

Best practice in the engagement and empowerment of families and carers affected by eating disorders



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Introduction

An estimated 1.25 million people in the UK suffer from an eating disorder at any one time (1). While the issue remains under-resourced and under-researched, it is nevertheless attracting increased attention from governments, the NHS and the media. Much of this focus is on the need to reduce the period of delay and waiting between someone falling ill and starting treatment for an eating disorder.

However, this does not address the distress suffered by the 4- or 5- million family members who are also affected by the illness, nor will it enable those family members and other carers to support their loved one into a sustained recovery.

There is considerable evidence for the positive impact on treatment outcomes for someone with an eating disorder if their families are fully informed and engaged at all stages from diagnosis, through treatment and after discharge. Nevertheless, families and carers of people affected by eating disorders commonly report that they do not understand the illness or what to do about it. They also complain that they do not receive useful information from their health services when treatment begins. They are therefore not empowered to stop things getting worse while their loved ones wait for treatment to start, nor do they know how to support their treatment regime.

Families and carers also often report that supporting the sufferer has a negative impact on their own physical and mental health. They frequently report feeling burnt out and depressed, as well as isolated from those around them, which is likely to affect their ability to care for the sufferer.

Unsurprisingly, the majority of families and carers are keen to be involved in supporting their loved one into, through and out of treatment. They therefore represent a huge untapped resource which can be much better empowered to enhance treatment outcomes for their loved ones. But they can only play their role if they have full understanding, are fully supported and engaged, and if their own wellbeing is protected.

Change is therefore needed in order to permit families and carers to play a crucial role in helping their loved one throughout the process of recovery, enabling them to feel confident in the support they are giving their loved one, and capable of managing the difficult conflicts resulting from the eating disorder.

This paper proposes a series of best practice standards for adoption by all health care providers offering eating disorder services. These standards build on the NICE eating disorder guidelines (2), standards proposed by the Academy for Eating Disorders (3), the community standards proposed by the Quality Network for Eating Disorders (QED) and Quality Network for Community Eating Disorder Services for Children and Young People (QNCC-ED) (4,5) and wider research evidence and expert clinical guidance.

In this paper, the term 'carer' refers to any family member, partner, loved one or close friend who is responsible for looking after the person with an eating disorder. The term 'eating disorder' refers to any eating disorder, rather than a specific diagnostic category.

Best practice standards for the empowerment of families and carers affected by eating disorders

All providers of eating disorder services should:

1. Have a policy that ensures optimum involvement of and support for all carers as soon as a loved one starts treatment.
2. Train all service staff in the application of the policy and these standards with particular focus on the importance of carers as a resource for recovery.
3. Provide all carers with useful and comprehensive information about eating disorders when their loved one receives a diagnosis.
4. Offer all carers and siblings an assessment of their own needs when a loved one receives an eating disorder diagnosis, continue to monitor their wellbeing throughout the sufferer's treatment and, where necessary, refer carers to specialist services.
5. Offer all carers options for peer-to-peer support.
6. Offer all carers opportunities to learn the necessary skills to provide optimum support for their loved ones.
7. Inform and engage carers when a loved one faces a transition between services and ensure that effective communication between both services and carers takes place.
8. Provide a mechanism by which carers' input and feedback is sought and acted upon.

We recognise that some patients will not want their carers to be involved in their recovery. However it is important that these carers are still respected by the service and offered support and information within the constraints of confidentiality.

Resources to support the implementation of these standards, including sources of guidance, can be found in the appendix.

Why are standards to ensure optimum involvement of all carers needed?

By adopting these standards, eating disorder services will be helping to ensure:

- That sufferers are more likely to begin, stay in and comply with treatment
- Consistent provision of evidence-based treatment
- Improved treatment outcomes
- Increased compliance with care plans after discharge
- The sufferer is supported during any transitions
- Reductions in relapse and readmission
- Reduced distress and burden for carers and siblings

To ensure that sufferers stay in and comply with treatment

People with eating disorders are often reluctant to change and ambivalent towards treatment (6–10). They may also feel hopeless about their ability to change (11,12). These factors can lead to premature drop-out from treatment and undermine compliance

with treatment, therefore putting the sufferer at risk. For this reason, empowering carers to know how best to support their loved one through the challenges of treatment and to aid their compliance with treatment is crucial (13). This is recognised by the NICE guidelines (2), the Academy for Eating Disorders' Healthcare Rights (3) and the Quality of Eating Disorder Network standards (4,5) which all recommend that carers should be offered information about eating disorders and the treatments that are available. Despite these recommendations, carers currently report a lack of information about the illness, including what treatment involves and how best to support their loved one (14–23).

To ensure consistent provision of evidence-based treatment

Empowering carers with knowledge of what treatment should entail is important to ensure that optimum evidence-based treatments are delivered, and that the carer feels confident in challenging the treatment team if necessary. This will help prevent "therapist drift", a phenomenon identified by Waller (24), in which the therapist fails to deliver the manualised, evidence-based treatment despite having the resources. Therapist drift has been identified in treatments

recommended by the NICE guidelines for eating disorders, such as Family-Based Therapy (25) and Cognitive Behavioural Therapy (24,26), and occurs due to reasons such as the clinician's attitudes and beliefs.

A qualitative study of the experiences of 11 carers of a loved one with an eating disorder by Beat (15) highlighted that at times, carers have felt it necessary to guide or challenge their loved one's professional in order to further treatment, emphasising the importance of providing carers with knowledge about what treatment should involve. For example, one carer reported:

"I actually had to complain to the head of the service. How has my daughter not been flagged up yet? She's clearly disappearing in front of our eyes."

To improve treatment outcomes and compliance with care plans after discharge

Since the sufferer's home environment is commonly where the disordered behaviours have emerged and become entrenched, it is likely that it holds certain psychosocial triggers which maintain the illness. Therefore, giving carers full information about how treatment will proceed, and practical guidance on how they can support treatment (including after discharge) will help ensure that they understand the illness, can support their loved one in challenging disordered behaviours and can help them manage difficult feelings. This is crucial if the family and home environment are going to optimally support the sufferer in a sustainable recovery. By extension, this suggests that empowering carers to best support their loved one will also reduce relapse and readmission into services.

This has been supported by interviews with people who have experiences of eating disorders, who have cited family members, partners and close friends, as significantly influential in the sufferer's desire to recover (27–30). For example, Linville et al. (27) interviewed 22 women who had recovered from an eating disorder in order to gain a sense of how helpful or harmful their support networks were. Ten participants highlighted the importance to their recovery of support received from family member, whilst twelve participants spoke about viewing their friends as an ongoing resource in their recovery.

Additionally, a qualitative study by Tierney (29) in which 10 adolescents receiving treatment for anorexia nervosa were interviewed about their experiences of care, highlighted the way in which families could be a crucial resource in recovery. One young person stated:

"I think the main thing has been my mum. If it wasn't for her... She was just there, she was going through it with me. We were kind of on a roller coaster together".

Carer awareness of different challenges throughout treatment and recovery are also likely to improve treatment outcomes and compliance with care plans following discharge (31).

To support the sufferer during transitions

Transitions between services, for reasons such as a change in location or moving to adult services from child and adolescent treatment, can be a time when the sufferer is particularly vulnerable (32–34). Poor planning and a lack of communication between services can lead to the sufferer disengaging from treatment and being readmitted to hospital where otherwise avoidable (35).

Transitions can also be a difficult time for carers. For example, when moving from Child and Adolescent Mental Health Services (CAMHS) to adult services there is an increased onus on the sufferer taking responsibility for their own recovery, which can lead to the carer feeling excluded (16,17). The transition from inpatient to outpatient treatment can also be a particularly anxious time for carers. A qualitative study of the experiences of 11 carers of a loved one with an eating disorder by Beat (15) emphasised this anxiety. One carer reported:

"But it's just like we're feeling really worried about her coming home [from inpatient]. Because obviously we want her home, but there's just this fear of "Oh my God, [what] if it happens again."

NICE (2), QED (4) and QNCC-ED (5) all support the importance of carers being involved throughout the entire process of treatment. For example, the NICE guidelines for eating disorders (2) state that, where appropriate, inpatient or day patient services should collaborate with carers to help with treatment and the transition period across services. Additionally, the Royal College of Psychiatrists (34) also recommends ensuring that carers and family members are involved and provided with good information during transitions in order to ensure that carers know what to expect at the next stage of treatment and to help reduce carer burden through the provision of support and information.

Reduced distress and burden for carers and siblings

There is an abundance of research highlighting the significant impact that eating disorders have on both

the physical and mental health of carers. Surveys and interviews with carers of individuals with eating disorders have identified that carers' physical and mental wellbeing is negatively affected by the illness, with carers reporting feeling burned out, helpless and depressed (14–16,19,22,23,30,36–45). For example, Kyriacou, Treasure and Schmidt (42) found that in a sample of 151 parents of people with anorexia nervosa, over 50% of parents scored over the clinical threshold for anxiety, and 13% for depression.

Interviews with 11 carers of a loved one with an eating disorder by Beat (15) found a picture of considerable distress and feelings of hopelessness among carers, who had often received little or no support from the eating disorder service. For instance, one mother described the detrimental effect of the eating disorder on the family:

"We have had had no respite from the illness whatsoever and there's nothing. There's nothing anyone can do because she's too sick to go... You can't send someone who is potentially suicidal and not going to eat anything to stay with a relative"

This highlights the need for increased support for anyone supporting someone with an eating disorder – "a carer with an excessive burden is not a good carer" (46). The NICE guidelines (2) recommend that carers are offered an assessment of their own needs throughout their loved ones' care due to this increased distress, however, often this is not undertaken. For example, research by the QED (17) found that of 176 carers of adult inpatients surveyed, only 37% were advised on how to obtain an assessment of their own needs.

Carers also report the strain that the illness puts on maintaining other relationships, including family unity and friendships (15,16,20,39,41,44) which is likely to increase carers' feelings of isolation. This isolation has also been described as being exacerbated by the stigma and lack of understanding of eating disorders within the community, again highlighting the need for carer support (44).

Eating disorders have a profound negative impact on the siblings of the sufferer (15,16,30,39,41,44,47–54) For example, Latzer and Berger (51) found that females who had a sister with an eating disorder had significantly greater levels of depression compared to those who had a sister without an eating disorder. Siblings also commonly reported fears that their sibling with the eating disorder would never recover and would die (49,53). This need to support siblings and the isolation they feel was reported in qualitative research by Beat (15):

"[I] wanted to talk to somebody about it... there's never really anything for siblings of people with eating disorders..."

Research highlights the detrimental effect the eating disorder has on a partner's wellbeing (15,16,18,19,39, 44,55). For example, Schmit and Bell (18) interviewed 12 partners of someone recovering from an eating disorder. They found that partners were continually worried about their loved one's health and wellbeing, and experienced considerable stress due to the illness. They were often confused by their partner's behaviours and unsure how to adjust their own behaviour, as they were worried they would say or do the wrong thing and make their partner worse. Partners also reported feeling isolated and unable to talk to anyone about the eating disorder, for reasons such as their loved one not wanting them to. For instance, one partner stated:

"... it definitely put a strain on the relationship... and I was worried, I was worried you know, that she might start doing it again, or she might try to hurt herself."

Peer support has been identified by carers as a helpful means to pass on information about the eating disorder to others and a way in which to feel supported amongst those who understand (14–16,18,19,21–23,44). For example, qualitative research by Highet et al. (44) explored the experience of living with a person with an eating disorder through interviews with 24 carers. One carer stated:

"I needed another parent to tell me 'you will be all right' because I just felt I couldn't survive."

Similarly, Schmit and Bell's (18) interviews with 12 partners of someone recovering from an eating disorder also identified this theme of the importance of talking to others who have had experiences of caring for a loved one. One partner stated:

"I wish that I had maybe known a little more about it, or even known somebody who had gone through it before"

Workshops and interventions which help carers to support their loved one can also be of significant benefit to both the carer and the sufferer (56–66), for example through reducing carer anxiety and depression. Hibbs et al. (61) applied skills training integrated with coaching sessions for caregivers of a loved one with anorexia nervosa, and found a subsequent reduction in number of days as an inpatient, reduced eating disorder psychopathology, and improved quality of life. Two years following discharge, patients had better outcomes (62).

Conclusion

Families and other carers can play an essential role in the recovery of someone with an eating disorder, helping them to access treatment, advocating for evidence-based treatment to be provided, and supporting them with the challenges of recovery. However, carers often feel disempowered, alone and distressed, and also report deteriorating physical and mental health.

It is therefore of great importance for services to empower and support carers. By adopting the best practice standards proposed in this paper, services will achieve increased engagement and support, improve treatment outcomes and enhance the likelihood of sustained recovery.

We recognise that the research base for some of the proposed standards is weaker than we would prefer and that more research is needed into the optimum approaches to family and carer empowerment.

Nevertheless, given the strong demand from families, carers and sufferers for such changes to be adopted, and the absence of any feasible negative impact of their adoption, we believe that the existing evidence base is more than sufficient to argue for the standards to be adopted by all providers, who should in turn monitor their implementation and strive for continual further improvement.

Beat therefore intends to promote, monitor and report on the adoption of these standards by all providers of eating disorder services. We will develop new resources to support their adoption, highlight examples of good practice developed by others and update the evidence base as new research findings emerge.

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The Academy for Eating Disorders' World Eating Disorder Healthcare Rights

(selected elements relevant to carers (3))

Respect: All patients, caregivers, and family members have the right to be treated with respect throughout the assessment, planning and treatment process. Patients and carers should never be judged or stigmatized based on symptoms, behaviors or past treatment history.

Informed consent: When making healthcare decisions, patients and caregivers have the right to full disclosure by healthcare professionals about treatment best-practices, risks, costs, expected services outcomes, other treatment options, and the training and expertise of their clinician.

Participation: Families and other designated carers have a right to participate in treatment as advocates for the best interests of their loved-one. Caregiving responsibilities and degrees of participation will necessarily vary depending on the age, mental state and diagnosis of the patient, as well as the caregiver's skills, availability, personal health, resources and other circumstances.

Communication: All patients and carers have the right to establish regular and ongoing communications through clearly defined channels. Caregivers and family members have the right to communicate their observations and concerns to professionals and to receive information when the patient's medical stability and/or psychiatric safety is threatened or at risk.

Privacy: All patients and carers have a right to expect their health professionals to understand, communicate and respect the applicable privacy or age-of-consent regulations that govern the communication of health and treatment information, as well as the circumstances and conditions that may override privacy concerns or transfer authority regarding treatment decisions.

Support: All caregivers have a right to receive information, resources and support services to help them understand and carry out the expectations and responsibilities of their roles as partners in treatment.

NICE Eating Disorder Guidelines (selected paragraphs relevant to carers (2))

1.1.2. Ensure that all people with an eating disorder and their parents or carers (as appropriate) have equal access to treatments (including through self-referral) for eating disorders...

1.1.4. When assessing a person with a suspected eating disorder, find out what they and their family members or carers (as appropriate) know about eating disorders and address any misconceptions.

1.1.5 Offer people with an eating disorder and their family members or carers (as appropriate) education and information on:

The nature and risks of the eating disorder and how it is likely to affect them

The treatments available and their likely benefits and limitations.

1.1.6. When communicating with people with an eating disorder and their family members or carers (as appropriate):

Be sensitive when discussing a person's weight and appearance

Be aware that family members or carers may feel guilty and responsible for the eating disorder

Show empathy, compassion and respect

Provide information in a format suitable for them, and check they understand it.

1.1.7. Ensure that people with an eating disorder and their parents or carers (as appropriate) understand the purpose of any meetings and the reasons for sharing information about their care with others.

1.1.10. Be aware that the family members or carers of a person with an eating disorder may experience severe distress. Offer family members or carers assessments of their own needs as treatment progresses, including:

What impact the eating disorder has on them and their mental health

What support they need, including practical support and emergency plans if the person with the eating disorder is at high medical or psychiatric risk.

1.1.11. If appropriate, provide written information for family members or carers who do not attend assessment or treatment meetings with the person with an eating disorder.

1.1.7 When a person is admitted to inpatient care for medical stabilisation, specialist eating disorder or liaison psychiatry services should: ... keep the person's family members or carers involved.

1.1.8 Inpatient or day patient services should collaborate with other teams (including the community team) and the person's family members or carers (as appropriate), to help with treatment and transition.

1.1.11. Develop a care plan for each person with an eating disorder who is admitted to inpatient care. The care plan should: ... be developed in collaboration with the person, their family members or carers (as appropriate), and the community-based eating disorder service.

1.1.12. Whether or not the person is medically stable, within 1 month of admission review with them, their parents or carers (as appropriate) and the referring team, whether inpatient care should be continued or stepped down to a less intensive setting.

The Quality Network for Eating Disorders' Quality Standards for Adult Community Eating Disorder Services (carer engagement and support section (5))

13.1 Carers (where appropriate and with patient consent) are involved in discussions and decisions about the patient's care, treatment and discharge planning.

13.2 Carers are advised on how to access a statutory carers' assessment, provided by an appropriate agency.

Guidance: This advice is offered at the time of the patient's initial assessment, or at the first opportunity.

13.3 Carers are offered individual time with staff members to discuss concerns, family history and their own needs.

13.4 The team provides each carer with carer's information. Guidance: Information is provided verbally and in writing (e.g. carer's pack). This includes the names and contact details of key staff members in the team and who to contact in an emergency. It also includes information about confidentiality, and the parameters professionals have to work within, as well as local sources of advice and support such as local carers' groups, carers' workshops and relevant charities.

13.5 Staff understand carers have a right to access them for information and support even if the patient does not consent to confidential information to be shared.

13.6 Carers feel supported by staff members. Guidance: This could be through the provision/ sign-posting to carer support networks or groups. It could be through provision of a designated staff member dedicated to carer support.

Appendix: Useful resources

Below is a list of resources which services should find helpful in providing comprehensive and effective information to carers about an eating disorder.

Confidentiality is often cited as a barrier to why carers cannot be involved in their loved one's treatment (15,67). Although we recognise the importance of confidentiality and maintaining this trust between patient and clinician, confidentiality does not mean that healthcare providers cannot provide carers with general information on the illness, the risks associated with it, what treatment involves and advice on managing the eating disorder.

Websites

Beat: www.beateatingdisorders.org.uk

Beat's website information about eating disorders; blogs written by people who have an eating disorder, those who have recovered and carers; and a HelpFinder tool.

Beat's Support Services:

www.beateatingdisorders.org.uk/support-services

Beat also has multiple support services including a helpline which is open 365 days a year, online moderated support groups, and message boards.

CaredScotland: www.caredscotland.co.uk

Provides information for parents and carers of young people who have recently received a diagnosis of an eating disorder, through both text and videos.

Eva Musby: <https://anorexiafamily.com>

Provides practical and emotional support for parents supporting a child with an eating disorder, based upon Eva's own experiences of caring for a daughter with anorexia nervosa. Eva's book which provides practical support and advice for carers can also be found on her website.

F.E.A.S.T. (Families Empowered and Supporting Treatment of Eating Disorders): www.feast-ed.org

Provides information about eating disorders and support, for example, through their online forum - Around the Dinner Table.

MaleVoiced: www.malevoiced.com

Provides information and support specific to males with eating disorders.

NHS: www.nhs.uk/conditions/eating-disorders

Provides information on eating disorders.

Books and printed guidance for carers:

Services should refer carers to useful books (and where possible have a library of these for carers to borrow)

Beat Carers' Pack: This is in production and is intended to help services to empower carers to help them best support their loved one, minimise distress caused by the eating disorder, and to enhance the recovery process.

In loose leaf format, it will help services to tailor contents to the individual carer.

"Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method" by Janet Treasure, Gráinne Smith and Anna Crane
Provides skills and knowledge for carers – talks about trying to guide the carer to be like a dolphin swimming alongside the person, and gently encouraging them, rather than for example, being a rhino and being forceful in their behaviours.

"Help Your Teenager Beat an Eating Disorder, Second Edition" by James Lock and Daniel Le Grange
Presents evidence that parents often play a key role in their child's recovery, and offers practical advice and support around this.

"ED Says U Said: Eating Disorder Translator" by June Alexander and Cate Sangster
Describes the internal dialogue that people with eating disorders often experience, and provides interpretations for what the eating disorder may hear based upon what has been said to the person.

"Food Refusal and Avoidant Eating in Children, including those with Autism Spectrum Conditions: A Practical Guide for Parents and Professionals" by Gillian Harris and Elizabeth Shea
Provides support and understanding around Avoidant or Restrictive Food Intake Disorder (ARFID).

"ARFID Avoidant Restrictive Food Intake Disorder: A Guide for Parents and Carers" by Rachel Bryant-Waugh
Provides practical tips and strategies to help equip carers of someone with ARFID.

"Beating Your Eating Disorder: A Cognitive Behavioural Self-Help Guide for Adult Sufferers and their Carers" by Glen Waller, Victoria Mountford, Rachel Lawson, Emma Gray, Helen Cordery and Hendrik Hinrichsen

A self-help guide to help adults with anorexia nervosa and bulimia nervosa in their recovery, and teach skills to carers based upon cognitive behavioural therapy.

“Anorexia and other Eating Disorders: how to help your child eat well and be well: Practical solutions, compassionate communication tools and emotional support for parents of children and teenagers” by Eva Musby

Written by the mother of someone with anorexia nervosa, following their experiences of evidence-based treatment. Offers practical advice for managing mealtimes, information about helpful things/ unhelpful things to say, and advice on developing one’s own emotional resources.

“Survive FBT: Skills Manual for Parents Undertaking Family Based Treatment (FBT) for Child and Adolescent Anorexia Nervosa” by Maria Ganci

Provides practical advice to empower parents undertaking FBT with their child.

“Decoding Anorexia” by Carrie Arnold

Explains anorexia nervosa from a biological perspective, which can be helpful for carers who wish to know more about the science behind their loved one’s behaviours. These scientific descriptions are paired with personal narratives and examples.

“Overcoming Binge Eating, Second Edition: The Proven Program to Learn Why You Binge and How You Can Stop” by Christopher Fairburn

Presents information about binge eating disorder followed by an evidence-based self-help programme to help people to overcome their binge eating disorder.

Peer-to-peer support

Peer support is often requested by carers and can help them to feel less isolated. Peer support may be provided face to face, online or by telephone. Services should provide, commission and/or signpost carers to peer support options suited to their needs.

Beat’s ECHO Peer Coaching: A confidential telephone-based service for anyone caring for someone with an eating disorder, matching carers with Beat volunteers who have supported a loved one into recovery, for a scheduled weekly call for 6 months.

www.beateatingdisorders.org.uk/echo

Beat’s online support groups every evening for both sufferers and carers: www.beateatingdisorders.org.uk/support-services/online-groups

Beat’s HelpFinder tool lists locally-run face to face support groups: helpfinder.beateatingdisorders.org.uk

F.E.A.S.T (Families Empowered and Supporting Treatment of Eating Disorders) provides information and online support forums for carers of anyone with an eating disorder: www.feast-ed.org

MaleVoiceED provides support groups for males with eating disorders: www.malevoiced.com/peer-support

Guidance on joining or setting up a peer support group is provided by Mind: www.mind.org.uk/information-support/drugs-and-treatments/peer-support/running-a-peer-support-group

Skills training for carers

Services should provide, commission and/or signpost carers to learning opportunities suited to their needs. This may be in the form of workshops such as those listed here and/or via relevant books and other literature such as that listed above.

Developing Dolphins: Beat’s two-day workshop to help carers understand their loved one’s illness and help ensure that they are able to support their treatment and recovery. www.beateatingdisorders.org.uk/training-cpd/developing-dolphins

Coping with Christmas: Beat’s one-day workshop to help people caring for someone with an eating disorder cope with the particular challenges that come with Christmas. www.beateatingdisorders.org.uk/training-cpd/coping-with-christmas

Beat’s suite of training and support services for carers is being expanded. Please check www.beateatingdisorders.org.uk/training-events for updates.

Practical guidance for services

Managing transitions when the patient has an eating disorder: The Royal College of Psychiatrists’ guidance for good practice for transitions, for example from home to University and between CAMHS to adult services. www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2017-college-reports/managing-transitions-when-the-patient-has-an-eating-disorder-cr208-nov-2017

Developing peer support: a toolkit: A guide from Mind on setting up or commissioning peer support locally: www.mind.org.uk/media/17944275/peer-support-toolkit-final.pdf

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