

Living With Someone Who Has OCD: Guidelines for Family Members

(From Learning to Live with OCD)

In an effort to strengthen relationships between individuals with OCD and their family members and to promote understanding and cooperation within households, we have developed the following list of useful guidelines. These guidelines are meant as tools for family members, to be tailored for individual situations, sometimes more powerfully employed with the help of a therapist with expertise in working with OCD.

1. Recognize Signals

The first guideline stresses that family members learn to 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 behavior changes. It is important to not dismiss significant behavioral changes as “just their personality”. Remember that these changes can be gradual but overall different from how the person has generally behaved in the past.

Signals to watch for include, but are not limited to:

1. Large blocks of unexplained time that the person is spending alone (in the bathroom, getting dressed, doing homework, etc.).
2. Doing things again and again (repetitive behaviors).
3. Constant questioning of self-judgment; excessive need for 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.
13. Increased irritability and indecisiveness.

People with OCD usually report that their symptoms get worse the more they are criticized or blamed, because these emotions generate more anxiety. So, it is essential that you learn to view these features as signals of OCD and not as personality traits. This way, you can join the person with OCD to combat the symptoms rather than become alienated from them.

2. Modify Expectations

People with OCD consistently report that change of any kind, even positive change, can be experienced as stressful. It is often during these times that OC symptoms tend to flare up; however, you can help to moderate stress by modifying your expectations during these times of transition. Family conflict only fuels the fire and promotes symptom escalation (“Just snap out of it!”). Instead, a statement such as: “No wonder your symptoms are worse - look at the changes you are going through,” is validating, supportive, and encouraging. Remind yourself the impact of change will also change; that is, the person with OCD has survived many ups and downs and set backs are not permanent. You must adjust your expectations accordingly which does not mean to not expect something!

3. Remember That People Get Better at Different Rates

There is a wide variation in the severity of OC symptoms between individuals. Remember to measure progress according to the individual’s own level of functioning, not to that of others. You should encourage the person to push him/herself and to function at the highest level possible; yet, if the pressure to function “perfectly” is greater than a person’s actual ability, it creates more stress which leads to more symptoms. 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

You might hear your loved ones say they feel like they are “back at the start” during symptomatic times. Or, you might be making the mistake of comparing your family member’s progress (or lack thereof) with how he/she functioned before developing OCD. It is important to look at overall changes since treatment began. Day-to-day comparisons are misleading because they don’t represent the bigger picture. When you see “slips”, a gentle reminder of “tomorrow is another day to try” can combat self destructive labeling of “failure”, “imperfect”, or “out of control” which could result in a worsening of symptoms! You can make a difference with

reminders of how much progress has been made since the worst episode and since beginning treatment. Encourage the use of questionnaires to have an objective measure of progress that both you and your loved one can refer back to (for example, the Yale Brown Obsessive Compulsive Scale). Even a 1-10 rating scale can be helpful. Ask, “How would you rate yourself when OCD was at it’s worst? When was that? How is it today? Let’s think about this again in a week.”

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 these gains may seem insignificant to family members, it is a very big step for your loved one. Acknowledgment of these seemingly small accomplishments is a powerful tool that encourages them to keep trying. This lets them know that their hard work to get better is being recognized and can be a powerful motivator.

6. Create a Supportive Environment

The more you can avoid personal criticism, the better – remember that 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 as a person, but remember that acceptance and support does not mean ignoring the compulsive behavior. Do your best to not participate in the compulsions. In an even tone of voice explain that the compulsions are symptoms of OCD and that you will not assist in carrying them out because you want them to resist as well. Gang up on the OCD not on each other!

7. Set Limits, But Be Sensitive to Mood (refer to #14)

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 individuals with OCD that mood dictates the degree to which they can divert obsessions and resist compulsions. Likewise, family members have commented that they can tell when someone with OCD 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” individuals should be encouraged to resist compulsions as much as possible. Limit setting works best when these expectations are discussed ahead of time and not in the middle of a conflict. It is critical to minimize family accommodation to OCD.

8. Support Taking Medication as Prescribed

Be sure to not undermine the medication instructions that have been prescribed. All medications have side effects that range in severity. Ask your family member if you could periodically attend their appointments with the prescribing physician. In this way you can ask questions, learn about side effects, and report any behavioral changes that you notice

9. 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?” or “Did I really clean well enough?” You have probably found that the more you try to prove that the individual 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 individual with OCD and it may be tough. Recognize that the person with OCD is triggered by doubt, label the problem as one of trying to gain total certainty about something that cannot be provided, this is the essence of OCD and the goal is to accept uncertainty in life. Avoid lengthy rationales and debates.

10. Separate Time Is Important

Family members often have the natural tendency to feel like they should protect the individual with OCD by being with him all the time. This can be destructive because family members need their private time, as do people with OCD. Give them the message that they can be left alone and can care for themselves. Also, OCD cannot run everybody’s life; you have other responsibilities besides “babysitting.” You need and deserve time to pursue your interests too! This not only keeps you from resenting the OCD, it is also a good role model to the person with the OCD that there is more to life than anxiety.

11. It Has Become All About the OCD!

Whether it is about asking and providing reassurance to the family member with OCD or talking about the desperation and anxiety that the illness causes, families struggle with the challenge of engaging in conversations that are “symptom free,” an experience that feels liberating when achieved. 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. It is okay not to ask, “How is your OCD today?” 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.

12. Keep Your Family Routine “Normal”

Often families ask how to undo all of the effects of months or years of going along with OC symptoms. For example, to “keep the peace” a husband allowed his wife’s contamination fear to prohibit their children from having any friends into the household. An initial attempt to avoid conflict by giving in just grows; however, 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 individual’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.

13. Be Aware of Family Accommodation Behaviors (refer to #14)

First, there must be an agreement between all parties that it is in everyone’s best interest for family members to not participate in rituals (Family Accommodation Behaviors). However, in this effort to help your loved one reduce compulsive behavior, you may be easily perceived as being mean or rejecting even though you are trying to be helpful. It may seem obvious that family members and individuals with OCD are working toward the common goal of symptom reduction, but the ways in which people do this varies. Attending a family educational support group for OCD or seeing a family therapist with expertise in OCD often facilitates family communication.

14. Consider Using a Family Contract

The primary objective of a family contract is to get family members and individuals with OCD to work together to develop realistic plans for managing the OC symptoms in behavioral terms. Creating goals as a team reduces conflict, preserves the household, and provides a platform for families to begin to “take back” the household in situations where most routines and activities

have been dictated by an individual's OCD. By improving communication and developing a greater understanding of each other's perspective, it is easier for the individual to have family members help them to reduce OC symptoms instead of enable. It is essential that all goals are clearly defined, understood, and agreed upon by any family members involved with carrying out the tasks in the contract. Families who decide to enforce rules without discussing it with the person with OCD first find that their plans tend to backfire. Some families are able to develop a contract by themselves, while most need some professional guidance and instruction. Be sure to reach out for professional assistance if you think that you could benefit from it.

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