

Support for Carers and Families

If someone you live with or are close to is struggling with OCD or a related condition, this may at times impact your wellbeing, mental health, and day-to-day life. As a paid or unpaid carer, you are entitled to support in caring for your loved one and around your own needs and experience. While you may not consider yourself to be a carer you are still entitled to support with your own needs whilst you care for your loved one.

Watching a loved one struggle with a distressing condition like OCD or a related condition is difficult in itself, and very often carers find themselves feeling powerless to help. OCD and related conditions also tend to worsen and intensify over time if they go untreated, meaning that the care needed from you might increase. In addition to this, due to the nature of these conditions, it is very common for carers to become involved in compulsions in order to alleviate the distress experienced by their loved one in the moment. This can feel like a double-edged sword because of the knowledge that engaging in compulsions ultimately does not help with the individual's recovery as it feeds into the condition's cycle, which can bring on feelings of shame, guilt, and frustration. If you are a parent, partner, family member, or friend, it can therefore feel difficult at times to separate yourself from the debilitating experiences your loved one is going through, and this may result in you feeling that a huge amount of responsibility falls on you to care for them in the best way possible. Unfortunately, this can create a situation where you feel that your needs and difficulties need to take a backseat, which is a common experience for many carers because of the sheer nature of what it means to care for someone who is very unwell.

Here are some self-care tips that might be helpful to consider within your journey as a carer:

➤ **You Matter!**

Taking care of someone struggling with OCD or a related condition can become a full-time job for many carers, and this can ultimately lead to someone forgetting that they have needs too and that their feelings, wellbeing and general health matter – but they do! Although you are your loved one's carer, you are also *you*, and this means that you have value and worth and that your feelings and needs are valid and important.

➤ **Drawing a Line When Possible**

Often times, carers of people with OCD or a related condition feel drawn into doing or engaging in compulsions in order to alleviate the distress being experienced, to 'keep the peace', or sometimes because this is the only way to keep life moving and get their loved one where they need to be, which is quite common for parents of children with OCD or a related condition. The only long-term solution to tackling these conditions is to secure and access the recommended treatments for them, though there

will be times when your loved one is having to wait for long periods of time in order to access treatment or may be resistant to access treatment at all. Although there is no easy answer with regards to how to deal with compulsions, in the short term it might help to draw a line in terms of how far you're willing to go to engage with these compulsions. This may cause upset or distress for your loved one because of the false sense of security that their OCD or related condition gives around why these compulsions need to be carried out, but the aim of drawing this line is to find a compromise that works for you both and that allows you to apply personal boundaries that help you feel comfortable too. Talking to mental health professionals with expertise in your loved one's condition can be very helpful with regards to short-term and long-term management, and there are important sections of the NICE OCD and BDD Treatment Guidelines that refer to this which you can read more about at the bottom this resource.

➤ **Finding Some Time and Space Just for You**

Finding some time or carving out some space for yourself may feel difficult and even impossible at times whilst caring for someone with OCD or a related condition, but can be so very important. This allows for some breathing space and some time for you to just focus on you and unwind, even if only for a few moments. This may include going on a walk, seeing a friend, or running a bath, but if physical separation from your loved one is not an option, then even little things like listening to music or speaking to someone over the phone can be helpful. Sometimes it may feel like you are the only person who is able or 'allowed' to care for your loved one, and in some situations this may be the case. If there is another adult in your home with whom you can share this caring role with, this may help relieve you from the stress you're under and help others in the household feel like they can be more involved in helping.

➤ **Reaching Out for Support**

Sometimes carers can feel isolated in their role and begin to internalise expectations around how well they should be doing as a carer, often blaming themselves for how bad the situation's gotten or for not being able to make the OCD or related condition go away, or feeling ashamed that their lives are being "controlled" by OCD. You may even find it hard speaking about your situation to someone outside your family for fear of being judged, patronised, or misunderstood, and general stigma around mental health and around OCD and related conditions in specific makes matters worse. However, it can be so very helpful to find someone you trust or who understands your situation to speak to, as this can help lift the weight from your shoulders and help you to feel less isolated and alone in your situation. This can be a friend or a family member, or you can find this kind of support by joining support groups, speaking to someone on a helpline, or finding a therapist.

Getting a Carer's Assessment

As a paid or unpaid carer, you have a 'statutory' right to a carer's assessment. This means that your local authority legally must offer this type of assessment to you if you feel you need it to help make your life easier. This assessment will look at your social, practical, and mental health needs, and at the

end you and all professionals involved should receive a report about what support you will be offered.

This could cover many areas of your life, including:

- Support to improve your wellbeing such as exercise classes or social activities
- Mental health support such as counselling or psychotherapy
- Social support such as support groups, befriending, or social prescribing
- Training and information around caring for your loved one
- Psychoeducation around taking care of yourself while caring for someone else
- Breaks from caring, such as respite care for the person you care for
- Advice around benefits for carers

You can read more about this on the [NHS's page on carer's assessments](#).

NICE Guidance

Alongside providing information on the recommended treatments, the [NICE guidelines for OCD and BDD](#) also outline helpful information about the impact on families and the support that should be offered to carers. Such information can be found in but is not limited to: sections **3.5 Understanding the Impact of OCD on Family Members and Carers**, **3.6 Specific Issues for Children and families**, and **3.7 Sources of User and Carer Advice**.

Recently, NICE also published [Guidelines for Supporting Adult Carers](#), which give more information about how carer's assessments should be run and the level of knowledge that is expected of professionals carrying out these assessments. These guidelines emphasise the importance of identifying carers, encouraging them to engage with their own support, and treating them like a valued member of the patient's care team:

"1.1.11 Health and social care organisations should promote ways of working with carers that acknowledge them as expert partners in care and value their skills and knowledge about the person they care for. These approaches should be incorporated into formal policies and processes."

If you or your loved one would like further information about OCD or a related condition and what support and help is out there, you can contact the OCD Action Helpline on support@ocdaction.org.uk, 0300 6365478, or visit our website at www.ocdaction.org.uk.