

She has an eating disorder!

What do we say?

What do we do?

One of the most distressing things the loved ones of someone with an eating disorder has to face is the fear of doing or saying the wrong thing. At times it can seem like everything you do or say is wrong. Although there are no absolute guidelines to follow, here are some general suggestions to try to use.

- * Focus on feelings and relationships, not on weight and food.
- * Convey concern for her/his health while still respecting their privacy. Eating disorders are often a cry for help, and the individual will appreciate knowing that someone is concerned.
- * A family should not allow their own lives and habits to be hindered by a dieting child.
- * A family should set caring and reasonable but firm limits in a consistent manner. This may come up when the person having the problem wants to skip meals or eat alone or gets mad when someone eats her "special" food.
- * Avoid commenting on weight or body appearance; the person is already overly focused on this. Comments on weight or appearance, even if the intent is complimentary, will only perpetuate the obsession with body-image.
- * Demanding change or berating the person for his/her eating habits will not work. Avoid power struggles around eating. Eating disorders are often expressions of a need for control, a substitution for lack of control that the person feels in other areas of her/his life. Trying to trick or force someone to eat can make things worse.
- * Realize that the individual will go at his or her own pace in getting better. By gently giving them information and being supportive, you are enabling them to see and consider alternatives to the present situation.
- * Ask questions about "the person" rather than questions about their eating disorder. Have a relationship with them – not their eating disorder. Even if they act as if 90% of their life is their eating disorder, treat them as a person – not a behaviour.

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Greetings!!

This is the first edition of our newsletter, and we have chosen to focus on the loved ones of a person with an eating disorder as a theme. We want to offer tips on coping with a disorder in our newsletter, and wish to provide information of general interest to those battling the disorders, as well as to family and friends.

As the mother of a young anorexic once commented during a support group meeting, "If your family wasn't dysfunctional before the disorder, it soon will be!" In those few words she expressed the frustration felt by families and victims alike, as well as underscoring the devastating effects the disorders can have on everyone they touch.

In this edition we have also provided some observations about the stages families often go through in coping with these disorders. It is no small task to accept and adapt to the fact of someone you love behaving in a manner that seems so foreign, and at times bizarre.

We have also provided a note on resources found on the World Wide Web on the internet, a list of some books focused on families and loved ones of people with eating disorders, as well as an article by one of the people running one of the websites. We hope to frequently provide at least one first person article from someone who has recovered from these devastating disorders.

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What's on the Web

Here are a few of the best web sites on eating disorders:

Something Fishy is run by Amy Medina in New York. She and her husband do an excellent job of maintaining a huge site full of information, including an excellent treatment locator - allowing people the opportunity to look for resources either locally or internationally. They have several addresses, but look for them at: www.something-fishy.com

mirror-mirror is a site run by Colleen Thompson in Sudbury, Ontario, Canada. Like Something Fishy, it is an excellent resource center. Look for it at : www.mirror-mirror.org

The above sites are linked to one another, and provide links to many other sites. **Mental Health Net** has quite a bit of information on mental health issues in general, and in the eating disorder section there are many web sites, news groups, and other resources listed. They give a quick summary of each web site, as well as a rating. A very extensive resource site. It can be found at www.cmhc.com/guide/eating.html

This newsletter is a publication of the Westwind eating disorder recovery centre, and is intended for general information only. It is not intended to provide personal medical or psychological advice, which should be obtained from a qualified health professional.

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...talking with loved ones

* Examine your own attitudes about food, weight, body-image, and body size to ensure you do not convey any fat prejudice, or exacerbate their desire to be thin. If she/he expresses feeling fat or wanting to lose weight, instead of saying "you're not fat," suggest they explore their fears about being fat, and what they think they can achieve by being thin. Encourage reflection on the pressures in society to look a certain way, and how this negatively impacts their self-esteem. Think about the way you personally are affected by body-image pressures, and share these with the person in a supportive manner.

* Find alternatives to current ways of communication. For example, instead of saying things like "Why are you doing this to me?" or "You are ruining our family/relationship," or "You could control/stop this if you wanted to," it would be better to say, "Would you like to talk now?", "This is difficult for both of us, so let's try to discuss it," or "I know how hard it is for you." You will need to find alternatives to yelling, punishing, etc.

* Seeing someone you love struggling with an eating disorder might make you feel very scared, angry, frustrated and helpless. However, be careful not to blame them for their struggle. Try to understand eating problems as a coping strategy for dealing with painful emotions or experiences. Despite the grief the eating disorder causes her/him and those around them, it may be hard to let it go.

* Provide hope. Discouragement, fear and at times feelings of hopelessness are common to those suffering from eating disorders. These feelings don't need fuel — but correction. There is hope, there is something worth encouraging. Find it and

do some coaching. After listening, acknowledging, empathizing, and validating feelings, move on to ideas, hopes, and positive possibilities.

* Don't blame yourself. It's not your fault. Whatever your mistakes or weaknesses as a parent, spouse, or loved one, you did not create this eating disorder. Take ownership for your weaknesses and frailties, take stock of your talents, gifts, and resources, and get to work providing love, support, and open invitations for them to come into a safe relationship with you as they are ready.

* Finally, it is important that you do not take on the role of a therapist. Do only what you feel capable of. It is often helpful for family members or friends to get some support for themselves. You need to take care of yourself while dealing with your friend/family member.

The majority of the above information was adapted from information published by the National Eating Disorders Information Center, Toronto.

NUTRITION TIP:

Vit B 12 is a very important vitamin because it maintains the myelin sheath that insulates nerve fibres from each other. With Vit B12 deficiency, the sheath is slowly destroyed and eventually causes paralysis and even death. Vit B 12 can only be obtained from animal sources. The strict vegan who eats no animal products, may take a supplement or consume a fortified soy milk or a special yeast grown in a Vit B 12 rich media. However, this is not a guarantee that they will be able to obtain all the B12 they need. The best insurance is to consume some animal products.

Why Treatment Fails

All too often people enter treatment programs, either as outpatients or into inpatient or residential care facilities, only to be met with disappointment rather than the success they sought. What are some of the reasons for such a dissatisfactory outcome? Don't people ever get better? Don't they recover from these disorders?

The following comments are some of the reasons an effort to change may not be successful. There are about eight reasons that one can quickly summarize as contributing to such a poor result. These are:

1. Too much focus on one dimension (usually weight) at the expense of other dimensions, and / or Insistence on weight gain as an absolute measure of change.
2. Hierarchical decision making vs Collaboration
3. Failure to recognize some of the effects of eating.
4. No preparation (staff and client) for the panic at small weight gains, as well as the plateau or relapse that may occur.
5. No preparation (by staff, or parents) for the opposition that will likely take place as a natural developmental task.
6. Where secondary gain exists, it needs to be countered and replaced.
7. Client expectations of outcome.

Many treatment programs insist on weight gain when the client is underweight. There are many reasons given for this - usually that concentration and memory are too poor to allow for progress in psychotherapy until weight has been gained and the client's body is not functioning from a position of starvation. While this argument has some superficial merit, it is generally based on a study published in 1950 by a

researcher in Minnesota. That study did show significant impairment in concentration and memory, but there are some significant differences between the study participants and underweight anorexic clients.

The study participants were male volunteers, and were underweight and poorly nourished for much less time than the average person who has anorexia. While the effects are real, people with anorexia have routinely done well in psychotherapy as outpatients long before any weight gain is evident, and many do quite well in school in spite of the evident malnourishment and anorexic symptoms.

Although they tried to get clients to gain weight, The Renfrew Center in Philadelphia reported an average gain of less than 3 pounds during inpatient treatment, and just less than 10 pounds on follow-up. Although the clients had improved psychologically, and their health was improved, 46% of them were still more than 15% below what might be considered an "ideal" weight. In spite of the modest weight gains, the clients were improving, and that does suggest that an over emphasis on rapid weight gain may be misplaced.

The collaborative approach.

Psychologists Don Meichenbaum and Dennis Turk wrote a book titled *Facilitating Treatment Adherence* in which they review the literature on that topic. Over and over again, they found that a collaborative approach in which the client or patient is treated in a respectful manner, and included in the decision making process, resulted in better adherence to treatment programs. The hierarchical model in which the health care professional assumes the role of "expert" and simply directs the client to follow instructions (orders) simply failed to result in compliance, and patients dropped out of treatment, or failed to do as well as they might have.

Effects of refeeding

A number of things happen when underweight clients with anorexia begin to eat larger amounts of food. In many instances, the client will actually begin to lose weight as her metabolism speeds up. If treatment staff are not prepared for this, they will often blame the client - wrongfully accusing her of deliberately losing weight. This can be quite distressing to a client who is trying her best to eat better. Similarly, weight gain may simply plateau temporarily, and a client may be unreasonably pushed to eat far more than would be considered "normal" to continue to gain weight at a steady pace - even though the behaviour being encouraged is one of overeating.

The most common effect, however, is the feeling on the part of the client that she has gained weight after only a single meal, and considerable anxiety resulting from that. The belief that one's stomach is actually protruding is often expressed, even though there is no physical change to be seen. People dealing with the client often discount those anxious reports as "silly" or "foolish", and do not actually listen to the anxiety being expressed. That anxiety needs to be addressed to allow the client to progress more comfortably. Anxiety management may be a skill that needs to be built, or at least strengthened.

Opposition

Many experts on eating disorders have noted that some common personality features in many people with anorexia may include a degree of interpersonal dependency and concern with pleasing other people. Developing the skills of being more assertive with others is often included in the treatment plan. When the client - especially an adolescent client - is assertive to the treatment staff or therapist about her eating preferences, however, that behaviour is often punished. The client gets very mixed messages, even though such efforts at

being more independent and making decisions are regarded as important developmental steps for adolescents.

Secondary Gain

This point is related somewhat to the first one addressed. For some people with eating disorders, the disorder has become part of his or her identity. Giving it up is giving up a part of what makes that person unique. If this is not addressed, a focus on eating behaviours will have little effect. Other forms of secondary gain include using the disorder to gain a sense of control over one's life, coping with the anxiety or distress of trauma, or simply coping with emotions in general. All of these issues require problems to be solved, and some new skills to be developed to replace the need for the disorder, before significant headway will be made in overcoming it.

Expectations

There are some occasions when clients enter treatment with a set of expectations that are simply not realistic. This may pertain to a wish to eat "normally", but gain no weight (in an underweight person), or to gain weight only in certain parts of the body, or to make progress in a very short time frame. When it becomes apparent that these expectations just cannot be met, clients may simply drop out of treatment rather than examine their goals.

Recovery is possible, and there is no reason why every person with an eating disorder cannot recover. Addressing issues of motivation, unresolved problems that contribute to the disorder, or coping skills that are being overwhelmed is the responsibility of the therapist. Working at solving the problems, and at developing coping skills through practice is the responsibility of the client.

STAGES OF GROWTH EXPERIENCED BY FAMILY MEMBERS AFTER BECOMING AWARE THAT A PERSON THEY LOVE HAS AN EATING DISORDER

Stage 1: *Denial*

Stage 2: *Fear, ignorance, and panic*

- a. Why can't she stop?
- b. What kind of treatment should she have?
- c. The measure of recovery is behaviour change, isn't it?
- d. How do I respond to her behaviours?

Stage 3: *Increasing realization of the psychological basis for the eating disorder*

- a. Family members question their roles in the development of the eating disorder.
- b. There is increased understanding that the process of recovery takes time and that there is no quick fix.
- c. Parents / spouses are increasingly involved in therapy.
- d. Appropriate responses to the food and weight-related behaviour are learned.

Stage 4: *Impatience / despair*

- a. Progress seems too slow.
- b. The focus shifts from trying to change or control the person with the eating disorder to working on oneself.
- c. Parents / spouses need support.
- d. Anger / detachment is felt.
- e. Parents/spouses let go.

Stage 5: *Hope*

- a. Signs of progress are noticed in the person with the eating disorder and oneself.
- b. It becomes possible to develop a healthier relationship with the person with the eating disorder.

Stage 6: *Acceptance / peace*

From Reiff, D. W. & Reiff K. K., *Eating Disorders: Nutrition Therapy in the Recovery Process*, Aspen, 1992

Suggested books for families:

Anorexia and Bulimia: Your questions answered. By Julia Buckroyd, Element Books Inc, 1996

Bulimia: A guide for family and friends. By R.T.Sherman, and R.A.Thompson, Jossey-Bass, 1990

Surviving an Eating Disorder: Strategies for family and friends. By M. Seigel, J. Brisman, and M. Weinshel, HarperCollins Publishers, 1998.

Your Dieting Daughter. By Carolyn Costin, Brunner Mazel, 1996.

Food for thought.....

Obstacles are necessary for success. Victory comes only after many struggles and countless defeats. Yet each struggle, each defeat, sharpens your skills, your courage and your endurance, your ability and confidence and thus each obstacle is a comrade-in-arms forcing you to become better.....

- Og Mandino

THE VOICES FROM WITHIN

Colleen Thompson

“You’re fat”, “You’re disgusting”, “You’re worthless”, “You don’t deserve to eat”, “You deserve to die”

The voices of an eating disorder. A never ending dialogue that plays inside the mind of a person suffering with an eating disorder. Those voices and the cruel words they speak are with a person from the minute they wake up, until the minute they fall asleep. They encourage the victims to continue to abuse their bodies through starvation, bingeing, purging and other dangerous methods of weight control, and can bring them to the brink of death.

Whenever you read about eating disorders or hear people talking about them, you usually hear about the eating disorder behaviours or the emotional issues causing them. It is not very often you hear people talk about the voices that go along with having an eating disorder. I feel it is very important to talk about those voices because they do play a big role in keeping the eating disorder active. They convince us that we are worthless, unlovable, fat, ugly, disgusting, hopeless, and so much more. They convince us that the world would be better off without us and that we deserve to die.

Most eating disorder sufferers are too afraid to reveal to anyone that they hear voices inside their heads. In the beginning, I was afraid to tell anyone because I thought I was crazy and assumed whomever I told would feel the same way and have me locked up somewhere. I can now see that I am not crazy and many people with eating disorders do have these voices.

“Those voices lied to me and they are lying to you.”

It is very understandable why victims of eating disorders have so much trouble developing a self-esteem and finding a reason to live. When you have such negative voices yelling at you constantly, it is hard not to believe what they say. You can never feel good about yourself or the things that you do, because whatever you do is just not good enough for those voices. They will say anything to try and convince you not to eat.

They will tell you that someone so horrible does not deserve that food. If you do eat, they are screaming at you to get rid of it. They tell you that you are weak for eating and that if you do not get rid of it, you will surely become fat. They will tell you that no one will love you if you gain weight. These voices are very powerful and their ultimate goal is to destroy you.

Sometimes those voices try to fool us into believing they are really our only friend. They will convince you that you can not live without them. They will promise you that wonderful things will happen, but only if you listen to them. They convince us that life will be so wonderful, once we have lost enough weight. Those voices will tell us that if we lose just five more pounds, then we will be happy. I used to believe those voices, but no matter how much weight I lost, those promises never came true. I was not happy and my life was not perfect. No matter what the scale said, it was never low enough. Those voices lied to me and they are lying to you.

It sometimes surprises me that we do not hear more discussions about the voices that are constantly playing inside the minds of someone suffering with an eating disorder. Those voices are usually present, long before the symptoms of the

...VOICES FROM WITHIN

eating disorder actually appeared. People need to be made aware of these voices and the power that they have, especially the people that are involved in trying to help someone that is suffering.

These voices provide us with the reasons to continue to abuse ourselves in the way that we do. It is impossible for someone to destroy these voices on their own. We need help doing that, before those voices have the chance to destroy us.

If you know someone that is suffering with an eating disorder, it is important that you do what you can to help the person free themselves from that negative dialogue they hear constantly. It can be frustrating dealing with someone that is suffering, but you need to be encouraging, supportive, and provide that person with your unconditional love.

Don't get angry at the person and don't yell at them. Don't make them feel guilty for having a problem or tell them that they are destroying the family and making your life a living hell. Even though you are very concerned about the person, don't make them feel bad by telling them that you are losing sleep over it. Even though you may have lost a few hours sleep worrying, the people that suffer have probably lost years of their lives to it.

By telling us those things, you will in fact be giving those voices even more power. They will tell us that since we cause so much problems for other people and upset them, we really do not deserve to eat. We only deserve to die. Those voices we hear are negative enough, but having the people around us saying negative things only makes it worse. How can someone make progress and get better, if all we hear are negative things?

In order to help someone that is suffering, you need to break into that negative dialogue they hear constantly. The person needs to hear good things about themselves. You need to point out the positive things and stop focusing on the eating disorder behaviours. Encourage them to talk about what those voices are saying and help to show them that they are wrong and only lying to them. They need to know that they are in fact wonderful people that do not deserve to live this way and they especially need to know that you love them. They probably will not believe any positive things about themselves in the beginning, but the more they hear it, the more likely they are to start listening to what you say. They will then slowly develop a will to live and they will begin fighting against those voices.

It takes a long time to destroy those voices, but it can be done. It is also important for everyone suffering to know that they do have a choice about whether or not to listen to those voices. No matter what they say, you do not have to listen to them. Remember that they only lie to you and you can go against them. The more you do that, the weaker they become. It is not easy to go against those voices, but you do have the power within yourself to do it. I still struggle with my voices daily, but I do try to go against them. I do not always succeed, but I am determined not to let them win. Recovery takes a long time, but one day you will be able to live the happy, healthy life that you deserve and you will be able to silence those voices forever.

Colleen runs a web site on the internet about eating disorders where you can find a lot of very good information. See the listing in "What's on the Web".