

G U I D E L I N E S F O R

The following is an excerpt from "Learning To Live With OCD" (Van Noppen, Pato, Rasmussen and Boudouvas), a booklet published by the OC Foundation, which will be released in its 6th edition this year.

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 you can learn about family responses to OCD and the impact that these responses have on the person with OCD, the more you and other family members become 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 over-involved, 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 him/her to "just snap out of it" may be perpetuating symptoms as well. Research has found that some criticism of the OCD symptoms that is not directed toward the person can be a useful motivator and may help the person with OCD face his/her 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 to the effect OCD has 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 everyone 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 for family members:

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. Realize that separate time for other family members is important.
14. Maintain flexibility throughout the family!

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, they reveal differences 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 help 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. Constantly asking for or needing 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.

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.

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 among OCD sufferers 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

L I V I N G W I T H O C D

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.

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 and 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.

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 not 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!!

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 and that you won't help because you want the sufferer to resist. This projects more of a non-judg-

mental attitude that reflects acceptance of the person.

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?"

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 the family not to participate in rituals (this includes responding to incessant requests for 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.

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, and, 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.

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 visit 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 his fears and to be reminded of others' needs. As he begins to regain function, his wish to be able to do more increases.

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.

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.

It should be noted here that 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.

Assure Separate Time for Everyone

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."

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.