

Wendy Preskow: Educating about eating disorders

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Of all the mental illnesses, the medical world recognizes eating disorders as the most deadly. Yet in our society, eating disorders are largely misunderstood. Wendy Preskow is the voice for Canadian families, caregivers and individuals who have been affected by eating disorders. Preskow spoke to *The CJN* about the National Initiative For Eating Disorders (NIED), the organization that she co-founded in 2012.

What was the impetus for creating the National Initiative For Eating Disorders?

I have a sick daughter, Amy, who has been suffering for two decades from anorexia and bulimia. Imagine someone with a chronological age of 34 with incredible potential, but with a seven year old's lack of social and emotional independence and the osteoporosis of a senior. In high school, Amy would ask herself, "Who am I?" There was never abuse or trauma. She was never an overweight child. But she always felt she was never enough.

We found there were a lack of resources and an incredible lack of awareness and understanding that an eating disorder is a mental illness. What we came to realize was how many thousands and thousands of other families there are across the country in the same or worse situations than us. I could not just sit back. I had to take action.

For the very first time in the eating disorders landscape in Canada, NIED was the catalyst to bring multiple stakeholders together in Winnipeg in September 2016. Four Canadian national organizations united to formulate a national eating disorder strategy, which will include six pillars: treatment, training, education, prevention, caregivers and research. This strategy will be launched later this year.

An estimated one million Canadians are struggling with eating disorders. Please explain what an eating disorder is.

There are different types of eating disorders and the most common disorders that people hear about are: anorexia nervosa (starving); bulimia (binging and purging); and binge eating (constant eating). From our daughter's perspective, anorexia is all about control. Something in her life that she found she could have control over was food. Food is actually a symptom of the disease. All of these disorders are deep psychological and psychiatric illness, in which the food is a symptom of the disease. It manifests in what they do with food – whether they starve, or whether they binge. The binging and the purging is more about wanting to numb the emotions because they get a high from the purging. It's been said that it's the same kind of high that somebody would get using cocaine.

Who is at risk of developing an eating disorder?

Anybody can be at risk. The doctors say that 80 per cent is genetics, which loads the gun, and 20 per cent is the environment, which pulls the trigger. If you are predisposed, you can end up being a drug addict or abusing alcohol, or end up with an eating disorder. As Jews, we take care of others who are struggling and cannot help themselves, and who certainly do not choose to live this way.

Statistics indicate that one in 10 people suffering from an eating disorder will die. What are the health consequences of an eating disorder?

Eating disorders are serious mental illnesses associated with significant medical complications that affect every organ of the body. My daughter has osteoporosis in her spine, because of the starving and lack



Wendy Preskow LEN PRESKOW PHOTO

of nutrition. Amy's iron levels, growth, menstrual cycles and electrolytes are out of balance. There have been frequent visits to the emergency room for fainting.

What is the treatment for eating disorders?

If people are medically unstable, they need to be hospitalized. Once they are medically stable, there are different methods therapists will use, such as dialectical behavioural therapy and family based therapy. There are only 20 residential beds in all of Ontario for anyone over the age of 18. There is no funded residential treatment centres for adults like there are in the United States, the U.K. and Australia. The goal is to nourish the person so the brain can start functioning again, but it becomes a revolving door, because there are not enough resources to work on an individual basis. Once they are medically stabilized, they need a place to get well and to heal – ideally a residential government-funded, community-based program.

What does recovery look like?

Recovery means so many different things to so many different people. Our daughter

has been sick for too long, so for her to be completely free of her eating disorder for the rest of her life, I don't think will happen. Recovery would mean to be a functional citizen and to be able to be part of society and be included in society, and for her to feel that she can cope in society. Eating disorders often come with depression, anxiety, ADHD and OCD issues. It's hard to say whether the anxiety came first or the eating disorder.

How important is education, not only for the patient, but the entire family?

The caregivers need help. It's such a complex, long and lonely illness. NIED has hosted 67 free symposia for the public to attend. They are intended to help families, friends and loved ones understand what they are dealing with and educate those affected by eating disorders. It's an illness of the brain and families just don't know which way to turn.

How accessible is it for Canadians suffering from eating disorders to receive timely, comprehensive and specialized treatment?

The provincial costs associated with patients who have anorexia nervosa and are on long-term disability may be as high as \$101.7 million a year – 30 times the cost of all provincial specialized eating disorder services. Too many Canadians suffering from eating disorders do not have reasonable access to timely, comprehensive and specialized treatment. There are waiting lists for assessments. If and when they eventually get into treatment, they often have to wait at least four to six months to actually start treatment. If your child is in danger and he or she won't go to emergency, then you should phone the police. ■

This interview has been edited and condensed for style and clarity