

Understanding  
starts here



**NIED**  
NATIONAL INITIATIVE FOR  
EATING DISORDERS



## **A message from our founder - Wendy Preskow**

A huge special ***Thank You*** to my NIED team: Patti Perry, Lynne Koss, Dr. Heather Wheeler, Carly Crawford, Lauren Jawno, Marlene Sachs and Alex Franceschini. Without your input, expertise, support and dedication, NIED would not be where we are today. Thank you also to Richard Ponsonby for generously donating his time and creative talents to produce this booklet and our monthly flyers. To Lowell Brown for creating and hosting our website. And last but not least my husband Len, for always being on the same page as me.

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 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 a not-for-profit coalition of dedicated health care professionals, counsellors and parents with children suffering from Eating Disorders. Since our founding in February of 2012, we have become the collective voice promoting education, collaborating with community groups, doctors, nutritionists, psychologists, schools, social workers, the courts, agencies and like-minded organizations to increase awareness and create positive change.

Our mission is to increase awareness and education of the chronic situation facing Eating Disorder sufferers and their families in Canada.

Eating Disorders are misunderstood, inadequately treated, underfunded, 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 biologically-based chronic mental illnesses. Because of the way that imbalances in weight and food impact the brain, the person struggling does not think or behave rationally with regard to food. Research suggests that the brains of those with EDs have predisposed 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. Due to the biologically-based reduced energy and mood and more rigid thinking, there is an inherent lack of motivation to change in Eating Disorders. The positive reinforcement that comes from the way disordered eating reduces or regulates emotions is a more powerful motivator than is normalized eating. Also, there is most often denial 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, like snakes and ladders, such that periods of growth and positivity vacillate with periods of no change or slips in eating. Food is medicine but food is the greatest source of fear. This makes it particularly challenging to treat Eating Disorders. The nature of treatment is different for everyone yet many require intensive, long-term, and multiple forms of treatment. It is best if Eating Disorders can be treated within the first year of onset.

#### **4. Nature of Eating Disorder Recovery**

Recovery involves learning evidence-based information that goes against what society teaches about eating and weight, 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 thinness (and therefore pain). It involves a lot of anxiety and distress, including physiologically. There is a lot of shame and withdrawing from others as part of the illness. The only way to overcome this is to encourage talking and sharing one's struggle with others and asking for help.

#### **5. Standing Firm on Recovery**

Full recovery ensures lasting recovery. Where there is less than 100% weight restoration to the body's set point weight range, sustainable recovery is difficult to maintain. The body's genetically set point range is not 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 controlling lifestyle rather than weight. The alternative is staying stuck in a life-long battle with our body's natural instincts. Also, just deciding to "recover" isn't enough to recover from an Eating Disorder and can reinforce the myth that Eating Disorders are a choice. Recovery most often requires treatment intervention.

#### **6. The Integrative Nature of the Disease**

Eating Disorders affect physiological, biological, behavioural, emotional, cognitive and social functioning, which require substantive therapeutic collaboration between professionals, parents, and families. Treatment requires a team approach combining medical, nutritional, psychological, and psychiatric professionals.

#### **7. Eating Disorders are Relational/Attachment Disorders**

Eating Disorders require a strong healing connection within the therapeutic relationship. Through psychotherapy, "external" developmental and therapeutic attachment experiences are transformed into "internal" regulatory capacities. This takes a long time.

# Approaching Someone With An Eating Disorder



The first step in approaching someone with an Eating Disorder is educating yourself. Eating Disorders are often misunderstood and it is important to have a knowledge base prior to approaching someone to ensure that some of the common myths and misinterpretations are not transferred to the sufferer. Secondly, it is also imperative that you understand the theory behind stages of change. Your concern will be interpreted very differently based on where the sufferer fits on the stages of change scale, and the concern and ability to use that concern in a productive way will change.

## The Stages of Change are:

<b>PRE-CONTEMPLATION</b>	Not yet acknowledging that there is a problem behaviour that needs to be changed
<b>CONTEMPLATION</b>	Acknowledging that there is a problem but not yet ready or sure of wanting to make a change
<b>PREPARATION/ DETERMINATION</b>	Getting ready to change
<b>ACTION</b>	Changing behaviour
<b>MAINTENANCE</b>	Maintaining the behaviour change
<b>RELAPSE</b>	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 they are at, which is key to sustaining motivation to change when they are 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 maladaptive attempts to deal with fears of being inadequate and out of control in their lives. These are the issues for which they need non-judgmental support in order to overcome.
- 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 force them to eat.
- Do not comment on their weight or appearance.
- Do not blame the individual and do not get angry with them.
- Be patient. Recovery takes a long time (average 6 years) and hard work.
- 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 need to talk. This step may have to take place several times before the sufferer is willing to see your side of things.

Watching someone you care about suffer is very frightening. You will probably experience feelings of distress, anger, guilt and confusion. No matter how much you want to help them, you must remember that only they can make the decision to get help. You cannot force them to do this.

## For sufferers...

- Recovery IS possible
- There is a life worth living waiting for you without this Eating Disorder
- 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 a therapist who is a good fit for you
- Treatment it is the biggest gift you can give yourself AND you deserve it even if at times you might not believe that

# 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 takes a long time and hard work, and is not “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 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. Supporting someone with an Eating Disorder is very hard work and it can be confusing, frustrating and emotionally exhausting. In order to best care for the sufferer, it's important for you to also care for yourself, including 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 regard to dieting and body wellness. Your biases will affect the extent to which someone can get better. 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 suffering means genuinely caring for

them and their survival. Focusing on the reasons why you love them, as a person and spirit, is key to successful recovery.

- 3. Become a team with them against the Eating Disorder.** This 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. Remind them you will not trick them into treatment and that by recommending treatment you (and the professionals helping them) have no interest in making them "fat".
- 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.** Having and setting firm limits (e.g., how much money they can have each week so they don't keep overspending on binge food). It is also important to be consistent with house rules and things you are doing in your life. Life should not change because the Eating Disorder says so ~ this simply gives it power. We want to pose obstacles for the Eating Disorder to grow, but not for the person. Because the individual will often merge who they are with the Eating Disorder voice, it is important to separate them as much as possible. It is also important to be on the same page as other key support people (e.g., husband and wife).
- 5. Remember that the individual with an Eating Disorder is doing the best they can.** They are suffering and this is why sometimes they engage in irrational behavior and tell lies or have secrets (e.g., about what they are eating). Do not engage in power struggles about food. It is because they feel badly about themselves that they engage in behaviours that are consistent with their negative view of themselves. They are not trying to manipulate you. Your job is to recognize and validate the struggle beneath the behavior, including anxiety, shame, anger, and sadness so that they don't feel they have to hide or get rid of those feelings.

# 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](http://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](http://www.connexontario.ca)

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

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- Getting help takes courage, and you need a lot of support – take one step at a time
- Keep searching for a therapist who is a good fit for you
- Treatment it is the biggest gift you can give yourself AND you deserve it even if at times you might not believe that



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