

A person is standing in a narrow, brightly lit doorway in a dark room. The light from the doorway illuminates the person and the surrounding walls, creating a strong contrast with the deep shadows of the rest of the room. The person is silhouetted against the light, and their presence adds a sense of scale and human connection to the abstract space.

Understanding
starts here

2nd Edition 2018

NIED
NATIONAL INITIATIVE FOR
EATING DISORDERS



A message from our President - Wendy Preskow

A huge special ***Thank You*** to my NIED team: Without your valuable input, expertise, support and dedication, NIED would not be where we are today. Thank you to our creative team for generously donating time and talents to produce this booklet and our monthly flyers.

We hope this booklet will offer you a better understanding of the bizarre and unforgiving world of Eating Disorders. Our free symposia continue to bring so many families, caregivers and friends together – please come in person, or join our livestream, and learn more whenever you can. Please continue to share NIED information and news with your contacts. You could be saving someone's life. Thank you for your support and for the love you share with your loved ones.

We would like to introduce you to NIED – the National Initiative for Eating Disorders

NIED is the voice for Canadian families, caregivers and individuals who have been affected by Eating Disorders and other co-morbid and concurrent diagnoses.

We help caregivers, patients and health care providers fill gaps in care through education and by highlighting better practices in prevention, health promotion and treatment.

NIED is working with stakeholders across the country to address the gaps in current services, delays in treatment, lack of pan-Canadian data and insufficient training for clinicians and healthcare professionals.

Eating Disorders are serious mental illnesses associated with significant medical complications that affect every organ of the body.

Eating Disorders are not a choice and affect all genders, ages, racial and ethnic identities, sexual orientations and socio-economic backgrounds.

Eating Disorders are misunderstood, inadequately treated, under-funded, devastating to deal with and the deadliest of all mental illnesses.

Eating Disorder Recovery



1. The Nature of Eating Disorders: Eating Disorders are NOT a lifestyle choice. They are serious mental and behavioral disorders, the causes of which are complex. Because of the way that imbalances in weight and food impact the brain, the person living with the Eating Disorder does not think or behave rationally with regards to food. Research suggests that the brains of those with EDs have pre-disposed sensitivities, and then with disordered eating we see further brain changes which lead to a worsening of the obsession and constant preoccupation with food and body. There can be an inherent disinterest in motivation to change due to the biologically-based reduced energy & mood states as well as more rigid thinking commonly associated with Eating Disorders. The positive reinforcement that can come from the way disordered eating reduces or regulates emotions can be a more powerful motivator than is gained from more normalized eating. Also, there can be a lack of awareness and/or outright denial about the illness or seriousness of the illness because the individual is afraid.

2. Lethality. Eating Disorders are 12 times more likely to lead to death than any other mental illness. They are the most lethal and complex of all mental health disorders.

3. The Nature of the Treatment Process. Motivation to change comes in waves, and behavioral changes can happen like a game of snakes and ladders, such that Recovery is typically not a straight line. It is marked by periods of growth and positivity. Periods vacillate with periods of no change or slips with symptoms. Food is medicine but can also be the greatest source of fear. This makes it particularly challenging to treat Eating Disorders, which is why building a knowledgeable team consisting of professionals from

different disciplines is important. At the centre of the team is the individual and their family, with support from professionals who can assist with medical monitoring, nutritional counselling as well as mental health treatment. The process of recovery is different for everyone. Many require intensive, longer courses of treatment, and others can find great success early on. The type of treatment received will vary depending on the individual's specific needs. It is best if Eating Disorders can be treated within three years after onset.

4. Nature of Eating Disorder Recovery. Recovery often involves learning and living by information and practices that go against what society teaches us about eating and weight. It involves taking risks and facing one's fears and gaining the courage to be unique and different in a way that does not have to involve focusing on body shape and size (and therefore pain). It can involve a lot of anxiety and distress. Many living with Eating Disorders experience feelings of shame and isolation. The only way to overcome this disconnection from self and others is to encourage individuals to talk about their experiences and seek help from family, friends and professionals.

5. Standing Firm on Recovery. Full recovery ensures lasting recovery. The body's genetically "set-point" range is not necessarily where one's "ideal" weight is, and so the goal is working towards acceptance of this (just as we have to accept our set height and shoe size!). The goal is to focus on lifestyle and overall wellbeing rather than on weight. The alternative is staying stuck in a lifelong battle with our body's natural instincts. Achieving recovery most often requires treatment intervention, which involves both weight restoration and a focus on psychological wellbeing. Deciding to "recover" isn't enough to achieve recovery from an Eating Disorder and this belief can reinforce the myth that Eating Disorders are a choice.

6. The Integrative Nature of the Disease. Eating Disorders affect physiological, biological, behavioural, emotional, cognitive and social functioning, which require substantive therapeutic collaboration. The person living with the illness, alongside their family and other supports in their network, should be considered central stakeholders in the treatment.

7. Eating Disorders are Relational/Attachment Disorders. Eating Disorders require a strong healing connection within the therapeutic relationship and within families. Through psychotherapy, "external" developmental and therapeutic attachment experiences are transformed into "internal" regulatory capacities.

Approaching an Adult Living with an Eating Disorder



The first step in approaching an adult living with an Eating Disorder is to educate yourself. Eating Disorders are often misunderstood. It is helpful to have some knowledge of Eating Disorders prior to approaching someone. This will help ensure that some of the common myths and misinterpretations are not projected on the individual living with the Eating Disorder. It can also be helpful to understand the theory behind the stages of change and to know that people can move between these different stages, across different subjects, in a non-linear way.

The Stages of Change are:

PRE-CONTEMPLATION	Not yet acknowledging that there is a problem behaviour that needs to be changed
CONTEMPLATION	Acknowledging that there is a problem but not yet ready or sure of wanting to make a change
PREPARATION/ DETERMINATION	Getting ready to change
ACTION	Changing behaviour
MAINTENANCE	Maintaining the behaviour change
RELAPSE	Returning to older behaviours and abandoning the new changes

Being aware of these different stages of readiness to change may alter your approach and help you understand where the individuals living with an Eating Disorder are at. This is key to sustaining motivation to change when the individual is ready.

When you feel it is the right time to bring up the topic with someone you care about, the following are good tips to take into account:

- Avoid talking about food and weight; those are not the real issues. Their eating symptoms are coping strategies to deal with fears of being inadequate and feeling out of control in their lives. These are the issues for which they need non-judgmental support in order to be able to move toward recovery.
- Assure them that they are not alone and that you love them and want to help in any way that you can.
- Encourage them to seek help. Provide them with some resources to help them take that first step (NIED is a good starting point).
- Never try to take a forceful role around eating if you have not been asked to assist in this way.
- Do not comment on their weight or appearance.
- Do not blame them or get angry with them.
- **Be patient. Recovery is hard work and can take a long time.**
- Do not make mealtimes a battleground.
- Listen to them; validate their feelings even if you do not understand them.
- Do not be quick to give opinions and advice.
- Do not take on the role of a therapist – encourage them to get professional help.

It is important to remember that when you first approach the person you suspect has an Eating Disorder, they may react with anger or they may deny that anything is wrong. Do not push the issue; just let them know that you will always be there for them if they want to talk. This step may have to take place several times before the individual with an Eating Disorder is able to open up.

Watching someone you care about suffer is very frightening. You may experience feelings of distress, anger, guilt and/or confusion. No matter how much you want to help, you must remember that you cannot force someone to seek help.

Tips for Parents, Families, Spouses & Significant Others



A person in recovery from an Eating Disorder needs encouragement; they do not need to be made to feel worse. Recovery is hard work. It can take a long time and is not always “linear” in nature. There will be many periods of growth combined with plateaus and steps backwards. Individuals with Eating Disorders often refuse life-saving treatment and it seems like they are simply being stubborn. Unfortunately, this seemingly willful character is the nature of their illness and the biological impact of semi-starvation or starvation.

Someone living with an Eating Disorder has the best chance for recovery when they are surrounded by people who are loving and supportive. This is why it is very important for families to get support for themselves. In order to care for and support someone living with an Eating Disorder, it’s important for you to take care of yourself. This might include seeking guidance and emotional support from a therapist or a support group.

In addition to the tips listed above, parents/spouses/families/significant others can:

- 1. Be aware of your own issues with food, exercise, and body.** There are many myths out there with regards to dieting and body wellness. Your biases can affect the extent to which someone can recover from an Eating Disorder. Being a part of the therapy process and learning from professionals who are trained in Eating Disorders can help build a consistent and healthy perspective for all.
- 2. Recognize that love based on weight, food, or eating leads the individual to feel manipulated and controlled.** Unconditional positive regard and love for this person who is living with an Eating Disorder means genuinely caring for them and their survival. Focusing on the reasons why you love them, as a person, is key to recovery.

3. Become a team with them against the Eating Disorder. The Eating Disorder is like a nasty voice that continually criticizes and punishes them for everything. Help them feel safe in the recovery process by working towards the same goal of being healthy and not listening to that irrational voice. They may need help getting away from the ED thoughts – have conversations that are also outside of the Eating Disorder so that other topics and activities can take the focus off when that “voice” gets loud.

4. Being a team against the Eating Disorder means that it is important to notice if there is anything you are doing to enable the Eating Disorder to stick around. It is ok to have and set firm limits around topics that promote recovery and help restore a healthy balance to the home – particularly if these are part of the therapy goals that have been set. Since the individual is at risk of hearing the voice of the Eating Disorder as their own, it is important to separate them as much as possible remembering that this is an illness. It is also important to be on the same page as other key support people (e.g., other caregivers or health care providers).

5. Remember that the individual with an Eating Disorder is doing the best they can. They are in pain which can reinforce their use of symptoms including telling lies or having secrets (e.g., about what they are eating). Do not engage in power struggles about food if that is not the role you have taken in their recovery journey. Low self-worth can lead to shame which can drive the individual to feel badly about themselves. A little compassion can go a long way – both for yourself and the individual you are supporting.

For Individuals Living with an Eating Disorder...

- Recovery IS possible
- You don't need to do this on your own
- You are not your body, emotions, thoughts, and behaviours. You can learn how to relate to them so you don't have to escape them
- Getting help takes courage, and you need a lot of support – take one step at a time
- Keep searching for treatment providers who understand the illness and are a good fit for you or your child or loved one
- Treatment is the biggest gift you can give yourself AND you deserve to be well.

Eating Disorders Information, Resources and Support



The following organizations have comprehensive Eating Disorders information to share, including up-to-date databases on Treatment Centres, Support Groups and individual Therapists, Nutritionists and Registered Dietitians.

National:

National Eating Disorders Information Centre (NEDIC)

National information, resources and links.

www.nedic.ca

1-866-NEDIC-20 (1-866-633-4220)

Toronto: 416-340-4156

Ontario:

ConnexOntario

Health Services Information. Provides free and confidential health services for people experiencing problems with mental health, gambling, alcohol or drugs.

www.connexontario.ca

1-866-531-2600 (Mental Health Helpline)

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