Renata's World

Understanding Anorexia and Other Eating Disorders

By Jeanette O'Keefe

Renata was a smart, attractive 27-year-old woman. She had a university education,

came from a good home, was an athlete, and had good grades. But at 5'10" and weighing only 70 pounds, when she looked in the mirror, Renata thought she was overweight. An eating disorder claimed Renata's life in August of 2005, after a five-year struggle with the disease.

Renata went through all the typical symptoms of an eating disorder. She started to pull back from her family, she always found a reason not to go out for dinner or go on family vacations, she ate alone, she was always reading food labels, she over- exercised, and spent a lot of time in her room.

"Some of these things just happened over time, there was no big bang," says Vince Withers, Renata's father. "But it became more noticeable every day. She went down hill to the point where her heart stopped and she died a skeleton, an absolute skeleton."

Since his daughter's death, Withers has dedicated his time to creating awareness about the disease, advocating for changes in the system, and providing support to hundreds of people in this province who are in desperate need of help and treatment.

Serious Statistics

Eating disorders have a mortality rate of up to 20 per cent, according to Olga Heath, Psychologist at Memorial

University's Counselling Centre and Chair of the Eastern Health Eating Disorder Working Group.

"This is a staggering number when you consider that these are otherwise healthy young people and that's higher than for any other psychiatric disorder," she adds.

In the fall of 2002, Statistics Canada released a publication that measured eating pathology in the population across Canada. The data showed there were between 7,000 and 8,000 people in Newfoundland and Labrador at significant risk of having an eating disorder, and who already have what is described as "disordered eating". Disordered eating refers to an eating disorder not otherwise specified. The person might not meet the criteria for an eating disorder, but when surveyed, responded to the following statements with either always, usually, or often:

- I am terrified that I'm going to gain weight
- · I am terrified about being over weight
- · I avoid eating when I am hungry
- I have gone on eating binges where I feel like I may not be able to stop
- I particularly avoid foods with a high carbohydrate content
- I vomit after I have eaten
- · I feel extremely guilty after eating
- · I am preoccupied with the desire to be thinner

Warning Signs

Awareness is key in dealing with this illness, according to Withers, because stemming from awareness comes



early treatment. "When you know what signs to watch for, you can prevent the illness from getting worse."

The following behaviour changes could be warning signs that a person is suffering from an eating disorder:

- *Changes in Eating Behaviour*. When a child, friend or spouse is eating dramatically less than normal, hiding food, eating a lot at one time, or developing peculiar behaviours around food.
- Changes in Socialization. When you notice social changes, for example, if the person has stopped hanging out with friends, doesn't want to go out to dinner, doesn't want to eat with family, etc.
- Changes in Mood accompanied by Weight Gain/Loss. It may be depression, it may be some kind of physical disorder, but it's something you may want to look into to.

If someone you know has displayed any of the above changes, coupled with ongoing comments about his/her weight, concerns about how he/she looks, or if the person has lost a significant amount of weight, this could be cause for concern.

Understanding the Illness

Eating disorders are diagnosed as a psychiatric disorder, but they are unique in that they are a combination of both complex psychiatric and medical problems.

"It's never usually one simple thing that contributes to a person getting an eating disorder," says Heath. "It's kind of a constellation of events and personality factors."

People can be genetically predisposed to eating disorders as well, according to Heath, but that doesn't necessarily mean they will develop one.

"You may have two people in the same family, for example, with the same or very similar genetic predisposition - one of whom will develop an eating disorder and the other one won't, so it's clearly not purely genetic," says Heath. "But if you have that genetic predisposition, you have a number of stressful experiences, and you're a particular type of personality, then that puts you at a very high risk."

One of the difficulties with this disease, according to Withers, is the stigma attached.

"When people won't accept that there's an eating disorder, you lose valuable treatment opportunities," he says. "If you're in a stage of illness and you get early treatment then you can prevent an awful lot of things from happening to you."

Eating disorders can leave young women with very serious, irreversible medical problems such as osteoporosis (a disease characterized by low bone mass and deterioration of bone tissue), brain atrophy (brain shrinkage), and cardiomyopathy (a disease in which the heart muscle becomes inflamed). However, most other medical complications associated with eating disorders are reversible when treated early.

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Renata Withers



Getting Help

Along with her parents, Renata regularly went to doctor's appointments, she saw nutritionists and psychologists. She was in and out of hospitals and emergency rooms on a regular basis, but it wasn't until the very end of her life that she realized what the eating disorder had done to her.

"Renata hardly admitted [she was ill] any where along the way," says Withers. "At the very end she said to her mother one day 'am I going to die?' and 'what have I done to myself?"".

Reaching out to someone who you think may have an eating disorder can be as complicated as the eating disorder itself. Depending on your relationship with the individual, assuming it's a friend that you are really close to or a family member, it is always recommended to tell them about your concerns, not in a confrontational or angry way, but in a concerned way, says Heath. For example, saying something like 'I noticed that you've lost a lot of weight over the past couple of months and I'm really concerned about your health'.

There are non-profit organizations available to support individuals and families affected by eating disorders.

In November of 2006, Vince Withers launched the Eating Disorder Foundation of Newfoundland and Labrador. The Foundation is a leadership advocacy group dedicated to promoting research and providing public support services and information about matters related to eating disorders, including information on available treatment services for individuals and families who experience disordered eating.

Eating disorders can have a significant impact on families as they try and cope with a loved one struggling with the disease. *Parents of Hope* is an organization established to provide support and hope for families that have a loved one battling an eating disorder. The group encourages families to join and meet other parents who are going through the same experience.

Historically, there has been limited professional support available in this province for people who suffer from eating disorders. "But that's what we're working so hard to get," says Heath.

Below are the supports that are currently available:

 Adults who may be suffering from an eating disorder should see their family doctor. "The most significant concern is ensuring the person is medically stable," says Heath. "If they are not medically stable, the family physician needs to send them to emergency and then emergency will connect the individual with the appropriate support services."

- In St. John's, if you're under the age of 18, the Adolescent Medicine Team at the Janeway Health and Rehabilitation Centre provides treatment and support. Contact 777-4963 for more information.
- Memorial University's Counseling Centre offers an assessment service and individual therapy for students struggling with eating disorders. The Centre is hoping to broaden those services over the next couple of years. Contact 737-8874 for more information.
- Eastern Health offers an Eating Disorder Therapy Group, led by psychologist Valerie Crewe.
- Some individuals are referred to Homewood Health Centre in Guelph, Ontario, which is a specialized inpatient service for people with eating disorders. "If there is a recommendation from the family doctor and the government agrees, the provincial government will pay the cost because there is nothing equivalent here," says Heath.

"Unfortunately, all these services are in very short supply. There is a huge demand and the waiting time is longer that you would ideally like to see it," says Heath. "The family doctor needs to be prepared to follow these people to ensure they are safe until they can get the therapy they need."

Future Supports

In an effort to build capacity in communities across Newfoundland and Labrador, the Eating Disorder Working Group has just developed an Eating Disorder Resource Centre, which will provide health professionals with access to a number of educational, evidence-based materials, such as books, videos and work books. The resource centre will lend these materials to health professionals so they can become educated on eating disorders, as well as provide the information to their patients and clients.

Heath says she is also excited about a proposed Intensive Outpatient Eating Disorder Treatment Program for the province.

"This is something that I think could make a huge difference in terms of our ability to appropriately respond to the numbers of people with eating disorders in our province," she says.

If approved, this will be a provincial program based in St. John's for adolescents and adults aged 15 years and older. It would be five days a week, 11 hours a day; however, not everyone will require that level of treatment, they may just need to come for one day a month if they are stable.

Dr. Olga Heath: "Some of us are not meant to be slim, we're meant to be heavier and that's okay, there's nothing wrong with that, as long as you're active and you're making reasonably healthy choices, which involve having potato chips and a chocolate bar every now and again."



"I believe if we get that unit, we'll have what I like to refer to as a front door. We don't have a front door right now. It doesn't mean that if we get the front door that everything is going to be hunky dory when you get inside, but what will happen is they'll know who you are, they can establish a file for you, they can treat you, but then if you're referred to an in-patient clinic like the Homewood you can go with that kind of professional referral," says Withers.

Finding the Balance

With the recent focus in Newfoundland and Labrador on obesity, it is often a challenge to find the balance between encouraging people to maintain a healthy body weight and not become obsessed with being thin.

"As a parent, I can think about my children and think you know if I had a child that was significantly overweight, I would worry about that and because that's immediate and the eating disorder isn't there at the moment, the tendency would be to focus on that and to want to put a lot of pressure on," says Heath.

She adds that the focus on obesity is very important, but it needs to be balanced with the healthy body image - loving yourself whatever size you are and then trying to make healthy choices around activity and eating.

Defining Eating Disorders

Anorexia nervosa - When you lose a lot of weight because you're hardly eating anything, and might over-exercise. You probably can't or don't admit how underweight you are. You may not initially look very thin, but may be far too thin to support your health. You can be so thin that every bone in your body shows, but still feel "fat". When you feel fat it makes it hard to ask for help or hear advice from others because, to you, "fat" has come to mean "being bad". You could also know that you are much too thin but don't make changes because you're so afraid of food and gaining weight. To you, this would represent losing control over yourself.

Bulimia nervosa - When you binge and purge. You eat out of control and then try to get rid of the calories. You fast, make yourself vomit, abuse laxatives, or exercise too much. These ways of purging harm your body and don't help you accomplish what you want. Your weight may go up and down a lot.

Binge-eating disorder (BED) - When you eat so much you're uncomfortable, eat to comfort yourself, eat in secret, or keep eating as part of a meal or between meals. You feel a lot of shame or guilt about your eating. Binge eating is also called compulsive eating. It is not the same as bulimia because you do not usually try to get rid of the food you've eaten.

Eating Disorder Not Otherwise Specified (ED-NOS) - Individuals who experience a mix of anorexia, and/or bulimia, and/or binge-eating symptoms, but who don't fall neatly into one of the medical categories, are said to have an Eating Disorder Not Otherwise Specified (ED-NOS). These individuals should also receive the help and resources provided to individuals who have a "neat" clinical diagnosis.

