they thought I was ill” said a caller to our helpline.

A unique feature of an eating disorder is that the person affected may truly and genuinely believe there is nothing wrong with them. The illness itself distorts their thinking and ability to judge. They are not lying, manipulative and deceitful, but fearful, ashamed and self-loathing.

“I don’t deserve the pleasure I know food would give me” was another chilling insight shared.

There are so many people who could and – indeed many who should – be able to understand, to act and to get the help that people with eating disorders desperately need. Teachers, Doctors, Nurses, Sports Coaches, Dance Teachers, Gym Instructors, Personal Trainers, Girl Guide Leaders and families themselves... the list goes on. But they too need assistance in terms of being able to recognise the condition and then knowing how to help those affected.

Those showing concern and compassion cannot make it worse, but can make the difference to someone being able to seek help. Everyone who has recovered says something along the lines of thank goodness people didn't give up, didn't stop trying to reach out, cared enough to drag them – literally sometimes – out of the deep dark pit of their illness.

Beat will do all we can to make sure that the window of opportunity – the chance to notice, speak up and act – is taken full advantage of. We will provide information and advice to those who need it so that they can reach out and be able to do the best for their loved ones.

But that won't be enough unless the Government also acts to guarantee that window of opportunity remains open wide.

There is much to be done on so many fronts;

- GPs and Practice Nurses need to all be up to date and up to speed on the need for early diagnosis and access to treatment. "Wait and see" can be a death sentence for some.

- Schools, Colleges and Universities need to have eating disorders on their agenda, for staff, for the curriculum and for pastoral care.
- And most crucial of all, Mental Health Services need to be joined up, comprehensive and responsive. The current pattern of fragmented provision with its silos of expertise concentrated in the in-patient treatment services so few people can access is no longer fit for purpose.

PwC estimate that the cost to society of eating disorders is circa £15 billion per annum. They also indicate that early intervention can pay massive dividends given the high relapse rates.

The latest Government initiative to focus on eating disorders and self-harming is to be applauded, but given the scale of the problem, our journey to eradicate – or at least massively decrease – the incidence of Eating Disorders has only just started.

Plans to do more in schools and primary care are urgently needed and Beat is ready to work with Government to define and implement such high impact programmes.

Their impact will be hugely value creating at both the societal and individual levels.



Chris Outram
Chairman Beat



Susan Ringwood
Chief Executive Beat

Introduction

This report that Beat have commissioned from PwC is most welcome, and timely. The need to provide comprehensive access to effective, evidence based treatment is growing. Resources are finite, and a strong case needs to be made for investment in this most challenging of illnesses.

The health, social and economic data together with the survey findings from sufferers and their carers which make up the substance of this report all amplify what I have seen in my 30+ years of clinical and research practice.

It is particularly resonant that PwC's survey shows that the speed at which help is sought and provided are important factors that determine the response to treatment, with my experience showing that younger people respond more favourably as do those who receive treatment quickly.

The picture presented by PwC of a cycle of treatment, recovery and relapse also resonates. The clinical picture in the later stages of illness becomes more complex with more comorbidities. The illness becomes entrenched and the response to first line treatments reduces. This interrupts the usual developmental milestones and so further education and transition to independence is impeded – which is a big concern.

Over time, untreated, eating disorders may become entrenched with more profound physical and psychiatric co-morbidity. Neuroprogressive changes occur as an adaptation to prolonged starvation and/or abnormal eating behaviours. These can make the cognitive, social and emotional vulnerabilities more pronounced. Many such patients can remain dependent on their families or the state during

their lifetime. Early intervention is essential in order to prevent the neuroprogression which causes these illnesses to become entrenched. Families play a huge role in managing the illness and whenever possible they should be included and informed about how to help. Their role as part of the treatment team whatever the stage of illness should be respected.

The inclusion of the impact on families and carers within this report is particularly welcome. The need for more accurate information to help with their care giving role is a common call from carers, no matter what the stage of illness. A helpful aphorism is that families are the solution and not the problem. The burden on care givers needs to be considered particularly as they are now expected to contribute to symptom management in the early phase of the illness. Helping the carer to understand and cope with the illness is essential.

The symptoms are pervasive and intrusive into family life. Their life threatening nature contrasts with the individual's own unwillingness to accept their illness. Carers themselves have their own practical and emotional reaction to the illness. In my experience of adult services, carers can be excluded from treatment and liaison with families is often difficult as people may be admitted to units distant from their home.

The key message from this report for me is the need to get the right treatment and help quickly if we are to improve the outcomes for individuals suffering from eating disorders and their carers and families. There remain many unknowns that must yet be addressed, but the need for urgent change is clear.



**Professor Janet Treasure OBE
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Director of Eating Disorders Unit and
Professor of Psychiatry at Kings College
London, Chief Medical Advisor, Beat.

Executive summary

Beat, the UK's only nationwide organisation supporting people affected by eating disorders, commissioned PwC to conduct a programme of primary and secondary research – including an electronic survey of 435 sufferers of a range of eating disorders and 82 carers across the UK – to assess some of the key economic, health and social impacts attributable to such disorders.

Based on our survey findings, and supporting evidence from previous research, this report outlines the impacts of eating disorders upon individuals, their families, the health sector and wider UK economy. Our findings provide a compelling case for future (preferably early) interventions to improve recovery rates for sufferers and to reduce the overall incidence of eating disorders. This conclusion is pertinent to both the Deputy Prime Minister's recent announcement of £150 million of investment for children and young people with eating disorders, or who self-harm, and the Labour Party's announcement that, if it wins May's general election, it will prioritise spending on children's mental health.

Eating disorders are a group of illnesses defined by the National Institute of Mental Health as being those in which the sufferer experiences a preoccupation with body weight and shape which disturbs their everyday diet and attitude towards food. Unusually, compared with other mental health issues, eating disorders result in **both physical and psychological symptoms** and can have long term physical side effects including organ failure, with Anorexia Nervosa standing out as the disorder with the highest mortality rate. They include the more widely known

Anorexia Nervosa and Bulimia Nervosa as well as lesser known disorders such as binge eating disorder.

The Royal College of Psychiatrists suggest that a combination of influencing factors (including genetics, age and social pressures) cause eating disorders and that they are often seen alongside other conditions (most frequently depression or anxiety disorder). This makes recognition of the underlying eating disorder – by individuals, their families, their teachers, colleagues and friends and GPs – much more difficult. It is the role of these wider groups, in recognising disorders and supporting sufferers, that has led us to include carers within our study bringing to light a new set of social and economic impacts that to date have not been widely reported.

Historical challenges in recognising eating disorders have influenced previous estimates of national prevalence. We have updated these estimates with recent population figures. For example, figures published by the King's Fund (2008) updated to 2013 population levels suggests that c600,000 people in the UK suffer from an eating disorder while, in contrast, the National Institute for Clinical Excellence (2004) suggest a higher level at c725,000. Notwithstanding the difficulty in quantifying the 'total population' of sufferers the number of people being diagnosed and entering inpatient treatment for eating disorders in England alone has increased at an average rate of 7% year on year since 2009.

Our analysis indicates that many of the established viewpoints about the prevalence of eating disorders continue to prevail namely that they affect more women than men and typically emerge during teenage years although our analysis also shows that disorders often last well into adulthood.

Our respondents indicated that symptoms of eating disorders are first recognised under the age of 16 in 62% of cases. This is particularly striking as it means the cycle of treatment, recovery and relapse can cause severe disruption to sufferers' education, with the potential for long term impacts on their employment, professional development and lifetime earnings. **In many cases, therefore, the effects are life long and thus highly costly to the sufferer, their families, and to society generally.**

We have also identified stark trends in the times involved both in seeking help, getting effective help, and relapse rates (with relapse referring to repeat treatment for sufferers who had previously accessed treatment). Our survey indicates that **almost half of sufferers will wait longer than a year after recognising symptoms before seeking help.** This is of particular concern as the speed at which help is sought appears to be the single most important factor materially impacting on the likelihood of relapse. Those of our respondents who sought early help have a relapse rate of only 33% compared to an average level of 63% for all those who sought later help.

The delay in seeking help is often coupled with a year long period of waiting for a diagnosis followed by periods waiting for treatment often over 6 months. **Consequently on average our survey respondents experienced a lag of 15 months or more between recognising symptoms and treatment starting with 18% waiting 2 years or more.** Addressing waiting times has already been identified as a priority for the Government's £150m investment, but our findings suggest that this should be coupled with a broader review of what can be done to help sufferers, their families, their friends, teachers and GPs recognise symptoms and seek help earlier. Early identification and intervention will thus have substantial benefits.

Our survey results also suggest that there are substantial variances in waiting times, referral pathways,

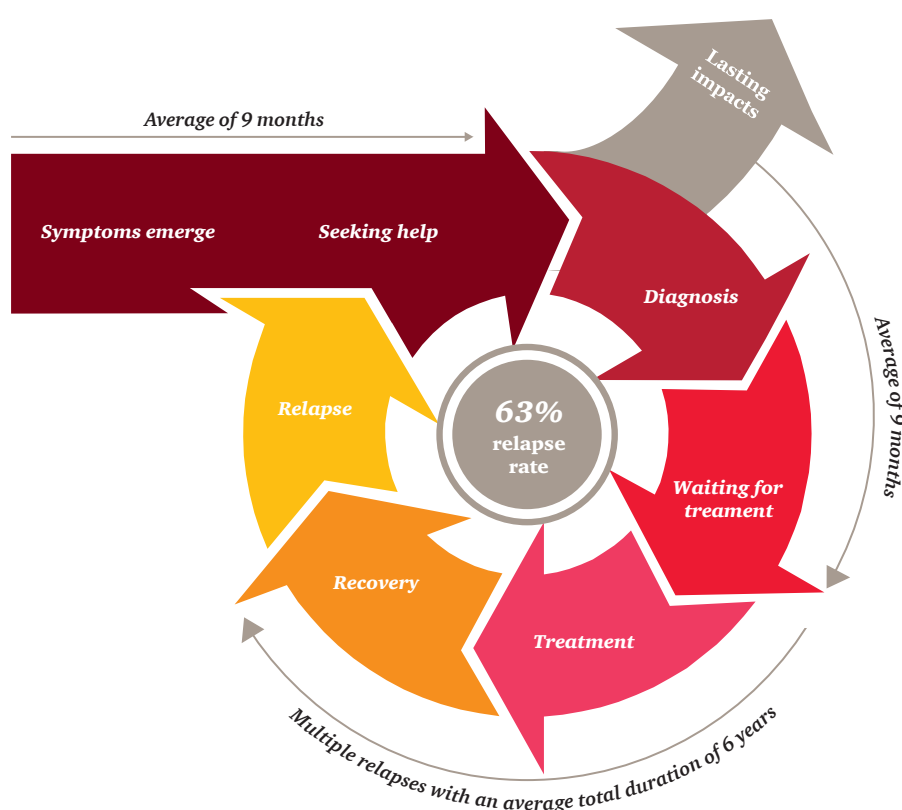
types of care provided and duration of treatment not only between regions but also between sufferer groups (particularly men and women). **These results support Beat's long-held view that access to treatment is inconsistent and arguably inequitable.**

On average 63% of our respondents experienced at least one relapse requiring repeat treatment. With no single treatment regime or type of intervention standing out from our analysis as being substantially superior to other interventions, i.e. capable of improving the chances of recovery for this group, more research is needed to understand what works and why. Nevertheless, the case for earlier intervention appears to be supported given the marked reduction in relapse (of 33%) for those sufferers that recognised their symptoms and sought help quickly.

As indicated, in Figure 1.0 below, our findings suggest that most sufferers are trapped in a repeating cycle of seeking help, waiting for diagnosis, waiting for and receiving treatment and ultimately relapsing and requiring repeat treatment. The average time lag of 9 months between symptoms being noticed and help being sought is a critical component that requires the most attention if eating disorders are to be tackled, and sufferers effectively supported. **For more than half of sufferers this recurring cycle (of waiting, treatment, recovery and relapse requiring repeat treatment) lasts for more than 6 years.** This has severe long term implications given that such an extended period of disruption (to education or employment) often arises at the most critical period in a young person's life.

Figure 1.0

Treatment, recovery and relapse – the 6 year cycle



In assessing the implications to the individual and society of this cycle we have focused upon three cost categories:

1. The direct financial burden to sufferers and carers (excluding any payment for private treatment);
2. Treatment costs (including both NHS and private providers); and
3. The loss of earnings, to sufferers and carers, resulting from disruption to education, employment and professional development.

For sufferers in our survey the direct financial burden, related to treatment travel and other costs (such as lost university fees) are **on average c. £1,500 per year**. This impact is also mirrored for carers who reported an **average level of c. £2,800** across the same categories.

In calculating average treatment costs we have combined our survey data of different treatment pathways with national data on such pathway costs. **We have identified an annual average cost of £8,850 to treat someone suffering with an eating disorder.** These costs are based on mental health treatment types and, therefore, do not include the treatment of physical symptoms that are commonly prescribed for a typical eating disorder sufferer. As such they may overestimate or underestimate the actual treatment costs involved. In the latter case, for example, some of our respondents indicated levels of up to £100,000 annual treatment costs.

In relation to the impact of time off work and education across all our respondents levels of c. £650 per annum were recorded for sufferers under the age of 20, c. £9500 for sufferers over the age of 20 and c. £5,950 per annum for carers. In addition the qualitative responses to our survey – vignettes of which have been included throughout the report – indicate that there is also a longer term impact on earnings well beyond the initial average 6 year cycle of treatment.

Based on prevalence estimates drawn from previous studies, of between 600,000 and 725,000, these costs suggest – assuming a ratio of 1 carer to 1 sufferer – **an annual direct financial burden of between £2.6 billion and £3.1 billion** on sufferers and carers, **total treatment costs to the NHS of between £3.9 billion and £ 4.6 billion** (and, potentially, a further **£0.9 – £1.1 billion** of private treatment costs) and **lost income to the economy of between £6.8 billion and £8 billion.**

These costs sit alongside much broader personal impacts on the lives of sufferers and their carers and families with **over 90% of our survey respondents reporting a very significant or significant impact on their well-being and quality of life.**

When these broader impacts, and the financial costs and loss of earnings, are considered in the context of the potential range of sufferers in the UK there is a compelling case for change.

We have proposed three key priorities for further investment: equipping sufferers and their GPs, teachers, families and peers to recognise and refer cases more quickly to create the opportunity for early intervention; unblocking the delays in receiving diagnosis and effective treatment; and funding holistic treatments that not only enable better treatment outcomes, but also reduce the lifetime impact of eating disorders on the well-being of sufferers and their carers and families.

Finally, in supporting effective investment, we have also recognised two important areas urgently requiring further investigation, namely establishing the full size of the issue – confirming current UK-wide prevalence rates – and reviewing which treatments and interventions can enable greater levels of permanent recovery.

Context

“My daughter has suffered from anorexia nervosa for 25 years. She has had various treatments over the years and lasting different periods of time.”



Beat¹ is the UK's only nationwide organisation supporting people affected by eating disorders, their family members and friends and campaigning on their behalf². They also provide advice, support and information for those suffering from a range of eating disorders². Beat aims to change the way people think and talk about eating disorders, to improve the way services and treatment are provided and to help anyone believe that their eating disorder can be beaten. In order to achieve these aims, Beat challenges the stereotypes and stigma that people with eating disorders face, campaigns for better services and treatment and provides information, support and encouragement to seek treatment and, ultimately recover.

Beat commissioned PwC to conduct a programme of primary and secondary research in order to assess some of the key economic, health and social impacts attributable to eating disorders. The primary objective of this work was to review and gather evidence in relation to the:

- Scale and challenge associated with eating disorders in the UK, focusing on economic, health and social impacts;
- Prevalence and trends associated with eating disorders in the UK; and
- Financial burden on the exchequer as a consequence of eating disorders, and consequent exchequer savings of addressing such disorders.

In addressing these questions we have carried out a wide range of secondary research summarised in the bibliography at the end of this report. Alongside this we surveyed 435 sufferers of eating disorders and 82 individuals who described themselves in a caring or supportive role to sufferers. There were 27 male and 490 female respondents. Our survey also represented a range of age-groups with 123 sufferers aged under 20, 245 between the ages of 20 and 29, 106 between the ages of 30 and 39 and 43 aged 40 and over (at the time of answering the survey). We also received survey responses across all 12 of the UK Government Office Regions providing a breadth of geographical perspectives.

Whilst the survey findings cannot be described as “statistically representative”, as a result of the accepted lack of clarity on overall prevalence estimates described throughout this report, it does present a detailed and consistent overview of the range of impacts (both costs and outcomes based) experienced across a large sample. Full details of our research approach are included at Appendix 1 with the supporting questionnaire referenced at Appendix 2.

In terms of the wider policy context, that the findings of this report are pertinent to, the Deputy Prime Minister recently announced £150 million of investment to improve the treatment of

children and young people with eating disorders and those who self-harm³. The investment is due to be spent over 5 years and will focus on channelling money to local service provision in order to develop waiting time and access standards for eating disorders by 2016.

In addition to this the Labour Party has announced that if it wins May's general election it will prioritise children's mental health by increasing the proportion of the budget assigned in order to improve waiting times and ensuring all schools have access to a counsellor amongst a series of supporting measures⁴.

This report allows for a greater understanding of the impacts upon individuals, their families, the health sector and the wider economy. It is clear from this review that the impacts of eating disorders upon individuals are severe and often long lasting, but pathways to recovery are both possible and achievable if effectively recognised, tackled and supported.

¹ Beat is legally registered as the Eating Disorders Association; however it chose to be recognised as Beat from February 2007.

² Beat About Us, Available at: <http://www.b-eat.co.uk/about-beat/about-us/>

³ UK Government (2014) *Deputy PM announces £150m investment to transform treatment for eating disorders*, Available at <https://www.gov.uk/government/news/deputy-pm-announces-150m-investment-to-transform-treatment-for-eating-disorders>

⁴ BBC (2015) *Miliband pledges to end child mental health "neglect"*, Available at :<http://www.bbc.co.uk/news/uk-politics-30871900>

What are eating disorders?



“My ED started age 10 after a death in the family as a way of coping. 10 years later and although I’ve moved on, I still find my eating habits hard and still have issues every day.”

Overview

Research involving GP data in the UK indicates an increase in the age-standardised annual incidence of all diagnosed eating disorders (for ages 10-49) from 32.3 to 37.2 per 100,000 between 2000 and 2009. This was mainly due to an increase in the unspecified eating disorder category (EDU), as Anorexia Nervosa (AN) and Bulimia Nervosa (BN) numbers remained fairly stable²⁴. An increase has also been observed in hospital admissions for a primary diagnosis of eating disorders.

A time series analysis of data on the total number of cases of eating disorders being diagnosed in England illustrates a similar trend in increasing prevalence over time.

Increases in understanding of eating disorders, especially the lesser known disorders, may explain the increase in levels of reporting. The improvement in reporting systems and accuracy of data may also have exposed cases previously disguised in national data sets by co-morbidities.

It should also be noted that binge eating disorder has only recently been acknowledged as an eating disorder²⁵. Based on our survey sample, 3.5% of respondents were suffering from binge eating disorder.

“I have headaches, kidney infections, digestive problems (IBS), sore throat, and physical weakness/pain, and dizziness, hair falling out, muscle cramps, bloating, depression, and sleep disturbances. I worry all the time about passing this disorder on to my daughter.”

Figure 2.1

What are eating disorders?

There are many different types of eating disorder, not just anorexia nervosa and bulimia nervosa

Eating disorders can involve either overeating (e.g. binge eating disorder, bulimia nervosa) or undereating (anorexia nervosa)

Eating disorders are predominantly found in adolescent females however males and females of all ages can be affected

There is no one cause of eating disorders, it is thought to be a range of influencing factors

There is a wide range of symptoms of eating disorders, both physical and psychological. These have a range of impacts up to and including death

Reports estimate that with the right treatment almost half of sufferers make a full recovery, with many more making significant improvements

What are eating disorders?

Eating disorders are a group of illnesses in which the sufferer experiences issues with body weight and shape, which disturbs their everyday diet and attitude towards food⁵.

The World Health Organisation (WHO)⁶ provides in-depth definitions for anorexia nervosa (AN) and bulimia nervosa (BN) and these were the basis of our research into eating disorders (for full definitions see Appendix 1). The WHO acknowledges that AN involves deliberate weight loss induced and sustained by the patient due to an excessive preoccupation with their body weight and shape. The fear of gaining weight leads to a restricted diet (which may result in under-nutrition), excessive exercise, use of purgatives etc. It is also noted that BN consists of repeated bouts of overeating followed by vomiting or use of purgatives to ensure control of body weight.

AN has also been defined in the following way by the Parliamentary Office of Science and Technology⁷ and by the National Health Service:

- A maintained body weight at least 15% below that expected for a person given their age and height;
- An intense fear of gaining weight or becoming fat;
- A distorted view of one's body weight and shape which strongly influences self-image and self-worth; and

- Self-avoidance of fattening foods and possible compensatory measures e.g. self-induced vomiting, excessive laxative use or use of appetite suppressants⁸.

Similarly BN is defined as:

- Recurrent episodes of binge eating and experiencing a lack of control over the quantities consumed;
- Recurrent compensatory behaviour, such as self-induced vomiting, misuse of medication (e.g. laxatives), fasting or excessive exercise; and
- These behaviours must have occurred on average twice a week for the last three months.

Other Eating Disorders

While anorexia nervosa and bulimia nervosa are the most commonly known eating disorders, it is important to note that there is a much wider range of eating disorders that can impact on people's lives, their families, carers and communities. In statistical terms these fall into the category of "Eating Disorder Unspecified"⁹ or "other". One such eating disorder is binge eating disorder¹⁰, which is characterised as:

- Eating, in a discrete period of time, an amount of food that is definitely larger than most people would eat in a similar period of time under similar circumstances; and
- A sense of loss of control over eating during the episode (for example, a feeling that one cannot stop eating or control what or how much one is eating).

Whilst this report covers disorders that may in turn lead to sufferers becoming obese rather than underweight, such as binge eating disorder, it does not deal explicitly with those eating disorders which may be associated with pure obesity even though it is widely accepted that an important subset of obese people do indeed have a profound and debilitating unhealthy relationship with food just as those with AN and BN do. As such, our estimates of incidence and impact are likely to be an underestimate of the impact of all eating disorders.

⁵ National Institute of Mental Health (2011) Eating Disorders, Available at: <http://www.nimh.nih.gov/health/publications/eating-disorders/index.shtml#pub1>

⁶ World Health Organisation (2010) ICD-10, Available at: <http://apps.who.int/classifications/icd10/browse/2010/en#/F50>

⁷ Parliamentary Office of Science and Technology (2007) Eating Disorders, London.

⁸ National Health Service (2014) Eating Disorders – Introduction, Available at: <https://www.evidence.nhs.uk/topic/eating-disorders>

⁹ Eating disorder unspecified (EDU) is an eating disorder that does not meet the criteria for anorexia nervosa or bulimia nervosa.

¹⁰ American Psychiatric Publishing (2013) DSM-5, Available at: <http://www.dsm5.org/documents/leating%20disorders%20fact%20sheet.pdf>

Who gets eating disorders?

Eating disorders tend to be more common in females than in males, with research indicating that less than 10% (9.2%) of those admitted to hospital with eating disorders in 2012/13 are male¹¹. Other research, however, indicates that up to 25% of sufferers are males¹². It is possible that because males make up the minority of sufferers, there are issues around diagnosis due to lack of awareness of the problem among men. They may also be reluctant to come forward due to the stigma attached¹³.

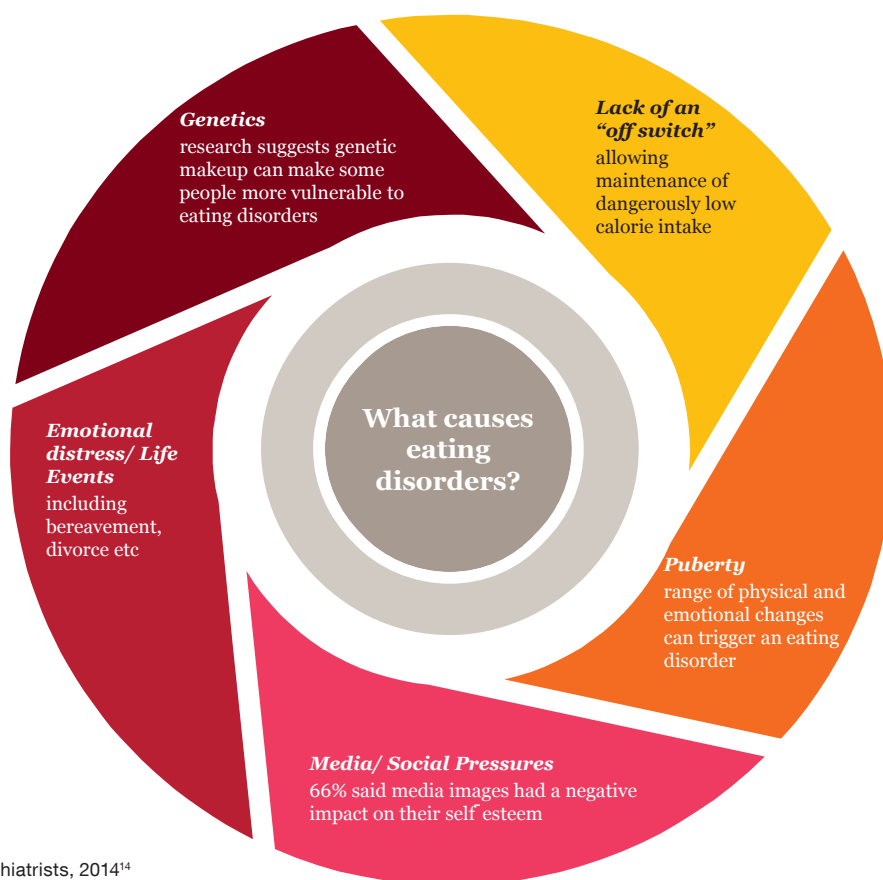
It is acknowledged that eating disorders can develop at any age, with reported cases in children as young as 6 and women in their 70s¹⁴. Most eating disorders, however, develop in adolescence with those under 20 making up almost half (49%) of all those receiving inpatient treatment for an eating disorder in England. NHS guidance on eating disorders notes that anorexia nervosa commonly develops around the ages of 16-17, while bulimia nervosa develops at 18-19 and binge eating disorder appears later in life, usually between the ages of 30-40¹⁵.

What causes eating disorders?

There is no simple answer to the question of what causes eating disorders, with research indicating that it is usually a combination of influencing factors¹⁶. As illustrated at Figure 2.2, typical contributing factors can include genetic influences, the impact of puberty, stress, life events and the growing influence of social media driven pressures.

Figure 2.2

What causes eating disorders?



Source: Royal College of Psychiatrists, 2014¹⁴

¹¹ Health and Social Care Information Centre (2013) Hospital Episode Statistics, Admitted Patient Care, England 2012-2013, Available at: <http://www.hscic.gov.uk/catalogue/PUB12566>

¹² Beat (2010) Beat: Facts and Figures, Available at: <http://www.b-eat.co.uk/about-beat/media-centre/facts-and-figures/>

¹³ Parliamentary Office of Science and Technology (2007) Eating Disorders, London

¹⁴ Royal College of Psychiatrists (2014) Anorexia and Bulimia, Available at: <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/anorexiaandbulimia.aspx>

¹⁵ NHS Choices (2013) Eating Disorders, Available at: <http://www.nhs.uk/conditions/eating-disorders/pages/introduction.aspx>

¹⁶ Strober, M., Freeman, R., Lampert, C., Diamond, J. and Kaye, W (2000) 'Controlled Family Study of Anorexia Nervosa and Bulimia Nervosa: Evidence Shared Liability and Transmission of Partial Syndromes', The American Journal of Psychiatry, 157, pp. 393-401 [Online]. Available at: <http://ajp.psychiatryonline.org/110000article.aspx?articleid=174007>

“My first occurrence went undiagnosed – treated as depression; only offered antidepressants”

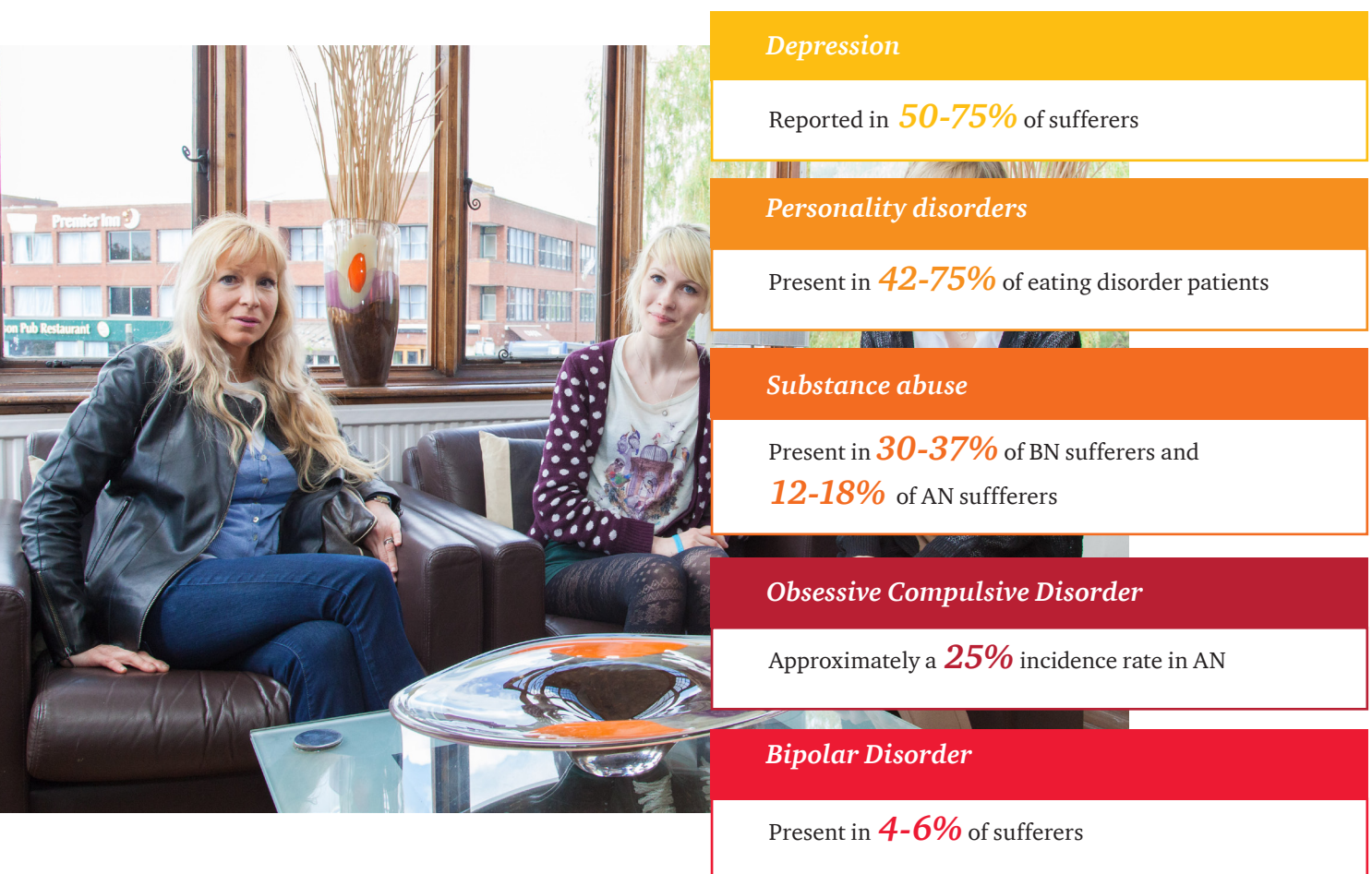
Linked Conditions

One of the persistent challenges in diagnosing and treating eating disorders, and indeed in analysing trends in prevalence and reporting, is that it is common for eating disorders to occur alongside other mental health issues, as illustrated in Figure 2.3.

Therefore, eating disorders are often one of a number of conditions that simultaneously impact upon individuals. This is a contributing factor to the difficulty in recognising and ultimately treating eating disorders.

Figure 2.3

Other conditions linked to eating disorders



Source: Practice Guidelines produced by American Psychiatric Association¹⁷

¹⁷ American Psychiatric Association (2006), 'Practice guideline for the treatment of patients with eating Disorders', available at: http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/eatingdisorders.pdf

What are the physical impacts and long term side effects of an eating disorder?

Among mental health conditions, eating disorders are unusual in that the symptoms are both psychological and physical. Physical symptoms can have long-term health implications, although each sufferer will experience different symptoms at different times during their illness.

There are also many long-term side effects which may carry on even after recovery¹⁸:

- **Anorexia Nervosa** – poor functioning of the body (especially brain, heart, liver and kidneys); infertility; osteoporosis and stunted growth; and
- **Bulimia Nervosa** – painful swallowing due to drying of the salivary glands; imbalance or low levels of essential minerals; increased risk of heart problems; severe damage to the stomach, oesophagus, teeth, salivary glands and bowel.

Those who suffer from a long term eating disorder may also struggle due to associated impairment in areas such as social, work, leisure and family life¹⁹. Many of these elements are perhaps not as well understood. They can have lasting impacts in terms of continuing education, gaining or sustaining employment as well as maintaining an active social life – with eating disorders often the key contributing factor to these impacts.

Physical Impacts¹⁷

- Difficulty eating due to a shrunk stomach
- Feel tired, weak and cold as metabolism slows
- Constipation
- Changes in hair and skin including hair loss, growing downy hair, dry skin
- Not growing to full height or losing height with a bowed over appearance
- Brittle bones

Psychological¹⁷

- Sleep problems
- Anxiety disorders
- Difficulty concentrating on anything other than food and calories
- Feeling down or depressed
- Loss of interest in other people
- Obsessive behaviours related to food may transfer to other areas such as cleaning, washing, etc.

What tools are currently available to support diagnosis?

Eating Disorders are typically diagnosed once a sufferer or their carer seeks medical help (often from their GP) for the symptoms that are present. There are a variety of ways in which an eating disorder can be recognised and diagnosed, from medical tests to the SCOFF screening tool (see appendix 5).

Calculating BMI (Body Mass Index) and conducting blood tests can help diagnosis but provide inadequate findings in isolation. A number of tests

can be carried out, including muscle strength, hydration, blood pressure and pulse rate, peripheral circulation and core temperature²⁰.

Other indicators of risk that may support a diagnosis include excessive exercise with low body weight, blood in vomit, inadequate fluid intake and rapid weight loss²¹.

¹⁷ Beat (2010) Beat: Facts and Figures, Available at: <http://www.b-eat.co.uk/about-beat/media-centre/facts-and-figures/>

¹⁸ Beat (2011) Caring for a child or adolescent with an eating disorder.

¹⁹ Mitchison, D., Hay, P., Engel, S., Crosby, R., Le Grange, D., Lacey, H., Mond, J., Slewa-Younan, S. and Touyz, S. (2013) 'Assessment of quality of life in people with severe and enduring anorexia nervosa: a comparison of generic and specific instruments', BMC Psychiatry, 13(284), pp. [Online]. Available at: <http://www.biomedcentral.com/1471-244X/13/284>

²⁰ American Psychiatric Publishing (2013) DSM-5, Available at: <http://www.dsm5.org/documents/eating%20disorders%20fact%20sheet.pdf>

²¹ Treasure, J. (2009) A Guide to the Medical Risk Assessment for Eating Disorders, South London: King's College London/ South London and Maudsley NHS Foundation Trust.

How can eating disorders be treated?

Once diagnosed, there are many potential therapies that can aid the treatment of eating disorders, as shown in Figure 2.4. These include cognitive behavior therapy (CBT) and other forms of psychotherapy including family therapy and self-help programmes²². The most severe cases can involve extended periods of inpatient treatment, delivered either privately or through the NHS.

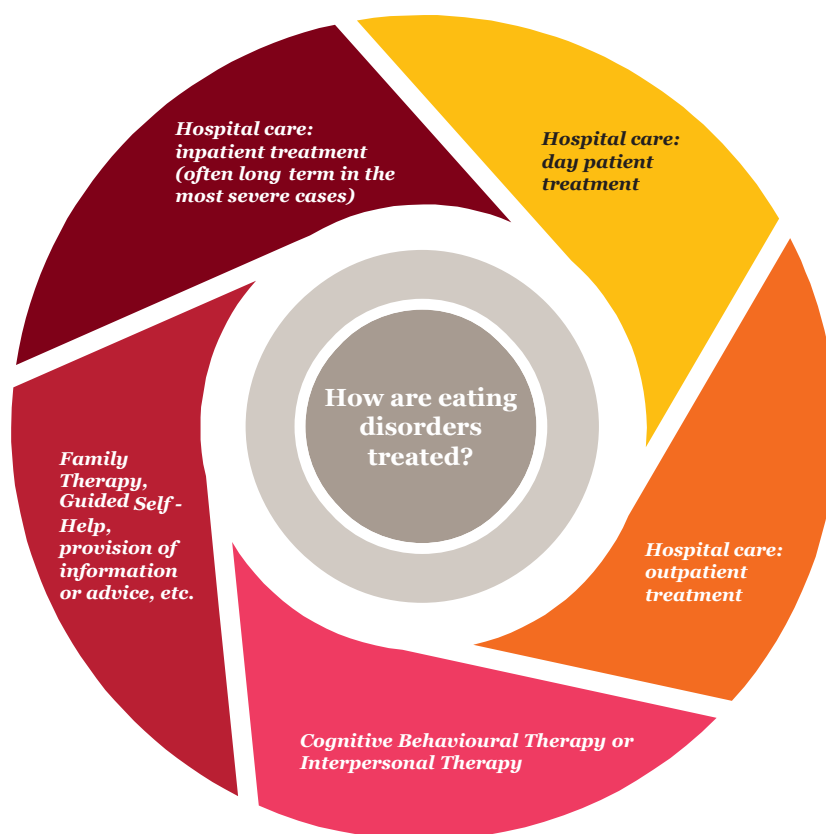
Treatment goals across this range of options are not always based on full recovery and remission of all symptoms but instead reflect improvements in social and occupational function²³. This allows patients to have a more positive focus on improving their quality of life instead of focusing solely on their weight.

Those who are suffering from eating disorders rarely seek professional help unless prompted due to fear of gaining weight, which can make treatment very

difficult and may also impact on the perception of the care received. In the most severe cases of patients refusing treatment due to fear of gaining weight they may be treated under the Mental Health Act.^{24, 25}

Figure 2.4

Forms of treatment for eating disorders



²² NICE (2004), 'Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders' as cited in Parliamentary Office of Science and Technology (2007) Eating Disorders, London: POST.

²³ American Psychiatric Association (2006), 'Practice guideline for the treatment of patients with eating Disorders', available at: http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/eatingdisorders.pdf

²⁴ Royal College of Psychiatrists (2012) "Main findings of the 2008 survey of eating disorder services in the UK and Ireland" in Eating Disorders in the UK: service distribution, service development and training, London: Royal College of Psychiatrists.

²⁵ Beat (2011) Caring for a child or adolescent with an eating disorder.

Carers

Eating disorders – like other mental and physical health conditions – require non-medical care and support in the home. In many cases, this is provided by a friend or family member. The NHS states that anyone looking after an ill, disabled or frail relative or friend should be recognised as a carer²⁶, with a carer defined by The Carers Trust – a national network charity, supporting unpaid carers across the UK – as “anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.” It is thought that there are up to 7 million carers in the UK, 1.5 million of whom care for someone with mental health problems. The cost savings to the NHS due to the work of carers in the UK is approximately £119 billion a year²⁷.

The Carers Trust has specifically acknowledged the critical role of carers in the treatment of people with mental health disorders, in their “Triangle of Care” guide launched in July 2010²⁸, emphasising the need for better local strategic involvement of carers and families in the care planning and treatment of people with mental ill-health.

The Department of Health also acknowledged in 2014²⁹ that supporting carers and involving carers in treatment decisions was a key priority in improving mental health provision, and whilst no specific provisions are made for eating disorders within this strategy, there are parallels between the emotional and financial “drains” on carers that form the basis of this priority and those reported in our survey. Further work to understand the specific needs of carers of sufferers of eating disorders and the most appropriate support to them should therefore be considered in any review of treatment interventions.

Recovering from eating disorders

Beat has campaigned vigorously about the fact that people can overcome their eating disorders, although people can and do die. Previous studies have found that of those who had been diagnosed with anorexia nervosa, 46% made a full recovery, 33% improve without making a full recovery and 20% remain chronically ill³⁰. A similar study into bulimia nervosa found that 45% recover, 27% make a considerable improvement and 23% remain chronically ill³¹.

“Doctors wanted to treat me as an inpatient, but as there was a waiting list they agreed that if my mum took time off and was my full time carer I could stay at home. So this impacted on her greatly.”

²⁶ NHS (2015) Your guide to care and support. Available at: <http://www.nhs.uk/conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx>

²⁷ Carers Trust (2012) Key facts about carers, Available at: <http://www.carers.org/key-facts-about-carers>

²⁸ The Triangle of Care Guide was launched as a joint piece of work between Carers Trust and the National Mental Health Development Unit (<https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>)

²⁹ Closing the Gap: Priorities for essential change in mental health

³⁰ Steinhausen, HC. (2002) ‘The outcome of anorexia nervosa in the 20th century’, American Journal of Psychiatry, 159(8), pp. 1284-1293.

³¹ Steinhausen, HC. and Weber, S. (2009) ‘The Outcome of Bulimia Nervosa: Findings from One-Quarter Century of Research’, The American Journal of Psychiatry, 166(12), pp. 1331-1341.

Prevalence



“My daughter has suffered from anorexia nervosa for 25 years. She has had various treatments over the years and lasting different periods of time.”

This section contains the basis upon which we have estimated the prevalence of eating disorders in the UK. Given the underlying complexity of eating disorders (leading to inconsistency in how they are diagnosed) there is a wide variance in previous national prevalence estimates which, in turn, are often derived from historical or international studies. This is, in part, a reflection of the lack of consistent or comprehensive reporting within the health care sector – eating disorders have until recently only been specifically categorised under in-patient data. Similarly, and as reflected by our survey results, there may be cases where eating disorders are recorded wrongly or not at all.

Notwithstanding the above, BEAT has several concerns about the published studies of prevalence that we equally share. For example the “lowest” level of prevalence – at around 91,600 sufferers in the UK – is recorded by a 2008 study conducted by the Kings Fund. This level is based on:

- Estimates of the likelihood of prevalence in those up to the age of 34; and
- The exclusion of any estimates of EDU (including binge eating disorder).

To address these two issues, we have:

- Refreshed the Kings Fund data with up-to-date population statistics from ONS;
- Added – based on Hoek & van Hoeken study data (2003) – the total number of under 34 people suffering in the UK from binge eating disorders at a level of 281,000; and

- Taken the proportion of hospital admissions to total admissions of those with eating disorders aged over 35 (at a level of 21%) as a proxy of the total percentage of those likely to be missed by both of these studies.

As a result we estimate that prevalence, as illustrated in Table 3.1, could be at a level of 608,849.

Table 3.1
Adjustments to Kings Fund estimates

Updated initial projections (under 34, AN and BN only)	199,167
Binge Eating Disorder prevalence	281,823
Assumed 21% of 35 or older sufferers	127,859
Total	608,849

At the “higher” end of the range of estimates, prevalence levels are most frequently derived from those included in National Collaborating Centre for Mental Health’s 2004 report³². Most frequently reported as a total UK sufferer count of 1.6m, the prevalence estimates contained in this report are based on comparative international studies covering:

- Total population estimates for AN for men and women;
- Total population estimates for BN for women and relative frequency for men; and
- Emerging conclusions on a wide range of incidence for binge eating disorder for women only.

To form a comparable estimate derived from this source to the estimates derived from the Kings Fund and Hoek & van Hoeken study data, we have:

- Refreshed the data to reflect the latest UK population statistics;
- Adopted the lower levels of prevalence recorded in the report for binge eating disorders given that the higher levels in the report are drawn specifically from studies of obese populations; and

- Added (based on the trends in male to female sufferer ratios from other disorder types at a level of 10%) an estimated prevalence rate for male sufferers of binge eating disorder.

As a result, as indicated in Table 3.2, we have derived a higher level estimate of 724,845.

Table 3.2
Application of National Collaborating Centre for Mental Health prevalence indicators

AN prevalence	6,819
BN prevalence	360,764
BED prevalence	357,261
Total ED prevalence	724,845

³² NICE (National Institute for Clinical Excellence) (2004) Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders, Great Britain: The British Psychological Society and Gaskell.

There are increasing numbers of reported cases of eating disorders in the UK

Separately from prevalence data research involving GP data in the UK indicates an increase in the age-standardised annual incidence of all diagnosed eating disorders (for ages 10-49) from 32.3 to 37.2 per 100,000 between 2000 and 2009. This increase appears to be due to an increase in the unspecified eating disorder category as AN and BN numbers remained fairly stable³³.

Separately, as outlined in Table 3.3, time series analysis of data on the total number of cases of eating disorders being diagnosed in England illustrates a similar trend in increasing prevalence over time with a 34% increase in admissions since 2005-06 – approximately 7% per annum.

These recorded changes may reflect increases in the understanding of eating disorders especially the lesser known disorders and particularly binge eating disorder which has only recently been acknowledged in statistical recording³⁴.

Our survey indicates that eating disorders most commonly initially present amongst the young, and national data indicates that they can also start later in life and can be life-long conditions

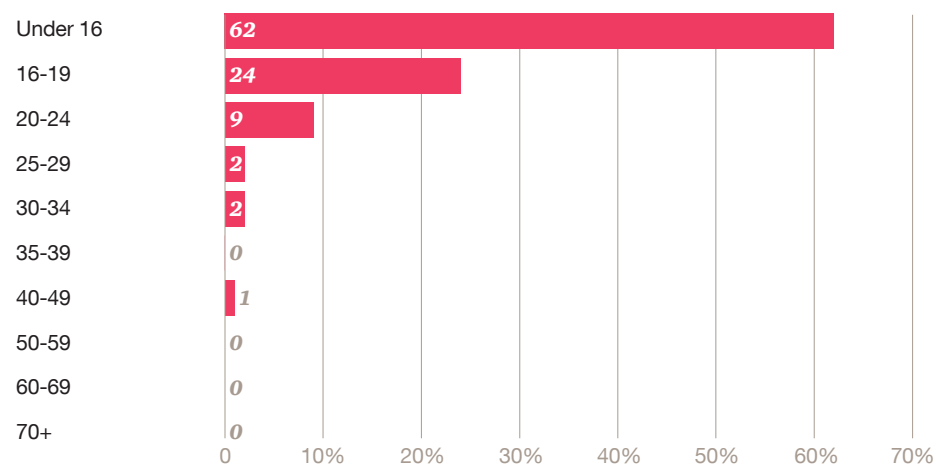
Table 3.3

Count of FAEs with primary diagnosis of eating disorder in England, 2005-2014

	Count of Finished Admissions Episodes (FAEs) where the primary diagnosis was of eating disorders (England)
2005-2006	1,882
2006-2007	1,924
2007-2008	1,872
2008-2009	1,868
2009-2010	2,067
2010-2011	[missing data]
2011-2012	2,285
2012-2013	2,380
2013-2014	2,855

Figure 3.1

Age when symptoms of an eating disorder first appeared



Base: 517

³³ Micali, N., Hagberg, K.W., Petersen, I. and Treasure, J.L. (2013) 'The incidence of eating disorders in the UK in 2000-2009: findings from the General Practice Research Database', BMJ Open, 3, pp. 1-9 [Online]. Available at: <http://bmjopen.bmj.com/content/3/5/e002646.full.pdf+html?sid=81b1351b-1ad6-4fca-a2e7-eea7cbf951be>

³⁴ American Psychiatric Association, (2013) Feeding and Eating Disorders, Available at: <http://www.dsm5.org/documents/eating%20disorders%20fact%20sheet.pdf>

Our respondent age profile is broadly consistent with other research which indicates that many eating disorders emerge in adolescence. The NHS, for example, noted that AN usually develops around 16-17, BN around the age of 18 or 19 with binge eating disorder emerging slightly later in life, between the ages of 30-40. Similarly hospital admissions data for 2012/13 also indicated that those under 20 made up almost half of all those admitted for treatment of eating disorders in England.

As illustrated, in Figure 3.2, over half of our respondents with eating disorders have suffered for more than 6 years. This is supported by previous studies, where it has been shown that some eating disorders can be life-long conditions with recovery rates for anorexia nervosa and bulimia nervosa both fewer than 50%³⁵.

Generally, women are more afflicted than men

While our survey respondents appear to be similar in breakdown as other studies and data (i.e. around 10% of sufferers are male) it should be noted that there may be under recording given lack of awareness of eating disorders in men.

Similarly there is also another, hidden group of sufferers who may never seek help for an eating disorder but nevertheless experience the impacts of an ED upon their life. This group may contain a high percentage of males given the reluctance among males to seek medical help³⁶.

Figure 3.2

Length of suffering from eating disorder

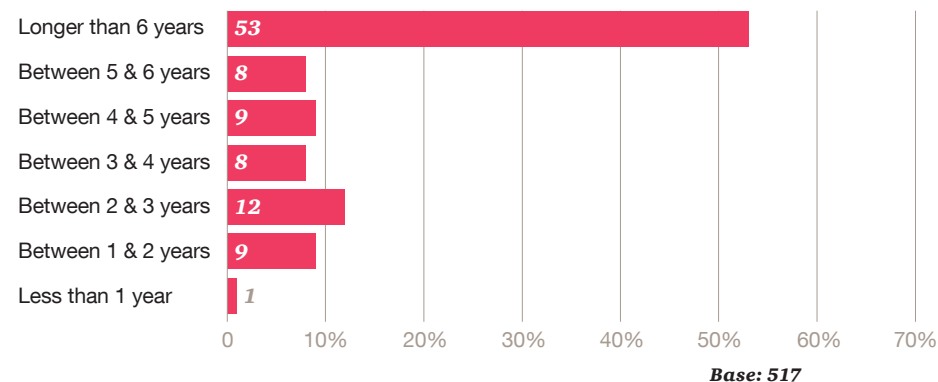
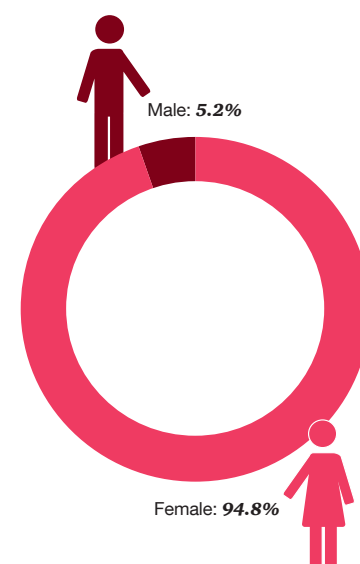


Figure 3.3

Gender breakdown of survey respondents



³⁵ Steinhausen, HC. (2002) 'The outcome of anorexia nervosa in the 20th century', American Journal of Psychiatry, 159(8), pp. 1284-1293.

³⁶ Juel and Christensen (2008) Are men seeking medical advice too late? Contacts to general practitioners and hospital admissions in Denmark 2005, Journal of Public Health.

Seeking help and diagnosis



“My daughter suffered age 12-14, had 4 good years then relapsed spectacularly when moving to university and was made to wait 10 months to get any help, which she had asked for and wanted. It was a nightmare to watch as she deteriorated and when she got to treatment it was already entrenched and she was more resistant to change. The impact of the poor treatment when she was 12/13 years old as an inpatient makes her reluctant to trust treatment again.”

The following section details our findings regarding the point of seeking help for eating disorder symptoms and subsequent diagnoses. Use of our survey and other national data sources has enabled conclusions to be made concerning the fundamental importance of early diagnosis. Our primary conclusion is that there is a clear pattern of delay in seeking help for eating disorders, which in turn delays diagnosis and treatment creating more severe and long term impacts. Our survey indicates that the speed at which help is initially sought has a material impact upon likelihood of relapse. This supports our recommendation that future investment be focused on supporting recognition of symptoms and creating opportunities for earlier intervention.

Delays in seeking help

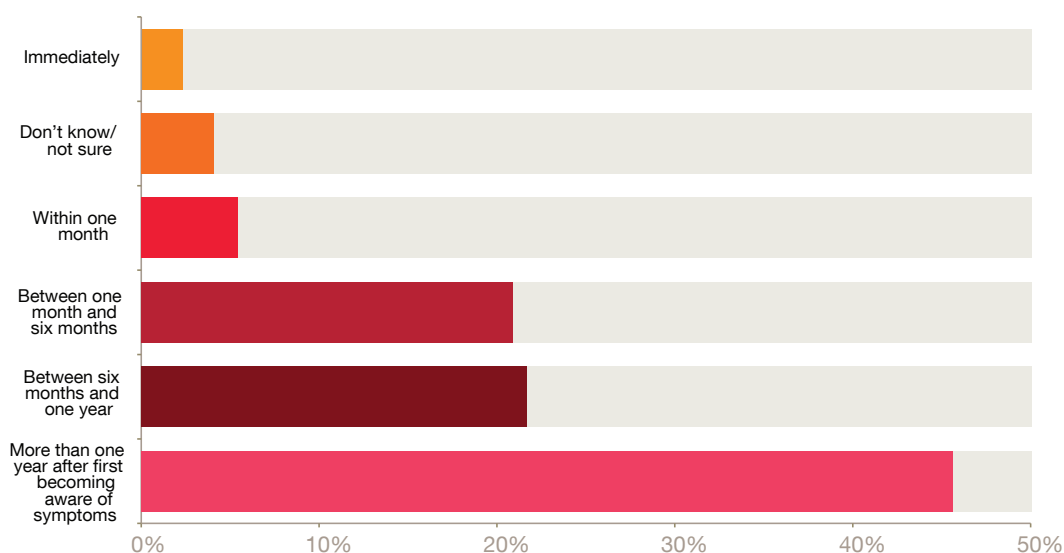
"I said I was fine and the GP left me alone. I didn't ask specifically for help until another 8 months later."



Almost half of sufferers wait longer than a year after recognising symptoms of an eating disorder before seeking help

Figure 4.1

Time between recognising symptoms and seeking help



**Base:
517**

As indicated at Figure 4.1, a large majority of sufferers wait longer than 6 months to seek help once they have noticed the symptoms, or become aware of, their eating disorder.

This delay is significant, as our survey has indicated that those who seek help immediately are significantly less likely to require multiple episodes of treatment for the eating disorder. For example, only 33% of those seeking help 'immediately' upon noticing symptoms require multiple episodes of treatment, compared to 63% of those who wait before seeking help.

As outlined in later sections, we believe this delay has a material impact on the outcomes for sufferers and carers, in terms of recovery, as well as extending the duration of impacts not only on the individual's health but also on their life more generally including work, relationships and education, which have associated economic impacts.

It should be noted that the delay we have identified does not account for the time before symptoms have been recognised by the sufferer, which previous studies have indicated may begin at the age of 6 in some cases³⁷.

³⁷ American Psychiatric Publishing (2013) DSM-5, Available at: <http://www.dsm5.org/documents/eating%20disorders%20fact%20sheet.pdf>



This delay is even worse for lesser known disorders (Eating Disorder Unspecified and ‘other’ disorders).

As presented in Table 4.1, symptoms of anorexia nervosa and bulimia nervosa tend to be acted upon earlier than those of less common disorders, perhaps due to a lack of awareness of these disorders, even among those potentially suffering from them. For all disorders other than anorexia nervosa, over half of all respondents waited more than a year before seeking help.

Table 4.1

Time taken to seek help for each eating disorder

	AN	BN	EDU	Other
Immediately	2.9%	1.3%	0.0%	0.0%
Within 1 month	5.5%	5.0%	3.3%	3.2%
Between 1 month and 6 months	24.2%	14.5%	11.7%	6.5%
Between 6 months and 1 year	23.2%	18.9%	20.0%	19.4%
More than 1 year	40.9%	54.1%	58.3%	64.5%
Don't know	3.3%	6.3%	6.7%	6.5%

AN tends to develop at the age of 16-17, BN at 18-19 and BED (grouped with EDU) around 30-40 years³⁸. With this in mind, it may be the case that parents of young people with AN recognise the problem quickly as a result of easier to identify symptoms and, therefore encourage them to seek help.

Those with binge eating disorder tend to be composed of an older group who are less likely to seek help as it is not viewed as severe and the physical symptoms may not be as easy for others to recognise.³⁹

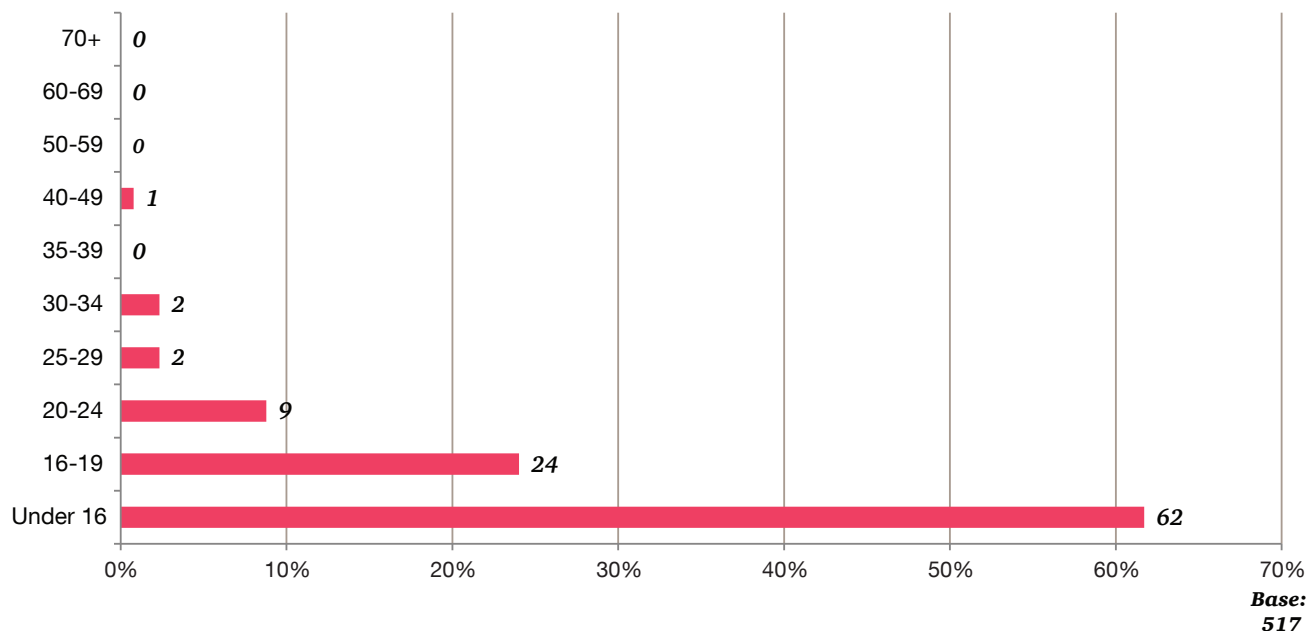
³⁸ NHS Choices (2013) Eating Disorders, Available at: <http://www.nhs.uk/conditions/eating-disorders/pages/introduction.aspx>

³⁹ Beat (2010) Beat: Facts and Figures, Available at: <http://www.b-eat.co.uk/about-beat/media-centre/facts-and-figures/>

The delay in seeking treatment has a further effect on impacts.

Figure 4.2

Age when symptoms of an eating disorder were first recognised



As above, we believe this delay in receiving care impacts upon the longer-term outcomes for sufferers. This, in part, results from the fact that eating disorders most frequently become apparent when people are in compulsory education (i.e. when they are under 16). As we will explore later, disruption to education (including periods of absence or permanent termination of education) are regular

outcomes for sufferers, and has associated long-term financial and non-financial impacts for sufferers and their carers. We believe this finding of the typical age of onset presents a clear opportunity to explore the case for early intervention in school years. If teachers and others such as peers and families have awareness training and understanding of the symptoms of eating disorders it may allow greater

recognition of the illness during an early stage. This links well to recent Government announcements towards improving early intervention services for eating disorders⁴⁰, with Labour party specifically prioritising access to counsellors in school to deal with mental health issues.⁴¹

The delay is even worse for young men. Despite making up a relatively small proportion of sufferers our survey indicates that they also display symptoms at a young age, and often take longer to seek help.

The small number of male respondents to our survey makes it difficult for us to draw robust conclusions on the differences in the lifecycle of symptoms, treatment and recovery for men and women. A further comparative study of these groups would be beneficial to support the development of recommendations specific to male sufferers.

⁴⁰ UK Government (2014) Deputy PM announces £150m investment to transform treatment for eating disorders, Available at: <https://www.gov.uk/government/news/deputy-pm-announces-150m-investment-to-transform-treatment-for-eating-disorders>

⁴¹ BBC News (2015) Miliband pledge to end child mental health 'neglect' Available at: <http://www.bbc.co.uk/news/uk-politics-30871900>

Diagnosis and waiting times

“I have been waiting for therapy for 13 months and it is predicted to take another 6 until I am at the top of the list.”

“Initially we were booked in to see the specialist consultant for a much later date however my mum was very persistent and luckily a cancellation meant that an appointment became available within a week. Had I not been able to see the consultant that week, I may not have survived.”





In over 40% of cases, time taken for a diagnosis and waiting time for appropriate treatment is more than 6 months

In addition to the delay in seeking help upon becoming aware of eating disorder symptoms, our survey has also indicated a further delay between seeking help and a diagnosis being made, or treatment starting. This, in effect, perpetuates both the suffering and associated impacts with a recurrent lag that permeates the timeline of symptoms, to help, to diagnosis and treatment.

Based on those who have had to wait for a diagnosis and/or treatment:

- 41% had to wait for more than 6 months; and
- 19% had to wait for more than 1 year.

Across the group of 517 respondents to our survey, the delay in seeking help is often coupled with a year long period of waiting for a diagnosis followed by a period waiting for treatment that is often over 6 months. Consequently on average our survey respondents experienced a lag of 15 months or more between recognising symptoms and treatment starting with 18% waiting 2 years or more.

In the majority of cases, individuals suffering from eating disorders and their carers believe they would have benefitted from a quicker referral. When asked how their treatment could have been improved, the most common answer across all individuals was to have had earlier access to specialists (cited in 27% of cases).

There are currently no national benchmarks for waiting times for eating disorder treatment; however this is now on the Government's agenda for the forthcoming year with the funding that has been allocated⁴². It should be noted that illnesses with benchmarks for waiting times tend to have shown improvements in treatment outcomes⁴³.

The pattern of delay is inconsistent across the different regions of the UK, with all of our survey respondents in some regions being treated within 18 weeks, while in other regions as few as 25% are treated within this same time period. This apparent inconsistency across the regions is an area where further and separate analysis is needed to identify the drivers that underpin this.

⁴² NHS England: Guidance to support the introduction of access and waiting time standards for mental health services for 2015/16 available at <http://www.england.nhs.uk/wp-content/uploads/2015/02/mh-access-wait-time-guid.pdf>.

⁴³ Department of Health (2014) Achieving better access to mental health treatment by 2020, available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/361648/mental-health-access.pdf.



Treatment

“I feel the impact of being a carer in every area of my life. My daughter’s been ill a long time – since she was 18, and she’s now 26. She’s been in hospital nearly 70 miles from home for 21 months and the previous year was in for 8 months, and has been under section for much of that time.

Had she had earlier specialist intervention she might not be where she is now. I feel traumatised by that period, and how things were handled. Financially, it’s been a real strain. I’ve spent thousands of pounds on petrol and parking alone.”

This section explores the trends in the provision of treatment to sufferers of eating disorders, which informs our understanding of not only the costs associated with the current treatment regime but also the full duration and nature of impacts on the individual. Our key finding from this area is that treatment is inconsistent, both across different disorders and different regions of the UK, supporting Beat's long-held view that access to care is inconsistent. We have also explored in this section the trends in treatment outcomes for sufferers, which paint a stark picture of a recurring cycle of diagnosis, treatment, recovery and relapse that more often than not lasts at least 6 years. These trends appear to be across all treatment types, leading us to conclude that more investment is needed into understanding what works, particular in the area of early intervention, in light of our findings in the previous section.

Variations in treatment

Our survey indicates that the treatment provided to those suffering from eating disorders varies widely. Typically, a first instance of treatment lasts 13 months and is made up of multiple intervention types. The most common combinations are:

- Repeated episodes of NHS outpatient (117 cases);
- NHS outpatient treatment followed by NHS inpatient (58 cases); and
- NHS inpatient treatment followed by NHS outpatient treatment (56 cases).

Treatment pathways vary by disorder type, with longer treatment periods for AN compared with BN and other disorders. This is most apparent in NHS treatments, when the average length of treatment for AN is 12.3 months, compared to 8.7 months for BN and 9 months for other disorders.

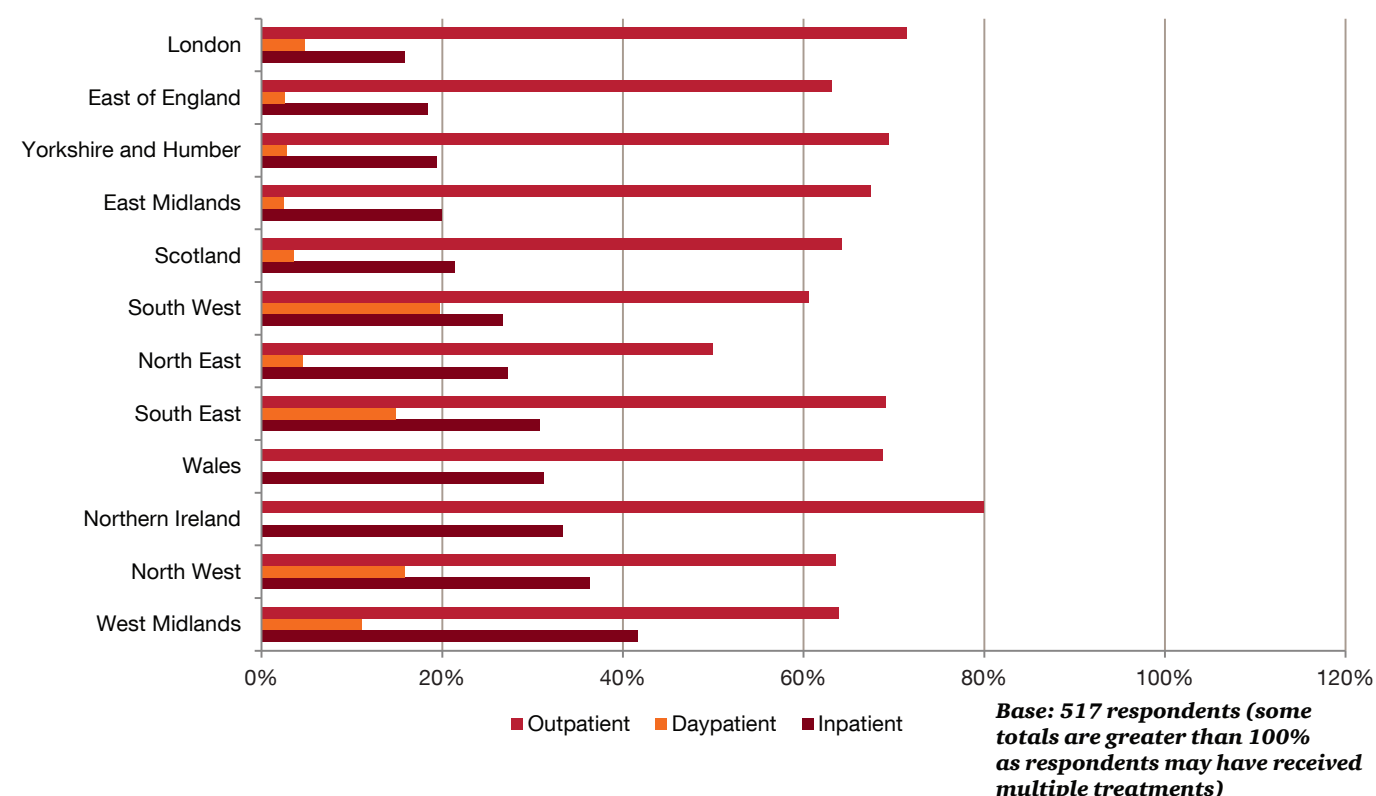
"I was not referred for specialist treatment until 3 years after I was diagnosed because I was told there was no specialist service in the area. I was just prescribed antidepressants. I only got specialist treatment when I moved to another area."

"I have to say I feel lucky as I had a GP who listened, referred my daughter to CAMHS and we were seen within 2 weeks. We had a fantastic support system and due to this my daughter is doing very well."



Figure 5.1

Type of care provided across the regions (including private care)



Male respondents to our survey also tend to have longer periods of treatment (with an average treatment period of 14.3 months compared to 8.8 months for female respondents), and take longer to recover.

Table 5.1

Length of eating disorder by gender

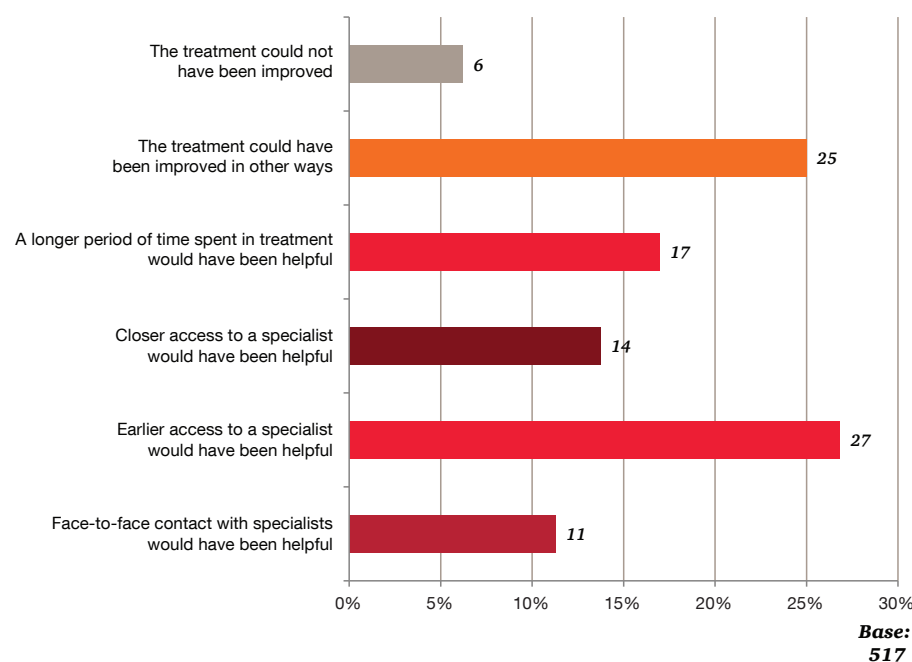
	Female	Male
Less than 1 year	1.4%	0.0%
Between 1 and 2 years	9.2%	14.8%
Between 2 and 3 years	11.8%	7.4%
Between 3 and 4 years	7.6%	7.4%
Between 4 and 5 years	9.2%	11.1%
Between 5 and 6 years	8.2%	0.0%
Longer than 6 years	52.7%	59.3%

We note that this finding is based on a small sample size of male respondents and may not therefore be reflective of all sufferers' experience. As above, we believe that a further comparative study of the differences between male and female eating disorders would allow firmer and more robust conclusions to be drawn. It is possible that the treatment duration is impacted by the fact that men wait longer to seek help and so the eating disorder has lasted for longer, and possibly increased in severity over time, thereby making it more difficult to treat.

Across all regions, and treatment types, our survey respondents have identified the need for improvement to treatment provided for their disorders. Most frequently, these improvements relate to waiting times for specialist help. The wide range of "other ways" suggested by our survey respondents – from more peer support, to earlier intervention, to prompter recognition by GPs of the underlying condition – supports our conclusions about the inconsistency in treatment provision across the UK.

Figure 5.2

How eating disorder treatment could be improved

**Treatment outcomes and relapse**

From our survey, we found that 63% of all respondents suffered a relapse and required subsequent treatment for their eating disorder. This merits a further examination of the factors that increase or decrease the chances of relapse. In addition, our survey indicates that a significantly higher proportion of females require multiple episodes of treatment in comparison with males (63% vs. 48%), but as above, this is derived from a small sample of male respondents and may not be indicative of all sufferers' experiences.

Relapse rates are particularly high where symptoms become apparent under the age of 16

Table 5.2

Rate of relapse and subsequent treatment by age group

	Under 16	16-19	20-24	25+
Percentage requiring subsequent episodes of treatment	66.5%	61.8%	44.4%	42.9%

Relapse is common across all types of eating disorders

Table 5.3

Rate of relapse and subsequent treatment by disorder type

	AN	BN	EDU	Other
Percentage requiring subsequent episodes of treatment	66.3%	64.2%	68.3%	58.1%

One explanation for this is that treatments typically reserved for the most severe cases result in higher levels of relapse. ‘Other’ treatments commonly included; Cognitive Behavioural Therapy, antidepressants, help from charities or community services, counselling, psychotherapy, treatment for other mental health problems or no treatment at all and across all of these, almost 50% of sufferers experience at least one relapse.

Table 5.4
Rate of relapse and subsequent treatment by first type of treatment

	Percentage requiring subsequent episodes of treatment
Inpatient treatment	77.6%
Day-patient treatment	70.8%
Outpatient treatment	62.2%
Provision of information or advice	51.5%
Guided Self Help	53.4%
Family therapy	66.4%
Another form of treatment or support	46.2%

It should be noted that the rate of relapse and subsequent treatment for the “other” category may be lower due to the fact many of this group either received no treatment in the first place or were treated only for another mental health issue such as depression.

The factor that has the most significant bearing on the likelihood of relapse is

the speed at which help is sought by the sufferer. Where sufferers in our survey reported to have sought help immediately, the chances of relapse are reduced to 33% (compared to 66% for those who wait before seeking help). This stark difference supports the case for exploring ways of increasing the early recognition of symptoms and access to help.

The 6 year cycle

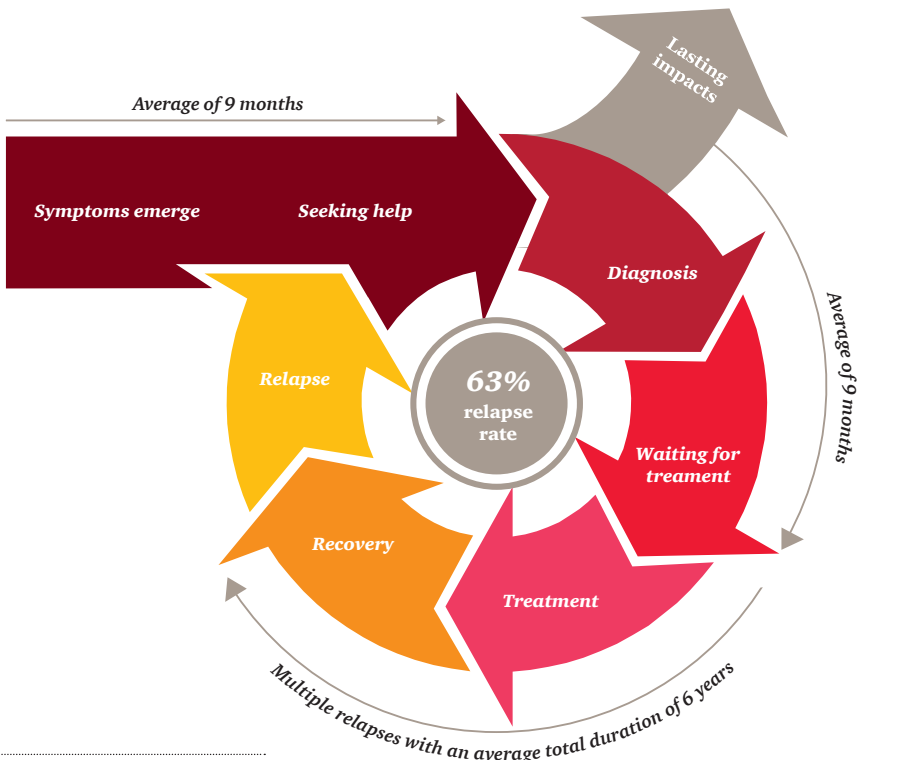
Figure 5.3 provides a graphical depiction reflecting a number of the key themes presented throughout this report. The ‘symptoms emerge’ and ‘seeking help’ stages, and the average time lag of 9 months, is a critical component that requires the most significant attention if eating disorders are to be tackled and effectively supported. The evidence suggests that whilst eating disorders can have severe impacts upon the health and lifetime opportunities of affected individuals together with the wider impacts and costs on their carers – if identified early and effectively treated – a sustainable recovery is both possible and achievable.

Thereafter, our primary and other secondary research evidence suggests a cyclical process of diagnosis, which can often be a process of mis-diagnosis for less commonly understood conditions, treatment waiting times that are unduly protracted culminating in treatments that lead to unsustainable

recoveries which, in 63% of our survey respondent cases, lead to periods of relapse that perpetuate this cyclical

process that creates long term impacts upon sufferers and carers.

Figure 5.3
Treatment, recovery and relapse – the 6 year cycle⁴⁴




⁴⁴ Lasting impacts are discussed further in Section 6 of this report.



“Relapse is viewed as being almost inevitable in many cases, and healthcare professionals themselves have described the current service as having a ‘revolving door’ policy – patient comes into care, restores some weight, is discharged then relapses – I fear this will continue to be the case for many long-term sufferers if the system remains unchanged.”

“I have suffered from bulimia for approximately 20 years. Three times I have asked for help and my GP was great and referred me appropriately but it was only on the third time that I actually felt like I truly wanted to get better. Miraculously I still managed to hold down my full-time job (thanks to a very understanding boss) and be a good mum to my kids. I finished treatment in 2012 and I feel like a big weight has been lifted. I do consider myself to be finally recovered.”

Outcomes and impacts



“My education was disrupted repeatedly: I had to leave during my A levels in 2001, my first attempt at university in 2004, my second and third attempts at university in 2005 and 2006 (same university, dropped out twice) and my fourth attempt in 2009 (I finally graduated with first class honours earlier this year). My eating disorder was partly responsible for breaking up one long term relationship, and also caused a lot of arguments in my family.

As a result of long periods spent too unwell to work I have big gaps in my CV and find it very hard to gain employment. I hoped I would be young enough to still rebuild my life when I started recovering (I was 24 and am now 30), but the eating disorder stole my teens and early 20s and I am correspondingly at 5-10 years behind my peers in terms of personal life, earning potential and education.”

In this section consideration is given to the financial, economic and other impacts associated with eating disorders. Based on our survey results, and publically available data in relation to treatment costs, we have assessed the financial burden on the individual, their carers and family, the implications upon the public sector and the economy more widely and, most importantly, the effects on individuals, carers and family wellbeing. Even if these costs and effects are only considered in light of the lowest of our potential national prevalence estimates, they provide a clear argument to increase those resources dedicated to addressing the challenges outlined in the previous sections of this report.

Financial impacts

In considering the costs to sufferers and carers of eating disorders we asked survey respondents to identify and, where incurred, value the annual costs associated with treatment, travel, loss of income and any other related effects. The costs fall into two distinct categories, namely:

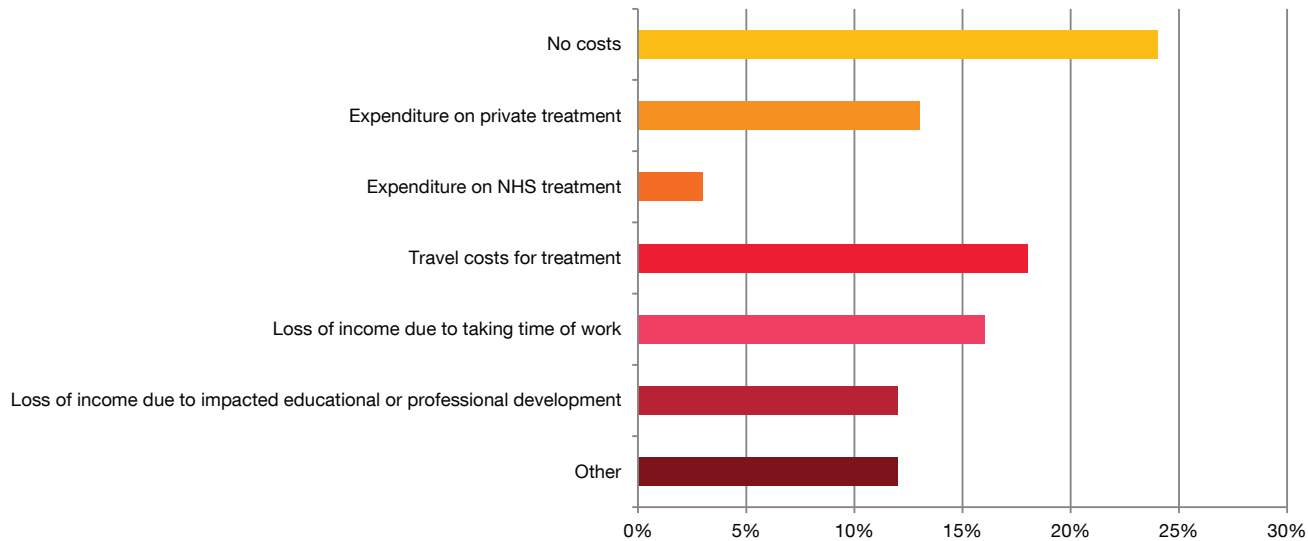
- 1. Direct financial costs to sufferers and carers; i.e. four elements comprising payment for private treatment, NHS treatment, travel costs associated with such treatments and any other costs incurred as a result of a disorder; and

- 2. The opportunity costs of not working or being in education; i.e. while not involving any direct payments (as above) they capture respondents' views of the impacts of disorders on the loss of income (for both sufferers and carers) due to taking time off work or education (and related professional development).

Impacts for sufferers

As illustrated, in Figure 6.1, the majority of respondents (over 75%) incurred one or more of the six costs categories identified by our survey.

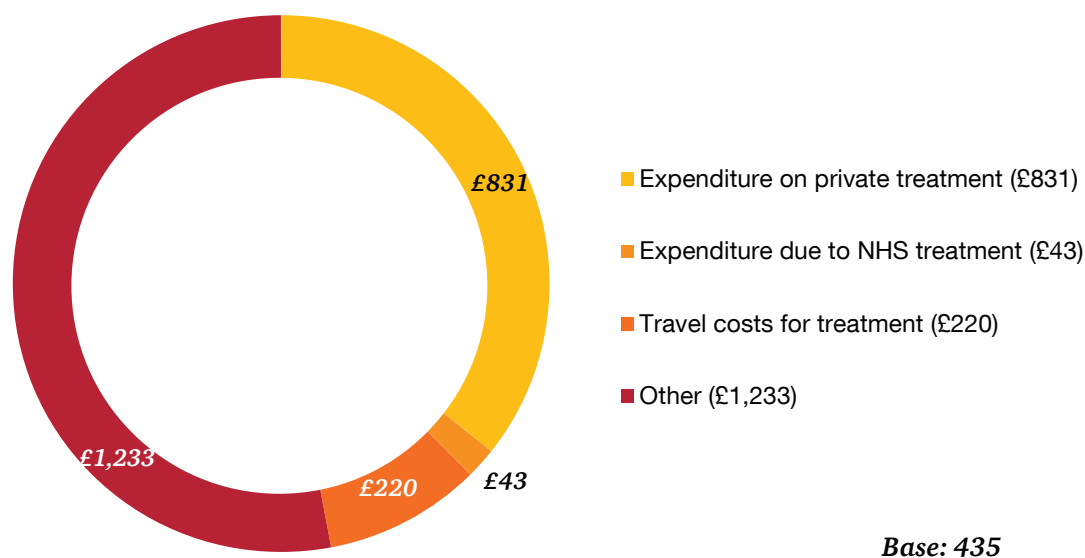
Figure 6.1
Costs associated with suffering from an eating disorder



Base: 435

As illustrated in Figure 6.2, sufferers (of any age) incur around £1,100 on average annually on different types of treatment-related costs and other costs of around £1,200 on average annually, based on our survey.

Figure 6.2
Breakdown of average financial costs as reported by all sufferers



The opportunity cost related to suffering from an eating disorder varies with age. Those aged under 20 at the time of answering our survey reported average economic costs of around £660 (Figure 6.3), while in contrast those aged 20 or above reported a much higher average cost of around £9,500 (Figure 6.4).

Figure 6.3
Breakdown of average economic costs associated with those aged under 20 and suffering from an eating disorder

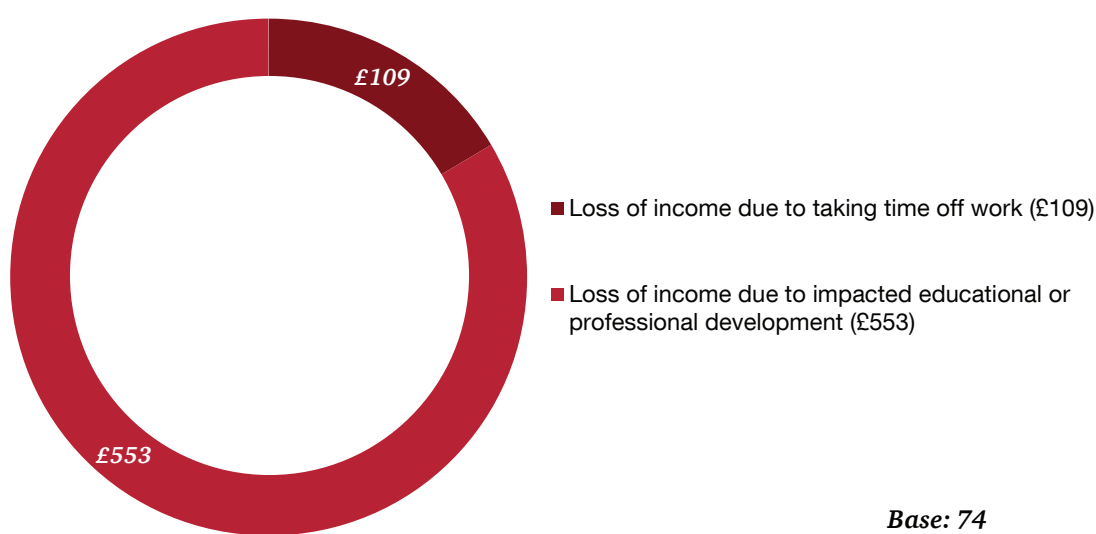
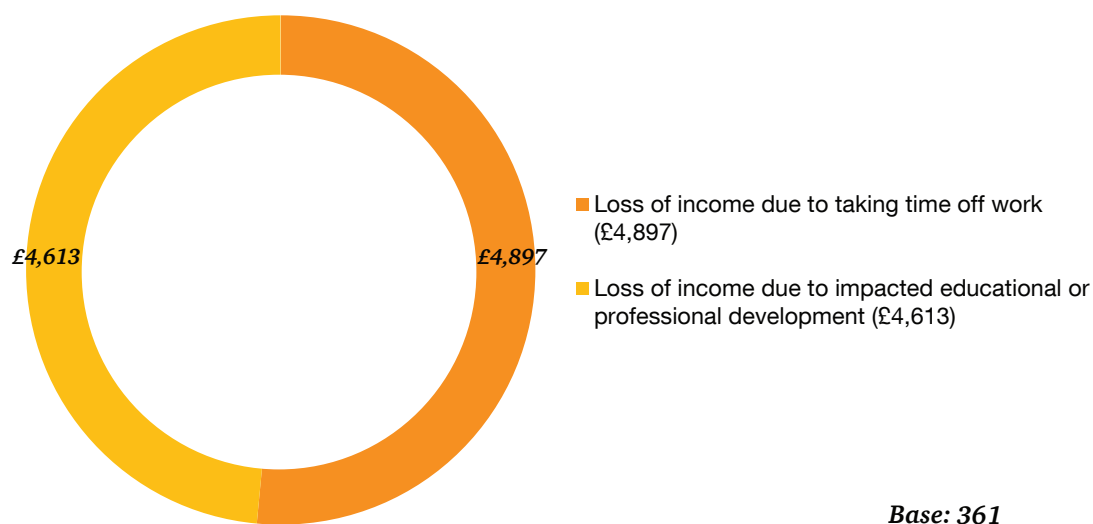


Figure 6.4

Breakdown of average economic costs associated with those aged 20 and over, and suffering from an eating disorder



Impacts for carers

Carers, in supporting sufferers, also face significant financial and opportunity costs. As illustrated, in Figure 6.5 below, over 85% identified one or more costs associated with caring for someone with an eating disorder.

Figure 6.5

Costs associated with caring for someone with an eating disorder

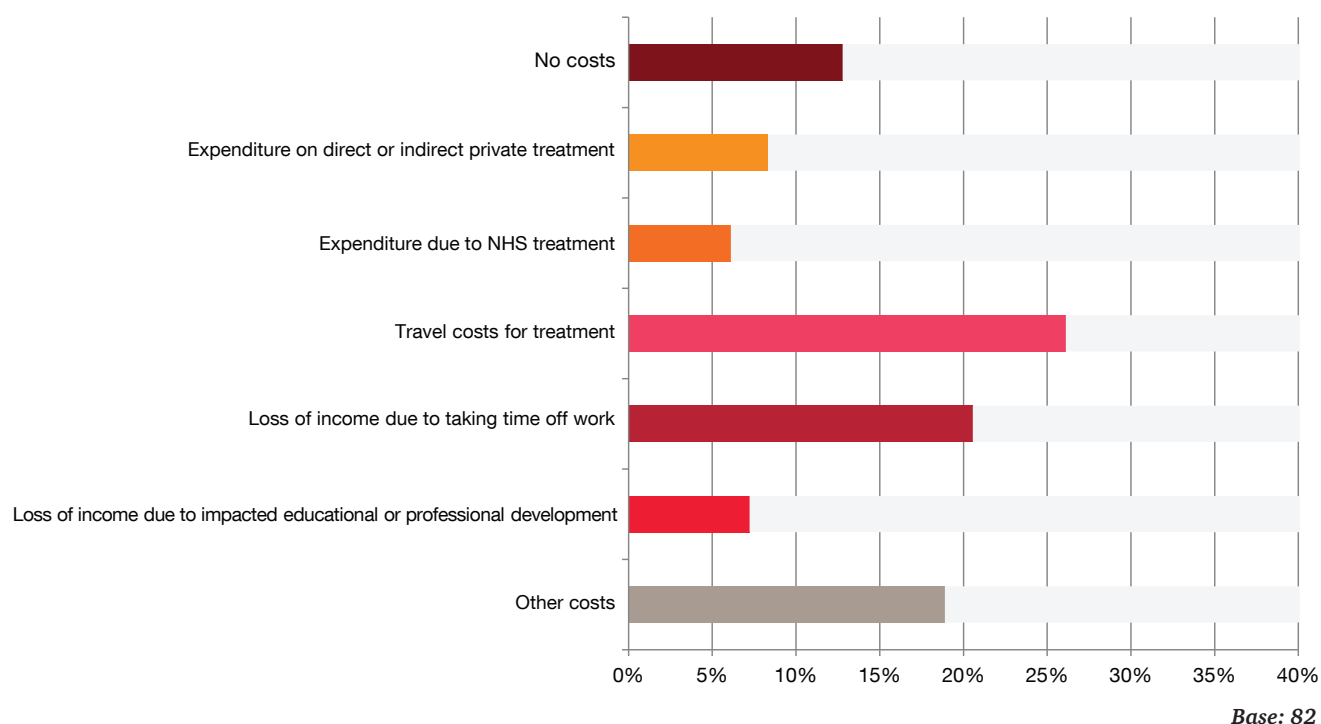


Figure 6.6
Breakdown of average financial costs associated with caring for someone with an eating disorder

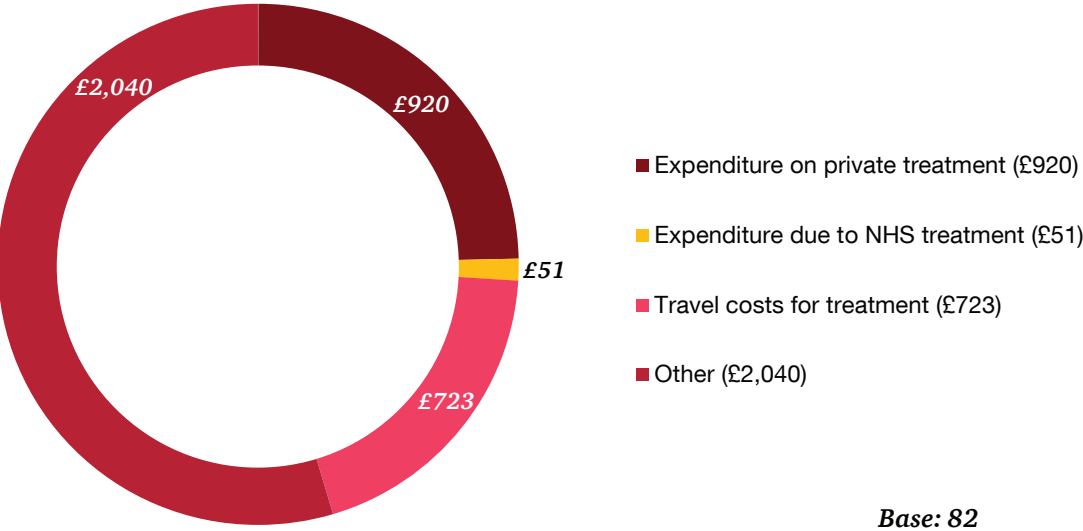
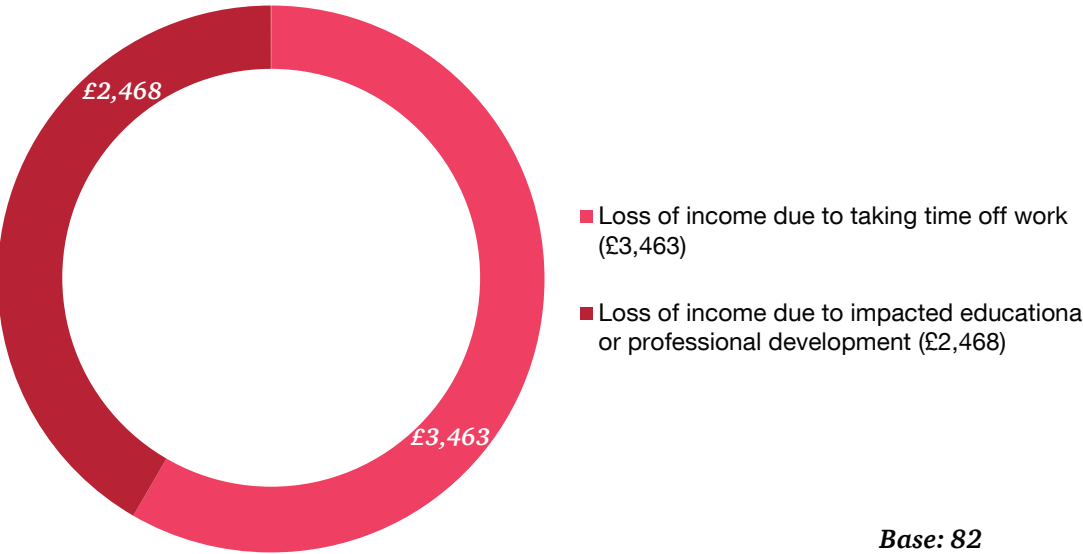


Figure 6.7
Breakdown of average economic costs associated with caring for someone with an eating disorder



The costs of healthcare

Beyond the personal costs and wider impacts on sufferers and carers associated with eating disorders there are also significant costs to the NHS of treating those who suffer from such conditions.

Through a combination of our primary research insights and secondary literature sources we have assessed the likely annual cost of the provision of core types of treatment.

Accordingly, we have assumed that the cost of providing healthcare may be represented by five elements;

1. NHS 'Inpatient' care⁴⁵;
2. A combined approach representing 'Day-patient', 'Outpatient', 'Guided Self-Help', and the 'Provision of information or advice' through the NHS⁴⁶;

3. NHS 'Family therapy'⁴⁷
4. 'GP Primary Care'⁴⁸; and
5. 'Private Treatment' (borne by the sufferer themselves) based upon our primary research data.

It should be noted that we have used Mental Health Care Clusters as a proxy for the costs associated with daypatient, outpatient, guided self-help and the provision of information and advice. As such our costs only account for the treatment of the psychological health symptoms of eating disorders. As these disorders are unique in manifesting through both mental and physical symptoms, our treatment costs in this instance do not cover the treatment of the physical impacts of EDs, and are arguably conservative.

As illustrated (in Table 6.1) we have taken the average costs associated with each of these forms of treatment and, in the absence of any NHS data, weighted each cost by the proportion of our survey respondents who identified receipt of each form of treatment. So, for example, while inpatient costs are £434 per day at an assumed average length of 82.5 days we have weighted this cost by 13.6% to reflect the proportion of sufferers in our survey that received such treatment. This methodology delivers a total weighted cost associated with all forms of NHS and private treatment of around £8,850 per annum.

Table 6.1
Cost of healthcare per sufferer

Type of care	Cost of treatment ⁴⁹	Likely percentage of all sufferers receiving this treatment (based on our survey results)	Weighted cost per sufferer
1 Inpatient (NHS)	£434 per day, for an average of 82.5 days	13.6%	£4,869
2 Outpatient, day-patient, Guided Self-Help and provision of information and advice (NHS)	£351 per attendance, with an average of 7.9 follow-up attendances (plus £267 for an initial assessment)	64.9%	£1,973
3 Family therapy (NHS)	£106 per visit, typically involving 12 visits per annum	18.2%	£232
4 GP/primary care (NHS)	£40 per visit, with an average of 3 visits per year	100%	£120
5 Private care	£7,295	22.7%	£1,656
Total weighted cost			£8,850

⁴⁵ HESonline (2012) Topic of interest – eating disorders

⁴⁶ NHS Reference Costs 2012-13, and The King's Fund (2008)

⁴⁷ Personal Social Services Research Unit: NHS Unit Costs 2013/14

⁴⁸ Pro Bono Economics: The Cost of Eating Disorders in England

⁴⁹ Taking the sources laid out above, we have used the daily cost of each treatment, along with the average duration of each treatment, to calculate a unit cost of caring for one individual in each of the ways set out in Table 6.1. We have then weighted these individual costs using data from our survey on the prevalence of each form of treatment to form a total average unit cost of healthcare across all types of treatments (i.e. a cost that applies to all sufferers, whichever treatment pathway has been taken).

This total weighted cost represents a typical annual treatment cost for eating disorders. As shown by our survey, however, not all those who suffer from an eating disorder receive treatment for the duration of the condition. Considering that 45% of respondents waited for at least one year before seeking help, and 19% had to wait for at least a year after seeking help before treatment began, there is a significant number of sufferers not receiving treatment in any one year. Taking these statistics into account, there may be as many as 11% of sufferers for whom these treatment costs do not apply in any given year.

Conclusion

Based on our survey results it is apparent that there are significant financial and opportunity costs associated with eating disorders. Assuming that our respondents are representative of all sufferers in the UK, the annual average burdens identified imply:

- **Sufferers:** an average economic cost of around £650 per annum for sufferers under the age of 20 and £9,510 for sufferers over the age of 20, and related financial costs

(excluding private treatment costs) to the sufferer of around £1,500 annually for the duration of the disorder across all age groups; and

- **Carers:** a parallel economic cost of £5,950 per annum for carers as well as a financial burden (excluding private treatment costs) of £2,800.

Weighting our results in line with the finding that 49% of sufferers reported to be under the age of 20⁵⁰, the total economic cost per 1,000 sufferers and 1,000 carers could be in the region of £11 million, the financial cost around £4.3 million and treatment costs of around £8.8 million as highlighted in Table 6.2.

Table 6.2

Total annual average costs (based on our survey results)

Type of care	Economic costs ⁵¹	Financial costs	Treatment costs
Per 1,000 sufferers	£5.2m	£1.5m	£8.8m
Per 1,000 carers	£5.9m	£2.8m	-
Total	£11.1m	£4.3m	

Drawing together this cost data, and estimates of prevalence set out in Section 3, provides one basis from which to provide an estimate of the potential financial burdens placed on sufferers, carers, the health sector and the UK economy.

Again, assuming our sample is representative, and that the likely levels of prevalence fall between 600,000 and 725,000 suggests, therefore:

- **Economic costs – in terms of lost income to the economy – of around £6.8 billion to £8 billion per annum;**
- **Annual financial costs to sufferers and carers of between £2.6 billion to £3.1 billion; and**
- **Health sector costs – to the NHS of between £3.9 billion and £ 4.6 billion and, potentially, a further £0.9 to £1.1 billion of private treatment costs (if our unit costs are applied only to those sufferers currently in treatment)⁵².**

Table 6.3

Total annual average costs (based on estimated prevalence)

Type of care	Economic costs	Financial costs	Treatment costs
At 600,000 sufferers	£6.8bn	£2.6bn	£4.8bn
At 725,000 sufferers	£8.0bn	£3.1bn	£5.7bn

⁵⁰ Royal College of Psychiatrists (2014) Anorexia and Bulimia, Available at: <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/anorexiaandbulimia.aspx>

⁵¹ In addition, we have excluded any public exchequer impacts in relation to benefit payments to either sufferers or carers that are registered as unemployed as a result of a disorder

⁵² We have deducted 11% from the total population to reflect the proportion of the population who, based on our survey responses, may not yet have sought help or not yet receiving treatment in any given year.

Wider impacts

Aside from the financial costs associated with suffering from an eating disorder, there are wider impacts that can affect other areas of life such as social and family life, work-life and education. Over 80% of sufferers stated that the eating disorder had a “very significant” or “significant” impact on their social and family life, while over 90% of respondents suffered

a “very significant” or “significant” impact on their overall well-being and quality of life.

As with the sufferers, the impact on carers is much broader than just financial costs. Over 90% of carers noted a “very significant” or “significant” impact on their social and family life, while over 80% experienced a “very significant” or

“significant” impact on their overall wellbeing and quality of life.

In addition to this over half of carers experienced “significant” or “very significant” impact on their participation and productivity at work, while a smaller proportion (less than 20%) reported a notable impact on their educational and professional development.

Figure 6.8

Impacts associated with suffering from an eating disorder

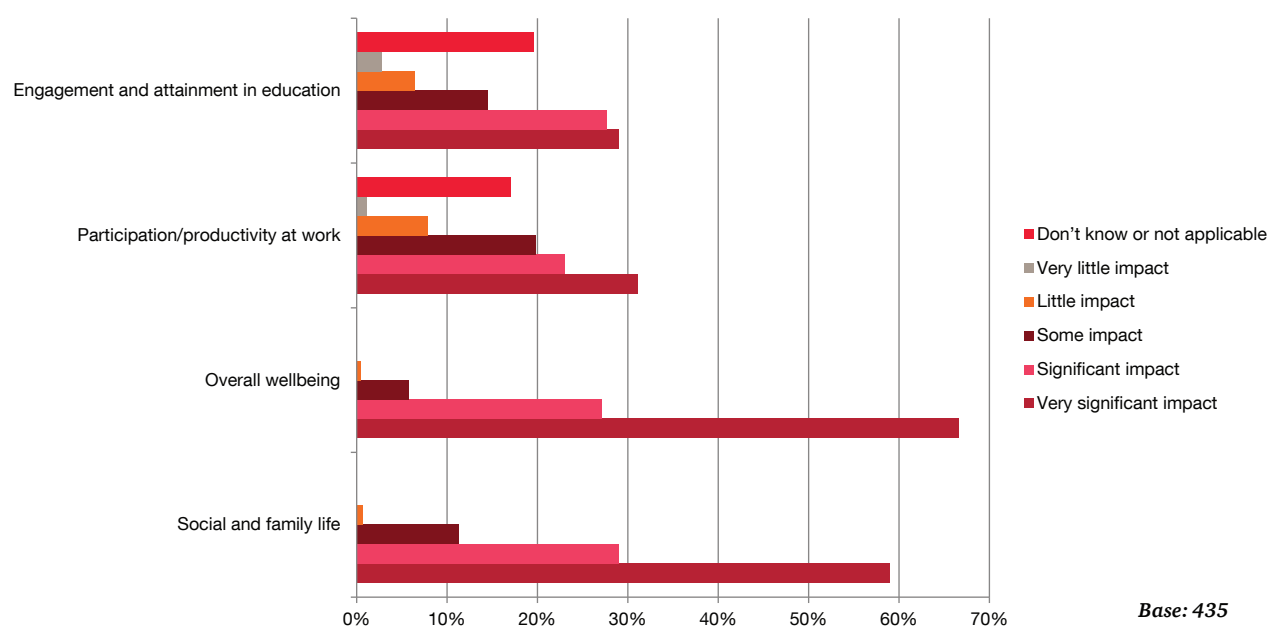
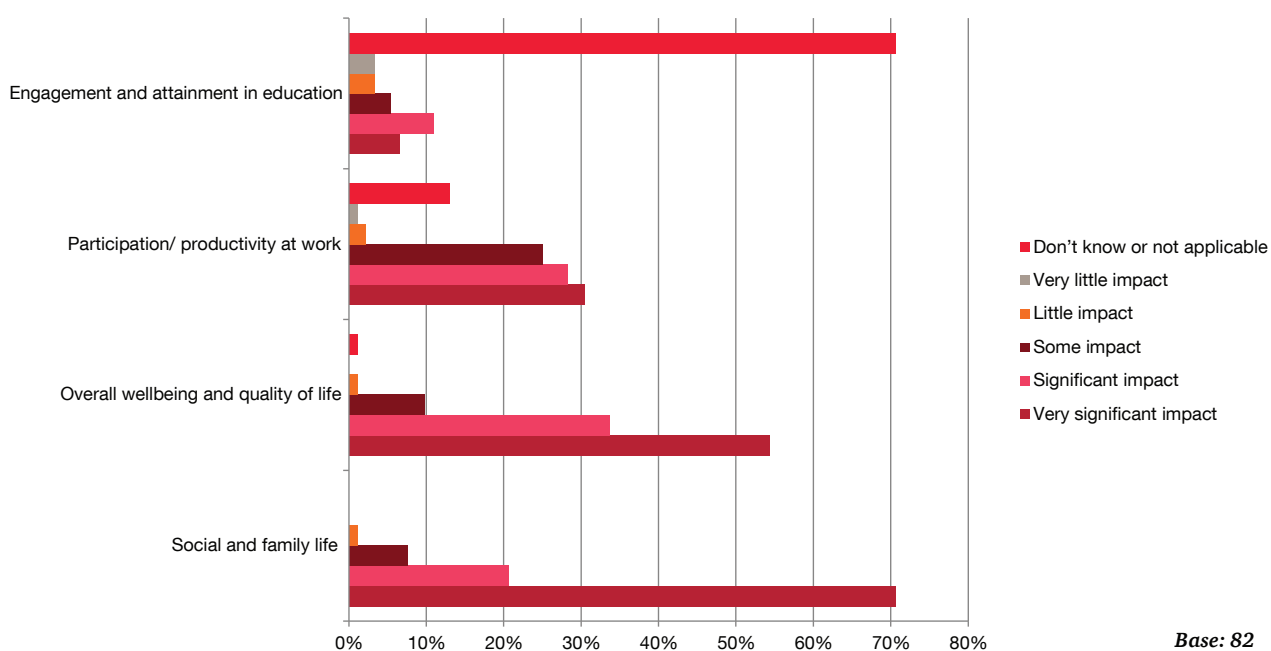


Figure 6.9

Impacts associated with caring for someone suffering from an eating disorder



So what?

The lifetime outcomes and impacts experienced by the majority of sufferers of eating disorders (and their carers) are startling especially in light of the potential national prevalence and the variances reported in different geographies and sufferer groups. In light of these findings we believe there are three key areas that should be addressed: investment in early identification and treatment, unblocking delays and reducing the costs to society and the individual.

1. Investment in early identification and treatment

Like many debilitating illnesses a focus on an early identified and effectively treated approach is fundamental. As this report has highlighted, however, eating disorders disproportionately impact upon younger people and, as such, responsibility for recognising eating disorders early and providing the most appropriate programmes of treatment may fall to others.

This responsibility does not rest with the health service and primary care alone and must involve parents, schools, colleges, community organisations and peers to provide a proactive approach that recognises the symptoms of eating disorders at the right time so that referrals can be made that have the most positive impact. Eating disorders have devastating impacts upon sufferers, carers and families – but they can be treated. Pathways to a sustainable recovery are possible if recognised early, appropriately diagnosed and referred to the most appropriate treatments on a case-by-case basis. The role of community based organisations, and Charities such as Beat, should not be underestimated in this respect.

2. Unblocking the delays

Our survey results suggest that for sufferers there can be a stark pattern of delays in seeking help, receiving a diagnosis and in starting treatment.

We believe more work is needed to explore what the barriers are to sufferers in seeking help in order to draw firm conclusions on what can be done to recognise the symptoms of eating disorders earlier (and consequently to ask for or seek help sooner). This work needs to encompass all those who may be in a position to recognise symptoms – sufferers, their families and friends and other key individuals such as teachers and GPs – and explore further the roles these people can and should play, and what must therefore be in place to make them aware of the early warning signs, provide them with education about the disorders, and support them, in order to create the opportunities for earlier intervention.

In addition while waiting times have already been identified as a priority for the £150m investment for children and young people with eating disorders, or who self-harm, we believe that this should address aiding early intervention, reduction of waiting times for a diagnosis and acceleration of time to treatment once diagnosis is received. Experience in other parts of the health sector shows that waiting time targets can have a positive impact on treatment outcomes and we believe targets for eating disorders (to reduce current delays) should also be combined (as outlined below) with a national review of service provision to identify what existing and potentially new treatments work well and can be replicated.

3. Reducing the costs to society and the individual

The impacts on individuals, both financial (£2.6 billion at the lower estimate of prevalence) and economic (£6.8 billion at the lower prevalence estimate) in themselves support the case for our recommendations above. Whilst many of our recommendations – to reduce overall prevalence, to catch and treat disorders earlier and to invest in interventions that reduce relapse rates – will affect the financial and economic costs associated with disorders, they only indirectly address the range of well-being issues that sufferers, carers and families face.

In considering the effectiveness of existing and new “treatments”, therefore, we believe consideration should be given to those interventions that help sufferers and their carers to continue to lead as full a life as possible. As our survey respondents indicated (as reflected in many of their quotes throughout our report) non-medical support – provided by Beat and other charities – played an important role in their overall recovery and should, in our view, be considered an integral part of the overall system of care.

Further questions

In addition, our report provides a number of compelling reasons for further investment into better understanding eating disorders and for providing accessible, effective care to those who are impacted by them. Indeed, our research also raises two questions where further urgent work is required, namely:

A. Sizing the issue

As we have outlined throughout our report it remains unclear exactly how many sufferers of eating disorders there are in the UK today. Whilst estimates, based on historical and international research have been made, we believe there is merit in further work to establish UK specific prevalence rates based on up to date knowledge of the different disorder groups. This would enable not only greater clarity on potential areas of most need in the UK but also support broader awareness raising across sufferers, families, schools and health professionals to address, in part, current delays in seeking help.

Similarly we suggest that further analysis should be undertaken to better understand the differences between disorders, potential causes and sufferer groups. For example the differences between male and female sufferer groups and their experiences appears to be relatively unexplored as does recently understood disorders like the EDNOS / EDU groups. Understanding more about potential causes – and those groups most at risk – is in our view a crucial first step to earlier intervention.

B. What works – breaking the 6 year cycle

While treatment outcomes for eating disorders are varied our survey results indicate a high level of relapse. Moreover our results suggest such rates of relapse across most disorder and treatment types making it difficult to draw recommendations on where investment could be prioritised. Consequently we believe more work is needed to review what works and build clear recommendations for interventions that support **permanent** recovery.

The one clear contributor to a reduced likelihood of relapse and therefore permanent recovery that we have identified is the speed at which help is first sought. In light of this we recommend that, in reviewing the effectiveness of treatment types, there should be a focus on early intervention and the opportunities to support sufferers and their carers in the early stages of any disorder.

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Appendix 1 – Research approach

PwC and Beat developed a research methodology to gather insights from secondary sources and validate emerging conclusions through primary research with sufferers and carers.

In the first instance we conducted extensive secondary research into eating disorders. This research included both literature and data to illustrate a full picture of current knowledge on the impact of eating disorders. Through this desk research we gained insight into the wide range of issues surrounding eating disorders and identified gaps in current research/knowledge that we could address through our survey.

The second part of our research consisted of a comprehensive questionnaire based on Beat's research requirements combined with the trends and gaps in research identified in the previous stage. For example, this included devising a set of questions that focused on sufferer and carer experiences of repeat episodes of treatment for their eating disorder in order that we could fully reflect the extent of issues such as relapse, incorrect diagnoses and the perceived inadequacy of specialist referrals.

Devising a sample of sufferers and carers

Working closely with the team at Beat we, drawing on the expertise of our in-house research specialists, developed an online eating disorder survey registration website. This registration website included a series of short pre-qualifying questions to assess respondent applicability to our full survey. The registration site included:

- Introductory context of who we were, the purpose and background

to the overall piece of work together with a request / call for participation amongst impacted individuals;

- Respondent email address and geographical region where they reside; and
- Whether they had either suffered from an eating disorder and / or cared for someone who had suffered from an eating disorder.

For those who answered yes to being either a sufferer or carer an email was issued outlining that we would be in touch by email in the coming days including an electronic survey link that their participation in would be greatly appreciated. This registration link was circulated widely by the team at Beat, included on mailing lists, sector newsletters and publicised via official Social Media Channels. Whilst the sample profile represents a “snapshot” of perspectives and experiences, and necessarily not statistically representative of the UK sufferer population, it does provide the most comprehensive survey response rate on this subject matter that we are aware of. Achieving a statistically representative survey, given the diverse range of prevalence estimates referred to earlier in this report, would not be possible.

520 individual sufferers and carers registered their interest via the registration site. In parallel, we designed and built a comprehensive online survey, with bespoke individual links, based on the questionnaire appended at Appendix 2. This survey was live for a 2 week period in December 2014. We received 517

completed survey responses. The sample of respondents comprised both males and females, carers and sufferers from across the UK, and across a range of ages and of eating disorders. Whilst not statistically representative, the volume and quality of responses has provided us with a wide range of perspectives and insights into the impact of eating disorders on their lives.

Figure 8.1
Gender breakdown of survey respondents

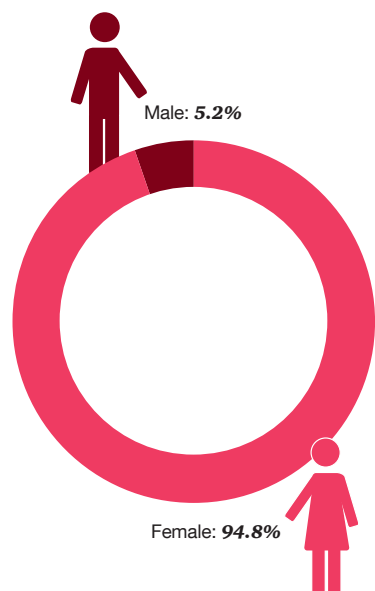


Table 8.1
Geographical location of survey respondents

	Number of respondents
London	63
South East	94
South West	71
East of England	38
East Midlands	40
West Midlands	36
North East	22
North West	44
Yorkshire and Humber	36
Scotland	28
Wales	16
Northern Ireland	15
Not currently in the UK	14

Figure 8.2

Age of respondents at the time of the survey

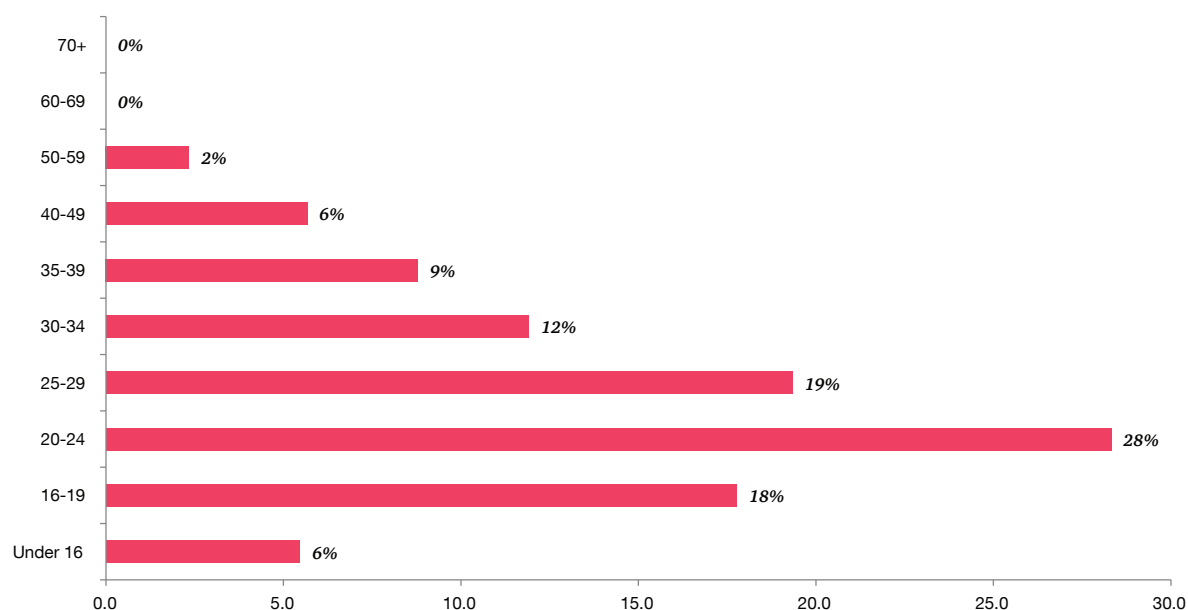
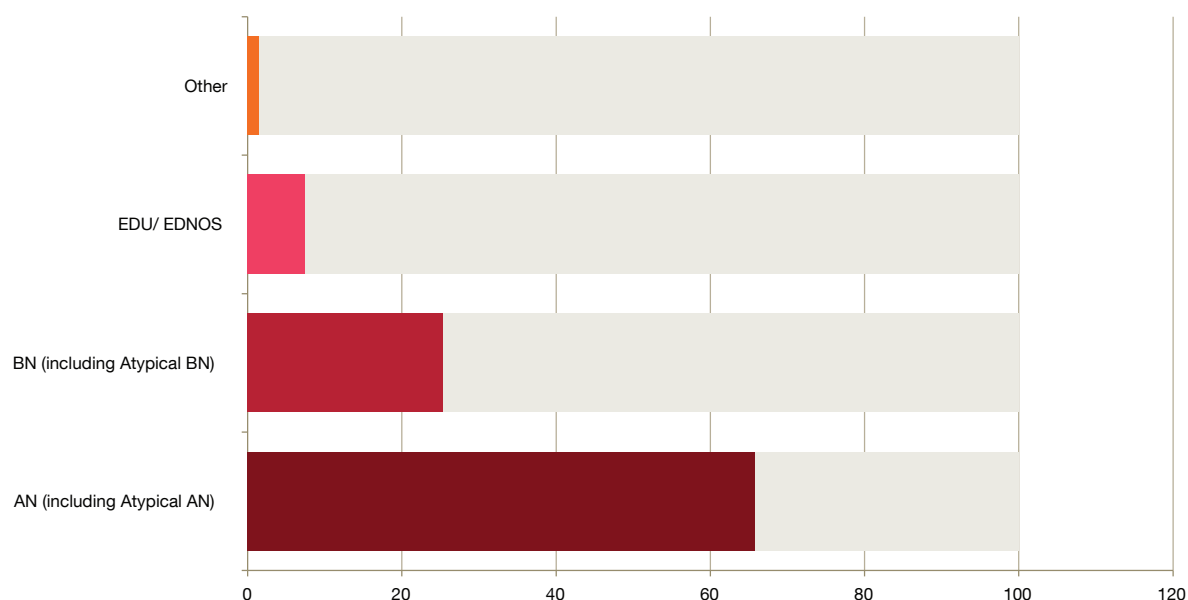


Figure 8.3

Relative prevalence of eating disorders among respondents



To generate as much insight as possible, PwC embarked on a comprehensive analysis of the data received, both qualitative and quantitative, with specific input from Beat as a subject matter expert.

In order to arrive at the cost estimates outlined at section 6, we used the daily cost of each eating disorder treatment type, along with the average duration of each treatment, to calculate a unit cost of caring for one individual. We have then weighted these individual

costs using data from our survey on the incidence of each form of treatment to form a total average unit cost of healthcare across all types of treatments (i.e. a cost that applies to all sufferers, whichever treatment pathway has been taken).

Appendix 2 – Online Survey



Beat

Eating Disorders Impact Study 2014

Online Questionnaire

Cover email

Thank you for registering your interest in participating in our survey. By way of a recap, Beat are currently working in partnership with PwC on an important piece of work that can be used by Beat and others to campaign for better services for those who are affected by an eating disorder (ED), as well as their families and carers. This work will report on the economic, social and health impacts associated with eating disorders.

Please access the survey using your personalised link below. It should take you no more than 15/20 minutes to complete. Please note that this link is only accessible by you, and should not be shared.

The information you provide will be treated in accordance with the Market Research Society Code of Conduct. This ensures that any information provided will be strictly treated in confidence and all responses will be anonymous.

The deadline for completing the survey is 7th December 2014.

Your participation in this work is very valuable to us.

Kind regards,

Lorna Garner

Thank and close message (to be used if respondents select 'Other/ neither' at QC):

Thank you for your interest in taking part in this research. Unfortunately, the answers you have provided do not fit the profile we are surveying at this time.

Once again, we appreciate your time, and if you are interested in finding out more about Beat, you can visit our website at: <http://www.b-eat.co.uk/> [hyperlink]



Completing the survey:

Welcome to this survey. Thank you for taking part and agreeing to share your experience and views with us. This survey should take you approximately 15-20 minutes to complete.

The 'Back' and 'Next' buttons at the bottom of each screen allow you to navigate through the survey. Please avoid using your browser's 'Back' button as this will take you out of the survey.

Some screens may require you to use the scroll bar at the right-hand side of the screen in order to move down the page and answer the rest of the question. The navigation buttons will be located at the end of each set of questions.

It is best to complete the survey at one time. However, if you need to save your questionnaire and return to it later, please click 'next' on the question you are completing, and then on the following page, close your browser window.. To restart the survey click on the link included in your email message again, and the survey will open at the last question completed.

Section 1 - About you

QA) Please confirm your gender Please select one option only

Female	1	CONTINUE TO QB
Male	2	

QB) Where in the UK do you currently live? Please select one option only

London	1	CONTINUE TO QC
South East	2	
South West	3	
East of England	4	
East Midlands	5	
West Midlands	6	
Yorkshire and Humber	7	
North West	8	
North East	9	
Wales	10	
Scotland	11	
Northern Ireland	12	
Not currently living in the UK	98	

QC) Please select the most appropriate answer as this applies to you. Please select all that apply:

I am someone who has suffered, or is suffering from an eating disorder	1	CONTINUE TO QE
I am caring for someone with an eating disorder, or have done so in the past.	2	CONTINUE TO QD
Other (please specify)	94	THANK AND CLOSE
Neither	98	THANK AND CLOSE

NOTE: QC DETERMINES THE SURVEY ROUTING AT Q11 AND Q12



FOR THOSE SELECTING OPTIONS 1 AND 2 AT QC ASK:

QCi) Would you prefer to answer this survey as someone who has personally suffered from an eating disorder, or as the carer of someone who has? Please select one option only

As someone who has suffered, or is suffering from an eating disorder	1	CONTINUE TO QE
As someone who is caring for someone with an eating disorder, or has done so in the past.	2	CONTINUE TO QD

SEEN by QCi answer 2 only.

QD) What best describes your relationship with the person affected by an eating disorder? Please select one option only

I am a family member	1	CONTINUE TO QDii
I am a friend	2	
Other (Please Specify)	94	CONTINUE TO QDi

SEEN by QCi answer 2 only.

QDii) Have you been bereaved as the result of a loved one passing away due to an eating disorder? Please select one option only

Yes	1	CONTINUE TO QE
No	2	CONTINUE TO QE

QE) What type of eating disorder have you/they suffered from? Please select all that apply

Anorexia Nervosa (including Atypical Anorexia Nervosa)	1	CONTINUE TO QF
Bulimia Nervosa (including Atypical Bulimia Nervosa)	2	
Eating Disorder Unspecified (EDU)	3	CONTINUE TO QEi
Other (please specify)	94	CONTINUE TO QF

QEI) Please select one of the following options:

I was diagnosed with Binge Eating Disorder	1	All: CONTINUE TO QF Hide 1-2 if QC = 2 OR QCi =2 Hide 3-4 if QC = 1 OR QCi =1
I was diagnosed with another form of EDNOS	2	
They were diagnosed with Binge Eating Disorder	3	
They were diagnosed with another form of EDNOS	4	

Seen by QC = 1 OR QCi =1

QFi) How old are you? Please select one option only

Under 16	1	CONTINUE TO QG
16-19	2	
20-24	3	
25-29	4	
30-34	5	
35-39	6	
40-49	7	
50-59	8	
60-69	9	
70+	10	

Seen by QC = 2 OR QCi =2

QFiA) How old is the person you care for? Please select one option only

Under 16	1	CONTINUE TO QG
16-19	2	
20-24	3	
25-29	4	

30-34	5	
35-39	6	
40-49	7	
50-59	8	
60-69	9	
70+	10	

QF1B) How old was the person you cared for when they passed away? Please select one option only

Under 16	1	CONTINUE TO QG
16-19	2	
20-24	3	
25-29	4	
30-34	5	
35-39	6	
40-49	7	
50-59	8	
60-69	9	
70+	10	

QG) How old were you/they when symptoms of an eating disorder first appeared? Please select one option only

Under 16	1	CONTINUE TO QH
16-19	2	
20-24	3	
25-29	4	
30-34	5	

35-39	6	
40-49	7	
50-59	8	
60-69	9	
70+	10	

QH) Are you happy for Beat to contact you about future research via the email address you have provided for this survey? Please select one option only

Yes	1	CONTINUE TO Q1
No	2	CONTINUE TO Q1

Section 2 - Care pathways

Q1) How long after becoming aware of the symptoms of an eating disorder did you/they first seek help, assistance or advice? (Please select one option only)

Immediately	1	CONTINUE TO Q2
Within 1 month	2	
Between 1 month and 6 months	3	
Between 6 months and 1 year	4	
More than 1 year after first becoming aware of symptoms	5	
Don't know	97	

Q2) How long after seeking help were you/they diagnosed with an eating disorder? (Please select one option only)

Immediately	1	CONTINUE TO Q3
Within 1 week	2	
Between 1 week and 1 month	3	
Between 1 month and 6 months	4	
Between 6 months and 1 year	5	
Between 1 year and 2 years	6	

More than 2 years after first seeking help	7	
I have not been diagnosed with an eating disorder	8	
Don't know	97	

Q3) After diagnosis, did a GP refer you/them to a specialist? (Please select all that apply)

Insert hover definition for specialist: Hover definition: A medical professional who treats eating disorders as their primary role.

No	1	CONTINUE TO Q5
Yes – I was referred to an eating disorder specialist clinician	2	CONTINUE TO Q4
Yes – I was referred to a psychiatrist	3	
Yes – I was referred to a team of various specialists	4	CONTINUE TO Q4
Yes – I was referred to another healthcare professional or advisor (Please specify)	5	CONTINUE TO Q4

Q4) Were you/they placed on a waiting list to see this specialist? (Please select one option only)

Yes	1	CONTINUE TO Q4i
No	2	CONTINUE TO Q5

Q4i) How long did you/they have to wait before seeing this specialist? (Please select one option only)

Less than 1 week	2	CONTINUE TO Q5
Between 1 week and 6 weeks	3	
Between 6 weeks and 18 weeks	4	
Between 18 weeks and 1 year	5	
More than 1 year	6	
Don't know	97	

Q5) What was the nature of treatment that you/they received in this instance? Please select all that apply. If you received a subsequent episode of treatment, you will be asked to comment on it later in the survey.

Inpatient treatment through the NHS	1	CONTINUE TO Q6
Daypatient treatment through the NHS	2	
Outpatient treatment through the NHS	3	
Private inpatient treatment	4	
Private daypatient treatment	5	
Private outpatient treatment	6	
Provision of information or advice	7	
Guided Self Help	8	
NHS family therapy	9	
Private family therapy	10	
Another form of treatment or support (Please Specify)	94	

ASK Q6 AND Q7 FOR EACH TREATMENT SELECTED AT Q5

Q6) Based on each of the previous episodes of treatments you/they have completed, please specify how long each lasted? (Please round your response to the nearest whole number e.g. 2 months 5 days = 2)

Inpatient treatment through the NHS	1	CONTINUE TO Q6
Daypatient treatment through the NHS	2	
Outpatient treatment through the NHS	3	
Private inpatient treatment	4	
Private daypatient treatment	5	
Private outpatient treatment	6	
Provision of information or advice	7	
Guided Self Help	8	
NHS family therapy	9	
Private family therapy	10	
Other from previous question	94	

Q7) How would you rate the quality of the treatment you received in helping with the eating disorder? (Please select one response in each row)

	Q7					
	Very poor	Poor	Fair	Good	Very good	Don't Know
Inpatient treatment through the NHS						
Daypatient treatment through the NHS						
Outpatient treatment through the NHS						
Private inpatient treatment						
Private daypatient treatment						
Private outpatient treatment						
Provision of information or advice						
Guided Self Help						
NHS family therapy						
Private family therapy						
Other from previous question						

Q8) Have there been any subsequent episodes of treatment for a recurrence of the eating disorder? Please select one option only

No	1	CONTINUE TO Q10
Yes	2	CONTINUE TO Q9

Q9) In this subsequent episode of treatment what was the first step you/they took? (Please select one option only)

Returning to the GP	1	Continue to 3-r
Returning to the specialist referred to previously	2	Continue to 4-r
Going directly to a different specialist	3	

Q3-r) After diagnosis, did a GP refer you/them to a specialist? (Please select all that apply)

Insert hover definition for specialist: Hover definition: A medical professional who treats eating disorders as their primary role.

No	1	CONTINUE TO Q5
Yes – I was referred to an eating disorder specialist clinician	2	CONTINUE TO Q4
Yes – I was referred to a psychiatrist	3	
Yes – I was referred to a team of various specialists	4	
Yes – I was referred to another healthcare professional or advisor (Please specify)	5	

Q4-r) Were you/they placed on a waiting list to see this specialist? (Please select one option only)

Yes	1	CONTINUE TO Q4i
No	2	CONTINUE TO Q5

Q4i-r) How long did you/they have to wait before seeing this specialist? (Please select one option only)

Less than 1 week	2	CONTINUE TO Q5
Between 1 week and 6 weeks	3	
Between 6 weeks and 18 weeks	4	
Between 18 weeks and 1 year	5	
More than 1 year	6	
Don't know	97	

Q5-r) What was the nature of treatment that you/they received in this instance? Please select all that apply. If you received a subsequent episode of treatment, you will be asked to comment on it later in the survey.

Inpatient treatment through the NHS	1	CONTINUE TO Q6
Daypatient treatment through the NHS	2	
Outpatient treatment through the NHS	3	

Private inpatient treatment	4	
Private daypatient treatment	5	
Private outpatient treatment	6	
Provision of information or advice	7	
Guided Self Help	8	
NHS family therapy	9	
Private family therapy	10	
Another form of treatment or support (Please Specify)	94	CONTINUE TO Q5i

ASK Q6-r AND Q7-r FOR EACH TREATMENT SELECTED AT Q5-r

Q6 –r) Based on each of the previous episodes of treatments you/they have completed, please specify how long each lasted? (Please round your response to the nearest whole number e.g. 2 months 5 days = 2)

Inpatient treatment through the NHS	1	CONTINUE TO Q6
Daypatient treatment through the NHS	2	
Outpatient treatment through the NHS	3	
Private inpatient treatment	4	
Private daypatient treatment	5	
Private outpatient treatment	6	
Provision of information or advice	7	
Guided Self Help	8	
NHS family therapy	9	
Private family therapy	10	
Other from previous question	94	

Q7-r) How would you rate the quality of the treatment you received in helping with the eating disorder? (Please select one option only)

	Q7					
	Very poor	Poor	Fair	Good	Very good	Don't Know
Inpatient treatment through the NHS						
Daypatient treatment through the NHS						
Outpatient treatment through the NHS						

Private inpatient treatment						
Private daypatient treatment						
Private outpatient treatment						
Provision of information or advice						
Guided Self Help						
NHS family therapy						
Private family therapy						
Other from previous question						

Section 3 - Impacts

Q10) How long have you/they suffered from the eating disorder? (Please select one option only)

Less than 1 year	1	CONTINUE
Between 1 and 2 years	2	
Between 2 and 3 years	3	
Between 3 and 4 years	4	
Between 4 and 5 years	5	
Between 5 and 6 years	6	
Longer than 6 years	7	

FOR THOSE SELECTING 1 AT QC ('I am someone who has suffered, or is suffering from an eating disorder')
ASK Q11 section:

Q11) Has suffering from an eating disorder had an impact on your social, family or work life?
Please select one option only

Yes	1	CONTINUE TO Q11A
No	2	CONTINUE TO Q11E

Q11A) What degree of impact do you think having an eating disorder has had on each of the following areas of your life: Please select one response in each row

	Q11A					
	Very significant impact	Significant impact	Some impact	Little impact	Very little or no impact	Not applicable
i) Your social and family life	5	4	3	2	1	97
ii) Your overall wellbeing and quality of life	5	4	3	2	1	97
iii) Your participation and productivity at work (if you are in work)	5	4	3	2	1	97
iv) Your engagement and attainment in your education (if you are in education)	5	4	3	2	1	97

FOR THOSE SELECTING 3-5 AT Q11Aiii ASK:

Q11B) Have you had to take an extended leave of absence (at least 4 weeks of sick leave) from your work due to suffering from an eating disorder? (Please select one option only)

Yes (please specify the length of absence)	1	CONTINUE TO Q11D
No	2	

FOR THOSE SELECTING 3-5 AT Q11Aiv ASK:

Q11C) Have you had to take a break, or permanently leave your education due to suffering from an eating disorder? Please select one option only

No	1	CONTINUE TO Q11D
Yes – I have taken a temporary break from my education	2	CONTINUE TO Q11Ci
Yes – I have permanently left a course of education	3	

Q11Ci) What stage were you at when you left, or took a break from your education? Please select one option only

I was at school	1	CONTINUE TO Q11D
I was in a course of further education	2	
I was in a course of higher education	3	

Q11D) Considering the impacts mentioned here, along with any others you have experienced, please use the box below to elaborate on the impact that the eating disorder has had on your life Please provide response in the field provided

[free text box]

CONTINUE TO Q11E

Q11E) Have you experienced any direct, personal financial impacts due to suffering from an eating disorder? Please select all that apply

No	1	CONTINUE TO Q13
Yes – expenditure on private treatment	2	CONTINUE TO Q11Eii
Yes – expenditure due to NHS treatment	3	
Yes – travel costs for treatment	4	
Yes – loss of income due to taking time off work	5	
Yes – loss of income due to impacted educational or professional development	6	
Yes – other costs (Please Specify)	94	

Q11Eii) Please provide an estimate of the annual financial cost to you of each of the factors below. Please use whole numbers only e.g. £100.50 = £100.

Expenditure on private treatment	£[numeric text box]	CONTINUE TO Q13
Expenditure due to NHS treatment	£[numeric text box]	
Travel costs for treatment	£[numeric text box]	
Loss of income due to taking time off work	£[numeric text box]	
Loss of income due to impacted educational or professional development	£[numeric text box]	
Other	£[numeric text box]	

FOR THOSE SELECTING 2 AT QC ('I am caring for someone with an eating disorder, or have done so in the past') ASK Q12 section:

Q12) Has caring for someone with an eating disorder had an impact on your own social, family or work life? Please select one option only

Yes	1	CONTINUE TO Q12A
No	2	CONTINUE TO Q12E

Q12A) What degree of impact do you think caring for someone with an eating disorder has had on each of the following areas of your own life: Please select one response in each row

	Q12A					
	Very significant impact	Significant impact	Some impact	Little impact	Very little or no impact	Not applicable
i) Your social and family life	5	4	3	2	1	97
ii) Your overall wellbeing and quality of life	5	4	3	2	1	97
iii) Your participation and productivity at work (if you are in work)	5	4	3	2	1	97
iv) Your engagement and attainment in your education (if you are in education)	5	4	3	2	1	97

FOR THOSE SELECTING 3-5 AT Q12Aiii ASK:

Q12B) Have you had to take an extended leave of absence (at least 4 weeks of sick leave) from your work due to caring for someone with an eating disorder? (Please select one option only)

Yes	1	CONTINUE TO Q12D
No	2	

FOR THOSE SELECTING 3-5 AT Q12Aiv ASK:

Q12C) Have you had to take a break, or permanently leave your education due to caring for someone with an eating disorder? Please select one option only

No	1	CONTINUE TO Q12D
Yes – I have taken a temporary break from my education	2	CONTINUE TO Q12Ci
Yes – I have permanently left a course of education	3	

Q12Ci) What stage were you at when you left, or took a break from your education? Please select one option only

I was at school	1	CONTINUE TO Q12D
I was in a course of further education	2	
I was in a course of higher education	3	

Q12D) Considering the impacts mentioned here, along with any others you have experienced, please use the box below to elaborate on the impact that caring for someone with an eating disorder has had on your life Please provide response in the field provided

[free text box]

CONTINUE TO Q12E

Q12E) Have you experienced any direct, personal financial impacts due to caring for someone with an eating disorder? Please select all that apply

No	1	CONTINUE TO Q12F
Yes – expenditure on direct or indirect private treatment	2	CONTINUE TO Q12Eii
Yes – expenditure due to NHS treatment	3	
Yes – travel costs for treatment	4	
Yes – loss of income due to taking time off work	5	

Yes – loss of income due to impacted educational or professional development	6	
Yes – other (Please specify)	94	CONTINUE TO Q12Ei

Q12Eii) Please provide an estimate of the annual financial cost to you of each of the factors below. Please use whole numbers only e.g. £100.50 = £100.

Expenditure on private treatment	£[numeric text box]	CONTINUE TO Q12F
Expenditure due to NHS treatment	£[numeric text box]	
Travel costs for treatment	£[numeric text box]	
Loss of income due to taking time off work	£[numeric text box]	
Loss of income due to impacted educational or professional development	£[numeric text box]	
Other	£[numeric text box]	

In the following questions we would like you to consider the impact that having an eating disorder has had on the person you have cared for.

Q12F) Has suffering from an eating disorder had an impact on their social, family or work life?
Please select one option only

Yes	1	CONTINUE TO Q12G
No	2	CONTINUE TO Q13

Q12G) What degree of impact do you think having an eating disorder has had on each of the following areas of their life: Please select one response in each row

	Q12G					
	Very significant impact	Significant impact	Some impact	Little impact	Very little or no impact	Not applicable
i) Their social and family life	5	4	3	2	1	97
ii) Their overall wellbeing and quality of life	5	4	3	2	1	97
iii) Their participation and productivity at work (if they are in work)	5	4	3	2	1	97

iv) Their engagement and attainment in their education (if they are in education)	5	4	3	2	1	97
---	---	---	---	---	---	----

FOR THOSE SELECTING 3-5 AT Q12Giii ASK:

Q12H) Have they had to take an extended leave of absence (at least 4 weeks of sick leave) from their work due to having an eating disorder, for which they have not been paid? (Please select one option only)

Yes	1	CONTINUE TO Q12J
No	2	

FOR THOSE SELECTING 3-5 AT Q12Giv ASK:

Q12I) Have they had to take a break, or permanently leave their education due to having an eating disorder? (Please select one option only)

No	1	CONTINUE TO Q12J
Yes – they have taken a temporary break from their education	2	CONTINUE TO Q12Ii
Yes – they have permanently left a course of education	3	

Q12Ii) What stage were they at when they had to leave their education? Please select one option only

They were at school	1	CONTINUE TO Q12J
They were in a course of further education	2	
They were in a course of higher education	3	

Q12J) Considering the impacts mentioned here, along with any others you have seen them experience, please use the box below to elaborate on the impact that having an eating disorder has had on their life Please provide response in the field provided

[free text box]

CONTINUE TO Q13

Improvements

Q13) Do you think the treatment you/they received could be improved in dealing with the specific eating disorder suffered? (Please select all that apply)

Yes – face-to-face contact with specialists would have been helpful	1	CONTINUE TO Q13ii
Yes – earlier access to a specialist would have been helpful	2	
Yes – closer access to a specialist would have been helpful	3	
Yes – a longer period of time spent in treatment would have been helpful	4	
Yes – I think the treatment could have been improved in other ways	5	
No	6	

Q13i) Please explain how this form of treatment could be improved

[free text box]

CONTINUE TO Q13ii

Q13ii) Do you think that you/they were offered evidence based treatment? Please select one option only

Yes	1	CONTINUE TO Q14
No	2	CONTINUE TO Q14
Don't know	97	CONTINUE TO Q14

Q14) Do you think that, in your case /(the case of the person you cared for / are caring for), there may have been a more appropriate or helpful form of treatment? (Please select one option only)

Yes	1	CONTINUE TO Q14i
No	2	CONTINUE TO Q15

Q14i) Please indicate what form of treatment you think would have been more appropriate in this case

[free text box]

CONTINUE TO Q15

Q15) Please use the box below to share any other comments you wish to share

[free text box]

Thank you very much for taking the time to participate in our research. Your answers are greatly valued by Beat.

If you are interested in finding out more about our work, you can visit our website at: <http://www.b-eat.co.uk/>
[hyperlink]

Appendix 3 – ICD-10 Classifications of Eating Disorders

ICD-10 provides the following definitions:

F50.0 Anorexia nervosa

A disorder characterized by deliberate weight loss, induced and sustained by the patient. It occurs most commonly in adolescent girls and young women, but adolescent boys and young men may also be affected, as may children approaching puberty and older women up to the menopause. The disorder is associated with a specific psychopathology whereby a dread of fatness and flabbiness of body contour persists as an intrusive overvalued idea, and the patients impose a low weight threshold on themselves. There is usually under-nutrition of varying severity with secondary endocrine and metabolic changes and disturbances of bodily function. The symptoms include restricted dietary choice, excessive exercise, induced vomiting and purgation, and use of appetite suppressants and diuretics.

F50.1 Atypical anorexia nervosa

Disorders that fulfil some of the features of anorexia nervosa but in which the overall clinical picture does not justify that diagnosis. For instance, one of the key symptoms, such as amenorrhea or marked dread of being fat, may be absent in the presence of marked weight loss and weight-reducing behaviour. This diagnosis should not be made in the presence of known physical disorders associated with weight loss.

F50.2 Bulimia nervosa

A syndrome characterized by repeated bouts of overeating and an excessive preoccupation with the control of body weight, leading to a pattern of overeating followed by vomiting or use of purgatives. This disorder shares many psychological features with anorexia nervosa, including an over-concern with body shape and weight. Repeated vomiting is likely to give rise to disturbances of body electrolytes and physical complications. There is often, but not always, a history of an earlier episode of anorexia nervosa, the interval ranging from a few months to several years.

F50.3 Atypical bulimia nervosa

Disorders that fulfil some of the features of bulimia nervosa, but in which the overall clinical picture does not justify that diagnosis. For instance, there may be recurrent bouts of overeating and overuse of purgatives without significant weight change, or the typical over-concern about body shape and weight may be absent.

F50.4 Overeating associated with other psychological disturbances

Overeating due to stressful events, such as bereavement, accident, childbirth, etc.

F50.5 Vomiting associated with other psychological disturbances

Repeated vomiting that occurs in dissociative disorders (F44.-) and hypochondriacal disorder (F45.2), and that is not solely due to conditions classified outside this chapter. This subcategory may also be used in addition to O21.- (excessive vomiting in pregnancy) when emotional factors are predominant in the causation of recurrent nausea and vomiting in pregnancy.

F50.8 Other eating disorders

Pica in adults.

Psychogenic loss of appetite.

F50.9 Eating disorder, unspecified

An eating disorder that does not fall under any other designation.

Appendix 4 – SCOFF screening tool

The SCOFF screening tool^{48,49} can indicate disordered eating and a need to consult a healthcare professional. It asks patients if they have experienced any of the following in the last year:

- Have you made yourself **SICK** because you feel uncomfortably full?
- Have you worried that you have lost **CONTROL** over how much you eat?
- Have you lost more than **ONE** stone in a 3 month period?

- Did you believe yourself to be **FAT** when others say you are too thin?
- Would you say that **FOOD** dominated your life?

For every “yes” that a patient gives, one point is allocated; if they score 2 or more it is likely that they are suffering from anorexia nervosa or bulimia nervosa.

⁴⁸ Morgan, J.F., Reid, F. and Lacey, J.H. (1999) 'The SCOFF questionnaire: assessment of a new screening tool for eating disorders', The British Medical Journal, 319(7223), pp. 1467-1468 [Online]. Available at: <http://w.bmj.com/content/319/7223/1467>

⁴⁹ The Health and Social Care Information Centre (2009) Adult psychiatric morbidity in England, 2007; Results of a household survey, United Kingdom: National Centre for Social Research and the Department of Health Sciences, University of Leicester.

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