

Learning to Live with OCD

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We Are Not Alone!

Finally, after years of not knowing where to turn, someone has given it a name. A family member has been diagnosed as having OCD (Obsessive Compulsive Disorder) and you want to learn all you can about the disorder. Caring about your loved one with OCD you have undoubtedly wondered, “What can I do to help?” Strangely enough, acting on instincts is not always in the best interest of your family member. Giving in, reassuring, or debating are not always constructive in helping to decrease the symptoms of OCD, nor do these responses always communicate support.

Knowing your family member has an identified disorder may provide some relief that, “at least now we know what to call it and can find someone to help us!” Realization that your family member has OCD is the first step toward learning how to better cope with the symptoms. It takes time and effort to learn to really understand OCD, to accept that someone you love has OCD, and to know how to cope effectively. The symptoms of OCD do not just go away, but with treatment and family support most patients experience some if not significant improvement. You can become proficient at coping; family relationships can improve, and symptoms can decrease. However, there are stages to reach these goals, and remember it takes time! There are also instances when a patient may have a co-morbid disorder that makes engagement in treatment more difficult. Another situation that poses an obstacle to treatment is when the person with OCD is resistant to getting help. In those circumstances you as a family member can begin to make small changes so that OCD does not continue to dominate and rule your life

After years of working with families who have a member with OCD, we have found some repetitive themes: feelings of isolation, frustration, shame, even guilt. Families wonder, “Why don’t they just stop?” Foremost is a plea for help: “What should we do?” Family members usually feel distraught, bewildered, overwhelmed, and frustrated. In an effort to help, you have probably tried to demand that the person with OCD stop his/her “silly” behavior, assist him/her with rituals, or actually perform tasks to “keep the peace.” Either extreme has a disruptive effect on your family’s functioning and can lead to an increase in obsessive-compulsive symptoms. Family conflict inevitably results. As your attempts to “help” the person with OCD are rejected or ineffective, you begin to feel helpless or impotent.

You Can Make A Difference!

A 40 year old woman, who had a 20 year history of severe OCD, and her 60 year old mother began to participate in a family psychoeducation group. They stated that they “had a great relationship and could talk about anything except for OCD.” By the third session, they joyously reported to the group that now they “could even talk openly about the OCD.” When others inquired what made the difference, the woman with OCD said “by my mother coming to the group, reading information on OCD, and listening to others with OCD talk

about their experiences, I feel like she is beginning to understand OCD and what I am going through.”

Conversely, we have worked with families who have come into treatment and report that all conversations are saturated with talk about OCD. Whether it is in asking and providing reassurance to the family member with OCD, or talking about the desperation and anxiety that the illness causes. When these family members are in treatment they are given the challenge of engaging in conversations that are “symptom free,” an experience that they report feels liberating. We have found that it is often difficult for family members to stop engaging in conversations around the anxiety because it has become a habit and such a central part of their life. Setting some limits on talking about OCD and the various worries is an important part of establishing a more normative routine. It also makes a statement that OCD is not allowed to run the household.

It has been our observation that education and an emotional understanding of what it is like to experience the symptoms of OCD should accompany the family's efforts to intervene. Since many people with OCD are otherwise very functional, it is no wonder that you may tend to see the compulsions as behaviors that are within the person's control to initiate or cease. This is a common misunderstanding. Coming to terms with the reality that your family member has “something wrong” with him/her which requires professional attention can be a painful process. Before you can effectively help, you must acknowledge the OCD and learn about it. You must know what the problem is before beginning to solve it! Education is the first step. As you learn more about the disorder, you begin to feel hopeful that you can do things to help the person with OCD. OCD is a biochemical disorder with clinical symptoms that go beyond personality traits. As your understanding increases, you will be able to view the irrational behaviors from a non-personalized perspective. You may be encouraged to engage in self-care behaviors that will impact your ability to problem solve and respond to your family member more constructively. Your family relationships will improve and the person with OCD will feel more supported. Positive family relationships and feeling understood greatly enhance the therapeutic benefits of adjunctive treatments (medication, behavior therapy).

Now We Know What to Call it. . . How Do We Know When OC Symptoms Require Professional Attention?

As you start to learn about OCD, you may find yourself thinking: “That sounds like me!” or “I do that!” Comparing personality traits to symptoms is a common mistake because at face value they seem the same. However, the reason for the behavior is very different. For example, a father who was finding it difficult to understand why his son couldn't “just stop” washing and get off to work, commented that he had cleaning “habits” too and, if he could stop, why couldn't his son? This enraged the sufferer making him more sympathetic. He felt frustrated that his father did not understand the important distinction between a habit and a compulsion.

Distinguishing obsessive-compulsive traits from OC symptoms is important. Studies have shown that almost everyone has one or two rituals. The difference lies in the degree of anxiety and conviction in the belief that the compulsion must be performed. People with OCD feel they cannot control their anxiety in any other way besides doing the compulsions. For people with OCD, their brains tell them to get rid of the feeling of anxiety by doing the ritual that they can count on for immediate relief. It always feels so urgent to people with OCD, as if the alarm is going off signaling danger. It is better to dismiss or identify the behavior as “symptoms” instead of “faults”. We all have one or two rituals, but the behaviors become “symptoms” of a disorder if they are experienced as “unwanted” and interfere with social and/or occupational functioning. When the person can’t control the compulsions, it is important not to blame them as if they did not exert enough will. On the other hand, OCD should not become an excuse for functional impairment. Sometimes, once the OCD is identified, people expect family members to take over their responsibilities so they can avoid situations. This is rarely helpful and in the long run it promotes more symptoms by reinforcing fear and avoidance of what were once neutral situations or objects.

If obsessional worries that are unreasonable in the content or degree of distress and/or repetitive behaviors (or mental rituals, such as praying, counting, reviewing) that are attempts to neutralize the anxiety generated by the worrying presents functional impairment in your loved one it is time to seek professional help. Don’t just go to anyone, though. Make sure the clinician you contact has a lot of experience in treating OCD. The OCD Foundation can provide a list of providers in your region.

What Causes OCD? Am I to Blame?

Some family members have asked, “If I have sub-clinical traits will I develop the disorder?” There is no evidence to support this link. In fact, many people have OC traits their whole life and never develop OCD. Both environmental and genetic factors appear to contribute to the development of OC symptoms. Recent genetic studies, coupled with neurobiological research in people with OCD, have suggested that OCD may run in families. Thus, multiple members of an extended family may be affected with OCD and/or related disorders, like Tourette syndrome (TS). Family members may have variety of symptoms, obsessions and compulsions, generalized anxiety, panic disorder and complex motor or vocal tics (Tourette syndrome). Genetic studies have found that there is a higher concordance rate of OCD in monozygotic twins (about 65%) as opposed to that in dizygotic twins (about 15%). For OCD to be completely genetic, the concordance rate in monozygotic twins would have to be 100%. Since this is not the case, researchers are trying to identify other factors that may contribute to the expression of the disorder. It seems that people with OCD have a genetic vulnerability that is impacted by life stress and environmental factors that results in the expression of symptoms.

While most of the abnormalities point to the neurotransmitter serotonin, other neurotransmitters may be involved. Additional research has implicated specific regions of

the brain in the causation of OC symptoms. It is not as simple as a lack or excess of a neurotransmitter. More likely the problem lies in how the systems in the brain are working. That is, an area (the frontal cortex) of the brain is responsible for executive functions, like logic and judgment. Another structure in the brain controls feeling and yet another behavior. Recent research using brain scanning technology reveals that it may be particular circuits connecting brain structures, driven by neurochemicals are not regulated thus resulting in an inability to use reason to decrease intense feelings of anxiety. These regions of the brain are rich in serotonin receptors and are involved in process and procedural learning and in approach/avoidance behavior.

Correlates of OCD in the animal kingdom have also been identified. A disorder of excessive grooming, acral lick disorder can affect dogs, cats or even birds. It leads to loss of hair or feathers through excessive licking or picking, behaviors appearing compulsive-like. Damage to the underlying skin can cause infection and be life threatening to the animal in extreme cases. Fortunately, the animals afflicted respond to the same medications that are used to treat OCD! These are the medications that work through a serotonin mechanism.

Other physiological factors that may be of consideration in the etiology of OCD are linked to hormonal changes that occur at puberty, pregnancy, nursing, and postpartum, menstrual-cycle correlates, and menopause. At present, OCD could be the result of one of many different biological routes that result in the symptoms. An increasing number of women are experiencing pregnancy or child-birth onset OCD, often mistaken as postpartum depression. This is a critical diagnostic issue because OCD requires specific cognitive behavioral treatment that differs from postpartum depression treatment. Delay in receiving the proper treatment will result in an increase in symptoms. Pregnancy and postpartum acute onset of OCD, though often severe, responds rapidly to cognitive behavioral treatment.

While much scientific research has centered on biologic factors, there is a large body of literature on the learning theory model of OCD. The most popular model draws from Mowrer's two-stage theory for the acquisition and maintenance of fear and avoidance behavior. In the first stage of acquisition, neutral objects (toilet seats, scissors), thoughts ("someone will get hurt"), or images (the devil) become associated with fear/anxiety by being coupled with an aversive stimulus that provokes discomfort. In stage two, or maintenance, avoidance of the triggers (situations, objects) is reinforced because anxiety is reduced. This explanation is simplistic and the interested should explore the resources in the suggested reading at the end of the booklet for more information. Also, internal triggers (thoughts, images, impulses) can evoke distress and set off compulsions. Furthermore, compulsions are not always overt. In fact many people with OCD describe mental compulsions, such as counting, reviewing a conversation, checking a room in one's mind. In addition, cognitive models complement behavioral, or learning models, by addressing the faulty cognitive processing typical in OCD. Although the thoughts that are so troublesome to people with OCD are common to most of us, those with OCD experience excessive discomfort, fear catastrophe and have more difficulty dismissing them. Researchers in the cognitive field are looking at cognitive phenomena (beliefs, memory,

information processing, attitudes, perceptions) to distinguish OC thought processes from normative ways of thinking.

A group of expert clinical researchers have identified 6 belief domains that are problematic for persons with OCD: 1) overimportance of thoughts, 2) importance of controlling one's thoughts, 3) perfectionism, 4) inflated responsibility, 5) overestimation of thought, and 6) intolerance for uncertainty. The overimportance of thoughts is a hallmark cognitive feature in OCD. That is, most people with aggressive, sexual, and magical thinking assume that if they have a thought it means they are likely to act on it; otherwise referred to as "thought-action fusion". Cognitive therapy is a systematic process of examining one's assumptions and beliefs and learning to explore alternative ways of thinking about automatic thoughts to reduce anxiety.

It is important to acknowledge that OCD is not the person's "fault." Similarly, you as a family member must learn you didn't cause OCD; it is not caused by upbringing. Parents with OCD worry they will teach their children to have symptoms. A parent who is a "washer" may have a child who is a "checker". Although genetics seems to play a role in OCD and children do mimic parents, kids cannot learn the anxiety that accompanies OCD from their parents. The symptoms of OCD are numerous and some are not so obvious; for a complete list and description, please see suggested reading.

Perhaps it is human nature to feel responsible for psychological phenomena which have no single clear explanation. You may ask yourself: "Well, if I didn't cause it, what did?" At present, the best general explanation is as follows: A genetic predisposition most likely involving the neurotransmitter serotonin, may make a person vulnerable to developing OCD. Certain values, ethics, and beliefs can have a contributing effect, but parents do not cause OCD. Families frequently express guilt in the way they have reared their children or responded to their spouses. Families who accommodate to their children's symptoms because of this sense of guilt may find that their son/daughter may develop symptoms of a behavioral disorder as a result of the accommodation. Parents have often talked to us about the fact that they give in to unreasonable demands because their son/daughter is so unhappy most of the time and because they themselves feel so powerless over the symptoms. We have worked with families that go out at midnight to buy fast food, or cleaning supplies for a son or daughter who has OCD, because he/she demanded it and the parents felt it could make them more comfortable and or happy. Although understandable, this type of accommodation only inflates the person's sense of power and control and can be detrimental to normal adolescent development. Blaming family members is unproductive. Rather, family members can learn how to become involved in the treatment in OCD and may play a critical role in facilitating improvement in functioning as opposed to enabling the continuation of symptoms. By learning supportive behaviors that extract you from the compulsions, as a family member, you can make a difference in the course of your loved one's symptoms and in their life!

What are OC-Spectrum Disorders?

There is research to suggest that OCD is best conceptualized along a spectrum of impulsive and compulsive disorders. There may be biological similarities among these disorders yet enough difference that results in distinct symptoms, such as hairpulling in Trichotillomania, preoccupation with an imagined or exaggerated body “defect” in Body Dysmorphic Disorder. Despite the biological variations, cognitive-behavioral treatment generally would proceed the same way it does for OCD and similar medications are beneficial.

Developmental Disorders in Children/Adolescents with OCD

In our work with adolescents we have had the opportunity to with young people who may have an autistic spectrum or other developmental disorder. At times these individuals have been misdiagnosed as having OCD, with professionals identifying their “special interest” as obsession and stereotypic movements as rituals. It is important to remember that with OCD, the obsession is an unwanted persistent thought that does not give pleasure to the person with OCD and that rituals are actions done (sometimes repetitively) in an effort to relieve anxiety related to a fear or thought.

There are young adults who are diagnosed with an autistic spectrum disorder such as Asperger’s disorder who also have OCD. In our experience, treatment may be more complicated due to the child’s difficulty tolerating anxiety and poor insight into OCD symptoms. A common characteristic of people with a developmental disorder is decreased executive functioning, which translates into rigidity in thinking and lack of cognitive flexibility. This area of functioning allows us to problem solve, plan, put off impulsive urges, tolerate frustration towards a greater end and be flexible in our thinking and actions. Since the treatment of OCD requires that one is able to engage in behaviors that may initially increase anxiety in the service of habituation and long term relief of symptoms one can see why standard exposure response prevention with this population may pose certain challenges. Discussion of how to get around these challenges is too large a topic for this pamphlet, we refer you to the books in the list of resources at the end.

Does OCD Go Away?

Most patients with OCD have an up and down (waxing and waning) course. You may set yourself up for disappointment by expecting that once the obsessive-compulsive symptoms go away, they are gone forever. There are some people who may have one episode and then remain symptom-free for the rest of their lives. However, it is best that you be prepared for symptoms to flare up during stressful times or during changes and to help the person with OCD to anticipate this, too. The up and down course of OCD can be influenced by a number of factors, most often stress. The stressful event can be almost anything, including happy or positive occasions. People with OCD often comment that they don’t like change and find any kind of change difficult. At this point in time, there is no guaranteed “cure”

for OCD. There are effective forms of treatment which can allow the sufferer to lead a “normal life”. As a family member you can learn what to expect and how to respond to the “ups and downs”. This is the good news about the diagnosis of OCD. The treatment works, if you use it!!

Treatment

Experienced clinicians agree that a multimodal treatment approach that includes medication, behavior therapy, and family education and support is optimal.

Medication

Several medications that are now available have a beneficial effect for individuals with OCD. These medications are: clomipramine (Anafranil), fluvoxamine (Luvox), sertraline (Zoloft), fluoxetine (Prozac), and paroxetine (Paxil), citalopram (Celexa). These medications lead to changes in the serotonin system in the brain. A number of these medications are marketed as antidepressants as well. This is fortunate, since many patients with OCD additionally suffer with symptoms of depression, including loss of interest and energy, poor concentration, difficulty with sleep, perhaps even suicidal thoughts. It is not always clear if these symptoms are secondary to the OCD, that is, depression in response to living with OCD, or a separate illness (primary depression). Fortunately, the medications prescribed treat both the OC and the depressive symptoms. At present, citalopram is not FDA approved in the treatment of OCD; however it is used in clinical practice. With regard to medications approved in the treatment of OCD for children, sertraline, fluvoxamine and clomipramine have been FDA approved.

Sometimes additional shorter-acting antianxiety medications, such as clonazepam (Klonopin) or lorazepam (Ativan), may be helpful is used with discretion. In cases where the person with OCD has little or poor insight into the unreasonableness of their fears, a psychiatrist may recommend an atypical neuroleptic such as olanzapine (Zyprexa), orap (Pimozide) or risperidone (Risperdal) in addition t the SSRI, to help the person think more rationally. For more information about medication, see [Drug Treatment of OCD in Adults: A guide](#), by Michael Jenike, MD, available through the OCF.

It is important for people with OCD and family members to recognize that medication alone rarely takes away all the symptoms. Adding other treatment modalities helps the person with OCD to better control their symptoms. To date, it appears that medication only works to control and not to "cure" symptoms in most cases. Again, contrary to popular belief, medication, by itself, hardly ever completely obliterates the symptoms of OCD. When the medications are effective, most people with OCD say that it helps them to dismiss the worries and resist the compulsions more easily. So, some effort by the person with OCD is necessary to decrease symptoms and medication may help to facilitate this process. When the medication is stopped, however, symptoms usually return within several weeks and it once again becomes more difficult to resist urges to perform compulsions.

Adding other forms of treatment, particularly cognitive behavioral therapy, offers the best hope of getting by with less medication or no medication in the long run.

Cognitive Behavior Therapy

Cognitive behavior therapy (CBT) is the clinically researched and proven effective treatment of choice, whether with or without medication. Unlike psychotherapy, which often delves into one's past to find the "root" of problems, CBT takes a practical "here and now" approach to eliminate unwanted behaviors.

Exposure and Response Prevention

In particular, for OCD, exposure and response prevention (ERP) is the potent ingredient of CBT. To proceed with ERP, one must generate a hierarchy, or list, of feared/avoided situations, objects (external triggers), and thoughts, images, impulses (internal triggers) that evoke distress. Each item is rated on a scale of 0-100 in terms of the amount of distress generated and this is called subjective units of distress (SUDs). To eliminate symptoms, people with OCD must expose themselves directly to those situations that are feared or avoided. The exposure is best done in a stepwise progression, beginning with the items lowest in SUDs ratings. Next, the person needs to be encouraged to resist, or at least delay, the compulsions they feel must be performed because of a feared consequence or heightened anxiety. This part is called response prevention. As exposure and response prevention is practiced over and over, the person with OCD learns that "nothing bad happens" when the rituals are resisted. At first, anxiety soars because of unreasonable fears of catastrophe. In time, the person can say to him or herself, "Well, I only washed once, no one got hurt." For those with a sense of incompleteness or general discomfort from anxiety if compulsions are not performed, exposure to "trigger" situations and resisting rituals, decreases discomfort over time, as well. Be aware that exposure and response prevention often evokes an initial increase in anxiety, as compulsions are resisted. We have had patients and family members return to a session complaining that the OCD seems worse and that the treatment is not working. Although compulsions decrease rapidly, anxiety and often obsessions can increase. It takes longer for anxiety and obsessions to extinguish. Persistence and repetition are essential.

With this approach, a person basically learns to reprogram their nervous system and establish the brain circuits to function properly again. This process is called habituation. It is the same biological phenomenon that occurs when you visit someone who lives near train tracks. Initially you think, "How could anyone live with all of that noise?" But, if you stay at their house all weekend, you stop noticing the passing trains, too! Our nervous systems are equipped to adapt to changing environments and aversive stimuli. People with OCD prevent this through avoidance of the stimuli and neutralizing rituals.

Imaginal Exposure

The same process is used to treat internal triggers (thoughts and images) that evoke anxiety. Imaginal exposure is used to neutralize anxiety through repeated exposure to dreaded thoughts, words, or images. This is accomplished several ways. Sometimes simply writing the words or statements that provoke anxiety that the person tries to avoid is enough in itself. The person with OCD writes and says aloud such things as "I am a child molester",

“I will stab my baby”, “I will get AIDS”, over and over until the discomfort provoked by these statements subsides. You are probably wondering, “why in the world would you have someone do this?!! Won’t it make them worse? Then, they will never stop thinking about that!” This is a very counterintuitive approach; however, this type of exposure directly to the obsessive thought is very potent. If we are trying to convince the person that their thoughts are unreasonable and generate unreasonable anxiety, then they ought to be able to make themselves think them and not be afraid that any thought can lead to action. This approach decreased the importance that people with OCD give to their thoughts. A thought is just a thought! In order to believe this, one must practice this. Initially people feel very distressed doing imaginal exposure but with repetition, our patients actually tell us they get bored thinking of this and nothing else over periods of time! Family members are amazed by the results, too. Because the delivery of this intervention is crucial, imaginal exposure is best conducted under the supervision and guidance of a therapist experienced in CBT for OCD.

Another way to approach imaginal exposure is to by first write and then tape a highly detailed story of the feared consequence as if it were occurring in the first-person present tense. Listening to the tape of the story neutralizes the internal triggers (thoughts images impulses) the same way it works by direct exposure to objects and situations.

The imaginal exposure exercises are purposeful and occur at planned time during the day. At all other times, when the obsessions erupt spontaneously throughout the day the person with OCD must try to use distraction, dismissal and delay to train their mind to “put aside” what seem like urgent worries. This also means resisting compulsions such as reassurance seeking, avoidance and mental compulsions (e.g., checking, praying, counting). Like direct ERP, these two procedures (imaginal exposure and resisting rituals) in tandem diminish the frequency and severity of intrusive thoughts, and reduce anxiety levels overall.

Flooding

Although proceeding in stepwise fashion is the first suggested course of action, there are times when flooding can be successful and may be necessary. Flooding is the term to define what happens when one is exposed to their highest items on their hierarchy first. Some people with OCD have found that once they are able to expose themselves to these items, the ones lower on the hierarchy do not impact them as much. While we do not suggest flooding as primary intervention especially without the person’s knowledge, there are circumstances when this needs to happen, especially if physical health is impacted and/or if safety is an issue. We have worked with families where a patient has refused to eat due to their fear of contamination of food. In such a situation, we would encourage family members to get this patient to a medical setting regardless of contamination fears. Another example is less drastic but involves a family where the person may be demanding that their children and spouse to go through extensive cleaning rituals before entering the house. In this situation, while the patient is in therapy, or even if patient is resistant to therapy but the family member is seeking help for him/her self and family, we would encourage family members to stop accommodating behaviors that directly impact their functioning. This, of course, is done with care and concern and also by letting the OCD patient know the timeline for withdrawing accommodating behaviors. For example, the

family member may say, “in 3 days, we (the kids and I) are going to stop showering after we’ve gone out of the house. We won’t go into your room, that is your ‘safe’ zone”, but we will not limit our activities within the rest of the house.”

Behavior therapy takes an enormous amount of practice and patience as well as a strong sense of motivation to tolerate increasingly high levels of anxiety. A good analogy for exposure and response prevention is exercise. When a person begins to run, for example, they start off at a slow pace and a small distance. As strength and endurance is built, greater distances can be covered at faster paces. Sore muscles along the way are interpreted as signs of good use in areas that were lacking conditioning. Have you ever heard anyone say they are giving up exercise because their muscles were sore and that it must be bad for them?

As a person begins behavioral therapy, an initial increase in anxiety is often viewed as "I must be doing something wrong because this is supposed to make me feel better", instead of "This anxiety is a good sign that I'm confronting the things that make me distressed, so I will feel more uncomfortable at first". Too often people stop behavioral treatment because of the initial increase in anxiety, unaware that the habituation process takes time to occur. Compared to the length of time someone is symptomatic with OCD, decreases in distress and compulsions occur quite quickly with consistent use of exposure and response prevention. Despite this, most people are impatient and expect the worries to go away more speedily than is realistic. Even after compulsions stop, worries will linger because behaviors change faster than thoughts and feelings. Understanding all of this helps you as a support person, to be a better coach.

Cognitive Therapy

In addition to behavior therapy, cognitive therapy may be added. True cognitive therapy will assist the person to examine their thought processes to label faulty assumptions. Some of the faulty thinking that is prominent in OCD is: all or nothing thinking; thought-action fusion (If I have a thought it will lead to action; overestimation of risk, danger, harm; heightened responsibility; magical thinking; overimportance of thoughts; intolerance of anxiety/uncertainty. Cognitive therapy is aimed to lead people to develop insight into their thought processes and to understand how thoughts are connected to behaviors and feelings. A goal is to change the way a person responds to automatic thoughts. We cannot help what pops into our heads, but we can choose how we respond!

A thought record is a useful tool to examine the reasonableness of the content of thoughts, label the type of thinking and learn to respond differently. Even if people at first don't believe alternative ways of thinking, over time, one can change the way one thinks. Other cognitive techniques include pie chart and probability estimates, downward arrow, challenging faulty beliefs, practicing alternative thought responses.

Family Interventions

Family intervention is an important adjunct to pharmacologic and behavioral treatment. One format that has been effective is the multifamily psychoeducational support group. This is a group comprised of family members and sufferers who meet for the purpose of

learning about OCD, its impact on the family, and strategies to cope. One report on clinical research stated that 88% of family members they surveyed participated in some way in OCD symptoms. In this study, greater family participation in symptoms significantly correlated with dysfunction in the family and negative attitudes toward the person with OCD. These features may serve to maintain the severity of OC symptoms and family groups can help to address these difficulties that could affect recovery.

Support Groups

Multifamily Psychoeducational Support Groups are unique in that they provide a rare opportunity for family members and sufferers to feel less isolated and less estranged. It is an empowering process to learn about OCD, share similar experiences, and discuss alternative problem-solving approaches. You will feel relieved to know that others are struggling with the same fears, concerns, questions, and conflicts related to OCD. Studies have shown that family members who respond to the sufferer with decreased expressed emotion (over involvement/accommodating or critically/hostile attitude) have poorer treatment outcome. Multi-family psychoeducational support groups can help family members share experience, strength and hope and support learning and the use of new coping skills

Multifamily psychoeducational support groups can be professionally facilitated or founded on self-help principles. If you are about to begin a group like this on your own, it is advisable to consult with professionals to obtain accurate clinical information. Also, families can educate themselves by viewing videotapes and reading literature. (You can request resources from the OC Foundation).

Family Behavioral Treatment Groups

Another multifamily approach that actually incorporates family/support persons in treatment is multifamily behavioral treatment (MFBT). The MFBT we have developed is comprised of 6-7 families and includes the person with OCD. There is a private meeting with each family unit alone twice, each session lasts 1.5 hours and the purpose is to gather information and describe the MFBT in detail. Then, there are 12, 2 hour weekly multifamily sessions and 6 monthly check-in sessions. During the 12 weekly sessions, psychoeducation about OCD and active behavioral therapy are provided. The treatment is modeled after individual behavioral treatment, consisting of in vivo exposure and response prevention with between session homework and self-monitoring. In addition, families observe the exposure and response prevention exercises, share experiences and problem solving strategies with other families, and learning how to negotiate agreements on how to best respond to the demands of OCD. These agreements are called family behavioral contracts.

Family Behavioral Contracts

The primary objective of the behavioral contract is to facilitate the family members and sufferers to work together to devise specific plans on how to manage the OC symptoms in behavioral terms. This reduces conflict and preserves the household. It also provides a platform for families to begin to “take back” the household in situations where all household routines and activities have been dictated by OCD rules. By improving

communication and developing a greater understanding of each other's perspective, it is easier for the individual with OCD to have family members help them to reduce OC symptoms instead of enable. Experience has proven that the most effective family behavioral therapy results from family members and individuals with OCD negotiating these "contracts". Some families are able to do this by themselves while most need some professional guidance and instruction. The idea behind family contracting is that realistic goals are established by people with OCD and family members together.

The process itself is reassuring and validating to the individual with OCD. The family's message is: "We recognize that something is wrong, and we will all work together to make it better!" For example, the person may choose the goal of sorting through and washing a pile of "contaminated" clothes that has been avoided. The individual with OCD then discusses with family members explicitly how they can help. This may mean: accompanying the person while doing the task, agreeing that the person with OCD will only receive reassurance once from family members that in fact the clothes are not contaminated, and providing some kind of reward after the goal has been achieved (going out to dinner, a lot of praise) as a positive reinforcer. Another example of how family behavioral contracting works can be illustrated is the case of a 35 year old man with a hoarding compulsion. He had garments from his teens that he hadn't worn in 20 years. Due to an overfilled closet, the bedroom, as well as other rooms, became extremely cluttered and unbearable. This man and his wife agreed that he would relinquish one article of clothing from his closet each day for a month. Because it is so difficult for hoarders to let go of anything, limits needed to be set. If by 8:00 p.m. each evening, the man with OCD did not give his wife one garment, she had his permission to go into his closet and select 3 items out of which he would choose one. If by 8:30 p.m. he still did not choose one item to relinquish, she would. Thus, the person with OCD is firmly encouraged by family, but given the responsibility of confronting his/her fears and resisting compulsions or avoidance.

The Transition Zone

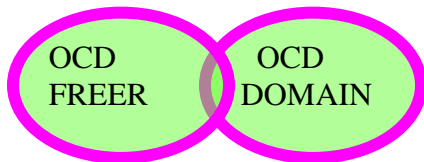
Below is a diagram that we have used as a tool with families to help them with behavioral planning. This tool gives everyone a visual map of identified behaviors that will be targeted in the behavior plan to begin to free up areas of the household; relationships and lives that may be dominated by OCD symptoms.

Again this is a collaborative endeavor and one in which we encourage the person with OCD and family member to participate in equally. By this we mean that the family member can identify an accommodating behavior that they have been engaging in that is bothersome to them and that they wish to stop. This accommodating behavior is placed in the "transition zone" area of the diagram. If a family member identifies a behavior that they would like to put into the transition zone, that the person with OCD is not ready to face, then negotiating needs to occur to define a timeline for how the family member will withdraw the accommodation.

The diagram also calls for families to identify areas of their lives/relationships that are 'freer' of OCD. This encourages family members to look for the exceptions to when OCD

symptoms are dominating the household. The OCD Domain identifies household routines/activities and relationships that are impacted and sometimes entrenched in OCD rules/behaviors.

In families with adolescents who have OCD where family routines have been absolutely taken over by the disorder (such as in the example below) we suggest that the family cease the accommodation that changes their family culture/routine while showing support and encouragement for the young person with OCD.



Transition Zone

For one family, mealtimes were exceptionally difficult because the person with OCD insisted that everyone wait until she was done serving herself before others could sit down to eat. This person was often late, stuck in other cleaning rituals and the family at times would wait until very late to eat dinner. For this family “mealtime” was put into the transition zone. Although the daughter was not ready to deal with her contamination issues and wanted her family to continue to wait for her to start before they served themselves, their contact read like this:

At mealtimes, the person with OCD cannot insist that everyone wait to eat until after she has taken her food. Family members will state that meal is going to start and will give the person with OCD 5 minutes to get a head start on serving herself. If the young woman with OCD feels she cannot make it to the table some food will be put on the counter so that she can eat later. In this fashion, the impact on the family from the OCD contamination problem is diminished, while compassion is demonstrated for the person with the OCD. Ultimately, it is the person with the disorder that has to expose themselves to the triggers to overcome their anxiety and fears.

A word of caution before employing any of these strategies on your own: all goals and contingencies must be clearly defined, understood, and agreed upon by any family members involved with carrying out the tasks. Families who decide to enforce “OCD rules,” without discussing it with the person with OCD first, find that their intention to stop the OCD backfires. Implementing a plan to change existing behaviors should proceed in clearly defined and discussed steps. After attending a family education and support group for the first time, a husband left with the message to refuse to participate or assist in rituals

and to reduce avoidance as much as possible. After 20 years of assisting his wife, “to keep the peace,” the husband went home and stopped “helping” her with compulsions. You can imagine the rage that flared, and the husband reverted back to his old style, feeling bewildered, angry, misinformed, misled, and impotent once again. The husband did take home the correct message from that first meeting; the way he put it into practice was the mistake. Those of you who have felt “pushed” (to the point of turning off the water in the house to stop washing compulsions, or removing switches or doorknobs to stop checking) now find that interrupting the compulsion to put an end to it often results in intense family conflict which is often as painful as living with the OC symptoms. Thus, the point of utmost importance is that before family members intervene, there should be discussion, negotiation, and agreement between the person with OCD and the family member(s) to move forward with the plan. For family behavior therapy to work this process is critical. The exception is in a situation that is life threatening or dangerous when you may be called to act despite the OCD "rules".

In some cases, Individual Family Behavioral Therapy can be particularly helpful for those who need more intensive professional attention than can be obtained in a group.

Residential Treatment

People with OCD who have not been successful with CBT on an outpatient basis now have several opportunities to receive residential treatment. For more information about the facilities that offer such treatment, contact the OCF or visit the web-site:

<http://www.ocfoundation.org>.

When the Person with OCD Won't Recognize It

I have received calls and letters describing perhaps the most difficult situation: when family members recognize symptoms of OCD and the person with OCD will not do so and refuses to be helped. The ideal is not always reality. Some of you may have a family member who absolutely refuses any treatment or may even deny that the symptoms of a disorder exist. These are extremely trying situations that evoke feelings of despair. Sometimes you may have no choice left but to carry on with your life, while reminding the sufferer periodically that you are willing to help, that you recognize their shame and distress, and that people get better from OCD. In general, people with OCD cannot begin behavioral or medication treatment unless they are willing to. Sometimes when the discomfort or impairment becomes so great that it affects a job, relationships, enjoyment of life, the person with OCD will come forward to accept professional advice. Families have told me of watching the bottom “fall out” and just how badly things deteriorated before their loved one would admit to a problem. This is a painful process and you have choices as a support person. Often, admission to “a problem” does not mean acceptance of the problem. For the whole family, acceptance is a process that takes time. As a family member, your goal is threefold - 1) get support and help yourself, 2) try to help the person with OCD learn about the disorder and the treatment available, and 3) allow natural consequences to occur for the person with OCD so that this may motivate them to seek treatment (late for work, miss school)

That a parent or a loved one recognizes OCD is the first step. Then it is important to learn as much about the OCD as you can. In addition, attend any support groups for OCD that are available, join the OCD Foundation, get the OCD newsletter and perhaps even find a family buddy (through the OC Foundation). Talking to other family members so you can share your feelings of anger, sadness, guilt, shame, and isolation is very important. Discussing how other families handle the symptoms and getting feedback about how you can deal with the OCD will make you think more critically about your responses and offers alternatives. In general you should:

- 1) Bring literature, video tapes, and audio tapes on OCD into the house. Offer the information to the sufferer or leave it around (strategically) so they can read/listen to it on their own.
- 2) Inform your loved one that it is in their best interest for you to be involved as little as possible with the behaviors they feel they need to do. You are here to help them resist their compulsions, but you cannot assist or do them. Explain that you are doing all you can to understand their pain but that your giving in to the unreasonable demands will only make the situation worse.
- 3) Encourage the person with the assurance that through available treatments most people experience a significant decrease in symptoms. There is help and there are others with the same problems.
- 4) Suggest the person with OCD attend support groups with or without you, talk to an OCD buddy (through the OC Foundation) or speak to a professional in a local OCD clinic.

If the person with OCD still refuses to acknowledge that there is anything wrong, you can take definitive action. These actions may include:

- 1) Continue support for yourself and, if available, seek professional advice/support from someone experienced with OCD.
- 2) Refuse to be involved with the OCD - no reassurance giving, no extra hand washes, no checking, and no avoidance.

This may make the individual with OCD more hostile because he/she feels thwarted. Again, gently explain that you offered to seek professional help together, but you cannot continue to live by OCD rules and you won't. Remind him/her that your giving in may make him/her feel better temporarily, but that it doesn't help the symptoms to decrease, in fact, it only makes them spiral downward. This is usually the most difficult part for families to enforce. It is hard to set limits with empathy. Often this must be done to help the person acknowledge that a problem exists. After all, if you continue to make them comfortable, by helping to reduce their anxiety temporarily, why would they want to face the seemingly insurmountable task of changing? If you have been an "accomplice" in the OCD and now recognize this, gently withdraw and hold the line. On the other hand, if you have refused to

have anything to do with the OCD besides yelling “knock it off”, you must stop that too and learn more so that you can say the same thing, but in a way that feels more supportive and shows your understanding of the struggle the person with OCD is experiencing. In any case, it is essential to be consistent. This may mean talking with other family members to ensure a unified approach; otherwise your good intentions could be undermined. For example, in one family, the mother stopped doing the laundry for her 28 year old son, but her husband did it instead, because they did not have an agreed upon plan on how to handle the OCD symptoms.

In some very severe cases, a sufferer will eventually choose to move out of the house. If the sufferer is not a minor, lives alone, and is not a danger to himself or others, there may be only so much you can do to get him/her to seek help. This does not mean to stop getting support for yourself or to stop trying. Sometimes it takes years of perseverance. Again, remember that learning to accept OCD and benefiting from treatment is a process.

Guidelines for Living with OCD

Families are constantly affected by the demands of OCD. Results from research investigating family and OCD suggest that family responses may play a role in maintaining or even facilitating OCD symptoms. The more that family members can learn about their responses to OCD and the impact that their responses have on the person with OCD, the more the family becomes empowered to make a difference!

Responses of families to the person with OCD vary. There are five typical responses: 1) families who assist with the rituals and encourage avoidance (do things for the person with OCD) to keep peace, 2) families who do not participate in them but allow the compulsions, 3) families who refuse to acknowledge or allow the compulsions in their presence, 4) families who split in their responses - some family members giving in all the time and some refusing to and 5) families whose members swing from one extreme to the other, trying to find the “right” solution. In any case, extreme and/or inconsistent family responses create more feelings of frustration and helplessness as the OCD symptoms seem to increase.

Family members who take over roles and participate in or assist with compulsions tend to become emotionally overinvolved, often neglecting their own needs and at the same time fostering the cycle of obsessions and compulsions. On the other hand, those family members who express hostile criticism by labeling the person as “crazy” or telling them to “just snap out of it” may be perpetuating symptoms as well. Research has found that some criticism of the OCD symptoms but not directed toward the person can be a useful motivator and may help the person with OCD face their fears, consistent with exposure-based therapy. The rules of OCD cannot become everyone’s reality. It is hard to find this fine line between setting limits of the affect of OCD on the family and expressing support and empathy for the person afflicted. OCD is a family affair and the sooner you can learn to respond in more therapeutic ways, the better you will feel as recovery begins.

The natural tendency to put the warning signs of OCD aside seems to prolong seeking professional help. As more is learned about OCD, one can be more optimistic about treatment and recovery.

In an effort to help families, the following list of guidelines has been developed by family members and people with OCD who have experienced the difficulty in coping first hand.

General Guidelines

1. Learn to recognize the signals that indicate a person is having problems.
2. Modify expectations during stressful times.
3. Measure progress according to the person's level of functioning.
4. Don't make day-to-day comparisons.
5. Give recognition for "small" improvements.
6. Create a strong supportive home environment.
7. Keep communication clear and simple.
8. Stick to a behavioral contract.
9. Set limits, yet be sensitive to the person's moods.
10. Keep your family routine "normal."
11. Use humor.
12. Support the person's medication regime.
13. Separate time for other family members is important.
14. Family members must be flexible!

(1) Recognize Signals

The first family guideline stresses that family members recognize the "warning signals" of OCD. Sometimes people with OCD are thinking things you don't know about as part of the OCD, so watch for behavioral changes. This list of 12 signals is by no means exhaustive. Do not dismiss significant changes as "just their personality". Remember changes can be gradual, but overall different from how the person generally has behaved in the past. When asked to list behaviors noticed as changes or peculiarities that begin to interfere with someone's social and/or occupational functioning, families commonly report noticing unexplained blocks of time that the person is spending alone (in the bathroom, getting dressed, doing homework), avoidance, irritability, indecisiveness. These behaviors can be easily mistaken for laziness or manipulation. It is essential that you learn to view these features as signals of OCD, not personality traits. This way, you can join the person with OCD to combat the symptoms, rather than become alienated from the OCD sufferer. People with OCD usually report that the more they are criticized or blamed, the worse the symptoms get!

Signals to watch for include:

1. Large blocks of unexplained time.

2. Doing things again and again - repetitive behaviors.
3. Constant questioning of own need for constant reassurance.
4. Simple tasks taking longer than usual.
5. Perpetual tardiness.
6. Increased concern for minor things and details.
7. Severe and extreme emotional reactions to small things.
8. Inability to sleep properly.
9. Staying up late to get things done.
10. Significant change in eating habits.
11. Daily life becomes a struggle.
12. Avoidance.

(2) Modify Expectations

Consistently, people with OCD report that change of any kind (even positive change) is experienced as stressful. It is during those times that symptoms flare. Along with being able to identify OC symptoms, you can help to moderate stress by modifying your expectations during times of transition. Instead of projecting a frustrating “Snap out of it!” message, a statement such as: “No wonder your symptoms are worse, look at the changes you are going through,” is validating, supportive, and creates a positive alliance. Further, family conflict only fuels the fire and promotes symptom escalation. It helps to be flexible with the behavioral treatment program during stressful times.

(3) People Get Better at Different Rates

The severity of OC symptoms is a continuum. Severity is usually rated by the degree of emotional distress and the degree of functional impairment. There is a wide variation in severity of symptoms between individuals. You should measure progress according to the person’s own level of functioning, not to that of others. You should encourage the sufferer to “push” himself as much as possible, to function at the highest level possible. Yet, if the pressure to function “perfectly” is greater than a person’s ability, it creates another stress which leads to more symptoms. For example, you may have observed differences between those with OC symptoms and have made comments (or thought): “Well, if that person can uphold family responsibilities and work, why can’t you?” This may be an unreasonable expectation given an individual’s pattern or course of illness. Just as there is a wide variation between individuals regarding the severity of their OC symptoms, there is also wide variation in how rapidly individuals respond to treatment. Be patient. Slow, gradual improvement may be better in the end if relapses are to be prevented.

(4) Avoid Day-To-Day Comparisons

Often sufferers feel like they are “back at the start” during symptomatic times. You may have made the mistake of comparing your family member’s progress with how he functioned before developing OCD. Due to the “waxing and waning” course of OCD, it is important to look at overall changes since treatment began. Day-to-day comparisons are misleading because they don’t accurately reflect improvement. Help the person to develop

a realistic “internal yardstick” to measure progress. On the days that the sufferer “slips”, you can remind him that “tomorrow is another day to try”, so that the increased rituals won’t be interpreted as failure. Feeling as though one is a failure is self-destructive: it leads to feeling guilty, feeling “imperfect”. These distortions create stress which can exacerbate symptoms and lead to feeling more “out of control”. You can make a difference, if you remind the sufferer of how much progress he has made since the worst episode and since beginning treatment. Become knowledgeable with the Yale Brown Obsessive Compulsive Scale (Y-BOCS) and refer patient to last score. This can help everyone avoid the use of emotional reasoning in measuring success and provide an objective evaluation. This is an evaluation that the patient’s therapist can assist you and your family with.

(5) Recognize “Small” Improvements

People with OCD often complain that family members don’t understand what it takes to accomplish something such as cutting down a shower by five minutes or resisting asking for reassurance one more time. While this may seem insignificant to family members, it is a very big step for them. Acknowledgement of these seemingly “small” accomplishments is a powerful tool that encourages the person with OCD to keep trying. This lets the sufferer know that his hard work to get better is recognized by you. Verbal praise is a strong positive reinforcer. Don’t hesitate to use it!!

Family members sometimes struggle with finding a balance of recognizing small improvements and a fear that bringing attention to it may trigger the OCD sufferer. At dinner a family member recognized that his child could pass the salt/pepper shaker when previously they would not have been able to. This parent struggled with whether or not to recognize this success for fear that doing so might make his daughter anxious. We encourage families to use verbal praise as a positive reinforcer and also to balance how much of family time/conversations are symptom focused. Finding a balance and being flexible is the goal.

(6) Create a Supportive Environment

The more you can avoid personal criticism, the better. It is the OCD that gets on everyone’s nerves. Try to learn as much about OCD as you can. Your family member still needs your encouragement and your acceptance of him as a person. Remember that acceptance and support does not mean ignoring the compulsive behavior. Do your best not to participate in the compulsions. Without hostility, explain that the compulsions are symptoms of OCD with which you won’t help because you want the sufferer to resist. This projects more of a non-judgmental attitude that reflects acceptance of the person.

(7) Keep Communication Clear and Simple

Avoid lengthy explanations. This is often easier said than done, because most people with OCD constantly ask those around them for reassurance: “Are you sure I locked the door?” “Can I be certain that I cleaned well enough?” You have probably found that the more you try to prove that the sufferer need not worry, the more he disproves you. Even the most

sophisticated explanations won't work. There is always that lingering "what if?" Tolerating this uncertainty is an exposure for the OCD sufferer and may be tough. Recognize this and let the conversation go.

(8) Stick to a Behavioral Contract

In your efforts to help the sufferer reduce his compulsions you may easily be perceived as being "mean or rejecting," although you are trying to be "supportive." It may seem obvious that family members and sufferers are working toward the common goal of symptom reduction, but the ways in which people do this varies. First, there must be an agreement between family members and sufferers that it is in the sufferer's best interest for family not to participate in rituals (this includes responding to incessant requests reassurance). It is ideal for both family members and sufferers to reach this agreement. Often attending a family educational support group for OCD or seeing a family therapist with expertise in OCD facilitates family communication. As a general rule, short, simple responses are best.

(9) Set Limits But Be Sensitive to Mood

With the goal of working together to decrease compulsions, family members may find that they have to be firm about: 1) prior agreements regarding assisting with compulsions, 2) how much time is spent discussing OCD, 3) how much reassurance is given or, 4) how much the compulsions infringe upon others' lives. It is commonly reported by sufferers that mood dictates the degree to which the sufferer can divert obsessions and resist compulsions. Likewise, family members have commented that they can tell when the sufferer is "having a bad day." Those are the times when family may need to "back off", unless there is potential for a life-threatening or violent situation. On "good days", sufferers should be encouraged to resist compulsions as much as possible.

(10) Keep Your Family Routine "Normal"

Often families ask how to "undo" all of the effects of months or years of going along with obsessive-compulsive symptoms. For example, to "keep the peace" a husband allowed his wife's contamination fear to prohibit their five children from having any friends into the household. An initial attempt to avoid conflict by giving in just grows. Obsessions and compulsions must be contained. It is important that children have friends in their home or that family members use any sink, sit on any chair, etc. Through negotiation and limit setting, family life and "routines" can be preserved. Remember, it is in the sufferer's best interest to tolerate the exposure to their fears and to be reminded of others' needs. As they begin to regain function, their wish to be able to do more increases.

(11) Use Humor

The ability to distance oneself from irrational fears and laugh is healthy, especially when done in company. Both family members and sufferers report this to be a relief. Again, sensitivity to the sufferer's mood should be considered before gently poking fun at the

OCD. Although humor has been recognized for its healing properties for ages, it may not be best to joke when the OC symptoms are acute.

(12) Support the Medication Regime

Always check with the physician about questions, side effects, changes that you notice. Don't undermine the medication instructions the physician and/or clinical professional have given.

All medications have side effects that range in severity. Some are very bothersome (dry mouth, constipation, sexual dysfunction). Discuss these with the treating physician and evaluate the risks and benefits.

For people who cannot pay for medication, it can be obtained at a reduced fee through a special program for OCD medication. The treating psychiatrist can request a copy of the guide by calling 1-800-PMA-INFO.

(13) Separate Time Is Important

Often, family members have the natural tendency to feel like they should protect the sufferer by being with him all the time. This can be destructive because family members need their private time, as do sufferers. Give the sufferer the message that he can be left alone and can care for himself. Also, OCD cannot run everybody's life; you have other responsibilities besides "babysitting."

(14) Be Flexible

Above all, these are guidelines! Always consider the severity of the OC symptoms and the sufferer's mood as well as level of stress when making decisions about enforcing limits. Be reasonable, and try to convey caring in your actions.

Guidelines for Educators and Employers

The preceding sections are written for families, but many of the suggestions are applicable for educators, guidance counselors, and employers. However, the latter are in the unique position of assisting and directing patients to treatment without being emotionally involved. Like families, educators and counselors might view OC symptoms as character flaws or quirks of behavior that can be easily avoided. Often the symptoms are unrecognized and misunderstood. People with OCD worry about their school and/or job performance and worry about others "finding out" about their OCD. Their worries create additional anxiety, thereby exacerbating the symptoms and creating further impairment. While not all educators or employers may be receptive to learning about OCD, those that are, can help OCD sufferers to maintain functioning and self esteem as they battle their symptoms.

A supportive academic/employment setting that treats the person with dignity is optimal. Try to work with the individual to allow some flexibility, when possible, to maximize

successes. This does not necessarily mean lowering standards or requirements. For example, a college student with OCD asked me to speak to one of his professors, whom he felt was giving him lower grades than he deserved, because he included more detail in his papers than he needed to, asked her to repeat assignments to “make sure” he heard them correctly, and asked for reassurance about his responses to “make sure” he was “saying the right thing.” After obtaining his written consent, I called and the professor, who had just started to identify some of her students' behaviors as OCD, confided in me that a relative of hers had OCD. She acknowledged some of her reactions had been brusque and were an attempt to put an end to the seemingly endless questions. In a three-way conversation, we discussed some of the principles of behavioral therapy and decided that the professor would offer her student a meeting, once a week for 15 minutes, to go over his concerns and questions. Outside of this time, the student was to resist asking for reassurance. If he did ask, the professor would remind him of their agreement. I sent a package of additional literature on OCD to the professor. The student even invited her to attend our monthly support group, if she were interested to learn more. This is a wonderful example of how behavioral contracting was utilized outside the home.

Similar examples in the employment setting, as in the academic setting, can be found. Again it is important to be flexible. OCD sufferers are conscientious, hard-working and care about doing things right. While this can be a problem at times, the sympathetic employer can use this to their advantage and may be able to keep a reliable, dependable employee working even during periods of symptom exacerbation. I have on occasion intervened with employers to educate them on OCD symptoms and advocate for changes in scheduling in order to help the employee manage her symptoms during the work day. Employers should be aware that, as of July 26, 1992, Title 1 of the Americans With Disabilities Act was passed. This law requires employers to make “reasonable accommodations” for a person’s mental illness unless the accommodations impose “undue hardship” on the employer. It prohibits discrimination in job application, hiring, promotion, and firing.

Special Guidelines for Children and Adolescents

“When my parents call me lazy, it makes things worse. I know I’m not lazy, but I can’t help avoiding things that make me so nervous.”

Many of the adults I see can clearly trace the beginnings of their OCD back to childhood. Recalling feelings of shame, isolation and fear, adult sufferers say they wish someone had taken the time to sit and talk with them about their odd behavior, instead of criticizing them for it. Children are aware that they are doing things other kids their age aren’t. In fact, they are dreadfully self-conscious of this. They are afraid of telling a parent (or any authority figure) about dressing routines, brushing teeth a certain number of times, weird and crazy thoughts about God or hurting people, “germs” on the desk at school, crossing “t’s” just right, shooting the basketball until a “good” thought replaces a “bad” thought. Kids (like adolescents and adults) try very hard to hide the compulsive behaviors out of fear that if

anyone knew: “They’d lock me up.” “They’d know I am really crazy.” “They’d take me away.” Unaware of psychiatric treatment, children assume there is something intrinsically wrong with them that cannot be corrected. They also, like adults, think they might be the only one alive to be this way.

You can imagine how terrifying it might be for a child who is just mastering the developmental task of differentiating real from make-believe to have thoughts such as those mentioned above. Having an adult to talk to who can help them identify the thoughts as OCD can provide much initial relief. The first step is to recognize excessive ritualistic behavior or preoccupation with thoughts. Beware though - most children go through a developmental phase that is steeped in rituals. Bedtime rituals and prayers provide a sense of security and comfort; so do “lucky” charms, ordering toys, collecting “special” items. When rituals and “routines” begin to interfere with the child’s social and school functioning - like staying home to “finish up” incomplete assignments, withdrawal from usual activities a warning sign should flash. In addition, if interruption in the “routine” creates undue anxiety, frustration and hostility, it is probably time to seek psychiatric advice. Another sign that accompanies early onset of OCD symptoms is a marked and decreased sense of confidence in class, and with friends. In light of how scary and overwhelming the OCD thoughts may be for a child, it makes sense that their level of self-confidence would be impacted.

An anecdotal note from an OCD sufferer who is now 34 highlights the issues often faced as a child with OCD. This woman recalls great emotional pain as a child afflicted with aggressive obsessions (worrying she somehow hurt someone). The worst part she says was keeping all of her fears in, because her parents expected her to “snap out of it” and “pull it together.” She strongly asserts, as do others, that parents should open the door for discussion. Making an attempt to connect with the child on an emotional level, offers them an opportunity to respond; it’s like extending a hand. Children need to be given some framework to understand what is happening to them. Sometimes they don’t have the ability to explain unless an adult offers some possibilities. With relief a child may say, “Wow! That is exactly what happens to me...how did you know?” This phenomenon is not exclusive to children. It occurs at any age when one feels desperately alone in their experience only to find out someone else feels the same way or understands.

Some suggestions for parents on how to open discussions with their children who might have OCD include: “Gee you seem so preoccupied all the time, can you tell us what’s on your mind.” “All people have worries and it’s okay to tell us about yours.” “We notice you repeating the same action, do you know you are? Are you afraid something will happen? Can you try to do it once? What happens then? Does it just not feel right?”

There are now many books out there to help children at all developmental stages learn about what OCD is. It is often easier for a child to identify one’s feelings through a third person such a character in a story or through play and so sharing some of these stories can open the door to talk about feelings and fears that they have. This can introduce the concept of psychiatric treatment in child friendly terms. Books such as these or video tapes such as *The Touching Tree* can help diminish a child’s sense of isolation. Please refer to the reference list for books that concentrate on children. To help increase awareness and

understanding of a child's lonely struggle with OCD, *The Touching Tree*, a video based on personal experience, has been produced by the OC Foundation. It may help children with OCD come forth to seek help, and it is an educational tool for parents and educators. Many parents are anxious about seeking psychiatric help for their child especially when medication is recommended. Although most professionals will agree that a trial of behavior therapy should be tried first, it has been our experience that behavior therapy and medication together is the best treatment for OCD in children as well. We use the metaphor of 'training wheels' with the child and the parents because we do believe that medication can offer some relief from anxiety which enables the patient to engage in exposures more readily. We often urge parents to make a pros and cons list around the medication issue. Often times a child who is struggling with OCD may feel sad and depressed, and may withdraw from social activities, peers and family relationships. They may become consumed with their worries and exhausted by the energy it takes them to challenge their fears. The increased feelings of depression, helplessness and hopelessness may have a more detrimental impact on psychosocial development and on school functioning. If the use of medication could halt this snowball effect of symptoms, then why not try it for initial relief of symptoms? We have seen many young children make significant gains with behavior therapy once they have medicine on board.

Parents of children and adolescents often struggle with whether or not to let teachers know about their child's diagnosis. The most common fear is that their child may be labeled in the school system. Considering the amount of time your child is in school, children's teachers are a great resource for parents. Often times they may be the first to recognize a change in your child's behavior, whether on the playground or in the classroom. If they know that your child is in treatment for OCD they can also help in reporting any changes in behavior.

Unfortunately, the stigma associated with mental illness is still very real in our society. As parents you can be role models and advocates for your children in breaking this stigma. By showing your child that OCD is not something "shameful" that ought to be kept secret, and empowering those important people in your child's life with information about OCD, you are only helping your child and helping educate others who may be able to offer help to other children and families. There is resource material that the OC Foundation has for schools to help educate them about OCD. Some therapists may also consult with school systems to help educate them on OCD and inform them about interventions at this systemic level.

The Special Case of Adolescence!

"My parents don't understand. I want to deal with this myself. If they didn't interrupt my rituals, I'd be fine."

Adolescents, in contrast to children, are expected to be more responsible and "grown up." In fact, the term adolescence is derived from the Latin verb "adolescere", which means "to

grow up.” Yet, there is still tremendous dependence upon parents for all sorts of things. For small children, it is not odd if a parent performs tasks the child should be doing or assists with dressing, bathing, eating. However, as the youth emerges into teenage years, impaired functioning becomes gravely disturbing to parents and to the adolescent sufferer. The hope that the child will “outgrow the quirks” becomes less likely. Interference in day-to-day functioning due to OC symptoms is less well tolerated. When interference in day to day functioning is tolerated, it is done so with excessive accommodation by one or both parents which only fosters dependence and impedes the adolescent’s age appropriate development .Rather than endless arguing and excessive threats of punishment, a clinical, psychiatric consultation may be beneficial.

Knowing the developmental task is to move away from parents emotionally, the adolescent with OCD is really caught in a bind, needing adults more than other peers and, at the same time, resenting it. Feelings of anger and hostility may be more prevalent than expected. Excessively worrying what others think and trying to keep symptoms a secret, can arrest the process of the adolescent developing a positive and self-respecting identity. Societal stigma of mental illness can compound the already existing pressure “to fit in” which the adolescent keenly feels. Some adolescents may feel these pressures and others may be so preoccupied with germs and their OCD thoughts and worries that they don’t have room or emotional resources to meet these natural developmental tasks. This is one reason why early intervention can be critical with children and adolescents.

The tendency of adolescents to form closely knit peer groups is indispensable to the process of decentering egocentrism. By sharing ideas with peers adolescents try out their theories and discover their weaknesses. The peer group provides some of the comforts of family with an added sense of independence. Furthermore, it is a time to ponder vocation and sexuality. Many of these normal developmental processes are hindered or blocked by OCD. Adolescents with OCD often feel extremely isolated and inadequate. They miss out on this typical experience of peer belongingness and individuation. It is common for them to be very fearful, wondering: “How will I ever be able to work?” and/or ashamed of their behaviors: “Who would marry me?” Should I have kids, or will I pass this on?

Increased internal conflict and a sense of alienation, magnified by coping with OC symptoms, are particularly painful for adolescents when the “normal” developmental tasks are pressing. “But mom, everybody’s doing it.” But not every teen has OCD. It may be cool to get a pierced ear, but it’s not cool to have raw hands from washing or to see a therapist! Adolescents can be difficult to engage. Getting to a support group with other young OCD sufferers may help with this. Also, parents of adolescents with OCD often forget that they are still the parents and can set limits. Expectations to do household chores or participate in family activities should not be altered to accommodate the OCD. This is easier said than done, as so many families have implored that cleaning up the dishes is not as important as getting out of the shower and to school on time. So while it is understandable how small accommodations and decreased expectations for the sufferer begins to occur in families, it is critical for parents to get help for an adolescent before symptoms get out of control.

Before the symptoms get out of control, there are steps the family can take to try to prevent a desperate situation: 1) Do your homework and learn as much as you can about OCD. Get to a support group. Talk to other parents and families. 2) In a non-judgmental way, encourage your teen to talk about his/her “worries”. Share your information with them and try to get them to a support group with or without you. 3) Don’t change routines or expectations around the house. If your daughter takes out the garbage for allowance and stops because of contamination, don’t give it to her anyway “because she has a problem.” Don’t do your kids’ homework for them. Don’t get them home schooled if they cannot leave home due to OCD fears. This is only further facilitating avoidance, dependence on systems to accommodate their symptoms and will impede their social development. If they generally do their own laundry and stop because they feel “they can’t”, don’t do it for them. Be there to coach, but don’t take over tasks they should do. Remember, this is the developmental phase of gaining independence, not taking it away. In addition, siblings resent taking on extra chores they shouldn’t have to do. 4) Family provides role-modeling and a shared sense of problem solving and is essential to help with limit setting. The family should be reminded of adolescent issues and how the OCD intensifies normal concerns - especially setting limits for example - where to draw the line or give in. “Splitting” can also create problems (one parent giving in to the demands of the OCD and the other refuses to do so). It is recommended that parents are unified in their rules and expectations (which may need to be revised given the varying severity of OCD). 5) Individual supportive behavioral therapy can assist the adolescent with the process of separation and symptom control. 6) Medication can reduce symptoms to a manageable level so that the whole family can cope better. 7) Multifamily Psychoeducational Support Groups can provide support and guidance to the person with OCD and all family members. 8) OCD teenage “buddy” can offer needed peer support. 9) Setting limits around out of control household behaviors and around the sufferer controlling the environment is critical with this age group. Adolescents are testing limits and spheres of control and the more control they experience in their own environment, they will expect in other environments as well. When OC symptoms are severe and family accommodation extreme, we have seen secondary behavioral problem that develops that also needs to be treated. 10) Family therapy can be helpful for all family members to have a place to talk about how OCD is impacting family, this may be especially supportive for siblings and for parents learning to work together better. 11) If you as a family member have OCD/anxiety disorder or depression, get help for yourself!

Once recovery from the symptoms of OCD begins, it is helpful for family members to realistically appraise their expectations. If the sufferer has “lost” a number of teenage years because of OCD, they have not had the full experience of adolescence. It may take a while longer to obtain a driver’s license, a job, a peer group and close friends, decide on future education or career. This may be discouraging for the OCD sufferer as they look around and see peers doing all these things they feel far from. This can evoke feelings of worthlessness or helplessness. If you can recognize this or the teen can talk about it, praise the teen for the accomplishment of overcoming the OCD. Remind the teen, with optimism, of skills they have acquired to help themselves and that they will “catch up” with others. With patience and a positive outlook, you can assist your loved one to continue on. Supportive counseling can be beneficial for the sufferer and/or the family. Again, don’t forget about support groups!

If an adolescent refuses to go to see a professional (with or without parents), parents should not forget that they can insist the teen go. This requires a serious commitment on the parents' part to really support the sufferer to learn all they can about OCD and to seek professional advice. You may need to prepare yourself to impose consequences if your home life is deteriorating because the OCD has been difficult to manage. Sometimes accommodation in household routine happens slowly, one change at a time and before long families find themselves embroiled in OCD rules and outbursts if they are not followed. If you get to this point, it is crucial to be firm, consistent and to follow through. The consequences of not going for treatment vary depending on individual situations. At times, symptoms may be so severe that the teen may risk being placed elsewhere to live or taken to a hospital against his/her will if the symptoms pose a dangerous threat to the sufferer's life or someone living with them. This should be determined by a skilled psychiatric clinician with knowledge of OCD.

A Word about Siblings

Siblings have a range of responses to OCD. They probably are faced with the same confusion and bewilderment as their sibling who has the OCD. Once an understanding of what is happening is gained, they can range from being supportive to antagonistic. The latter often leads to increased anxiety within the entire family system. Often times, their natural response is to resist giving in to unreasonable requests and demands by the OC sufferer. This can be helpful in maintaining some sense of normalcy in the household. However this can also cause intense conflict at times. Many siblings report feeling overprotective of their parents if there is yelling and fighting that goes on due to conflict over OC symptoms.

Often times siblings will assume that parents don't have time for their everyday needs, such as school projects, school supplies and other activities. In a sibling support group at an OC Conference, a sibling and leader of the support group shared this experience with the group. She recalled a support group she'd gone to with a mix of parents and siblings and talked about a parent who'd shared the relief that he could meet his son's needs around getting school supplies since he spent so much of his time feeling powerless over helping his daughter with OCD. The take home message, to the siblings from the parents was, "please ask us for what you need!"

Even with this information, siblings often report feeling that they need to take care of themselves because family resources are used up by the person with OCD. Sometimes this can lead to frustration, anger and resentment. Other times, it helps foster a sense of independence in the sibling, but one that may at a later time come with some grief about not being able to be an adolescent due to a sense of having to make up for the behavior of the family member with OCD. Some siblings have reported some grief over this. For parents who have more than one child, it is important that you have open family discussions about OCD. Do not accommodate or change family routines to diminish the

anxiety. Be consistent with limit setting with all children and follow through on consequences. Seek outside help for siblings if you feel they are being impacted adversely. Supportive therapy can help them manage some of their own issues in living with OCD.

Concluding Remarks

As family members, you may never completely get away from the feelings of isolation and frustration that come with the daily struggles of trying to cope with the challenges presented by OCD. Sharing these feelings with others living with OCD and offering support greatly enhances the process of healing. Learning as much as you can and using the proposed guidelines can answer such questions as: “Why can’t they stop?” “How can I help?” Family members can make a difference, through education and behavioral contracting to help the sufferer to overcome OCD.

It may be helpful for families to keep in mind that it is not uncommon for people with OCD to benefit from supportive therapy after the OCD has been treated. Symptoms of depression, marital conflict due to adjustment, and feelings of being out of pace with peers are typical and sometimes need further attention. After the symptoms of OCD decrease, the person may begin to realize how much of their life they missed out on. Family members are often confused by this because everyone assumed that once the OCD was better, everything else would be too! Again, the symptoms and feelings just mentioned are common and are part of the recovery process. Recovery and healing occur with professional help, family and friends understanding, and time.

Suggested Reading

The materials listed below are suggestions that we have found useful in clinical practice. This is not an exhaustive list and there are many more books you may find on the topic that are not on this list.

General, Adult and Professional Books

Anxiety Disorders in Children and Adolescents

March, John

The Guilford Press, 1995

Current Treatments of Obsessive Compulsive Disorder, 2nd edition

Edited by Pato, Michele Tortora, and Zohar, Joseph,

American Psychiatric Press, 2001

Brain Lock

Schwartz, Jeffrey

Regan Books, 1996

Everything in Its Place
Summers, Marc

Freedom from Obsessive-Compulsive Disorder: A personalized recovery program for living with uncertainty
Grayson, Jonathan
Tarcher/Penguin Putnam, 2003

Funny You Don't Look Crazy
Foster, Connie
Dilligaf, 1993

Getting Control
Baer, Lee
Little Brown and Company, 1991

Help For Hairpullers
Keuthen, Nancy, Stein, Dan, Christensen, Gary
New Harbinger Publications, 2001

Imp of The Mind
Baer, Lee
Penguin Putnam Inc., 2001

Mind Over Mood
Greenberger, Dennis and Padesky, Christine
The Guilford Press, 1995

Obsessive Compulsive Anonymous: Recovering form OCD, 2nd edition
C., Roy
Obsessive Compulsive Anonymous, Inc.

Obsessive Compulsive Checking: Free your mind from OCD
Munford, Paul
New Harbinger Publications, 2004

Obsessive Compulsive Disorders: A complete guide to getting well and staying well
Penzel, Fred
Oxford University Press, 2000

Obsessive Compulsive Disorders: Theory & Management, 3rd edition
Edited by Jenike, Michael, Baer, Lee. & Minichiello, William, Year Book, Medical Publishers, Inc., 1998

Obsessive-Compulsive Disorders
Edited by Hollander, Eric and Stein, Dan

Marcel Dekker, 1997

Over and Over Again

Neziroglu, Fugen, Ph.D. and Yaryura-Tobias, Jose, M.D.
Lexington Books, 1991

Polly's Magic Games

Foster, Connie
Dilligaf, 1993

Stop Obsessing!

Foa, Edna, Ph.D. and Wilson, Reid, Ph.D.
Bantam Books, 1991

Tormenting Thoughts and Secret Rituals

Osborn, Ian
Dell Publishing Company, 1999

The Boy Who Couldn't Stop Washing

Rapoport, Judith, M.D.
Penguin Books, 1990, 1991

The Broken Mirror, reprint edition

Phillips, Katharine
Oxford Press, 1998

The OCD Workbook, 2nd edition

Hyman, Bruce and Pedrick, Cherry
New Harbinger Publications, 2005

The BDD Workbook

Claiborn, James, and Pedrick, Cherry
New Harbinger Publications, 2002

The Hair-Pulling Problem: A complete guide to Trichotillomania

Penzel, Fred
Oxford University Press, 2003

Treatment of OCD

Steketee, Gail, Ph.D.
The Guilford Press, 1993

When Once Is Not Enough

Steketee, Gail, Ph.D. and White, Kerrin, M.D.
New Harbinger Publications, 1990

Books for Children, Adolescents and Parents

Asperger's Syndrome: A Guide for Parents and Professionals

Attwood, Tony

Athenaeum Press, Gateshead, Tyne and Wear

Freeing Your Child from Anxiety: Powerful, practical solutions to overcome your child's fears, worries and phobias

Chansky, Tamar

Broadway Books, 2004

Freeing Your Child from OCD: A powerful, practical program for parents of children and adolescents

Chansky, Tamar

Three Rivers Press, 2001

Helping Your Child with OCD: A workbook for parents of children with OCD

Fitzgibbons, Lee, and Pedrick, Cherry

New Harbinger Press, 2003

Loving Someone with OCD: Help for You and Your Family

Landsman, Karen, Rupertus, Kathleen, and Pedrick, Cherry

New Harbinger Publications Inc, Oakland CA

Misdiagnosis And Dual Diagnoses Of Gifted Children And Adults: And, Bipolar, OCD, Asperger's, Depression, And Other Disorders

Webb, James, Amend, Edward, Webb, Nadia, Goerss, Jean, Beljan, Paul, Olenchak, Richard

Great Potential Press, 2005

Up and Down The Worry Hill

Wagner-Pinto, Aureen

Lighthouse Press, Inc., 2000

What to Do When Your Child Has OCD: Strategies and solutions

Wagner-Pinto, Aureen

Lighthouse Press, Inc., 2002

Booklets

Drug Treatment of OCD in Adults

Jenike, Michael, M.D.

OC Foundation, Inc., 2001

Learning To Live With BDD

Phillips, Katharine, Van Noppen, Barbara, and Shapiro, Leslie

OC Foundation, Inc., 1997

Obsessive Compulsive Disorder: A Guide

Greist, John, M.D.

OCIC, Wisconsin, 1991.

Obsessive Compulsive Disorder in Children and Adolescents: A Guide

Johnston, Hugh, MD

Child Psychopharmacology Information Center, Univ. of Wisc.

Videos

The Touching Tree: A story about a young child with OCD

The Risk: The portrayal of a family struggling with OCD

Callner, James

National Organizations

The OC Foundation, Inc.

P.O. Box 961029

Boston, MA 02196

Phone: (617) 973-5801

Fax: (617) 973-5803

Email: info@ocfoundation.org

Website: <http://www.ocfoundation.org>

The Anxiety Disorders Association of America

8730 Georgia Avenue, Suite 600

Silver Spring, MD 20910

Phone: (240) 485-1001

Email: information@adaa.org

Website: <http://www.adaa.org>

Obsessive Compulsive Information Center

Madison Institute of Medicine

7617 Mineral Point Road, Suite 300

Madison, WI 53717

Phone: (608) 827-2470

Fax: (608) 827-2479

Email: mim@miminc.org

Website: <http://www.miminc.org/aboutocic.asp>

Obsessive Compulsive Anonymous (OCA)

P.O. Box 215

Hyde Park, New York 11040

Phone: (516) 739-0662

Website: <http://obsessivecompulsiveanonymous.org>

About the Authors

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Michele Tortora Pato, MD has been involved in research and treatment of OCD for over 15 years. First at the NIMH, later at Brown University and at the State University of New York. With a background in pharmacologic treatment trials, group behavior therapy and medication discontinuation, Dr. Pato is currently studying the genetics of OCD along with her psychiatrist/researcher husband, Carlos Pato at the University of Southern California, Zelko Institute. She is the co-author of Current Treatment of OCD, in its 2nd edition. The book provides a comprehensive review of diagnosis and treatment of OCD.

Steven Rasmussen, MD is the Director of the OCD clinic and Medical Director at Butler Hospital, Rhode Island. He is internationally known for his clinical research and treatment in OCD. Dr. Rasmussen is an Associate Professor of Psychiatry and Human Behavior at Brown University and has published numerous articles and given many presentations on OCD. Currently, Dr. Rasmussen is conducting research in several areas: longitudinal course of OCD, biological alternative treatments for refractory patients and genetics.

Constantina Helen Boudouvas, MSW is a Cognitive-Behavioral Therapist and Director of Social Work and Social Work Education at the Menninger Clinic in Houston, TX. She developed the current Menninger Post-Masters Fellowship in Clinical Social Work, including a fellowship in CBT training, and serves as volunteer faculty in the Menninger Department of Psychiatry at the Baylor College of Medicine, educating psychiatry residents in family therapy and family intervention. Ms. Boudouvas also developed the OCD specific Family Workshop component for families of both adolescents and adults who are engaged in the clinic's psychiatric inpatient specialty care treatment program for OC spectrum disorders. She maintains a private practice in the community and has written psycho-educational articles for families of individuals with OCD.

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