

Best practice in ensuring early intervention for eating disorders



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Introduction

Early intervention in eating disorders accelerates recovery, improves outcomes, reduces costs and, above all, saves lives (1, 2, 3, 4). Longer duration of an untreated eating disorder is a significant predictor of poorer outcomes, lower rates of recovery and longer hospitalization (3, 5, 6, 7). The early or 'subthreshold' stages (that is, when symptoms do not meet full diagnostic criteria) of an eating disorder are a critical period for preventing the progression of the illness (2). Disordered eating is the most common sign of the early development of an eating disorder and can have destructive impacts on a person's quality of life (2,8). We know that treatment is more effective if delivered earlier yet early intervention has not become the norm for eating disorders (9, 10, 11). Eating disorder services are increasingly stretched and, with current levels of funding and staffing, are not currently able to deliver effective early intervention.

A 2017 survey of people's experiences when seeking help for an eating disorder found an average delay between eating disorder symptoms emerging and someone accessing treatment of 176 weeks, or three and a half years (12). The average delay for those aged under 19 was 130 weeks, with adults not starting treatment until 256 weeks after falling ill (12). People took an average of 91 weeks after their symptoms emerged to realise that they had an eating disorder. After this, over one year passed before they sought help from the NHS and then a further 6 months elapsed before treatment began. Once treatment starts, the average eating disorder patient enters a cycle of relapse and recovery lasting for over six years, with major health, emotional and financial impacts on people with eating disorders, their families, and the NHS (13).

'Early intervention' is an ambiguous term, and definitions of it within eating disorder research are inconsistent (14). Treasure and Russell (2011) define early intervention as effective treatment given within the first three years of eating disorder onset (6). This three-year-mark is central to the stage of illness model of eating disorders, which shows a higher resistance to treatment as illness severity progresses and recognises the likelihood of achieving a full recovery to be significantly higher within the first three years of illness onset (14). The stage of illness model is supported by FREED (First Episode Rapid Early Intervention for Eating Disorders), the highest profile early intervention service model and care pathway in the UK, which identifies 'early intervention' as first specialist treatment of an eating disorder which has lasted less than three years (15). Other understandings of 'early intervention', however, are not consistent with this definition. Early intervention could be understood to mean: (i) intervention for those with high risk of developing an eating disorder, (ii) interventions to reduce the duration of untreated eating disorder (DUEd) or (iii) interventions tailored to the early years of an eating disorder. Early intervention has been also been defined as detection at the earliest stage possible, followed by appropriate or stage-specific intervention, for as long as is necessary and effective (16). Silber (2013), for example, defines 'early intervention' in children as intervention when the first signs of an eating disorder are suspected, and before all of the symptoms of an eating disorder have emerged (17).

Therefore, to outline a standard for early intervention in the context of eating disorders, a clear definition is required. Beat's position is that intervention is required at the very earliest stages of an eating disorder emerging in order to accelerate treatment, optimise recovery, minimise distress to patients and families, and reduce costs to the NHS and the wider economy (13). If untreated, subthreshold eating disorders are more likely to lead to full-syndrome eating disorders and are unlikely to remit spontaneously (2). This paper therefore proposes that 'early intervention' be defined as intervention when the earliest, subthreshold signs of an eating disorder begin to emerge, and gives recommendations for minimum standards to be met by all providers in order to meet this aim.

Early Intervention for Eating Disorders

Why is early intervention important for eating disorders?

Earlier intervention in eating disorders leads to more positive treatment outcomes (6,18). A growing body of evidence supports a stage of illness model of eating disorders, which shows a higher resistance to treatment as illness severity progresses (15). Increasing duration of an untreated eating disorder has been found to result in lower rates of full recovery, reduced compliance with treatment and lengthier hospitalisation (19). Early intervention in eating disorders is also supported by neurobiological evidence, with brain responses shown to be most malleable in early stages, and more entrenched and compulsive behaviours demonstrated in the later stages (20,21,22).

While recovery is possible at any stage of illness, studies have shown that long lasting anorexia nervosa (over 6–7 years) leads to a significantly lower likelihood of recovery following treatment (23,24). Longer duration of bulimia nervosa has also been shown to result in poorer treatment outcomes (25), and even a delay of three months before accessing treatment can lead to significantly less improvement (26). Studies of this kind regarding other eating disorder subtypes represent a gap in the literature yet, given the devastating effects of the illness on quality of life, there are clear ethical arguments for treatment to start as soon as possible (3).

Early intervention can also greatly reduce the cost of eating disorder treatment. Beat compared two hypothetical nineteen year old patients; one who avoids an in-patient stay, but instead receives intensive outpatient and then day care, with another who faces delays and duly spends six months in hospital followed by five months of community treatment. The cost of the first patient's treatment was estimated in 2017 at £40,716, compared with £83,807 for the patient needing an inpatient stay (13). The savings would be even greater with different comparisons involving truly early intervention and/or longer hospital stays and relapses. Services and new models of care groups should keep these savings in mind when investing in eating disorder service pathways.

What are the barriers to early intervention?

On average, people who responded to Beat's 2017 survey, waited almost three years before they sought help for an eating disorder (12). This included an

average of 91 weeks before realising they had an eating disorder, and 58 weeks before seeking help after recognising the signs (12). At every stage, adults waited significantly longer than those aged under nineteen, and on average waited almost five years (256 weeks) before receiving treatment. Three broad groups of barriers to early intervention were identified.

Patient and Family-Related Barriers

There is low understanding of eating disorders in the community and limited community outreach activity by UK eating disorder services. Families, other carers, schools, employers, and the community can play a central role in spotting the early signs, helping those affected realise they may have an eating disorder, and supporting them to seek treatment. However, they need support and guidance to do this. Distress around body image, weight and shape is reported by 20% of adolescents, while families and healthcare professionals often associate eating disorders with changes in weight disregarding earlier signs (27). It can therefore be difficult for families to know when to worry and to know which are the early symptoms of a possible eating disorder (28). Raising awareness of other signs and symptoms of eating disorders, which might occur before weight changes, is therefore crucial to early detection and the UK's community eating disorder services are best placed to perform this role.

Primary-Care Based Barriers

The historically inadequate coverage of eating disorders in UK medical education and training has left many GPs unable to understand eating disorders, or to know how to support people with their eating disorder (28,29). For most people with an eating disorder in the UK, their GP remains the principal or only route to the referral for the specialist assessment which they require before treatment can begin. 58% of people who responded to a 2021 Beat survey reported that they felt the first GP they sought support from did not understand eating disorders and 69% said that their GP did not know how to help them (30). Meanwhile 60% reported that their quality of care was 'poor' and only 31% reported that their GP referred them to a mental health service for treatment. The survey results also highlighted the missed opportunities for early intervention, with 67% believing that there were opportunities for early identification and intervention in their eating disorder that were missed (30).

Self-referral and/or direct referral from the voluntary sector for assessment has been presented as an alternative to seeking help via a GP (30). However, an assessment in 2020 found that just 44% of community eating disorder services for children and young people

in England accepted self-referrals (15% for adults), with just 6% offering an accessible route (0% for adults) (31,32). In the devolved nations, no services were found to offer an accessible self-referral mechanism (32).

Service related Barriers

Once they have been referred for assessment, people with eating disorders face significant delays before specialist treatment can start, largely due to shortfalls in funding, staffing, and the absence of appropriate and effectively monitored NHS targets.

Low staffing levels in eating disorder services create waiting lists and lead to unofficial means of rationing access). After referral, people wait an average of 21 weeks before beginning treatment (12). This includes 10 weeks before being assessed, and 11 weeks between assessment and treatment (12). Increased waiting list time has been shown to predict an increase in the rate of drop out from treatment (33). Meanwhile, the longer people with an eating disorder wait for treatment, the more severe and entrenched their illness is likely to become.

Currently, the UK's most ambitious targets for access and waiting times in eating disorders are those set by NHS England for children and adolescents, with a mandated maximum waiting time of four weeks between referral and start of treatment, falling to one week for urgent cases (31). No such targets have been set in Scotland, Northern Ireland, and Wales. In the absence of evidence for a better alternative, these targets should also be applied to adults and should be adopted UK-wide.

To achieve reasonable waiting time targets in a service which is already challenged by low staffing levels, a creative approach is needed. This should involve embracing the delivery of suitable low-level early interventions by peer support workers and other suitably trained non-clinical staff, while ensuring appropriate supervision by a clinician. Beat has found that guided self-help can be feasibly and acceptably delivered by telephone by non-clinicians, and can result in improving eating difficulties and psychopathology, mood, and the impact of eating difficulties on daily life (34).

Furthermore, in many areas, the NHS does not commission treatment for people with binge eating disorder for example, despite its severity and high prevalence (35). A Freedom of Information (FOI) request by Beat in 2020, for example, found that in Northern Ireland, none of the 5 Health and Social Care

Trusts were commissioned to provide treatment for binge eating disorder (36).

Similarly, services in some areas ration access to treatment based on criteria such as BMI, frequency of bingeing and/or purging episodes. For example, the 2020 Beat FOI request found that one provider in England specified that binge eating must occur twice per week, despite the DSM-5 criteria specifying binge eating must occur once per week for three months, meaning that people in that area can only access treatment when their illness has progressed to more severe presentations (36). This rationing goes against NICE guidelines, which states that measures such as BMI or duration of illness should not be used to determine whether someone should access specialist eating disorder treatment (36,37,38,39).

Learning from early intervention in other contexts: Cancer Early Diagnosis and Screening

The benefits of treating cancer early have long been recognized and accepted (40) with great progress made in early diagnosis and intervention, which has paved the way for the doubling of cancer survival and improved quality of life over the past few decades (41).

The NHS in each part of the UK has established a structured approach for early intervention for cancer. This includes achieving high community awareness of the early signs and symptoms of cancer, overcoming stigma, providing, and encouraging engagement with screening services, supporting people to seek treatment at the earliest stages and ensuring treatments are accessible and provided quickly once a diagnosis has been made.

National public awareness programmes such as 'Detect Cancer Early' in Scotland and Be Clear on Cancer in England reported success in improving awareness of signs of cancer, GP attendances, urgent achieved in early intervention for cancer with much cancer referrals and earlier cancer diagnosis (42). Key elements include a structured approach to screening and early diagnosis, supported by campaigns to raise public awareness of the early signs and symptoms of cancer, and a workforce plan to ensure high numbers of specialist staff and high quality care.

While cancers and eating disorders share few similarities, the NHS and the UK's eating disorder services can clearly learn much from the successes being readily transferrable to achieve progress in early intervention for eating disorders.

Towards true early intervention

For early detection of, and intervention for, eating disorders to be effective, emerging and subthreshold symptoms need to be identified, understood and taken seriously by people affected and their carers as well as their health services, education providers, employers, and wider community.

Before symptoms of an eating disorder meet the criteria for a diagnosis, individuals can currently be – or feel – dismissed as ‘not bad enough’, ‘not serious enough to get help’, ‘attention seeking’ or ‘not taken seriously’ (30). This stigma is not helped by a diagnostic framework which sets a binary between ‘health’ and ‘illness’, overlooking the broad spectrum between those two categories. Those who have emerging symptoms, or disordered behaviours around food and body image which do not yet fit the criteria for an eating disorder or cause significant disruption to everyday life, can be neglected by our current referral and treatment models.

People with suspected eating disorders currently face a care model in which individuals are expected to ‘get worse’ before they can access treatment to ‘get better’. Hospital admissions for eating disorders are rising steeply, having increased from 15,862 in 2019 to 22,254 in 2022 in England (43). Meanwhile waiting lists have lengthened – over 21,000 children and young people were waiting for eating disorder treatment at the end of March 2022 – more than three times the number waiting at the end of March 2020, and 39% of these had already been waiting for at least three months. Only 61% of urgent cases started treatment within 1 week during 2021/22, which was the lowest annual result in six years (44).

Clearly, intervention is essential to protect health and save lives when someone is severely ill. However, the current insufficiency of funding and staffing is preventing eating disorder services from focussing attention on both the patients in crisis and those at the earliest stages of their illness. While rationing a limited resource by focussing attention on the most unwell is inevitable under such circumstances, it condemns many patients to a long and damaging illness which could have been avoided and continues to contribute to the high numbers of patients in crisis.

Beat therefore proposes the following best practice standards in relation to early intervention for eating disorders which, if fully adopted, would enable many more people to seek and start suitable treatment as early as possible in their illness, resulting in shorter duration of illness, lower levels of relapse, reductions in

distress, improved job satisfaction among healthcare staff and, in time, significant cost savings to the NHS and the wider economy.

Best practice in early intervention for eating disorders

All providers of community eating disorder services should:

1. Run locally-specific outreach campaigns to increase community understanding of the early signs of eating disorders and how to access assessment, support and treatment.
2. Offer accessible self-referral or suitable alternative referral routes to specialist assessment which do not require people to seek help via their GP.
3. Provide assessment and start treatment within no more than 4 weeks of someone seeking help for everyone of any age with any eating disorder presentation.
4. Ensure that the service is staffed with sufficient numbers of suitably trained clinical and non-clinical staff in the correct mix of disciplines required to ensure continued and consistent high quality treatment for all patients regardless of the duration of their illness.

Community Outreach

As people wait for an average of 91 weeks before realising that their illness might be an eating disorder, and a further 58 weeks before starting to seek treatment (12), the greatest opportunity to decrease time from onset to treatment is by acting and intervening at the earliest stages of the illness. To achieve this, an enhanced effort to raise awareness around eating disorders is needed, with widespread local promotion of messaging which supports people to recognise the potential signs of an eating disorder, dispels eating disorder ‘myths’ and gives practical information to support and empower those affected and their families and other carers to seek a referral.

Accessible Self- and Direct Referral

In order to mitigate the challenges faced by many people when seeking a referral from their GP, and in turn to relieve workload pressure from GP surgeries, alternative routes to referral and assessment for eating disorders are essential. Allowing the service user and carers to seek an assessment directly from the eating disorder service is a proven route, although services must ensure that they do not place

unnecessary or insurmountable obstacles in the path of those attempting to make a self-referral (32). Accepting direct referral from schools, colleges, universities, eating disorder charities and other organisations which might identify the early signs offers a complementary approach to self-referral. The routes to referral should be included in community outreach communications, readily visible on the services' website, accessible through different routes including online and by telephone, while any forms and questionnaires should be kept to a minimum and be easy to complete.

Reduced Access and Waiting Times

All commissioners and providers should have standards and policies around waiting times to access eating disorder treatment, with the recommended maximum waiting time being one week for urgent cases and four weeks for routine treatment for people of all ages, and covering eating disorders of all types and levels of severity (31).

Adequate Staffing Levels

All eating disorder services should be adequately staffed with the correct mix of the different disciplines required to ensure a safe and effective service. In the face of the current critically low levels of clinical staffing in eating disorder services, creative approaches are essential in order to enable the delivery of interventions at the earliest stages of an eating disorder. Peer support workers and others without a clinical qualification can be properly trained and supervised to support clinical staff in promoting awareness and delivering guided self-help and other effective low level interventions to allow the qualified staff to manage the full-syndrome eating disorders. This is best delivered if the two are well integrated and embedded to allow for easy escalation from the early intervention pathway to the core team without any further delays that would be detrimental to the patient.

Policy context

England

NHS England requires eating disorder services to start treatment of children and young people under the age of 19 within one week of referral in urgent cases, and four weeks in all other cases. Services are expected to accept referrals from a wide range of sources, including self-referral (32). For adults it sets expectations that adult eating disorder services will remove any barriers to access (such as weight or BMI), and accept self-referrals and referrals from the voluntary sector (45). Additionally, a new 4-week access and waiting time standard for adult community mental health care (including eating disorders) is being developed (46,47). In the *NHS Long Term Plan* (48), NHS England has also committed to:

- Training senior leads in schools and colleges and rolling-out new NHS Mental Health Support Teams (MHSTs), in part to enable earlier identification and referral.
- Rolling out the FREED (First Episode Rapid Early Intervention for Eating Disorders) model for 16–25-year-olds (49).
- Joining-up budgets for inpatient and community-based treatment through new regional partnerships known as NHS-led provider collaboratives, so removing a significant barrier to investment in early intervention.

Northern Ireland

The *Mental Health Strategy 2021-2031* includes early intervention among its 'core principles', and pledges that services will be equipped to "offer specialist treatment to all those who are presenting with eating disorders, including mild to moderate cases, without delay." (50).

There is no formal eating disorder-specific waiting time target in Northern Ireland. The Health and Social Care Board (HSCB)'s *Regional Care Pathway for the Treatment of Eating Disorders* – published in 2016 – states that people "can expect to be seen" within 9 weeks for routine referrals, 5 working days for urgent referrals and 24 hours in an emergency. This 'care pathway' only covers anorexia nervosa and bulimia nervosa (and what it calls 'atypical' variants). It does not cover the management of binge eating disorder or "problems with eating that can be developed by children such as food phobias, selective eating, and poor appetite". It is not clear whether these 'expectations' refer solely to accessing an assessment, or the full waiting time from referral to the start of treatment (51).

Scotland

The *Scottish Eating Disorder Service Review* (2021) made recommendations including:

- Improving the knowledge and skills of key stakeholders and health professionals so that they can identify all eating disorders at early stages and can support and signpost people into treatment
- Acceptance of self-referral to specialist eating disorder teams in all areas
- Community eating disorder services for all ages being resourced to treat eating disorders of all types and levels of severity (52).

Wales

The *Welsh Eating Disorder Service Review 2018* called for much greater investment in early identification and rapid access to treatment. Its recommendations included:

- Services accepting eating disorder referrals from all sources, including self-referral.
- Rolling out the 'SPEED' early intervention model across Wales for young people, and a corresponding model for adults such as FREED (First Episode Rapid Early Intervention for Eating Disorders).
- Introducing ambitious new waiting time targets for all ages, in line with the targets currently in place for under 19-year-olds in England (53).

The Welsh Government, in its *Together for Mental Health Delivery Plan 2019–2022 in response to COVID-19*, committed to "develop a new model of [eating disorder] service in response to the recent independent review." (54).

Additional recommendations in order to facilitate the implementation of these standards in eating disorder services

Government and the NHS should:

- Develop and implement fully-funded long-term workforce planning in order to recruit, train, and retain sufficient health professionals specialising in eating disorders, with the right skill mix. This workforce planning should also promote the recruitment, training, and supervision of non-clinical staff to deliver early intervention services.
- Ensure that eating disorders are appropriately taught and assessed in all medical schools and foundation schools, so that future generations of doctors can spot the earliest signs of eating disorders developing, provide safe care, and facilitate referral for specialist assessment.
- Ensure that all health professionals in relevant sectors receive training to enable them to spot the earliest signs of a possible eating disorder developing, provide safe care, and facilitate referral for specialist assessment.
- Ensure that staff in all schools, colleges, and universities are trained to spot the earliest signs of a possible eating disorder developing and facilitate referral for specialist assessment. Eating disorder training for senior mental health leads – where they are in place – should be prioritised.
- Include disordered eating/eating disorder symptoms in public mental health campaigns (such as the 'Every Mind Matters campaign' in England and 'Clear Your Head' in Scotland) and ensure that public health campaigns that promote

exercise are informed by eating disorder risks.

- Allocate sufficient funding to commissioners and providers to enable the achievement of these best practice standards on early intervention in eating disorders, and ensure this funding reaches frontline services.
- Hold commissioners and providers accountable for the achievement of best practice in relation to community outreach, accessible self- and direct referral, maximum access and waiting times and adequate staffing levels.

Conclusion

Early intervention is crucial for effective treatment for eating disorders. The longer an eating disorder has persisted, the lower the rates of recovery, and the more detrimental the emotional, health and financial impacts on the individual, family and wider community (6). For too long, we have been working to an interpretation of early intervention which is unambitious and which has limited impact on the duration of untreated illness. Adoption of a new definition which encompasses the actions needed at all stages of an eating disorder from onset to the start of treatment is therefore needed.

For the benefits of early intervention to be experienced by everyone newly affected by an eating disorder, the NHS – and Community Eating Disorder Services in particular – must adopt the best practice standards outlined in this paper and the Government in each part of the UK must act immediately on the recommendations made here in order to facilitate and drive the changes necessary.

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