Eating Disorders – Prevalence and models of care

If you only read four things:
1. Symptoms usually begin in childhood (16 and under).
2. According to NICE\(^1\), almost 25,000 people in Suffolk may have an eating disorder, although estimates vary greatly.
3. Most people do not seek medical help.
4. Eating disorders reduce quality of life, not only for the sufferers but also for their carers and family members.

Key points
What is the issue?
Eating disorders (ED) affect children, young people and adults. DSM-5(2013)\(^2\) identifies eating disorders including:
- **Anorexia nervosa**: distorted body image and excessive dieting that leads to severe weight loss with a pathological fear of becoming fat
- **Bulimia nervosa**: frequent episodes of binge eating followed by behaviours such as self-induced vomiting to avoid weight gain
- **Binge eating disorder**: recurring episodes of eating significantly more food in a short period of time than most people would eat under similar circumstances, with episodes marked by feelings of lack of control
- **Eating disorders not otherwise specified** (EDNOS)

Early recognition and timely intervention, based on a developmentally appropriate, evidence-based, multidisciplinary team approach (medical, psychological & nutritional), is the ideal standard of care, wherever possible\(^5\).

Early recognition and intervention are important. However, EDs can be difficult to detect:
- screening tools (such as the SCOFF questionnaire\(^1\)) should not be the only method to establish whether a person has an eating disorder\(^1\)
- patients may not look emaciated, and their Body Mass Index (BMI) may be normal\(^4\)

What causes eating disorders?
Typical contributing factors include genetic influences\(^5\), the impact of puberty, stress, life events and the growing influence of social media driven pressures\(^6\).

The life events most frequently reported by patients were (in order): school transitions, death of a family member, relationship changes, home and job transitions, illness/hospitalisation, and abuse/sexual assault/incest\(^7\). Divorce can also be a trigger for older people\(^4\).

EDs may be triggered by changes in sex hormones at puberty (for boys and girls), pregnancy and the perimenopause\(^4\).

Body dissatisfaction precedes eating disorders and obesity. Young people who are overweight are more likely to develop eating disorders and binge eating. Unsupervised (by a doctor) dieting is associated with weight gain and disordered eating.
Why are eating disorders important for Suffolk?
Most people with an eating disorder do not seek help. People with an ED may not appear emaciated. Therefore, sufferers can be difficult to identify and support, but the impact of an eating disorder is great: the physical and mental health of the patient; the mental health of their families and carers; costs to the health service, patient and carers, and wider economy.

The numbers
Prevalence
The eating disorder estimates spreadsheet gives estimates of the prevalence of eating disorders in Suffolk. The estimates vary widely as they come from different sources, are based on different methodologies and age groups and may use different definitions and thresholds. Even these may underestimate actual need as, for example, only 11.9% of adolescents with binge-eating disorder (BED) seek medical help, and 30% or less of women with ED had ever sought help for their disorder or associated mental health issues.

The Costs of Eating Disorders - Social, Health and Economic Impacts, commissioned by the UK charity Beat and produced by PwC, attempts to address the wide variation in estimates. The estimates used recent ONS data to provide population estimates and adjusted prevalence based on recent research (e.g. rates of males with binge eating disorder and adjusted for studies on obese patients) and suggested that more than 725,000 people in the UK are affected by an eating disorder. They also identified that onset of symptoms is most commonly at age 19 and under, with most 16 and under.

Table 1: Estimated prevalence of eating disorders in the general population of Suffolk in 2018 (NICE, 2017)

<table>
<thead>
<tr>
<th>Disorder</th>
<th>CCGs</th>
<th>Suffolk local authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ipswich &amp; East Suffolk</td>
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<td></td>
<td>West Suffolk</td>
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<tr>
<td></td>
<td>Gt Yarmouth &amp; Waveney</td>
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<tr>
<td></td>
<td>WOC GPs</td>
<td></td>
</tr>
<tr>
<td>Anorexia Nervosa</td>
<td>1,221</td>
<td>751</td>
</tr>
<tr>
<td></td>
<td>719</td>
<td>200</td>
</tr>
<tr>
<td></td>
<td>2,256</td>
<td>270</td>
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<tr>
<td></td>
<td>199</td>
<td>414</td>
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<tr>
<td></td>
<td>305</td>
<td>341</td>
</tr>
<tr>
<td></td>
<td>377</td>
<td>351</td>
</tr>
<tr>
<td>Binge-eating Disorders</td>
<td>8,956</td>
<td>5,511</td>
</tr>
<tr>
<td></td>
<td>5,271</td>
<td>1,464</td>
</tr>
<tr>
<td></td>
<td>16,543</td>
<td>1,978</td>
</tr>
<tr>
<td></td>
<td>1,458</td>
<td>3,034</td>
</tr>
<tr>
<td></td>
<td>2,236</td>
<td>2,502</td>
</tr>
<tr>
<td></td>
<td>2,762</td>
<td>2,573</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>3,257</td>
<td>2,004</td>
</tr>
<tr>
<td></td>
<td>1,917</td>
<td>532</td>
</tr>
<tr>
<td></td>
<td>6,015</td>
<td>719</td>
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<td></td>
<td>530</td>
<td>1,103</td>
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<tr>
<td></td>
<td>813</td>
<td>910</td>
</tr>
<tr>
<td></td>
<td>1,004</td>
<td>936</td>
</tr>
</tbody>
</table>

Part of the eating disorder estimates spreadsheet

Incidence
A recent report in the BMJ, The incidence of eating disorders in the UK in 2000–2009: findings from the General Practice Research Database, identified an increase in incidence. They identified a total of 9,072 patients with a first-time diagnosis of an eating disorder. The age-standardised annual incidence rate of all diagnosed eating disorders for ages 10–49 increased from 32.3 (95% CI 31.7 to 32.9) to 37.2 (95% CI 36.6 to 37.9) per 100,000 between 2000 and 2009. The incidence of Anorexia and Bulimia was stable. However, the incidence of Eating Disorder Not Otherwise Specified (EDNOS) increased. The incidence of the diagnosed eating disorder was highest for girls aged 15–19 and for boys aged 10–14.
Table 2: Estimated incidence of eating disorders in the general population of Suffolk in 2018

<table>
<thead>
<tr>
<th>Disorder</th>
<th>CCGs</th>
<th>Suffolk local authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ipswich &amp; East Suffolk</td>
<td>Suffolk</td>
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<tr>
<td></td>
<td>West Suffolk</td>
<td>Babergh</td>
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<td></td>
<td>Great Yarmouth &amp; Waveney</td>
<td>Forest Heath</td>
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<td></td>
<td>WDC GPs</td>
<td>Ipswich</td>
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<td></td>
<td></td>
<td>Mid Suffolk</td>
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<tr>
<td></td>
<td></td>
<td>St. Edmundsbury</td>
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<tr>
<td></td>
<td></td>
<td>Suffolk Coastal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Waveney</td>
</tr>
<tr>
<td>Anorexia Nervosa</td>
<td>61</td>
<td>13</td>
</tr>
<tr>
<td>Binge-eating Disorders</td>
<td>102</td>
<td>18</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>90</td>
<td>20</td>
</tr>
<tr>
<td>Eating Disorders*</td>
<td>80</td>
<td>14</td>
</tr>
<tr>
<td>Eating Disorders in people aged 10-49</td>
<td>72</td>
<td>126</td>
</tr>
</tbody>
</table>

* On average General Practitioners (GPs) will see two new patients with ED per year of which a quarter will be managed exclusively in primary care.

Numbers supported locally

Suffolk data is not published on the number of people suffering from an eating disorder who contact GPs or other local health services, so it is not possible to report the full numbers supported locally. This also means that unmet need cannot be assessed, although it is likely to be high as research shows most sufferers do not get medical help (11.9% of adolescents with binge-eating disorder sought help\(^9\), no more than 30% of women with ED had ever sought medical help\(^{1,10–14}\)).

Figure 1 shows finished admission episodes for eating disorders for the three Suffolk CCGs over time. West Suffolk hospital admission crude rates (admissions per 1,000 registered patients) across the period (2010/11 to 2016/17) are significantly higher than those for the other two Suffolk CCGs (Figure 2).

Figure 1: Count of finished admission episodes (FAEs) with a primary or secondary diagnosis of 'eating disorder' by CCG, all ages, 2010/11 – 2016/17\(^{16}\)

Note: A finished admission episode (FAE) is the first period of admitted patient care under one consultant within one healthcare provider. FAEs are counted against the year or month in which the consultation begins.
admission episode finishes. Admissions do not represent the number of patients, as a person may have more than one admission within the period.

Figure 2: FAEs (crude rates for persons of all ages, per 1,000 registered patients) for eating disorders, 95% Confidence Interval, 2010/11 – 2016/17

The impact

The risk of premature death is 6-12 times higher in women with Anorexia Nervosa (AN) than the general population, adjusting for age\textsuperscript{5,17}. Mortality rates of bulimia nervosa and EDNOS may be as high, or higher than that of anorexia nervosa\textsuperscript{17,18}.

Eating disorders have major psychological, social and physical consequences for the patient\textsuperscript{8,9,18}. People with an eating disorder will usually have other mental health conditions\textsuperscript{8,19}.

EDs not only reduce the health-related quality of life (HRQoL) of patients, but that of their carers and family members\textsuperscript{19}. Carers, usually the family of the person with the eating disorder, can experience distress as severe as that of families dealing with psychoses, and sometimes greater than those caring for patients with other life-threatening conditions\textsuperscript{8,18,20}.

The World Health Organization ranks the United Kingdom tenth in the world for years of life lost (YLL) from eating disorders, estimating 2,273YLL for 2015\textsuperscript{21}.

Common chronic physical complications include: dental erosion (if there is frequent vomiting), slowed growth and development (in children and young people), osteoporosis, cardiovascular problems and kidney dysfunction\textsuperscript{1}. Mental health comorbidities are common, including:\textsuperscript{1}

- anxiety, often pre-dating the ED
- depression, that may be caused by malnutrition and associated low serotonin
- compulsive behaviours, such as skin-picking or compulsive exercise
- impulsive behaviours, including self-harm or substance misuse

ED prevalence may be twice as high amongst diabetic adolescent females than those without diabetes\textsuperscript{22}. Young people are likely to modify their insulin dose as part of their ED\textsuperscript{19,24}.

The rates of emergency admissions for diabetes in under-19s are significantly higher in Ipswich and East Suffolk Clinical Commissioning Group (CCG) than for England (see Figure 3a). However, further analysis is needed to see how this may be related to eating disorders.
What are the key inequalities?

People with ED had been stereotyped as young, white, well-to-do, well-educated, visibly underweight women. Research has challenged such views, showing similar rates of ED across all levels of income, education, and "urbanicity".

Socio-economic

Low socio-economic status does not protect against eating-disorders. Unemployment was associated with an increased risk of objective and subjective binge eating; not working due to disability was associated with an increased risk of objective binge eating and purging.

Over time, Suffolk has had lower rates of unemployment than Great Britain, however in 2017, the rate for females rose to above the regional and national average (Figure 3). The percentage of economically inactive Suffolk residents who are long-term sick is quite volatile compared to the East and Great Britain, but is currently higher than the GB average.
Higher parental education had been associated with EDs, but this may be a genetic not a social link.

**Age**

The risk is highest for young men and women between 13 and 17 years of age. Symptoms are beginning at a younger age, and awareness is increasing of eating disorders in middle age and older. Suffolk has a lower proportion of people in these age bands (0-4, 5-9, 10-14, 15-19) than England.

Young people who are overweight are more likely to develop eating disorders and binge eating. At 31%, prevalence of overweight (including obese) children in year 6 is significantly better (lower) than England (34.2%, 2016/17).

**Gender**

About 90% of those affected by eating disorders are female, although new studies suggest up to 25% of people with an eating disorder are male. Under-diagnosis of men may be due to historical perception that ED is a female disorder, bias in assessment tests, studies focusing on females,
reliance on clinical data rather than community studies\textsuperscript{26}, eating disorders hidden by excessive sports activity\textsuperscript{25}, or fear of being stigmatised\textsuperscript{18}.

Transgender people have a higher risk of EDs – perhaps as high as 16\% - compared to cisgender people\textsuperscript{4}.

**Ethnicity**

All ethnic groups are affected\textsuperscript{17}. The incidence of ED in the UK is increasing at the highest rate in young Asian females compared to other ethnic groups\textsuperscript{8}. There are 2,300 young Asian females in Suffolk: 2\% of Suffolk's female 0-24 years-old population, compared to 10\% for England as a whole (2011 Census\textsuperscript{35}).

**Sexuality**

Homosexual people are more likely to have an ED than heterosexuals; gay and bisexual men may be at a higher risk\textsuperscript{4}.

**Costs**

**Healthcare costs**

The worldwide burden and costs of EDs are high.

**Table 3: estimated annual healthcare costs\textsuperscript{19}**

In 2016, researchers reviewed existing literature and estimated annual healthcare costs per case (2014 values).

<table>
<thead>
<tr>
<th>Eating disorder</th>
<th>Annual estimated cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia Nervosa</td>
<td>€2,993 to €55,270</td>
</tr>
<tr>
<td>Bulimia Nervosa</td>
<td>€888 to €18,823</td>
</tr>
<tr>
<td>Binge-Eating Disorder</td>
<td>€1,762 to €2,902</td>
</tr>
</tbody>
</table>

**Table 4: UK treatments for anorexia nervosa\textsuperscript{36}**

A 2007 UK study of the outcomes and costs of treatments for anorexia nervosa found no statistically significant difference between outcomes, or between mean total costs after two years.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Mean total cost (2 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist out-patient group</td>
<td>£26,738</td>
</tr>
<tr>
<td>In-patient</td>
<td>£34,531</td>
</tr>
<tr>
<td>General out-patient treatment</td>
<td>£40,794</td>
</tr>
</tbody>
</table>

Exploration of the uncertainty of the three treatments’ costs and effects suggested that specialist out-patient treatment was most likely to be cost-effective.

**Overall costs**

Research by PwC for BEAT in 2015 estimated average annual UK costs for ED per person\textsuperscript{6}. The survey also showed there was a longer-term impact on earnings well beyond the initial average 6-year cycle of treatment.

**Table 5: Overall costs of eating disorders per sufferer\textsuperscript{6}**

<table>
<thead>
<tr>
<th>Item – costs for sufferers &amp; health services</th>
<th>Ave. cost p.a.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct costs to sufferers (treatment, travel, lost university fees etc)</td>
<td>£1,500</td>
</tr>
<tr>
<td>Treatment costs (average\textsuperscript{a} of different treatment pathways, excluding treatment of physical symptoms which are commonly prescribed)</td>
<td>£8,850</td>
</tr>
</tbody>
</table>
Impact of time off work and education
(range is between those under the age of 20 and over the age of 20) | £650 - £9,500
---|---
**Costs for carers**
Direct costs to carers | £2,800
Impact of time off work and education | £5,950

* some respondents estimated up to £100,000 in annual treatment costs.

Based on UK prevalence estimates drawn from previous studies\(^6\), of between 600,000 and 725,000, these costs suggest – assuming a ratio of one carer to one sufferer:

- annual direct financial burden to sufferers and carers: £2.6 billion - £3.1 billion
- total treatment costs to the NHS: £3.9 billion - £4.6 billion
- potentially, private treatment costs: £0.9 - £1.1 billion
- lost income to the economy: £6.8 billion - £8 billion

If these 2015 average costs are used with the NICE prevalence figures\(^1\) estimated for Suffolk, they would suggest an average total cost of eating disorders to Suffolk per annum of £4.7million - £7.1million.

**What are we doing?**

There is a Suffolk Eating Disorder Service that provides assessment and treatment to adults with serious eating disorders such as anorexia and bulimia. The team includes specialist nurses, psychiatrists and dieticians who offer a range of treatment options such as talking therapies, advice and physiotherapy. The focus of the service is directed at the treatment of anorexia nervosa and bulimia nervosa. The team also offers advice, support and supervision to professionals working with people whose illnesses are less severe.

A Children and Young People’s Community Eating Disorder Service (CEDS) was launched in 2016, run by the Norfolk and Suffolk Foundation Trust. Beat has provided training for people who work with young people and engaged with young people to increase understanding. Beat also provides online support.

**What else could we do?**

There is evidence that eating disorder risk factors can be reduced. A recent review (Watson HJ, et al. Prevention of eating disorders: A systematic review of randomized, controlled trials. Int J Eat Disord. 2016) was able to make recommendations for each level of prevention:

- universal (whole or general population): recommended media literacy training for universal prevention, although the impact was modest. Evidence was weakest for this level. Other research also recommends teaching mindfulness, functions of the body, acceptance and appreciation of different body shapes and diversity\(^38\)
- selective prevention (for those at higher risk of developing an ED than the general population): DBI (dissonance-based intervention) had moderate-to-large effects and showed better effects at follow-up 12 months later. CBT (cognitive behavioural therapy) was the next most effective approach. A healthy weight programme, media literacy and psychoeducation were also effective, and maintained effects at follow-up
- indicated prevention (for those at greatest risk of developing an ED, who may show some signs of a disorder, but haven’t received a diagnosis): CBT was supported, and effects were maintained at follow-up. DBI also showed promise\(^39\)

General health promotion for the whole population is important as campaigns on healthy eating.
exercise and mental wellbeing can address risk factors for ED (and subclinical ED) that are also psychiatric risk factors\textsuperscript{40} as well as addressing obesity\textsuperscript{41}. Changing the wider environment (e.g. by ensuring fashion models are a healthy weight or labelling photoshopped advertising) may also have an impact\textsuperscript{42,43}.

**Treating eating disorders**

NICE Clinical guidance was updated in 2017 (NG69)\textsuperscript{1}. This covers medication and psychological treatments of eating disorders and best options for services. The guideline applies to adults, adolescents and children of all ages\textsuperscript{1}.

Assessment of people with eating disorders should be comprehensive and include:

- physical, psychological and social needs
- a comprehensive assessment of risk to self
- signs of bullying, teasing, abuse or neglect
- impact of the home, education, work and wider social environment (including the internet and social media)\textsuperscript{1}

The Joint Commissioning Panel has produced guidance\textsuperscript{8} on commissioning comprehensive mental health services for people with eating disorders that are therapeutic and promote independence and recovery. The guidance includes ten key messages for commissioners (edited below):

1. Eating disorders have serious psychological, physical and social consequences.
2. The number of people with an eating disorder is probably underestimated as there is a huge level of unmet need in the community. These illnesses usually begin in adolescence and young adulthood with a trend towards younger children developing eating disorders.
3. Transitions between different services are usual for patients with eating disorders. Robust transitional policies must be developed, and training needs met to avoid risks to patients.
4. Caring for someone with an eating disorder carries a high emotional and economic cost. Carers of anorexic patients reported similar experiences, in terms of difficulties, to those of carers of adults with psychosis and higher psychological distress.
5. Anorexia does not improve spontaneously. The prognosis for all eating disorders worsens with time. Recovery is less likely if an eating disorder has remained untreated for more than 3-5 years. Early identification and intervention with access to effective stepped care pathways can improve clinical outcome and increase cost-effectiveness.
6. Access to specialist treatment for all people with eating disorders should be a priority.
7. Clinical and cost-effectiveness require flexible access to community and residential services, particularly for those with severe eating disorders. Commissioners must prioritise integrated care pathways that support flexible and seamless patient care.
8. Health costs for eating disorders in England have been estimated at £80-100m with overall cost likely to be over £1.26bn per year. Effective care pathways will help optimize services.
9. Stigma and misunderstanding related to eating disorders affect: people, who may not ask for help through fear of being judged; carers who often feel blamed; health professionals in deciding treatment; ED services and commissioners through lack of structural investment.
10. More research and investment are needed to develop optimal interventions and care pathways. Severe, enduring or ‘treatment resistant’ cases are the highest cost (per patient).
**Recommendations**

1. Ensure smooth transition between child/adolescent and adult services.
2. Services should follow NICE guidance on ED NG69 as well as local commissioning guidance.
3. Increase information on local prevalence of eating disorders. This could include: reporting from existing services, engagement with groups at higher risk (such as transgender).

**Useful links**

Related Suffolk Mental Health Needs Assessment topics


- Eating disorders in Suffolk: infographic
- Eating Disorders estimates 2018 MH Needs Assessment: data tables
- Trans and non-binary people and mental health

**References**


37. NICE. *Eating disorders in over 8s: management: Guidance and guidelines (CG9)*. (NICE, 2004).


