



CEED

THE VICTORIAN
CENTRE OF EXCELLENCE
IN EATING DISORDERS

WORKING WITH FAMILIES AND SUPPORTS OF ADULTS WITH AN EATING DISORDER – April 2024

This document is designed for use by services and clinicians in planning and delivering services. It is intended to be read as an adjunct to the Office of Chief Psychiatrist Guidelines for Working with Families and Carers (<https://www2.health.vic.gov.au/about/key-staff/chiefpsychiatrist/chief-psychiatrist-guidelines/working-together-with-families-and-carers>). It assumes services and clinicians are working in concurrence with these broader guidelines for mental health. Developed by the Victorian Centre of Excellence in Eating Disorders 2019



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The Specific Nature of Eating Disorders

- The ego syntonic nature of Anorexia Nervosa can make the person with the illness very attached to their illness and lacking in motivation to recover.
- The behaviours one has to interrupt and that cause intense fear are linked to behaviours one has to do several times a day every day in order to recover. These can be hard to commit to using internal motivation, even if present.
- If one is allowed to starve or continue to engage in ED behaviours, serious medical, psychological and social consequences.
- Bulimia Nervosa and Binge Eating Disorder may also benefit from behavioural interruption at times of urges and structured support around them.

Why Involve Family/Supports and Who?

Parents and partners are obvious close others to involve in eating disorder treatment and are discussed in more detail below, however support can come from a range of people in different configurations e.g., friends, siblings, extended relatives and more. The criterion for involvement is that they are willing and able to provide a negotiated form of appropriate support.

Rationale for Parent/Sibling Involvement

- Many young adults are still well integrated in the family system and/or this could be an option for increased support e.g., return home from university. Many young adults are still financially dependent on their families and families are still highly invested and/or feel a strong sense of responsibility for their wellbeing.
- Notwithstanding age and living circumstances, many families remain involved with their person with an ED for much of the lifespan. Reduced working capacity, anxiety, challenges in managing key life stressors and impaired health can make the person with an ED very dependent on family members.
- “The rationale for parental involvement in adolescent AN is intended to address the motivational deficits inherent in AN and the unique ego-syntonic nature of this illness. Likewise, motivational deficits and ego-syntonicity are issues in adult AN and may be improved by the enlistment of carers to manage and oversee initiation and maintenance of recovery-oriented behaviours in a modified, age-appropriate manner” (Knatz S, 2015).
- Parents are often very committed and ideally placed to play an active caring role.
- The care required could be likened to other ‘hospital in the home’ models where the carer is trained and supported to provide similar care to hospital, allowing the patient to reengage with normal life as much as possible

Rationale for Partners Involvement

Partners are frequently left out of treatment models despite the following:

“Not including partners in treatment perpetuates a culture of secrecy and maintains “no talk zones” around many aspects of the eating disorder. In many ways, allowing this secrecy to continue colludes in maintaining the disorder. In developing and piloting the UCAN trial, it became clear how poorly informed partners were about the illness. Many believed their loved ones were choosing to starve and failed to appreciate the underlying biological aspects of the illness. Most partners had preconceived expectations that recovery would be linear and had great difficulty appreciating, but also great relief when they learned, that recovery from AN was anything but a linear process. AN effectively mutes partners. Their deep concern is often trampled by the force with which the illness pummelled or scared them into silence. Partners clearly appreciated the gravity of the illness and feared for the patients’ lives, but they were often cornered into positions of learned helplessness, unable to find strategies or approaches that could “get through” to their loved one” (Bulik CM B. D., 2012)

“Stereotypes of individuals with AN not entering committed relationships and not having children have proven untrue. To the contrary, a substantial proportion of people presenting for treatment for AN report being in committed relationships. Not only are adults with AN frequently in relationships, but patients emphasize the centrality of their partners in the recovery process. For example, in a follow-up study of 70 women who had been treated for AN 10 years earlier, we explored the women’s perceptions of factors contributing to their recovery. The most commonly cited factor associated with recovery was having a supportive partner. In fact, women with AN reported that a supportive relationship was the “driving force” in their recovery.” (Bulik CM B. D., 2011)

Children of Parent with an Eating Disorder

While we cannot point to specific research in eating disorders, we can see children of parents with an eating disorder stepping in to support the parent via food shopping, preparing food etc. AND children are significantly impacted by living with someone with an eating disorder. Hence it is critical to include children of parents with an eating disorder in treatment planning and provide them with information in an age – appropriate way.

Family/Support Network Member Distress

Impact on Family/Support Network Member

- Research shows that carer anxiety, depression and stress levels are all very elevated in ED caring role, to the extent that it exceeds levels found in any other mental illness. (Zabala, 2009)
- Carers with their own eating difficulties are a high risk group for anxiety and depression and for accommodating and enabling behaviours and may benefit from specific individual work. (Goddard, Whitehead, L. , Schmidt, U. , & Treasure, J. , 2013)
- Carers experience these effects proportionately to the acuity and duration of the illness
- Researchers recommend routine mental health assessment for the carers.

Impact on Person with the Illness

“The prediction derived from the data presented is that a reduction in carer distress will lead to reduction in patients' distress and, subsequently, ED psychopathology. This remains to be tested but recent evidence suggests that interventions based on the interpersonal maintenance model can reduce carers' distress. Patient age did not contribute markedly to carer behaviours but was positively correlated with carer distress. Family interventions are recommended for adolescents with AN but the current data suggests family involvement in treatment could be considered across the age range, given interpersonal maintaining factors. Indeed, the importance of the social context in adults is emphasized in the ongoing development of a couple-based intervention for AN“(Goddard, Whitehead, L. , Schmidt, U. , & Treasure, J. , 2013).

Challenges

Confidentiality

“One frequently cited barrier to carer involvement in care planning is the right of the service user to confidentiality, which can prevent information being shared with carers by services. From a health professional perspective, some of the difficulties about confidentiality and information sharing are ethical and legal obligations, with a breach of confidence potentially resulting in disciplinary measures and legal proceedings. Barriers erected because of perceived rather than actual confidentiality issues can limit participation and dialogue between carers, the people that they care for, and professionals. It is believed that professionals are not always confident in where the limits of confidentiality lie, and that further training relating to specific legal requirements may be beneficial.” (Cree L, 2015).

The Office of Chief Psychiatrist Working with Families Guidelines have very clear guidelines around confidentiality and the importance of revisiting a client's refusal to share are different points in the treatment. Getting agreements between the clinicians and client about what can or cannot be shared can be useful. IN addition there are clear situations where clinicians and services are required to provide information to carers e.g. treatment order changes etc

Challenging Interpersonal Interaction Within Family

There are a range of interpersonal patterns that can result when a family member has an eating disorder. Shared traits such as anxiety, compulsivity and abnormal eating behaviours contribute to some of the misperceptions, misunderstandings and confusion about the meaning of the eating disorder for family members. Unhelpful attributions can fuel a variety of emotional reactions (criticism, hostility, overprotection, guilt and shame). Gradually the eating disorder may cause family members to accommodate to the illness or be drawn in to enable some of the core symptoms.

For people who have had longstanding eating disorders, families can have ‘lost patience’ or been burnt out with the interpersonal interactions. It is an illness which severely impacts a range of usual family social connection activities e.g., family meals become very stressful, birthday/festive season celebrations,

gatherings with friends and family. The person with the illness may express their anxiety in ways which are hurtful and destructive to family relationships. All of these combines to contribute to conflictual relationships and may need to be considered or supported when working with supports.

Enlistment of Supports to Support Initiation and Maintenance of Recovery Oriented Behaviours in a Modified, Age-Appropriate Manner

Assessment and Treatment Planning

- Family and supports know the history of the person with the ED, what they were like pre-ED, what might work as motivators or deterrents, and all of this information can be critical in developing a treatment plan that will work for that person. This is especially critical when the eating disorder is presenting with a significant lack of insight.
- Clinicians can also negotiate with family/supports what resources they have to bring to the table e.g., meal support, food preparation, transport, financial, distraction, calming of anxiety, emotion coaching, CBT skill reminders, extended family members/friends etc.

Meal Support

- Meal support can be a crucial knowledge and skill set required by families/supports.
- Negotiation of roles of different family/support network team members is needed around the following:
 - menu planning,
 - food purchasing,
 - food preparation,
 - at the table meal support coaching,
 - post meal distress support.
- Families need skills in at the table meal support coaching in terms of what to say or not say to support recovery-oriented eating
- Families may need information and support on the increased and often significant nutritional requirements of someone in recovery from an eating disorder

Interuption of or Distraction from Other ED Behaviours

- Negotiation of roles may be required of different family/support network team members re supporting cessation/minimisation of exercise, purging, laxative abuse etc.
- Distraction strategies for supporting someone to resist urges is helpful
- If a younger adult, families may be able to use leverage in terms of redirecting unhelpful behaviours e.g. not pay for gym memberships, restrict access to phones/internet if using pro-ana/fitspiration/fitbits etc.

Behavioural Contracts/Agreed Actions Plans

Where age or relationship appropriate, negotiating behavioural contracts or plans of actions for when certain circumstances arise can really assist and clarify the way forward for families/supports and the person with the ED. Things to think about including are what to do around:

- Meal plan/support
- Behaviour interruption
- Increase in distress e.g. distractions, when to bring in external resources
- Being unable to complete meals e.g. have plan a, b and c for meal non-completion
- Non-adherence to treatment goals
- Engagement in psychotherapy
- Medical monitoring

Emotion Coaching/Communication Strategies

Enhancing family/support network team member skills in effective communication/emotion coaching with the person with the eating disorder will reduce friction in the home and encourage constructive supportive relationships. Strategies to consider include:

- Workshops such as the Collaborative Care Skills Workshops
- Books such as Janet Treasure's "Skills Based Learning for Caring for a Loved One with an Eating Disorder"
- DBT skills for families, similar to those taught to carers of Borderline Personality Disorders e.g. Family Connections, one on one DBT work
- Emotion Focussed Family Therapy resources and scripts e.g. Boundary Setting
- Support family/support network team members to set age appropriate and supportive boundaries which enable recovery for the person with ED and protect them. For younger adults, it can be appropriate for families to make provision of certain privileges dependent on certain behaviours e.g. access to family car available if engaging in treatment, adhering to meal plan etc. For older adults, some non-negotiables may be attendance at family gatherings requires eating 'normally'. Supports should be encouraged to outline and execute all boundaries and non-negotiables in a non-judgemental and kind manner.
- It is important to support families to set clear boundaries around inappropriate use of violence and verbal abuse when person with ED is in high distress, by having a clear plan to manage this with appropriate back up with emergency services.

Support of the Families/Supports

- Ideally, in treatment plan, include plans for ensuring ongoing resilience and mental health of the family/support network team members, including respite if needed, to reduce burnout and make them available as carers for the full duration of the illness.

- Ensure online and face to face peer support options accessible e.g. www.aroundthedinertable.org , Closed Facebook groups (ATDTfb and Melbourne Eating Disorders Parent Support Group) and face to face groups run by Eating Disorders Victoria or Eating Disorders Families Australia.
- Encourage mental health assessment for family/support network members and facilitation of access to own psychological support.
- Grief and trauma support may be needed, especially when unable to be closely involved in care of the person with the ED because being held at bay.

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