

# OCD Chicago

## Roadmap to Recovery: Families of Adult OCD Sufferers Living at Home

*By John Hart and Thröstur Björguinsson  
Menninger OCD Treatment Program  
The Menninger Clinic  
Houston, Texas*

Because of the debilitating nature of OCD, many adult OCD sufferers find themselves living at home with parents or other family members. Since OCD sufferers are often unable to work, it can be financially impractical to live independently. A retrospective study of the adult patients admitted over a 7-month period in 2007 at the Menninger Clinic OCD Treatment Program confirms many of these difficulties (Björguinsson, Heffelfinger, Wetterneck, & Hart, 2007, March). Approximately 81% of adults lived at home with family, despite only 14% of them being married. Although most were unemployed (86%), many also required help with daily living tasks such as grooming and cleaning (62%). In addition, most sufferers (75%) reported a significant disruption in social activities and indicated the cost of treatment and the loss of wages were a significant financial burden on family (77%). These data suggest that OCD presents ongoing challenges to both the patient and the family system. Marital problems, family conflict, isolation, and financial strain are common results of the stress that OCD places on both the sufferer and the family.

This article addresses issues relevant to individuals who provide care to adult OCD sufferers living at home. Addressing the issues of caregivers directly may also contribute to the progress and well-being of sufferers. Individuals with OCD benefit from a reduction in family distress, on the one hand while being negatively impacted by family dysfunction on the other. That is, by reducing family stress and burdens involved in caring for a loved one with OCD, the entire family – including the sufferer – may benefit. The article reviews the unique stresses involved in caring for a family member with OCD, reviews relevant literature about family accommodation and treatment, and provides readers with suggestions on creating their own “roadmap” for recovery. It also provides suggestions for caregivers of sufferers who are not currently engaged in treatment.

### **The Burden of OCD**

The burden of OCD on diagnosed individuals is well documented. Families of sufferers with OCD know first-hand how debilitating the disorder can be. In 2001, the World Health Organization (2001) ranked OCD as one of the most debilitating disorders. In 2000, they estimated that OCD was among the top 20 causes of illness-related disability for people ages 15 to 44. OCD has a substantial effect on sufferers’ quality of life. In a recent study, researchers from Brown University found that a third of their sample of

OCD sufferers were unable to work due to their symptoms (Eisen, Mancebo, Pinto, Coles, & Rasmussen, 2006). As compared to non-OCD sufferers, this study found impairments in all domains of the sufferers' lives, including performance of household duties, subjective sense of wellbeing, social relationships, and the ability to enjoy leisure activities. While severity of compulsions was associated with decreased ability to work, the strongest correlation was found between severity of obsessions and overall impaired quality of life.

It is particularly troubling when adult sufferers are living at home because of the nature and severity of their symptoms. As the result of shame and embarrassment, it can be particularly demoralizing for the sufferer to be unable to live independently. As symptoms worsen, the OCD sufferer's world may become smaller and smaller. Adding to the demoralization is the reduction in social relationships and increased isolation. Research has indicated that as many as one quarter to one half of OCD sufferers are also struggling with major depression. Other research has shown that in almost all cases the OCD comes before the major depression (Abramowitz, 2004). This research finds what all OCD sufferers know already: It can be very depressing to have OCD, and depression adds to that burden.

The term "burden" is used here to describe the negative feelings associated with not only having a psychiatric disorder but for caring for someone with a mental health concern. Individuals with OCD did not choose to have the disorder, nor do their caregivers take on more accountability solely out of obligation. We define caregiving as assuming the extra responsibilities associated with the onset of a mental health problem. It is important to note that most of these responsibilities are performed out of love and concern, even necessity, for someone the caregiver cares deeply about.

Often the sufferer and caregivers are experiencing similar feelings of hopelessness and exasperation. The nature of OCD symptoms leaves no family untouched, since the rituals usually influence family interactions in various ways. The natural tendency for a family member is to soothe a loved one when they are in distress. To minimize anxiety and conflict, caregivers may "put up with" or accommodate the sufferers symptoms by changing family routines and schedules and altering normal family activities. Additionally, families of OCD sufferers face challenges that other families with relatives that have severe non-OCD psychiatric problems do not. OCD caregivers may become involved in the core symptoms of the disorder, beyond altering schedules and avoiding activities, by helping or even carrying out the rituals for the sufferer.

## **The Experience of Burden in Caring for those with Mental Health Disorders**

Since OCD is associated with a great deal of shame and fears of rejection, this may account for the long silences (sometimes years) that occur before sufferers ask for help. The concealment of obsessions is part of the make-up of the disorder (Newth & Rachman, 2001). Families may participate in this concealment to protect both the family and the sufferer from embarrassment and rejection from those outside of a trusted circle

of friends and relatives. Since the need for the concealment of symptoms is often so intense, the sufferer may offer a proclamation to family members not to reveal anything about the sufferer's illness. While family members often want and need to respect to the privacy of their family member, these vows of secrecy - whether imposed by sufferer or the family - adds an increased burden on everyone involved.

When OCD occurs in a family, either in childhood or adulthood, the dynamics of the family changes, so that caring often appears to be one-sided. Yet this doesn't typically happen over night. Often these family dynamics have changed before family members become fully aware of the shift. As symptoms of OCD worsen and some sufferers become more focused on their fears and may require more assistance from caregivers, this creates a discrepancy in attention in the various relationships. But this is the nature of fear and anxiety. It narrows attention and puts people on guard for further threat. Intense fears leave little room for anything else, including family life. This shift in attention adds to the burden of caregivers as family life becomes more and more focused on the OCD.

There are a number of areas that have been identified as sources of burden specifically for those who are caretakers for individuals with OCD. Researchers have tried to categorize the types of burden experienced by caregivers as either objective or subjective. OCD expert Gail Steketee (1997) provided a review of both objective and subjective sources of burden. Objective burden refers to variables that you can measure, such as the financial costs of treating the illness, lost wages, the time spent in caretaking activities, and a reduction in the time spent with friends or other family members. In Dr. Steketee's study, objective burdens included: unemployment or financial costs of treatment; reduction in social activities and loss of friendships; reduction in housework and grooming; neglect of children; increase in arguing; and accommodation of rituals. Subjective burden involves how the difficulties of caretaking influence the thoughts and feelings of caretakers. Examples include elevated levels of stress, frustration, hopelessness, guilt, or worry. Dr. Steketee's study found that areas of subjective burden included: feeling responsible for the sufferer's difficulties; feeling manipulated; difficulty managing anger; grief about the loss of functioning; neglect of the caretaker; and depression and worry about the future. Although there have been attempts to make a distinction between these types of burden, it appears as though the two areas are highly correlated (i.e., the level of subjective burden is related to the level of objective burden) (reference).

Elizabeth Kuipers and Paul Bebbington, (1997) researchers from King's College of London Institute of Psychiatry, have outlined a number of factors that seem to play a role in the experience of burden. They include the type and severity of symptoms, the beliefs about the disorder, the coping skills of the caretaker, and the availability of social support networks. Misunderstandings or misinformation about the nature of OCD will likely increase the feeling of burden for caregivers. Such misunderstanding or misinformation includes blaming oneself or the sufferer for the disorder, expecting the disorder will spontaneously disappear, or assuming that the sufferer can no longer handle any responsibilities. Many people experience some level of shock or confusion when encountering the symptoms of OCD or when they learn about the diagnosis of OCD,

particularly because of the often bizarre and frightening nature of the obsessions or the peculiar and nonsensical nature of the rituals. Having limited resources and ability to cope with the onset and progression of OCD will also influence the experience of a caregiver's burden.

## **How People Cope with Stressful Events: The Role of Hope**

The impact of the realization that a family member has a psychiatric illness can be experienced in different ways, particularly in terms of whether the onset of the OCD is seen as a challenge or a threat (Snyder, 2002). Practically speaking, when unfortunate things happened it is natural to experience the situation as both. Psychologists Richard Lazarus and Susan Folkman (Lazarus, 2000) developed and researched a model of how individuals react to stressful events. Their research indicated that when the event is viewed as a threat, people tend to use wishful thinking, avoidance, and even in some cases hostility and aggression as a coping strategy. When the stressful event is seen as a challenge, then they are more likely to use problem-solving and thoughtful action as a result of their perception.

Karl Menninger (1959) referred to hope as “a motive force for a plan of action” (p 439). Hope is an important factor in the ability to adapt and cope with stressful events. Unfortunately, hope is a word that is used so frequently, and has such similarity to so many other words, the full meaning is not always grasped. Here “hope” is used not just as word, but as useful concept to help sufferers and families navigate the difficulties that arise when OCD becomes part of the family. Social psychologist Ezra Stotland (1969) in his book, *The Psychology of Hope*, conceptualized hope as future-oriented and related to a desired goal or event. Hope also involves a positive attitude toward a desired outcome that is worth the effort. It is related to expectations that the desired future is valuable and worthwhile, as well as possible and probable.

The late psychologist Rick Snyder, who was the leading researcher on hope theory, conceived of hope as an active process. His ideas were different from the familiarly stoic “we will just hope for the best,” which tends to connote resignation. Rather, hope is something that people not only have, but more importantly, it is something people actually do. According to Snyder, hopeful people utilize to different but highly related types of thinking: pathways and agency. He believed that people who are actively engaged in hope clearly conceptualize their goals, develop specific strategies to reach those goals (pathways thinking), and stay motivated and persistent in pursuing those goals (agency) (Snyder, 2002).

Researchers at the University of Florida have investigated the role of hope in caregivers of OCD sufferers (Geffken et al., 2006). They found that hopefulness was positively related to active problem solving and social support, but negatively related to coping strategies that involved denial and disengagement. These findings suggest that levels of hope were related to coping strategies, with lower levels hope associated with less-adaptive coping strategies. Not surprisingly, these researchers found that caregivers who were higher in hope were lower in depression and vice versa. The term hopelessness has

often been used interchangeably with depression. When people are depressed, the future looks bleak and getting better feels impossible. Nonetheless, it is possible to be in a depressed mood and still be hopeful. As difficult as this may seem, it is possible to be depressed and have an expectation that things will get better.

## **Reducing Burden: A Roadmap to Recovery**

In the beginning, the families of OCD sufferers are functioning in survival mode. Their motivation is to just get through another day while stamping out one OCD fire after another. This mode often leads to confusion, resentment, and hopelessness. Typically there is no sense of direction, plan, or pathway. Mapping where the sufferer and caregiver are in the recovery process, can be very useful in reducing conflict and increasing hope and optimism. What do you mean by mapping their position in the recovery process? What does this look like and how specifically does it benefit them? Remember that, in addition to sufferers, families and caregivers also need to recover.

It would be too simplistic to state that the best way to deal with burden is to get treatment for the individual with OCD. Many OCD sufferers go untreated even when appropriate treatment is available. There are also many sufferers who have been engaged with well-meaning and competent mental health professionals that are not specialists, or who have not had the appropriate training and supervision to treat this difficult disorder. Cognitive-behavior therapy (CBT), which includes exposure and the response prevention, and SSRI medications are the treatments of choice (Björgvinsson & Hart, 2007). Although it is advantageous to find a psychiatrist who is well versed in OCD, SSRI and other pharmacological treatments are readily available. In contrast, finding a therapist trained in exposure and response prevention can still be relatively difficult, particularly in smaller communities. And unfortunately, even with the proper trained specialist, some OCD symptoms do not respond to treatment.

If feeling hopeless, sufferers may have lost the motivation to pursue worthwhile and valuable life goals because the intensity of OCD symptoms has become overwhelming. Many sufferers have become so demoralized that they have even given up fighting their fears through rituals. While this may seem like a good thing, typically this situation results in pervasive avoidance and isolation. For example, an OCD sufferer who has contamination fears and washing rituals may get to the point where the demands to be clean are so strong that the washing rituals cannot keep pace, so they may give up cleaning altogether. As a result, many may paradoxically live in an unhealthy state of dirtiness. For many OCD sufferers pursuing treatment is often a frightful and confusing venture. In essence, therapy is asking them to give up the very ways of doing things that they believe keep them safe. In fact, some sufferers believe that giving up their OCD will make them more vulnerable to threat and harm. When done properly, CBT is sensitive to these issues, and as part of the treatment will address the role of hope as essential to the recovery process.

Since OCD often takes a chronic course, and not everyone responds well to treatment, there must be other alternatives to reduce burden. Education about OCD is essential.

Despite the effectiveness of treatment for some individuals, obsessive thoughts may not ever fully disappear. Even those people who reduce the impact of OCD in their lives still struggle with OCD triggers and resisting rituals. Therefore, expecting a total remission may be unrealistic, and the disappointment associated with this realization may increase the sense of burden.

In addition to the appraisals (e.g., of whether OCD is a threat or a challenge), there are beliefs or appraisals commonly expressed by the caregivers that may contribute to burden. One such example is the attribution of responsibility to the OCD sufferer in their ability to control their symptoms. Given the irrational nature of some OCD fears, many caregivers feel that the sufferer should have greater control over their avoidance and ritualizing. This type of attribution seems linked to the psychological concept of high “expressed emotion” (i.e., mainly criticism or hostility), which has been found to be correlated with poor behavior therapy outcome and increased likelihood of treatment dropout (G Steketee, Van Noppen, Lam, & Shapiro, 1998). When faced with threatening OCD situations, people with OCD can sometimes react with anger, hostility, and even aggression. These angry episodes are most frequently defensive as opposed to offensive.

Although often challenging, caregivers must learn to accept the sufferer’s OCD fears and irrational thoughts as part of OCD, while still being sensitive to the enormous threat and terror OCD sufferers can be feeling. This often requires the caregiver to overcome their own fears about the loved one, in a similar way to how the loved one is asked to overcome their OCD fears when undergoing behavioral treatment. What fears, specifically, do caregivers need to overcome? This approach may not only reduce caregiver’s feelings of burden, but research also indicates that less anxious (i.e., firm, non-reactive) family members are more successful providing support and supervision in treatment than anxious inconsistent ones (G Steketee & Van Noppen, 2003).

Understanding the role of accommodations is also essential for both improving treatment and reducing burden. This is particularly relevant when the sufferer is living at home. Accommodation includes a number of activities such as: participating directly in rituals/compulsions; facilitating avoidance by insulating the loved one from triggers in the environment; taking over the responsibilities of the loved one; repeatedly answering questions for reassurance; and changing “normal” family routines. Accommodation serves to reinforce and maintain all aspects of the disorder. Most family members report accommodating symptoms, and research has shown that accommodations have been linked to global family disruption and distress (Amir, Freshman, & Foa, 2000). Thus, the act of trying to help may inadvertently lead to increased symptoms and increased burden, making the disorder worse over time. Unfortunately when caregivers become aware of the role of accommodation in the maintenance of OCD, there is often an accompanying sense of guilt and responsibility. This is where a “roadmap” can be useful. Efforts to abruptly end accommodating behavior usually result in frustration and disappointment. An organized plan that includes a hierarchy of accommodating behavior can foster some early (and often badly needed) successes on the way to recovery.

One route to enhance coping is involvement in a social support network. As the sufferer's symptoms progress, many people become more isolated from friends and activities they used to enjoy. Increasing the amount of professional or social support is likely to help to reduce the feelings of burden.

Psychiatrist John March and family therapist Karen Mullen (1998) introduced the concept of mapping in their treatment of children and adolescents. This concept has been adapted to incorporate the role of the family with adult sufferers living at home. In mapping, specific OCD symptoms that both caregivers and the sufferer agree to work on are identified as targets in treatment. Caregivers identify the symptoms that they will no longer accommodate, and make a gradual and systematic plan for disengagement. This plan will allow the sufferer to challenge a fear by taking on more responsibility and relieve the caregiver from an additional duty. It also provides a planned approach that gives direction to caregivers and sufferers. It helps relieve the burden of caregiving by reducing the expectation that accommodations should be eliminated all at once. Inevitable concessions and accommodations to active OCD symptoms are likely to be more tolerable when caregivers know what is being worked on and what is going to be worked on in the future.

At times the sufferers may be unwilling, unmotivated, or too frightened to pursue treatment or participate adaptively in a family recovery plan. Nonetheless, caregivers can continue to develop their own roadmap without the active or cooperative participation of the sufferer. No doubt this is a tricky enterprise, filled with conflict and tension. For example, many OCD sufferers with contamination fears may fear non-family members coming into the home. Not being able to have friends over for a visit can increase the family's isolation and contribute to the depressed mood of other family members. In such a situation, caregivers may set a date when friends or extended family may begin coming to the house. Most OCD sufferers do not like surprises. Setting a reasonable time for such things to commence allows sufferers a reasonable time to prepare for this change in family functioning. When sufferers are not a functioning component of the recovery process, the resulting strife can be intense when families proceed with developing their roadmap. Despite this significant difficulty, better family functioning overall has positive effects on everyone involved, which frequently includes the non-cooperating sufferer.

Another essential key to reducing burden is developing a social support network. This may include reestablishing ties with friends or family members that were lost as the illness seemed to take over the family. Support can also be found through treatment providers and others who are dealing with a loved one afflicted with OCD. There may not be existing support groups in your area, although starting one may help you and many others. The internet has become a huge source of information and support for many individuals. Support groups can occur online and one could benefit simply by posting a concern or expressing themselves on a message board and returning later to see replies of advice and encouragement.

## **The Importance of Self-Care**

Evidence from research by Gallagher and Mechanic (Gallagher & Mechanic, 1996) has indicated that those living with a family member with a mental illness had poorer perceptions of their own health. Family members with relatives who were diagnosed with psychiatric disorders reported more activity limitations, hospitalizations, and more physician visits. These researchers found that more severe mental illnesses and illnesses of greater duration of a psychiatrically ill family member generally did not have an impact on the health and functioning of caregivers. However, one factor did have significant impact on the caregiver. The more the family member's illness limited the activity of the family the poorer the health and well-being of the family members tended to be. As many caregivers have experienced, OCD symptoms can severely limit the activities of the entire family. Another trend in this research was that living with a mentally ill adult child more negatively affects health functioning and activity limitations than living with other mentally ill family members (e.g., spouse, minor child, sibling).

Other research points to the positive or negative perceptions that caregivers may have about their families. Individuals with a mentally ill family member who saw their families as "doing well" appear to have a good sense of humor, a more optimistic outlook, and a willingness to reach out to social support services (Walton-Moss, Gerson, & Rose, 2005). Hence, it is very important that caregivers focus on their own selfcare; this includes both their physical and mental well-being.

An additional piece of reducing the strain of OCD involves reintegrating enjoyable or positive family activities that may have been set aside due to OCD. The reinstatement of these activities should be systematically mapped out. Avoidance of worthwhile and necessary activities can directly lead to burnout and depression. Exercise schedules or hobbies that were given up can be returned to as a way of coping. Many caregivers, however, are frustrated with this advice and wonder where they are going to get the time and energy to engage in these activities. Caregivers often give up these activities because they have followed the path of least resistance by finding it easier to stay home or ignore their own needs rather than fight the sufferer's OCD symptoms. The fears that caregivers have (for example, something catastrophic may occur if they tend to their own needs) is understandable, given what many families have been through. No doubt sufferers will struggle more when a caregiver goes away for a weekend, or even a few hours in some cases. Allowing a sufferer to struggle on their own is part of the recovery process. Recovery is often painful progress for both caregiver and sufferer.

A comprehensive roadmap includes helping the sufferer begin or return to chores and responsibilities. In this way, the burden can be lifted from the caregiver and promote a sense of mastery and functioning to the sufferer. It is important to state that when OCD is successfully treated, the burden eases naturally. When the sufferer struggles in treatment, it is important to remember that the OCD symptoms worked hard to dramatically change the course of the family; caregivers may have to work just as hard to remain supportive and take back at least part of their lives to reduce burden.

Lastly, it is important that mental health professionals be compassionate to families struggling with OCD. It is easy for therapists to point out how many things families are

doing wrong and to prescribe a long list of “don’ts” that accommodate and maintain the OCD. Most therapists who treat OCD haven’t lived in a family with the disorder and don’t have a first hand experience of living full time with an OCD sufferer. So the challenge is not just to the sufferers and their families, it is a challenge to behavior therapists to become part of the roadmap to recovery themselves not merely the designers of it.