



REDC TRAJECTORY OF ED DRAFT

Eating Disorders are serious medical and psychological illnesses that can severely impact individuals' immediate and longterm health and their quality of life. The treatment of EDs has to address a wide range of complicated factors including heritable and temperamental factors, co-occurring psychiatric disorders, the effects of malnutrition, and disruptions in social and family connections.

Individuals with EDs and their families often confronted with confusing and contradictory information about the complexity of these disorders. This document is an effort to provide a realistic overview of the full trajectory of what patients and their families can expect as they begin treatment. We believe that a detailed understanding of this complexity of treatment and the recovery process clients and families evaluate treatment recommendations, manage expectations, and to establish clear markers for both short term and longer term recovery.

Eating Disorders are Treatable Illnesses

ED are treatable illnesses and most people who can access specialist treatment can and will recover. There is ample evidence that early intervention and treatment of ED increases the likelihood of full and lasting recovery.

Treatment Should Be Based on a Full Conceptualization of the Eating Disorder

Weight restoration for patients with AN and the resolution of eating disorder behaviors such as binge eating, purging, overexercise and laxative abuse are essential for establishing a foundation for full and lasting recovery. Many people with ED will require treatment that addresses a multitude of other contributory factors, both those that preceded the development of the ED and those that may influence the process of treatment and recovery. These may include co-occurring medical and psychiatric illnesses that often accompany an ED such as depression, anxiety, substance abuse disorder and PTSD.

Distinguishing Relapse from Remission and Recovery

Recovery from ED requires a cessation of eating disorder behaviors such as dietary restriction, purging, overexercise, and binge eating. But the elimination of these behaviors is not a sufficient marker of full recovery. The difference between behavioral remission and stable recovery can be difficult to define. While the majority of the medical and psychiatric symptoms of EDs improve dramatically with the re-establishment of nutritional stability, the risk for relapse can persist. It is essential for families and for people with EDs to recognize the importance of assessing and managing these post-remission risks. Physiological and psychological stability, do not re-activate at the moment of behavioral remission and full and stable recovery may take months and even years. Research on the treatment of ED indicates that while some people, particularly younger adolescents, will fully recover once they have normalized their eating and attained a healthy body weight, there is accumulating evidence that suggests that pre-



existing factors such as anxiety, perfectionism, depression, obsessionality, and emotional and behavioral impulsivity need to be fully addressed to establish a stable platform for a lasting recovery. Many people with EDs are always coping with co-occurring diagnoses such as substance abuse disorder and PTSD. People with ED, and their families, sometimes struggle to come to terms with the complexity of these different factors and with the reality that some of them will continue to constitute risks for relapse as people move through the phases of interim or partial recovery. Developing a personalized and detailed awareness of the way in which these factors contribute to the risk for relapse from the ED is key component of an individual's, and the family's, recovery.

Most people with ED who are able to access treatment can and will fully recover. Some, however, do not and may live their lives hampered by their illness. Some, unfortunately, will die from their ED. Yet, many people can recover even after long histories and after multiple treatment experiences. It is difficult to predict who will and who won't recover so it is essential to provide treatment opportunities to everyone with an expectation that recovery is possible.

A Full Continuum of Care and Recovery

A substantial number of people with ED will require multiple courses of treatment before they can establish a stable and enduring recovery path. The continuum of care model is stepped model of therapeutic support that ranges from 24 hour/7 day per week inpatient and residential care to partial hospital programs that provide full day therapeutic programming while people live at home. Intensive Outpatient Programs provide 3-4 hours of programming for several days per week so that people can begin to re-engage with their work and school commitments. The premise for the level of care continuum is that recovery must be built in small steps and that people can recover as they establish or re-establish a life without the ED. It is critical for people with ED, and for their families, to understand this step-by-step process. These steps take time and there are often slips and missteps along the way that require perspective and patience in order to remain committed and optimistic about the chance for full recovery.

Family Support is Critical

One of the factors that is most predictive of full recovery is ongoing social support. The experience of having an ED, and the experience of caring for and supporting someone with an ED, is often exhausting and frightening. Recognizing that everyone, the individual with the ED and all those that care for her or him, are all affected is essential for securing and maintaining essential relationships. Families, spouses, partners and friends all have an active role to play in supporting recovery. Their willingness to educate themselves about EDs and to examine and explore how they can best engage with the person they are supporting can create an environment that promotes full recovery.

What Patients and Families Should Expect from Treatment

- Treatment programming should be based on clinical standards that are derived from research evidence, clinical judgment, patient preferences and patient values. This is the accepted and



established definition of evidence based practice. Programs should provide clear and accessible explanations of their adherence to these standards to anyone seeking care.

- You should expect treatment that is inclusive and collaborative. Families are essential treatment partners and families should be presented with clear plans on how they can best support their loved one's treatment and recovery.
- You and your loved one should receive a full and comprehensive assessment of the full range of factors influencing the ED. These include medical, psychiatric, relational, and developmental factors. These factors may include
 - Nutritional Status
 - Medical Status
 - Mood
 - Anxiety
 - Trauma
 - Substance Abuse Disorder
 - Beliefs about the ED that affect motivation and commitment to recovery
 - Temperamental and Trait based dimensions that can affect recovery
 - Family Needs and Support
- The program or team should present you with a full and detailed formulation of the ways in which these factors are uniquely affecting the individual and the family and should present with you with a specific plan for addressing each of them.
- While treatment and recovery may take an extended period of time, families and the individual with the ED should be able to see small and measurable changes in the physical, psychological features of the ED within a short period of time. Treatment providers should work with you to define how to measure treatment progress. Families and individuals should receive descriptions of clear strategies for measurable changes in the ED symptoms within the initial days and weeks of treatment.
- There should also be a clear plan for addressing the full range of the other maintaining factors identified in the comprehensive assessment and formulation.