Chapter 9

What Can Family and Carers Do to Help a Person with OCD?

This chapter will examine what family members and carers can do to help someone with OCD. In the case of the parents of a person with OCD, the natural reaction is to try to prevent their offspring from experiencing extreme anxiety and distress. This reaction means they can often get caught up being asked to participate in OCD compulsions and rituals and also to obey many of the 'rules' which people with OCD may devise to avoid setting off OCD thoughts. Despite the fact that this compliance with the OCD rituals is done by the carers with the best of intentions, it serves to actually worsen the OCD symptoms over time. It can often be useful for carers to realise that they are the people without OCD, and thus they need to set the 'ground rules' of what they will or will not tolerate and do in their own home. However, in many cases, this is easier said than done. First, old habits die hard. Second, it can be extremely difficult to resist stepping in if a loved-one is highly distressed. This will be explored in this chapter as well as possible solutions.

Throughout this chapter, it is emphasised that the safety of any children, other family members, and the person with OCD is paramount. When an individual suffers from OCD, they can become very distressed and agitated when having extreme obsessive symptoms. A minority of these people may become violent at these times. Violence is never acceptable, and family, carers, and friends have a duty to themselves and also to the person with OCD to keep themselves safe at all times. This may require families to request help from the police in extreme cases. As stated at the beginning, children are the paramount consideration. They may be harmed not only by violent actions but also by being asked to engage in OCD activities and being required to have a restricted life rather than be outside playing with friends or inviting friends to their home. This can be a difficult area for the OCD sufferer and those around them, but it is vital that the welfare of any children is always considered first and foremost.

As demonstrated in previous chapters and through the case studies of OCD sufferers, OCD is a problem which has a huge impact on the whole family. Severe OCD can result in a delay of normal maturation, with a young person

living at home dependent on their parents and siblings for decades. On the other hand, many people with severe OCD are unable to work and unable to form long-lasting relationships. Many live alone and lead isolated and restricted lives, which can also cause worry and concern to friends and relatives.

One of the main problems of living with a person with OCD is knowing how to deal with their obsessions and compulsions. Family members may be asked for constant reassurance, asked to carry out activities which the person with OCD finds difficult, and often asked to carry out compulsive rituals. These requests and demands can cause major problems in families. Family members do not wish to see a loved one disturbed and upset and will understandably try to do everything they can to reduce the distress. As previously discussed, the problem is that reassurance-seeking or the completion of compulsive rituals may temporarily reduce the discomfort and anxiety, but this effect is short-lived and very soon more requests and demands are made. Similarly, it can often seem easier for family members to take on tasks and chores to help the person with OCD, but this can also escalate. A question I am often asked by relatives of people with OCD is how they should work with the person with OCD to prevent themselves from being dragged into the 'OCD quagmire'.

It is very important that family members not blame themselves for trying to help their loved one. This is a normal and natural reaction, and any caring person would do whatever they could to try to prevent the distress caused by OCD. It can be heartbreaking to witness the emotional turmoil being experienced by a loved-one. It would not be helpful or prudent for someone who has been providing reassurance and help to suddenly stop doing so. Full and frank discussions need to be held both with the person who has OCD and with other family members. First, the other family members need to establish in their own minds what is 'reasonable'. This may take some time to work out. OCD can often creep up gradually, and suddenly people find themselves living very restrictive lives with their relative with OCD. What has become 'normal' is far from normal in fact. However, it can be difficult to realise this when living with someone with OCD, and so it is worthwhile taking time to think through what is and what is not acceptable. If available, it can be useful to discuss this with another person who is outside the family, such as a general practitioner or a counsellor, who can help establish some ideas for the family. If a family member has OCD and is under the care of mental health services, their relatives can ask for a 'carer's assessment', in which their own problems and needs are assessed and help such as counselling can be offered.

Some relatives may find the obsessive fears so difficult to understand or so exaggerated that they are tempted to ridicule or belittle the fears. It is extremely important, however, to recognise that these thoughts are profoundly disturbing to the individual with OCD and are therefore extremely serious in their mind. Although they may realise their thoughts are either irrational or exaggerated, the fear accompanying these thoughts is very real and they are unable to 'snap out of it'. Instead, family and friends need to listen and try to understand what their loved one is experiencing.

A discussion must be held with the person who has OCD and their family members to ensure everyone involved understands OCD and that reassurance and compulsive rituals only temporarily help the symptoms of OCD and serve to increase symptoms in the long term. It is essential that everyone is open and clear about this as otherwise if reassurance and help with compulsions are suddenly withdrawn, it can feel like punishment to the person with OCD. It must also be clear that the ultimate responsibility for overcoming OCD lies with the person who has it. Other family members need to care for themselves and their own health and well-being. Although they will be supportive to their relative, they cannot take responsibility for their relative's treatment. Of course, the situation is different with a child who has OCD, in which case the parent has to assume much more responsibility in helping the child overcome OCD (see Chapter 6).

Once the ground rules have been established within the family, it is then time to try to implement them. This is unlikely to be a smooth ride. First, old habits die hard, and it is very easy for all family members to slip back into old routines. Second, the person with OCD may temporarily become more distressed, and this can make it very difficult to resist. It is vital that there be no violence or threats from anyone. Violence and similar behaviours are fully discussed later in this chapter.

Case Study 9.1

Violet, a 30-year-old woman, lives with her parents, who are both in their Sixties, in a house in a small market town. She was a much wanted child who was born after her parents had been told that they were unlikely to ever have children. Consequently, she was always rather 'spoiled' and was used to getting her own way. At the age of 11, she developed a fear of dirt and germs. This led to excessive washing and cleaning behaviours. In order to prevent distress to her daughter, Violet's mother did everything Violet asked her to do. At the time she was first seen in the clinic, Violet ruled her entire house. Her father had taken early retirement to care for Violet, and her mother had not worked since Violet was born. Most of their time was spent indoors, and her mother had a list of daily cleaning which Violet expected her to perform. If Violet did not believe this cleaning was performed 'properly', then she would demand her mother repeat the entire process. Occasionally, Violet's demands resulted in her mother cleaning for eight hours a day. Feeling unable to wash and care for herself, Violet also insisted that her mother wash her. She would stand in the shower whilst her mother cleaned her with antibacterial shower gel. Again, if Violet believed this was not performed 'properly', she would demand that her mother repeat it until she felt 'right'. Going to the toilet would take Violet up to an hour to urinate and four hours to defaecate. She performed these activities alone, but she demanded absolute silence in the house when these occurred. The slightest noise would result in her repeating her compulsions again and taking even longer. Her father was only allowed to leave

the house when Violet gave 'permission', and when he returned with shopping or other items, a strict 'decontamination' procedure of all items was demanded by Violet. The family rarely left the house but every year spend two weeks in a holiday camp in July, which had done for more than 20 years. Whilst away, there was little evidence of Violet's OCD, but it would return as soon as she came home.

Violet's story demonstrates the absolute control that a person with OCD can inflict on a household. Both parents were keen to 'do what was right' for their daughter, but in trying to avoid upsetting her, they had made the situation worse. The story also shows another interesting observation for some people with OCD: Their symptoms can sometimes 'disappear' in a new environment. Unfortunately, they will return the longer the person remains in this different environment. In other words, if Violet's family had remained in the holiday camp environment, her OCD would have gradually returned over the next weeks.

In this case, it is likely to be hopeless to work with just Violet. Her parents have adapted their whole lifestyle around her OCD. Indeed, in a case such as this in which the situation has developed over decades, it is often necessary to move those like Violet into a new environment away from her parents to work on her OCD treatment. Meanwhile, her parents would receive help to try to re-establish their own 'normal' life.

Case Study 9.1 (*cont.*)

A trial of inpatient treatment was offered to Violet. She was insistent that she would not move away from home. When her parents urged her to accept the treatment, pointing out that they were not going to be around forever to do everything for her, Violet responded saying, 'Well, I will then get myself a maid'. Because Violet refused to engage in any therapy, the therapist started to work with the family and to encourage the parents to establish 'ground rules' of what they would and would not tolerate. First, her mother said she was uncomfortable washing a 30-year-old woman. This was explained to Violet. The first time her mother refused to wash her and Violet was told to just stand in the shower if she could not wash herself, Violet screamed and cried for two hours. Her parents did not respond, and she eventually left the shower unassisted. This situation was extremely difficult for Violet's mother, Doris, who found herself unable to resist Violet's demands because she did not wish to see her daughter in a distressed state. Violet's care coordinator therefore arranged for her mother to have a carer's assessment to identify the support she needed. For the carer's assessment, Doris was offered an appointment at the community health team. She was seen by a member of the team, and it was agreed that whilst she was going through such a stressful period, she would need counselling so that she could discuss her feelings.

The next area that was agreed to be tackled was the household cleaning. Initially it was agreed that Violet's mother would clean the house for a maximum

of 30 minutes daily. Again, Violet screamed and cried, which her parents found very distressing but managed by supporting each other to resist the demands to repeat the clean.

After several weeks, Violet realised that her parents were not going to 'give in'. She agreed to accept treatment and to come to the hospital. Despite agreeing, she was extremely angry with her parents, who she believed were 'unreasonable' and that 'they ought to do what I tell them'. During her treatment, a new behaviour emerged whereby Violet would telephone her parents and demand that they tell her that 'all is OK and you won't catch an infection'. Obviously, this reassurance-seeking was not helpful in her programme. A meeting was held with the family, and it was agreed that when such requests were made, the parent would reply, 'Violet I love you very much but answering these questions is not helpful to you. I have been asked by the hospital not to answer these questions'.

After several weeks in the hospital, Violet was still insistent that she would not engage in an exposure and response prevention (ERP) programme, which she believed was 'disgusting and unreasonable'. She was still telephoning her parents both to seek reassurance and to beg them to take her home. This was an extremely difficult time for her parents as they felt guilty even though they also knew they were acting in Violet's best interests. Violet was started on a selective serotonin reuptake inhibitor, which she was happy to take, and this reduced some of her fears and worries. Still unwilling to embark on an ERP programme, a family meeting was held to discuss her future. With the support of their counsellor, Violet's parents told her that they were not willing to take her back home. Violet became very angry and abusive, and both parents were distraught. The counsellor reminded them that they were doing this for Violet's best interests. At a second meeting, Violet was calmer. Her parents explained that they would visit her and that she could come home, initially for daytime visits, but that they could no longer have her living at home. A discussion was then held as to where Violet should live. Her local social worker agreed to look for local supported accommodation.

Violet is currently settled in a hostel which is a few miles from her parents' home. Her parents visit once a week, and Violet goes home on Sunday afternoons. Her parents look more relaxed and happy. Violet is still unwilling to engage in ERP treatment but has improved in her symptoms due to the medication and also the change in environment. It is hoped she may accept ERP treatment in the future.

Violet's case is interesting because Violet herself is not keen to receive therapy. Her parents realise that for the benefit of everyone, she needs to change. It is neither ethical nor practical to 'force' Violet to accept treatment. From her point of view, she says she would be happy to remain at home and with her parents waiting on her and agreeing to her demands. This is not reasonable for her parents, who also need to live their lives. By altering what they will do in the home, Violet started to understand that life at home was changing and that she needed to think about accepting help and treatment.

Throughout the years, I have seen many people who are not willing to accept treatment with ERP at first. This can be because, at present, the treatment seems worse than the condition. Fear of the unknown is another major factor. People generally are fearful of change, and OCD can seem to be a 'reliable, good friend' rather than the life-destroying monster it appears to everyone else. It is not possible to 'do' ERP to anyone; they need to want to do it and to lead the process. The best thing to do in these cases is to leave the individual until they are ready and willing to accept treatment. This may take months, years, or even decades. Some people never decide to accept treatment. The key is to ensure they understand the treatment and to leave the door open for their return to therapy if they chose to do so.

Risk to Children When a Parent Has OCD

Children are the most vulnerable people in a family because they do not have the choices open to adults. When a parent has OCD, this can lead to a range of problems for the children. Parents who spend hours engaged in compulsive rituals may neglect their children, and occasionally in these cases, they might need to be taken into care. More frequently, there are less severe problems but still issues that need to be addressed and prevented.

Some parents with OCD incorporate their children in their compulsive rituals. This could involve extensive washing and cleaning compulsions. Indeed, I have seen children whose skin has been rubbed raw by an overzealous parent trying to 'decontaminate' them. This is unacceptable, and no child should be subjected to such treatment. If alerted to this, the children's welfare should be assessed by a qualified professional.

Parents may also demand children perform actions in a certain fashion guided by OCD, or they may restrict their children's ability to play outside or with friends and to bring friends home. Again, this is unacceptable. Children must be free to experience a 'normal' childhood, irrespective of the problems of their parents. In such situations, the children's welfare must always be the prime consideration. Again, the children need to be assessed by a qualified professional. The parent needs to stop placing these restrictions and demands on the children. This is easier said than done, but it is non-negotiable for the welfare of the children.

How Involved in Care and Treatment Should Families Be?

Assuming that the person with OCD is an adult, the level of involvement of the family and friends in the person's treatment will vary. Treatment with ERP or medication requires the person with OCD to want to engage in the treatment to try to overcome the problem. If the person with OCD wants friends and family to help with treatment, then it is best for that person to define how they can help. Similarly, the person with OCD will be able to say whether or not they would like family and friends to attend any appointments with them. It can be very difficult to see a loved one undergoing treatment and not to be asked to help, but

in fact, this may be the way in which the individual is learning to take a step forward and to overcome OCD themselves. It is usually best for family and friends to ask if they can help and to leave it to the individual to decide one way or other.

Sometimes an individual with OCD is reluctant to express their fears openly, and it can take careful and sympathetic listening and support to understand the obsessions. Indeed, if there is a high degree of shame and embarrassment concerning the obsessive thoughts, they may be unwilling to discuss these with those who are closest to them. In such situations, it is important that some ground rules are still set to keep everyone in the family on 'an even keel'.

Sometimes it can be difficult for families to withhold reassurance and not provide help with compulsions because it seems as if they do not care. It is important to demonstrate care in ways which are more 'healthy' and productive. Depending on the nature of the OCD and the stage of the individual in their 'OCD journey', care may be demonstrated by going for a walk with the loved one or having family dinners and discussions on non-OCD topics.

Violence and OCD

Violence, threats, and abusive behaviour are never acceptable. Sometimes, people with OCD may 'lash out' if a relative interrupts their compulsive rituals either on purpose or accidentally. Whatever the situation, violence is always unacceptable. Family members are often reluctant to report violence to the authorities. Although this is understandable, it may not be helpful. Although violence may be 'out of character' for the individual, there is still conscious control in OCD. Ignoring and 'brushing violent episodes under the carpet' can lead to an escalation of violence. Not only is this dangerous for the person who is the victim of this violence but also it is damaging to the person with OCD. If they learn to 'lash out' whenever their compulsions are interrupted or when someone does not meet their demands, they may some day commit a very serious violent act.

The rule for those who are threatened with violence is simple: They must protect themselves. This may mean leaving the situation or contacting the police. Acting in this way is to the benefit of other family members and the person with OCD. It can be difficult because families do not wish to inflict further distress on their loved one, but it is in the best interest of everyone involved that it is crystal clear that violence of any form is unacceptable.

Key Points

- OCD is a condition which affects all family members and not just the person with OCD.
- Family members may also need help and counselling. They can ask for this through a 'carer's assessment'.

- Family members need to establish 'ground rules' about what is and what is not acceptable and what they will tolerate.
- Giving reassurance to a person with OCD offers temporary relief, but then the anxiety returns.
- Giving reassurance or taking over jobs and performing compulsions for the person with OCD makes the situation worse in the long term.
- It is difficult to stop engaging in behaviours such as reassurance-seeking or helping with compulsive rituals because it can cause extreme distress to the OCD sufferer. A frank discussion needs to be held with them before implementing the change.
- The person with OCD needs to be willing to engage in ERP; it is not a treatment that can be 'done' to them.
- People with OCD have to determine their own 'rock bottom' point and when they will accept treatment. Family members must try to ensure that their own lives are as unimpaired by their relative's OCD as possible.
- Sometimes it is necessary to make difficult decisions, such as refusing to allow a son or daughter to remain living in the house, in order to help those with OCD start to change.
- If the person with OCD is a parent, the needs of the children are paramount. Children should be free to develop, grow, explore, and form friendships free of any OCD restrictions imposed by others. If this is not the case, then the child's well-being needs to be assessed by a child health professional.
- Violence and threats are never acceptable. Family members must always protect themselves. There should be consideration about calling the police after any violence has occurred.