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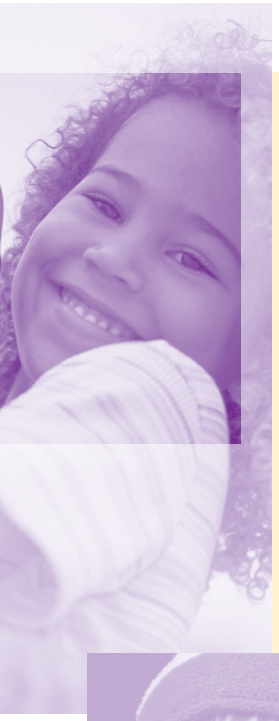

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Eating Disorders: Lessons Learned

Nine years ago I became the Psychiatric Director of the Eating Disorder team at the Children's Hospital of Eastern Ontario. Since then, and now with three daughters as well, my knowledge of eating disorders, girls and parenting has by necessity grown exponentially. I've learned that for parents, Eating Disorders are indeed "the ultimate food fight", one that seriously threatens the life, health and well-being of their child. Here are the 'top ten' lessons I've learned about eating disorders from my work at the Children's Hospital:

1. Eating Disorders are extremely dangerous. Eating disorders (anorexia nervosa, bulimia nervosa, and eating disorder not otherwise specified) affect approximately 2-5% of young females, and at least one-tenth that number of males (Yager & Powers, 2007). Most eating disorders begin in adolescence. They have devastating medical and psychological consequences, often respond poorly to treatment, and are associated with the highest rate of mortality of any psychiatric illness (Katzman, & Pinhas, 2005). Research suggests that 5-10% of patients die from their eating disorder; half of these from medical complications and half from suicide (Yager & Powers, 2007). Medical complications of eating disorders appear more quickly and can be more serious in young people, who are more prone to dehydration, electrolyte imbalances, osteoporosis, and effects on growth. Unfortunately, it can be very difficult to recognize how ill these youngsters are. Typically, we admit youth at assessment who insist they feel "fine," who have been attending school, gym classes, and often other extra-curricular activities such as dance or gymnastics, but who are dangerously underweight with abnormal vital signs (such as bradycardia, postural hypotension, or a large difference between lying and standing heart rates).

2. Eating Disorders are a mental illness, not a lifestyle choice. Eating disorders develop in susceptible individuals who suffer from a combination of low self-esteem and stress. Happy, well-adjusted teens who feel good about themselves don't develop eating disorders; the illness is often an attempt to cope with feelings of depression or anxiety. It usually starts as a desire to lose some weight in order to feel better. And it works: in our society, weight loss tends to be seen as an enviable goal, and achieving this goal makes a girl who started out feeling "not good enough" suddenly feel competent, successful, powerful, special or in control. The resulting starvation and preoccupation with food pushes pre-morbid sadness, anger or

worries away, while purging also serves to "purge" the youth of these intolerable feelings. Before long, a girl finds that she feels better with her eating disorder than without it, so she must defend and continue her weight-loss attempts. By this time, the eating disorder is out of the youth's control; she can no longer "just eat".

An eating disorder is probably best understood as a combination of obsessive-compulsive disorder, a phobia, an addiction, and a delusion, as eating disorders share properties with all of these illnesses. In many ways, an eating disorder is a form of OCD: the obsessive thought which plays over and over is "I'm fat," while the compulsion is to lose weight by restricting, over-exercising and/or purging. At the same time, anorexia nervosa is a severe phobia in which patients are literally terrified of calories and of weight gain; one need only visit our inpatient program to see the anxiety and agitation that results when these patients are presented with food. In contrast to this fear and agitation, the patients find relief and pleasure in weight loss and purging, such that they soon appear addicted to these behaviors and unable to stop. And finally, research has shown that girls with eating disorders are unable to see themselves realistically: when asked to point to a silhouette which most resembles their own shape, these patients typically choose silhouettes that are significantly larger than their actual shape, suggesting that their belief that they are "too fat" shares some qualities with a delusional disorder. Thus, by recognizing these similarities to other mental illnesses, and how severely ill our patients are, caregivers and families can be both more compassionate towards the suffering, and more realistic in their expectations.

3. Eating Disorders aren't really about weight. In some ways, of course, they are: our patients feel better at a lower weight, and worse as the number on the scale increases. But the obsessive thoughts are entirely linked to how a girl feels about herself; no girl ever seems to suffer from such obsessive thoughts as "I'm thin" or "I look great!" Rather, the eating disorder seems to be fuelled by feeling one is bad or 'not good enough'. Thus, the obsession "I'm fat" is really equated to "I'm disgusting"; these feelings of self-loathing get translated into feeling "fat" all the time, no matter what number the scale reads. This becomes apparent during treatment: a girl will come in to hospital at a low weight feeling "fat," agitated and compelled to lose weight. We re-nourish her body, and offer group, individual and family therapy. She is taught to separate from and turn against the illness, and given copious amounts of praise and encouragement when she is able to ignore or challenge the eating disorder thoughts and urges and work towards recovery. Many weeks later, when she is graduating from our Day program and getting her "star" on the ceiling, she is feeling better about herself and her body than she was at a lower weight. However, it is a fragile victory; stress at school, conflict with friends or family, or any perceived criticism, can quickly lead to feeling "fat" again and anger towards those (therapists, parents, doctors) who made her "fat".

4. Eating Disorders are associated with Anxiety and Depression. For the severely ill patients that I see in our inpatient program, virtually all of them suffer from anxiety, depression, or both. Given that eating disorders seem to arise from a combination of stress and low self-esteem, this relationship isn't surprising. Eating disorders often appear to be a way of coping with intolerable feelings of anxiety, frustration or sadness, and, though destructive, are fairly effective forms of self-treatment (similar to the use of alcohol or drugs to escape intolerable feelings). The effectiveness is related to the side effect of starvation: research shows that low-calorie diets (i.e. starvation) result in a complete preoccupation with food and calories such that other thoughts and worries are pushed away.

a) **Anxiety.** Clinically, the anxiety disorder we see most often in our eating disorder patients is a form of social anxiety, i.e. self-consciousness around others. Our patients worry all the time about what others think of them, and about the impression they are making on others. Some are obviously shy, while others have such active social lives that even their parents are unaware of how much these adoles-

cents worry about what others are thinking of them. This self-consciousness often goes hand in hand with perfectionism: a desire to be 'perfect' in order to not give others something to criticize. Thus, not only is being teased at school a common trigger for the development of an ED, but even seeing others being teased (e.g. typically we hear that an overweight child at school has been teased, and our slim patient reports fear that she could possibly be teased or that the kids at school could be thinking critical thoughts about her). Perfectionism itself is perhaps best thought of as an anxiety disorder: perfectionistic thinking results in a child who always worries about being good enough and always feels she should be better than she is. Thus, we often see girls with anorexia nervosa who come from good homes with caring parents and no history of abuse or trauma. Their parents struggle to understand how such a child can end up feeling so badly about herself, not recognizing the damaging effect that anxiety and perfectionism can have on a child's self-esteem. Generalized anxiety disorder can also have a devastating effect on self-esteem, and can cause severe stress for a child. This is the kind of anxiety that causes children to be 'worriers'. They may worry about schoolwork and marks, about harm coming to them or their families, about friends, or about what is going to happen tomorrow. When severe, it can result in a constant feeling of dread and fear for the child; such children typically grow up wondering "what is wrong with me?" Youth with social anxiety will describe lying in bed at night worrying about what they said and did that day that may have appeared 'stupid' to others, those with generalized anxiety lie in bed worrying about what's going to happen tomorrow, and when we ask our patients which of those scenarios best describes them, many respond "both." Sometimes the worry about being able to meet others' expectations, and fear of the future, results in a young adolescent with fears of growing up; this can include fears of going to middle school or high school. And lastly a genetic link between anorexia-nervosa and obsessive-compulsive disorder means that there is an increased incidence of OCD in our patients and their families. The OCD may have been manifest prior to the development of the ED, or it may develop at the same time as the eating disorder. This further strengthens the argument that anorexia nervosa may in fact be a variant of OCD. This debilitating illness may begin in early childhood, is associated with shame and social stigma, and may prevent children from being able to function normally or go to school. Such children are often afraid to tell others about their illness, and grow up trying to hide their embarrassing secret. In each of these instances, then, both the anxiety disorder itself and the resulting effect on self-esteem increases the risk for developing an eating disorder.

b) **Depression.** Typically, depression in this population occurs at any of three stages: prior to the eating disorder, during the illness, and with treatment. For some patients, the depression comes first, and the eating disorder is a way of coping; it improves self-esteem and self-image and replaces the sad feelings with calorie counting. However, once the illness has taken over, depression can develop when the youth realizes how hopelessly "stuck" she is; unable to eat without guilt or anxiety, hungry and scared all the time, completely preoccupied with food and weight, and causing worry and anger in the family. She feels guilty when she eats, and guilty when she doesn't eat, and can see no way out of her predicament. Such patients come to us describing low mood, hopelessness, guilt, and suicidal ideation. But for the patients for whom life was miserable prior to the eating disorder—associated with stress, worry, sadness and feelings of failure and incompetence—treatment causes depression: as weight increases, mood goes down. Such patients are typically angry, sullen and isolated from friends; many of them describe themselves as "too fat to be seen by anyone" as they approach their healthy weight.

5. **Patients need their Eating Disorders.** Given the association between eating disorders, anxiety, depression, and low self-esteem, we can understand why adolescent girls might need their eating disorder to help them feel "good enough." In a society obsessed with appearances and a thin ideal, weight loss is

seen as desirable, admirable, and enviable. Typically, our patients have either received praise all their life for being so slim, or have received praise for the weight loss that marked the onset of their eating disorder. Their ability to achieve a weight loss goal leads patients to feel attractive, powerful, superior, special, "pure," in control, and for the first time in their life, "good enough." Treatment is thus terrifying; as one patient put it, "without my eating disorder, I'm nothing." Many describe the eating disorder as "my best friend." Treatment can also be associated with fears of abandonment for some adolescents, who describe feeling as though they need to be sick in order to have people care for, worry about, and pay attention to them.

6. **Therapy and Nutrition can't be separated.** Both are crucial. The medical effects of starvation, such as we see in our patients, include bradycardia, hypothermia, hypotension, dizziness, hair loss, osteopenia, loss of menses in females, anemia, weakness, and possible heart arrhythmias, cardiac arrest or heart failure (Yager & Powers, 2007). The psychological effects, as carefully documented in the infamous Minnesota Starvation-Rehabilitation Experiment of the 1940s, include fatigue, irritability, mood swings, depression, loss of interest in relationships or sex, a complete preoccupation with food, insomnia, and even psychosis (Keys, Brozek, Henschel, Mickelsen, & Taylor, 1950). Cognitive effects (illustrated dramatically by the decrease in gray matter seen in images of brains of anorexic patients) include difficulty in complex problem solving; clinically this results in patients who seem rigid, "stuck" and unable to "think outside the box" (though often still able to get high marks in school!). The treatment for all of these symptoms is nutrition. No amount of therapy is going to be helpful without nutrition and weight gain. Goals of hospitalization for patients with anorexia nervosa include a weight gain of 1-2 kg per week; out of hospital we expect a slightly slower rate of weight gain. Typically, patients complain that we are going "too fast," and giving them too much food to tolerate. We point out that they have an illness that always tells them they are eating too much and gaining too much weight, no matter how slowly we go. Thus, slowing down the process too much merely prolongs the physical effects of malnutrition and the psychological agony. Better to correct the starvation, and combine it with therapy which is designed to separate the adolescent from the illness, to empathize with the process, and to help the patient to tolerate the process by distraction, or by motivating them to ignore or fight the urges to have symptoms. However, reducing symptoms and gaining weight is often associated with anxiety, agitation, depression and/or anger in our patients. Without therapy, which can be done in individual, family or group formats, the adolescent will find eating and weight gain intolerable.

7. **Externalizing the illness and separating it from the patient is a key component of therapy.** The easiest way to conceptualize this for patients and caregivers is to see the eating disorder as a form of obsessive-compulsive disorder. Rather than seeing the illness as a lifestyle choice or a stubborn refusal to eat (or to stop exercising or stop purging) it can be recognized as compulsive behavior designed to decrease the anxiety associated with the obsessive thought "I'm fat/disgusting" and "I have to lose weight". Thus, treatment can be informed by the treatment for OCD, as outlined in John March's book, "Talking Back to OCD." (March & Benton, 2007). For example, consider a child who has the obsessive thought that there are germs on his hands. He feels compelled to wash his hands, but as soon as he does, the thought returns, the anxiety escalates, and he is compelled to wash his hands again. Treatment involves helping the child to externalize the illness as a "monster" who lies to him, or like a computer virus that spews out the same message over and over; the message has nothing to do with "truth," even though it makes one feel like the thought is true and one's own. Often the illness, be it OCD or ED, is personified in therapy as an abusive being that wants to destroy its victim. Recovery involves "not listening" to the "lies" it uses to "trick" you. This approach to treating eating disorders can be found in the book "Biting the Hand that Starves You: Inspiring Resistance to Anorexia/Bulimia" by Richard Maisel et al

(2004), and it is the basis of group therapy in many Eating Disorder programs. It is a powerful and moving experience to listen to a group of adolescent girls cheer as one of them describes her successful battle with the abusive "Eating Disorder" and how she didn't give in to the urges when it "told" her not to eat. Patients are praised for the courage, strength and determination it takes to "stand up" to the Eating Disorder, a powerful and cunning enemy who tries to convince you it is your friend and protector. The more severely ill patients resist this separation from the eating disorder, while those who are motivated to recover often embrace it, sometimes drawing pictures of the eating disorder and giving it names like "Ed" (an inspirational book read by many patients is "Life without Ed: How One Woman Declared Independence from her Eating Disorder and How You Can Too" by Jenni Schaefer and Thom Rutledge, 2004).

8. **Parental involvement is crucial.** Unfortunately, psychiatry has a history of blaming parents—and mothers in particular—for illnesses which have since been found to have biological and genetic underpinnings; examples include schizophrenia, autism, obsessive-compulsive disorder and eating disorders. Imagine that you are the parent of a child who suddenly starts counting, ordering and washing obsessively (or hearing voices, or restricting her intake). You take the child to the hospital, where you are made to feel like the problem was the result of you being an over-protective, over-controlling parent. Your child is hospitalized and given therapy from which you are excluded, or else you are asked to participate in therapy aimed at correcting family dysfunction. This was the experience of many parents of children with mental illness, and even now, many parents feel blamed for their child's eating disorder, or excluded from treatment. We now know that there are definite genetic and temperamental predispositions to developing an eating disorder, and there is no evidence to suggest that parents "cause" eating disorders. Parents are expected to be at the bedside of a child with cancer; why would this be different for eating disorders? Do we encounter some parents who are unable to give their child the support she needs? Occasionally, of course, but not any more than one might find in any other clinic in the hospital. A helpful comparison here is to consider a child who is diagnosed with juvenile diabetes. Parents are expected to play a significant role in managing their child's illness: they are provided with education about the illness, taught the necessary diabetic meal plan to provide, taught how to test sugars and administer insulin, and to support their child in gradually becoming more independent in managing her own illness. A similar approach to treating eating disorders would involve psychoeducation for the family, including teaching parents the importance of weight gain and getting the nutrition into the child while empathizing with the distress this will cause. Fortunately, this is the basis of "Maudsley" family therapy, which is currently the recommended treatment for adolescent anorexia nervosa. This approach, which originated at the Maudsley Hospital in England, was popularized and brought to North America by James Lock and Daniel LeGrange, in their books "Treatment Manual for Anorexia Nervosa: A Family-Based Approach,"(Lock, Le Grange, Agras, & Dare, 2001). "Treating Adolescent Bulimia Nervosa: A Family-Based Approach," (Le Grange & Lock, 2007), and "Help Your Teenager Beat an Eating Disorder."(Lock & Le Grange, 2004). Family-based therapy involves lifting blame from the patient and the parents, raising parental anxiety (so that they recognize the power of the illness to destroy their child and the need to focus their energies on her recovery) and empowering parents to re-nourish their child while providing compassionate support and praise to counteract the severe distress that will be associated with this. When the patient responds with fear, anger and distress, we point out that a diabetic child with a needle phobia would still need to get the full dose of insulin into her; similarly, the child with an eating disorder needs the full "dose" of nutrition. Using this approach, I have been amazed by the love, strength, patience and determination parents find to support their children, sometimes for years without giving up. And I have learned that this kind of loving support is key to an adolescent's recovery from an eating disorder.

9. **Caregivers need to keep expectations low, and praise, praise, praise…**Remaining neutral and non-judgmental or listening quietly tends to not be enough with this population. The patients who come to us for assessment are full of shame and guilt; they feel "not good enough," and as though they are a burden and disappointment to their families. They tend to be extremely self-critical; typically, they have difficulty identifying any strengths or things they like about themselves. They are convinced that others see them in an equally critical and negative light, and only abundant praise and warm reassurance will help to counteract these beliefs. Of course, the praise has to be genuine, based on the recognition that it takes a great deal of courage and strength to come for an assessment, open up to a therapist, or eat food. My work with our severely ill inpatient population has helped me to keep expectations low: though rare, I have encountered patients who have refused all nutrition, run away, pulled out iv's or n/g tubes, refused to speak, refused to get out of bed, and even some who have become violent at times. Such experiences have helped me to genuinely appreciate the effort it takes for a patient to eat, to talk, to stay in hospital, to trust a therapist or doctor, or to function outside of hospital. Parents understandably have higher expectations: that a child will eat, accept treatment, go to school, do homework and chores, and so on. These expectations can overwhelm an adolescent with a severe eating disorder, leading her to feel inadequate, a burden, and a disappointment, and confirming her belief that she is 'not good enough." This in turn increases her need for the eating disorder as a way to cope with these feelings. It can be difficult to help parents to see that only by keeping our expectations low, and thus helping patients to feel as though parents and caregivers are genuinely impressed and pleased by their progress, that patients can then ultimately reach the goals that parents have for them. Most difficult and confusing of all for parents is helping them to cope with the "double-bind" we put them in regarding the need to keep expectations low, while ensuring that all the nutrition gets into their child. On the one hand, we speak of helping patients to feel "safe" from the destructive control of the eating disorder: eating must not be optional, the child must not be allowed to starve. On the other hand, we ask parents to understand that it is extremely difficult to eat when you have an eating disorder, or to trust those who threaten to take it away, or to concentrate on schoolwork when your head is full of self-loathing and calorie counting, or to attend school when you feel everyone will see how "fat" you are. With this understanding, parents can avoid criticism and be genuinely empathic if the illness overwhelms and the child is unable to do these things, or genuinely proud if their child is able to accomplish any of this.

10. **Our youth, and girls in particular, are growing up in a toxic environment.** Imagine that you have obsessive-compulsive disorder with a fear of germs, dirt and contamination. Everywhere you turn, there are stories in magazines, newspapers, radio, television and on the internet warning of the dangers of germs. The magazines at the grocery store have headlines that scream "Get rid of germs now!" and "How to purify your home in 10 easy steps," while the news on television is about the latest findings on the dangers of the germ epidemic. Did the news stories cause OCD? No, the root causes may have more to do with a combination of genetic, temperamental and early environmental predispositions, but the anxiety is strengthened and confirmed at every turn. This is the reality for those suffering from eating disorders. How do we help our patients to eat normally, choosing from a variety of foods, when they are flooded with stories on the dangers of cholesterol and "bad" fats? How do we help anxious, perfectionistic, literal-minded young people not to fear weight gain when experts warn of the dangers of the obesity epidemic? How do we help them to see their worth as inborn and a "given" when the focus is on marks and accomplishments? And how can we convince them that it's not about appearances in a society obsessed with Hollywood celebrities? Or help them to accept their bodies and feel good at a healthy Body Mass Index of 22, when the models in the magazines have BMIs of 16-17? Healthy adolescent girls menstruate when they reach 95% of their body's

ideal weight; research shows that on average for females with anorexia nervosa who have been re-nourished, this occurs at a BMI of 20.0 (Herrin & Marcia, 2003). For some girls, their bodies will need to be above this average in order to have normal menstrual and hormonal function. Sometimes, even parents will accuse us of making their daughter "overweight" with re-nourishment, because parents too have internalized the 'thin ideal' of the models and stars whose images bombard us daily.

I have learned many lessons from the patients and families I have been privileged to work with in the Eating Disorder program at CHEO. Most of all, I have learned that it takes a combination of strength, courage, and determination, the help of caring treatment providers, and the support of a loving family, to overcome these devastating and dangerous illnesses.

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