

Children and Youth with Eating Disorders: Anorexia, Bulimia, ARFID and Disturbed Eating Practices

Issues for Parents to Consider in Treatment

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Family involvement is an important component of the treatment of children and adolescents with eating disorders. Families who get involved in treatment can make a difference in the recovery process. As a family, you can be a primary resource to your son or daughter. You may benefit from counseling to: help to cope during the crisis, to deal with the effects of the eating disorder on your family and to maximize your approach as parents.

Often parents believe that individual therapy for their son or daughter will be the treatment for eating disorders. However, individual therapy is not useful with a starved brain. The initial focus of recovery needs to be on helping families to take charge of the food and actively support their child or adolescent to eat enough. This is a hard task. This is called Family Based Treatment and is the only evidence based treatment for children and youth facing eating disorders. Often people misunderstand the family dynamics around eating disorders and can blame parents or believe it is about the youth not having enough control. In order to effectively treat starvation, there needs to be less control by the youth as it is too overwhelming and choices are driven by fear. Parents need to be the reality check and support the youth to face the fear. The only way to get past the problem is to push through this fear of gaining weight which represents many issues for the youth.

As a family you are naturally very distraught about the impact that the eating disorder has had on the life of your son or daughter and on the whole family including siblings. Eating disorders profoundly affect families and parents are left feeling helpless and doubting their ability to help their child or youth. It is important to get help as a family to cope with the eating disorder. When your son or daughter is first diagnosed with an eating disorder, it is a time of intense emotions and fear. It is important to find experienced professionals where you can feel included as partners as you begin the treatment process. Your family doctor is often the best place to begin to locate such resources as most eating disorders programs require a physician's referral.

Establishing a Therapeutic Alliance with Eating Disorders Team

A crucial step in treatment is for you to develop a strong therapeutic alliance with the team working with your son or daughter. If possible, ensure that both of you as parents meet all members involved to have the opportunity to develop direct relationships. If the professionals meet with your son or daughter alone, it is important to respect the confidentiality necessary for them to establish an alliance with trust. However it is important to let the professionals know of your needs to be included as parents. With Family Based Treatment, you need to be fully informed of weight and medical concerns to effectively look after your child. This may involve meeting to review their recommendations and be part of treatment planning. You

need to get to know the professionals to build your own confidence in them as care providers. Once you trust the health care staff, your child or youth perceives this trust and can then establish trust. When one parent distrusts, even if the other parent trusts, the youth feels confusion and conflicted loyalties. This can interfere with treatment. Research has shown that the most effective component of any therapy is to have a good therapeutic alliance as defined by the client not the professionals. It is the most significant predictor of outcome for all problems.

Articulating Your Family's Perspective

As parents you can feel desperate in your attempts to find professional help for your son or daughter. You may have been trying to figure out the health care system related to eating disorders and find what services are available. This search is often fraught with fear, helplessness, guilt, self-blame and ambivalence. It is important to share your journey of trying to seek help so that the team realize where you are coming from and what your needs are. Your fears need to be addressed regarding safety issues. You can ask the professionals directly about these fears because you may be worrying more than necessary and could benefit by being reassured. Sometimes you may not realize the full extent of the physical dangers of the effects of eating disorders such as starvation, laxative misuse or excessive vomiting and having opportunities to ask questions of the health care providers is essential. You may find it helpful to write down questions beforehand because it is easy to forget when you in an emotionally charged or tense situation.

Feelings of Parental Self-blame

You may fear being judged by health care professionals. It is natural for you to feel to guilty already when your child faces any type of health problem. If you feel blamed by others, you will be less likely to get involved in the treatment process, and your self-doubt can have detrimental effects on your confidence as parents. There is a lot of information and misinformation written about eating disorders. It is your job to sift through the literature and find what relates to your situation. Parents are not to blame for eating disorders, however, you can help in the solution. Eating disorders develop as a way of coping and are multi-factoral, meaning that there are many contributing bio-psychosocial factors. There is not one cause or one trigger. It is helpful to the treatment team when you can be open about the issues that your child or youth has been struggling with. These may include factors in the family relationships that involve you talking about personal or painful issues. The more information the team has about your child and family, the more they will be able to help.

Demystifying Eating Disorders

You may worry that your son or daughter's behaviour is abnormal and that he or she must be suffering from a psychiatric problem requiring psychiatric care that is beyond your control. It helps to realize that your child or youth is trying to cope with something by not eating or bingeing and vomiting, and the demands of this problem may be helping her focus away from other distress. It holds meaning for your child. Underneath the symptoms that show up as fear of food, are fears of feeling vulnerable and inadequate, and basically not feeling good enough (not smart enough or attractive enough). The control over food may give a person a feeling of feeling in control when other areas in life feel out of control. You can try to understand what your child might be trying to cope with in life and relate the problem to real life experiences, rather than conceptualizing that it is an illness that came out of the blue. Your son or daughter may be trying to deal with a time of change such as starting high school, loss, being left out with peers or stress of some kind like school pressure. Many children and youth who develop anorexia tend to hold in their feelings, needs and problems and focus more on pleasing others. This can make it hard to

detect if and when your son or daughter is struggling with problems. Some youth appear to be managing life well on the surface, but underneath have many upset feelings or unmet needs.

Working Together as Parents

The eating disorder can result in you blaming each other as parents rather than working together against the problem. As parents it is crucial that you work together as a team to effectively help your son or daughter with this problem. Sharing and openness between you as parents helps to prevent secrecy and creates unity. If you are a separated parental unit, this is especially important if at all possible. Sometimes this can be as little as being able to talk together as parents about issues that affect the children even if you have two separate homes. This provides safety and lets the child or youth know that she is important. The young person feels relief and valued when separated parents can put aside their differences in order to help. The more you can agree on parenting approaches, the more successful you can be to help to fight against the eating disorder. If you have significant splits in ideas, then alliances can form between one parent and a professional, or one parent and the child. Children and youth then are unable to experience the safety they need to feel from a cohesive parenting unit. It is common for fear to push you as parents to do anything to coax your son or daughter to eat. Some parents bargain around food to try to keep the situation from getting worse and feel incredibly helpless when this does not work. Bargaining is a downward spiral. Although setting rational limits may at first upset the youth, this can actually lead to a sense of safety. It limits the power of the eating disorder over the child and family. You have skills and competence to draw on from other successes in parenting. It is okay to have expectations and set limits. You likely have good ideas about what you need to do, but fear and self-doubt may stop you from acting upon these ideas. Trust your own competence.

Communicating Openly with Helping Professionals

Ongoing direct communication between professionals and families is of utmost importance. As a family you need to be kept up to date on the process, progress and plans during treatment. You need to have an opportunity for direct communication not just through your son or daughter in order to decrease misinterpretation and misunderstanding. You need to find the courage and take the risk to talk directly with the professionals even if your son or daughter is present. This builds trust and ensures that everyone hears the same message. If you talk to the professionals behind your son or daughter's back, this leads to pockets of secrecy and distrust that can interfere with treatment. If you need to contact one of the professionals involved with your son or daughter, be open that you are doing this. Issues of power and control enter into the delicate balance of working with the child or youth. The professionals need to maintain confidentiality with your son or daughter as the primary client in order to build trust and a therapeutic alliance. This may make you feel excluded at times, but it is vital to the treatment process. Family involvement in decision-making depends upon the developmental age and stage of the child or youth. The younger the child, the more family involvement in decision-making is necessary. You need to talk to the professionals about what is confidential and to what degree you will be informed and involved, so expectations are clear from the start, especially around safety issues.

Parents' Motivation for Treatment

Your own motivation about how willing you are to be part of the therapy has an impact on recovery. Some parents want their child fixed without having to examine their own issues. You need to look at how you may need to change in order to help your son or daughter improve. Family therapy makes a difference in recovery. Embracing it is crucial modeling for your son or daughter because you will expect that they too will involve themselves in individual and family therapy. You can demonstrate the importance of engaging

in counseling through your willingness to share your personal stories and experience, and the value they see you show in therapy. If children and adolescents see you hesitating to participate in family counseling and yet you want your son or daughter to work with a therapist, then they see the hypocrisy in this action. They may then be skeptical of the value of counseling or therapy. As parents, you may be more motivated for change than your son or daughter. You may be very willing to get involved in family counseling and your son or daughter may not want to participate in individual or family counseling. It is important to not let them interfere with the support that you need. You can proceed with parental counseling and the counselor can continue to work to involve your child.

It is very tough if the young person does not want help with the eating disorder at all. You can continue to build a therapeutic alliance with the team, receive support, education and therapy as you tolerate your son or daughter's ambivalence about change. You can talk to the team about ways to help motivate your child by working on what he or she is ready to work on, even if it is small steps. You cannot make your child change and cannot fix the problem for her. This can leave you feeling very powerless or lead to power struggles or food battles. There may be a time when involuntary treatment is necessary because of your child's medical condition. You need to work with the team to ensure your son or daughter's safety until he or she is ready to make changes.

The Problem is External to Your Child

It is important to remember that your child or youth is not "anorexic" or "bulimic." Your son or daughter is a person struggling with the problem called anorexia or bulimia. The disorder is not who your son or daughter is. He or she is not a disorder and may feel like the disorder has taken over his or her identity. This is a significant differentiation to make when conceptualizing the problem and also when talking about the problem with your son or daughter or others. Even though your child or youth may very very consumed by the eating disorder, it is important to stay connected around other interests and not let the struggles destroy your relationship. Externalizing the problem as being outside of the identity of your child also helps you work toward recovery. You can then join together with your son or daughter, other family members and professionals to fight together against the problem, not against the person. The problem is external to your child. It is pathologizing and demeaning to refer to a person as an "anorexic." The way you use language conveys ideas to your child. You can help your son or daughter see that there is hope to get rid of something that is external rather than believing it is an internal and part of a person's identity.

Working on the Problem

There are precipitating or triggering factors that seem to set off the dieting practices that become the habit of restriction or lead to the cycle of restriction, bingeing and purging. This may be such things as current stresses, worries, growing up, changes, moving, loss, bullying or teasing. There can be factors that keep the problem going referred to as perpetuating factors. A perpetuating factor might be something positive that occurs from the not eating that reinforces the problem's usefulness. Examples could be such things as gaining caring and notice from people, bringing parents together around the problem, or feeling less pain through the numbness gained from not eating. There are also predisposing factors which could be related to a genetic predisposition toward eating disorders or personality traits such as perfectionism or lack of flexibility to change. There are two components of the problem that require change. First is dealing with the symptoms. This means changing the habits or eating disorder practices such as food restriction, over-exercise, bingeing or vomiting. It is important to remember that although the habit revolves around food, there are many layers of issues that need to be worked on in order to achieve recover. Although the problem looks like it is about food, it is not really about food. Food is the vehicle for dealing with other worries. Once an individual begins to let go of the habit as the way of coping, then the second step is to ensure that new coping mechanisms are developed to replace the eating disorder practices. This is

where it is important to understand how the eating disorder was helpful and what it means to give up this symptom. It may have been a way to feel more in control or a way to get needs noticed. This differs between individuals and each person needs to understand the significance of their eating practices and find new ways to deal with the issues in life. The child or youth needs to be able to learn to express feelings and needs and find healthy alternate ways to meet those needs without relying on destructive eating practices. As the child or youth starts to express his or her needs, then it is important for you as parents to learn to hear those concerns and needs. It is crucial that you find ways to tolerate the intense feelings that will be expressed and look at areas that require your own self-reflection and change.

Abuse is Only One of Many Risk Factors

As parents it is common to wonder if trauma of some kind, such as physical or sexual abuse, has precipitated the onset of the eating disorder. Trauma or abuse, physical, psychological or sexual, is only one risk a factor in the development of an eating disorder. Eating disorders are usually caused by a combination of risk factors rather than a single triggering event. It is usually a number of variables that culminate in the youth trying to gain control and cope through eating practices and perhaps exercise. It is important to remember that the majority of people with eating disorders have not experienced abuse. It is good clinical practice for the professionals to ask questions to screen for the range of potential trauma, to ensure that issues are not overlooked. So you can expect that your son or daughter will most likely be asked questions about abuse or trauma during an initial assessment for an eating disorder. As parents it is also important to ask your son or daughter about whether someone has touched them in an inappropriate manner that made them feel uncomfortable. Asking about abuse over time is important as children and youth are more likely to give you hints about situations gradually. There is no one symptom indicative of abuse. Unless you have a disclosure, you cannot assume that it has occurred.

Bullying, teasing, harassment, and peer exclusion can be more common forms of abuse and pain that children or youth experience as traumatic. They are common precipitating factors facing youth who develop eating disorders. Such experiences can be minimized by the young person. As parents, you may not have realized the extent of the bullying or teasing or seen it as all that significant. But for a young person, to be left out of a peer group and to be teased or bullied, or to have no friends and be lonely, is incredibly painful, embarrassing and traumatizing. Sometimes it is a family member who has made comments about the child or youth's weight, size or shape that becomes a precipitating factor in a diet. If as parents you have been critical or notice that siblings have said hurtful comments about weight, then it is crucial to take responsibility for such comments, apologize and stop this behaviour. Sometimes comments are said without realizing how hurtful they are or how sensitive the individual is to such remarks because of low self-esteem and lack of confidence. Some people say comments with a humorous edge and think that this makes it non-offensive. If you observe siblings teasing or saying cruel comments, then you need to intervene to ensure the feeling of trust and safety within your home.

Hope

Most children and youth with eating disorders recover. Just over one third completely recover and the problem doesn't recur once a healthy weight and relationship with food is established. Another third, hover a bit below their suggested body weight so are still thinking about food and don't have a healthy relationship with food. These folks can function at school or work but continue to be affected by the restrictive eating practices. You need to know that your son or daughter has the potential to fully recover from the eating disorder. You need to examine your beliefs about recovery. Only if you truly believe full recovery is possible, are you able to pass on this essential message of hope to your son or daughter. Hope can be generated when you perceive competence in the health care providers and their belief that you will get through this problem. You can also find light at the end of the tunnel by talking with parents of

others who have fully recovered. Many youth reflect back citing their parents' belief in their recovery as a motivational force helping them continue moving forward.

Motivators that usually work such as promises of rewards with weight gain such as vacations or pets, don't work as fear isn't rational. Experiencing boredom though does bring a powerful influence. The realization of what food restriction and purging bring with symptoms of starvation and limited social connection, poor concentration and mood dysregulation has an impact on motivation.

Family Based Therapy (FBT)

Family therapy and parental counseling can contribute to recovery of young people with eating disorders and are a necessary component of a comprehensive bio-psychosocial approach to the treatment of eating disorders. Family Based Therapy (FBT) is also known as the Maudsley Approach as it was originally developed at the Maudsley Hospital in London England. FBT is the research based approach that provides the best outcome with children and youth with eating disorders.

When family therapy is suggested, it is important to understand that this does not mean that you are to blame for the development of the eating disorder. Family Based Treatment helps you to feel competent in your role as parents to help your child recover. It is based on parental competence. Family therapy is a process of communicating, working together, building on family strengths and finding a way to help you cope with the eating disorder and its impact on family life. All family members including siblings are affected by the eating disorder. Through family therapy or parental counseling, you can help with recovery. Family therapy may have more impact for children and youth with eating disorders than for adults and needs to be considered whenever possible, especially for youth still living with parents.

Family based therapy for children and youth with eating disorders is considered best practice. FBT can help to: balance power and control; increase the voice of the youth, initially about everything other than food choices. It also enables parents to take charge where needed to provide safety and set limits around food and activity; encouraging food intake; provide structure; deal with conflict; promote family connection; examine your own issues as parents that may impact the eating disorder (such as parental depression or parental food issues); and help parents care for themselves as individuals and as a couple. In rare situations, there may be intense family dynamics that include sexual, physical or emotional abuse or neglect, or extremely destructive family conflict with verbal abuse. If family interaction continues to be destructive after attempts with FBT, then continuing family therapy may not be indicated, or the whole family may not be included.

Parents who work together as a team, even if they are separated, have the most impact in helping to defeat the power of the eating disorder. Parents need to step in regarding limits and decision-making when the eating disorder has impaired the child or youth's ability to make safe decisions. This can be challenging when the child or youth has been able to be very responsible and is competent in domains of their life other than food. Your child will initially resist you taking away food choices and fear is very strong. Once parents do take charge of food, this provides less choice and less time thinking about food, so relief occurs. Some youth feel relieved because they can deal with guilt by saying "I have to eat." Safety comes first. As parents you are responsible for decisions around safety. This can mean saying no such as not allowing a child or youth to participate in activities when malnourished. It means ensuring meals and snacks are scheduled and according to the meal plan without bargaining with the eating disorder. This is hard to do without family therapy.

If you live a long distance from the location where treatment is being provided, it is a barrier to treatment. Technical advances in the form of telehealth (videoconferencing) enable family therapy to be provided to many rural communities. Family therapy can be provided via telehealth as well as team and family meetings including professionals from different sites. Speaker phones and conference calls can also be utilized for this purpose.

Parent and Family Support Groups

Parent support groups draw on the resources of those who are struggling with youth with eating disorders in various stages of recovery. Support is provided through the group facilitators and the expertise of other parents who share experiences and offer possible solutions. Parents who share stories of recovery demonstrate hope. You can be connected with other parents outside of the group for support and can learn so much from someone who has been through the experience because they understand in a way that others may not. Support between parents often develops naturally in an informal way after attending a group. If there is a support group for parents in your area it is strongly recommended that you get involved. Sometimes psycho-educational groups are also offered. You can learn more through a group with other parents in similar situations where discussions can take place and your questions can be answered than reading a book in isolation.

Some groups for families may be called Multi-family Groups and can have an educational, support and therapy focus depending on the groups offered. Groups referred to as multi-family usually include the children and youth along with the parents and siblings in the group. It is important to include siblings as their needs may go unnoticed. Siblings often have a lot to say.

Eating Disorders Resources

The Kelty Resource Centre is a provincial resource that provides educational information to families and sufferers with eating disorders and other mental health problems. The Kelty Resource Centre has excellent videos of meal support to help parents. It is based in Vancouver, British Columbia at BC Children's Hospital and Women's Hospital & Health Centre at 4480 Oak Street. It is in the Mental Health building, 3rd floor. You may also have similar resources in your community.

The Maudsley Parents have a website is an excellent resource of information and videos on Family Based Treatment for eating disorders.