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# Obsessive Compulsive Disorder

A guide for family and friends

Second edition



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# Chapter 1: Introduction to the booklet

## Who is this booklet for?

It is estimated that around three quarters of a million people in the UK experience OCD. However, that figure doesn't include carers and family members who are often involved in supporting someone with OCD. This booklet has been designed as a tool for people who have a family member, friend, partner, or loved one who is experiencing OCD. For ease, we will refer to people with OCD as the 'family member' and those offering support as 'families', but we can appreciate that you may of course be supporting someone from outside of your family.

## Why have we developed this booklet?

OCD can be an extremely scary and isolating experience for adults of all ages. We understand that supporting someone with OCD at any stage of their recovery can be incredibly challenging and, at times, draining. Often, families desperately want to support their family member through OCD but they are unaware of how best to help. This can sometimes put a strain on relationships and on the mental health and wellbeing of the family more generally.

## What are we aiming to do?

The aim of this booklet is to help you understand more about OCD and ways you can support your family member to engage in therapy and take back their life. We hope that this booklet will give you ideas about how to have useful conversations with your family member and some techniques you might like to try together. We also hope that this booklet can give you some space to think about looking after your own wellbeing through this journey.

## Chapter 2: What is OCD?

OCD or Obsessive Compulsive Disorder is an anxiety disorder characterised by obsessive thoughts and physical and/or mental compulsions. Before thinking about how you can support the person in your life experiencing OCD, it is useful to think about the different ways OCD may impact the way they experience the world.

### What are obsessions?

An obsession is a persistent thought, image or urge that causes a person to feel distressed. Obsessive thoughts are usually frequent, unwanted and difficult to control or get rid of. In fact, the more a person tries to push away these thoughts, the more intense and unrelenting they can become. Common obsessions include:

- Fear of contamination from dirt, germs, viruses, bodily fluids, etc.
- Fear of being harmed (e.g. due to leaving the doors unlocked)
- Excessive concern with order or symmetry
- Obsessions with body or physical symptoms
- Blasphemous thoughts (e.g. offending God)
- Upsetting sexual thoughts
- Thoughts of violence or aggression

### What are compulsions?

Compulsions are repetitive behaviours or mental acts that a person feels an intense urge to perform in response to an obsession. Most people with OCD have more than one compulsion. Compulsions can often start as one or two actions or tasks but over time can increase in number and become more complicated.

Common compulsions include:

- Checking (e.g. taps, gas, locked doors)
- Cleaning/washing
- Repeating acts
- Ordering or striving for symmetry/ exactness
- Counting

## What Keeps OCD Going?

Some of the compulsions listed above might be very familiar to you. However, you might be starting to think of some other behaviours your family member engages in which seem to provoke or worsen their anxiety, or heighten their obsessive thoughts and urges. We call these 'Safety Behaviours'.

A Safety Behaviour is any behaviour that is intended to keep oneself or others safe from harm, but actually just serves to reinforce unhelpful OCD beliefs. They include compulsive rituals and more general unhelpful coping strategies. Broadly speaking, Safety Behaviours fall into the following categories:

### Checking

This could be checking a set number of times or until it feels 'right' e.g.

- Checking doors are locked
- Checking your baby is breathing

### Neutralising

e.g.

- Counting
- Reciting a prayer or mantra
- Thinking a good thought
- Clenching muscles

### Reassurance seeking

For example, the person with OCD asking:

- 'Did you see me lock the front door?'
- 'Can you promise me nothing bad will happen?'

### Avoidance

e.g.

- Avoiding public toilets or buses
- Avoiding films that trigger obsessive thoughts

Throughout this booklet we will explore ways in which these behaviours can exacerbate your family member's experience of OCD. We will explore ways that you, as a family, may have become involved in these safety behaviours. We will also think about the impact this could have on the individual's recovery from OCD and think about how to make changes to your own behaviour to support your family member.

We will be encouraging you to discourage your family member from engaging in Safety Behaviours. For them to experience their persistent thought, images, or urge – and to do nothing! Sometimes, though doing nothing can feel really difficult and we will give some ideas of how you and your family can practice doing nothing as we go through this booklet.

## Summary

OCD is an umbrella term for people who engage in compulsive behaviours in response to distressing and intrusive thoughts or images. Your family member engages in these behaviours in an attempt to keep themselves and others safe from harm or danger. However, these behaviours can often exacerbate their OCD.

This chapter provided a very brief overview of some of the things the person with OCD might experience in their day to day life. If you would like to read more about OCD, you can find further information in the Cardiff and Vale UHB 'CBT for OCD' Booklet. You can find this by going to [www.Stepiau.org](http://www.Stepiau.org) and typing 'OCD Booklet' in the search facility. The 'CBT for OCD' booklet was designed for people experiencing OCD and will give you a more in-depth explanation of the OCD experience.

In the next few chapters we will explore the role of families in OCD, focusing on the ways in which families can become directly or indirectly involved in facilitating safety behaviours.

## Chapter 3: OCD in Families

There are lots of different types and experiences of OCD and no two families will have the same experience of living with OCD. However, the behaviours that can *maintain* OCD are very similar across all different types of OCD. As we move through the booklet you will likely be able to recognise how some of the ideas we discuss are relevant to you and your family. In this chapter we are going to introduce you to Clive and his wife, Jayne. Throughout the booklet we will be using Clive and Jayne's experience to help us demonstrate how we might understand some of the challenges of living with OCD in families. We will also use Clive and Jayne's experiences to bring to life some of the skills and techniques which we suggest towards to the end of the booklet.

### Clive

Clive is continually troubled by the thought that his house will get burgled. He helps deliver food to elderly people but this is becoming difficult as he repeatedly drives home to check his house is locked. Clive is also finding it difficult to leave the house in the morning as he has to check all windows and doors at least five times. On weekends he avoids leaving the house at all so that he doesn't have to spend hours checking the doors and windows in his home. The more he wonders if he really has closed the upstairs window, the more unsure he becomes. Clive's problems are having a negative impact on his relationship with his wife and they have started to row over his checking. He is also spending significant amounts of money on continually upgrading his burglar alarm as he worries it will stop working.

### Jayne

Jayne is Clive's wife. Jayne will wait until Clive has left for work before she leaves so she can lock up. This way Clive avoids getting stuck in checking rituals before work. When they leave the house together, Jayne will often drive Clive back to the house so that he can check the doors and windows are locked, even though he checked a number of times before they left. Jayne will spend much of the day reassuring Clive that the house is locked and nothing will happen whilst they are out. Jayne has even started suggesting that Clive takes pictures so they do not have to turn around and go home; this seemed to have helped initially, but now Clive seems to check the pictures constantly. Jayne finds she often avoids suggesting they go out and spend time together because it can take so long and feels so stressful for them both.

## Chapter 4: Spotting OCD in Families

The research shows that, compared to other mental health conditions, the families of people experiencing OCD are far more likely to be involved in the day-to-day living with the condition. It also suggests that they are likely to experience higher levels of stress, fatigue, frustration and family tension as a result of their family member's experience of OCD. In the next part of the booklet we will explore behaviours which the wider family might engage in, in an attempt to help their family member cope with OCD. We call this Family Accommodation.

### What is Family Accommodation?

Family accommodation is an umbrella term that has been used to refer to behavioural changes or adaptations to day-to-day routines which families make in response to their family member's OCD. Despite being known as 'family' accommodation, the concept applies to anyone with whom the person with OCD has a close relationship with. So that could be family members, spouses, friends, support workers, etc. Family accommodation can be understood as behaviours which fall into the following four categories:

1. Reassurance Giving

2. Accommodating Avoidance

3. Engaging in Compulsions

4. Facilitating Compulsions

More often than not, families become involved in one or more of these kinds of accommodation because they find it incredibly difficult to watch their family member in distress. Some families also find that they agree to some accommodating behaviours to help the person with OCD get on with their day e.g. get to work, get children to school, socialise with friends. Sometimes families believe that their accommodation behaviours are helpful, but in other they are fully aware that the accommodation is ultimately unhelpful but feel at a loss to know what else to do to support their loved one.

## Why is family accommodation important in maintaining OCD?

Accommodating OCD by engaging in safety behaviours often comes from a place of love and compassion. It may seem helpful in the short term, but in the longer-term accommodation works to reinforce your family member's beliefs about their thoughts. Ultimately, this can play a big part in maintaining OCD. Below are some examples of how accommodating behaviours can keep OCD going. We'll use Clive and Jayne as an example here:

Impact of Family Accommodation	Example
Preventing the person with OCD from finding out that the worst may not happen when they do not perform their compulsions	When Jayne checks the doors are locked, it prevents Clive from finding out that his feared outcome may not come true, regardless of whether he does his compulsion(s) or not.
Taking responsibility away from your family member or sharing it	When Jayne checks the doors are locked at Clive's request, she takes on some of the responsibility. Clive believes that if someone did break into the house BOTH he and Jayne would be responsible. This prevents Clive from adjusting his beliefs around responsibility.
Reinforcing doubt	When Jayne checks the door is locked, Clive doesn't learn to tolerate not being 100% sure he locked the door. He also becomes more doubtful of his memory. He thinks 'I can only be sure the door is locked because Jayne checked / reassured me'.
Reinforcing that the 'risk' is real	When Jayne takes action by checking the door is locked, it 'proves' to Clive that his concern was valid and the 'risk' needed addressing.

Often families can experience feelings of guilt or shame when exploring family accommodation in OCD. It is important to remember that you are not alone in this journey, and that most families engage in some form of family accommodation.

## Summary

Family accommodation is a term used to refer to the changes or adaptations which families make in response to OCD. Some of the most helpful things that families can do to support the person with OCD are to:

- Understand more about family accommodation
- Learn to recognise and name it in their day-to-day lives
- Practise how to make changes so they are not engaging in unhelpful responses or 'safety behaviours' on behalf of the person with OCD.

# Chapter 5: Reassurance Seeking

## What is reassurance?

Reassurance is the action of removing someone's fears or doubts, and is an integral part of our relationships with others from the time we are babies. Reassurance can temporarily reduce our anxiety and help us to feel cared for and understood. For people experiencing OCD, their relationship with reassurance is often described as 'excessive reassurance seeking' meaning that requests for reassurance are frequent, unrelenting and often repetitive. The person with OCD may seek reassurance from:

- Themselves (e.g. mentally reviewing an activity or ritual in their mind)
- Online sources (e.g. researching symptoms of an illness)
- Other people (e.g. family and friends)

Evidence suggests that providing reassurance is the most common way in which families accommodate OCD.

## What does reassurance seeking look like?

Sometimes it is very easy to recognise when someone is seeking reassurance, but at other times it can be much more difficult. Part of the reason for this is because reassurance can be verbal or observational and can happen directly or indirectly. Below are some examples to help us understand more about the types of reassurance:

### Obsession

*Intrusive image:  
pushing cyclist into the  
road*

The obsessions might present itself as an intrusive thought, image or urge.

### Verbal Reassurance Seeking

*Asking partner 'did you see that cyclist fall into the road?'*

This is verbal reassurance as the person is asking their partner a question.

### Observational Reassurance Seeking

*Trying to observe facial expressions or reactions from their partner that would suggest they had seen a cyclist in the road.*

The person with OCD may think 'if I had pushed the cyclist my partner would have reacted' and thus feel reassured.

## Obsession

*Intrusive Thought 'Have I locked the back door?'*

The obsessions might present itself as an intrusive thought, image or urge.

## Direct Reassurance seeking

*"Can you check if I shut the back door please?"*

This is a direct request for someone else to perform the checking and reassure them that the obsessive thought over someone breaking in is not possible, because the door has been checked.

## Indirect reassurance seeking

*"I think I left my coat by the back door; can you grab it for me please?"*

This is an indirect request to gain reassurance, as they know that if someone collects their coat by the door (and the door is still open) they will shut it for them.

## How does reassurance maintain OCD?

It is understandable that as a family member or friend of someone with OCD, it can be incredibly difficult to watch someone in distress and so your natural instinct may be to offer the person with OCD reassurance when they ask for it. You might find that reassurance appears to help the person in the short term. However, by seeking reassurance, the person with OCD does not have to learn to tolerate any doubt or uncertainty. Here's an example of how this works:

1. If Clive asks Jayne for reassurance that the door is locked, he places some of the responsibility for the safety of the house to Jayne. Now, if something bad happened, Clive would feel less responsible because Jayne *reassured* him that he had locked the door. Clive doesn't learn to adjust his beliefs about responsibility and without adjusting his beliefs about responsibility, Clive's OCD persists.
2. Clive asks for reassurance because he is finding it hard to sit with the doubt and uncertainty that he *might not* have locked the door. By receiving reassurance from Jayne, Clive doesn't learn that he can trust his own memory, or judgement (that he locked the door) and his doubt only grows. This leads Clive to ask for more and more reassurance in the future.

**TIP:** It can be really difficult to know when reassurance stops being helpful and starts to become problematic. As a helpful guide, you can use the following rule: 'Once is a question; anything more is reassurance'.

## What can the research tell us about Excessive Reassurance Seeking?

In 2016, a group of researchers from Reading University published a study which aimed to help us further our understanding of excessive reassurance seeking in OCD. The researchers conducted interviews with ten carers of people experiencing OCD. The carers were asked a range of questions about their understanding of, and experience with, reassurance in OCD and the researchers tried to find common themes across all of the interviews.

### Key Findings from the study included:

- All participants reported experiencing frustration as a result of being asked to repeatedly provide reassurance to the person experiencing OCD.
- Caregivers clearly understood that providing reassurance is counterproductive for the person with OCD in the long term.
- Giving reassurance is seen as providing short term relief to the 'on the day' anxiety caused by OCD thoughts and behaviours. It was reported that caregivers felt reassurance was an effective way to help their family member 'move on' with their day rather than spending hours in distress.
- A fear of negative consequences if reassurance was withheld (e.g. verbal arguments or physical conflict) was cited by many participants as a reason for offering reassurance.
- Some caregivers had never felt able to try withholding reassurance, and those who had tried this, reported negative experiences.

Arguably one of the most powerful findings from this study, and the one that gave the study its name was: *"caregivers provided reassurance as they simply didn't know what else to do or offer to the person experiencing OCD without fear of making things worse"* (Halldorson *et al.*, 2016).

## Making changes

This research, and others like it, can help us to understand why it is so important that caregivers do not simply withhold all forms of reassurance at once, as this could lead to both you and the person with OCD feeling even more distressed and emotionally disconnected from each another. Instead, the research suggests that offering an alternative to reassurance can be a helpful tool. By offering an alternative, you are still able to provide emotional or physical support to the person with OCD, but without offering the reassurance that can leave you both feeling stuck and frustrated.

### Reassurance Seeking Vs. Support Seeking

So, what are the alternatives to reassurance? Well, the research suggests that shifting to offering support to aid the person in 'coping' with their anxiety or doubt could be a helpful tool. The idea is that, by finding non-reassurance-based ways to assist a person with OCD, caregivers feel able to empower and support the person to reduce their OCD behaviours in a way which is effective in the long term.

On the next page you'll find an example of how you and your family member could shift from reassurance seeking to support seeking.

## Reassurance Seeking Vs Support Seeking

### Reassurance Seeking:

'I'm really worried that I didn't check properly'



### Reassurance Giving:

Non-verbal reassurance e.g. watching the family member complete their checking ritual



Verbal reassurance and sharing responsibility e.g. 'I watched you check; you did do it'



Verbal reassurance e.g. 'It's going to be okay, nothing bad is going to happen'

### Support Seeking:

'I'm trying not to check but I'm finding it really difficult'



### Support Giving:

Offering words of encouragement e.g. 'I know this is hard for you, but you're doing really well and I know you can do this'.



Physical comfort or soothing e.g. giving the person with OCD a hug or having a cup of tea together.



Distraction e.g. watching a T.V. programme together to help the person with OCD to distract themselves from the anxiety or distress they are experiencing.

Making the change from Reassurance Seeking to Support Seeking may be a topic that the person with OCD first explores with their therapist. In an ideal world, this conversation is something that the person experiencing OCD feels empowered to lead. However, this is not always the case, and it may still be worth trying to have open conversations with your family member in an attempt to implement some of these ideas.

In chapter 8, we discuss 'Contracting', as a useful tool to support a slow and steady approach to reducing reassurance and other types of accommodating behaviours.

**REMEMBER:** You cannot control whether your family member seeks reassurance from you, but you can choose how you respond to their request for reassurance. Sometimes you will be able to do this, and other times you won't. That's okay, the most important thing here is just to feel able to try something different.

## Chapter 6: Accommodating Avoidance

Over time engaging in compulsive behaviours can become incredibly time consuming and exhausting for the whole family. Avoidance is a very common way for people to manage the fear and anxiety triggered by their intrusive thoughts without having to complete their compulsive rituals. There are lots of different ways people with OCD might engage in avoidance, for example:

*Clive avoids being the last person to leave his office so that he doesn't have to lock up. He also avoids leaving his house without Jayne nearby, as he wants her to reassure him.*

Often, in an attempt to help the person with OCD manage their anxiety, or even to help the whole family get on with their day, families engage in avoidance behaviours or facilitate their family member to avoid, for example:

*Jayne tells us that she will often leave late for work so that she can lock up instead of Clive.*

Below are some other examples of ways in which families can accommodate avoidance when a family member is experiencing OCD:

Preparing meals so the person with OCD can avoid rituals

Making small decisions for a family member when their OCD makes decision making challenging

Avoiding dinner with a friend, should this trigger cleaning compulsions for the person with OCD

Making excuses why a family member can't attend events, so that they can avoid triggering situations

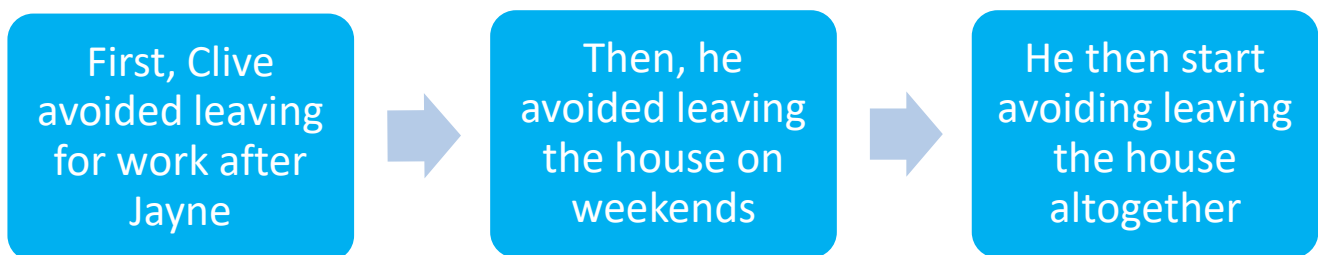
Avoiding watching certain TV programmes that might cause a family member to complete a compulsion

## How does avoidance maintain OCD?

The examples above might feel familiar to you, or perhaps you have found yourself reflecting on some of the changes that you have made to your routine or family life which might accommodate the person's OCD. But why is it helpful to identify behaviours which accommodate avoidance?

Well, accommodating avoidance means that your family member does not have to expose themselves to situations which trigger their OCD. In the short term this might help them get to get on with their day, for example getting to work on time and maintaining romantic relationships or friendships. However, over time the number of things your loved one avoids can become bigger and bigger and this means that the world around them can become smaller.

Let's think about Clive and his compulsions about locking the house as an example of this:

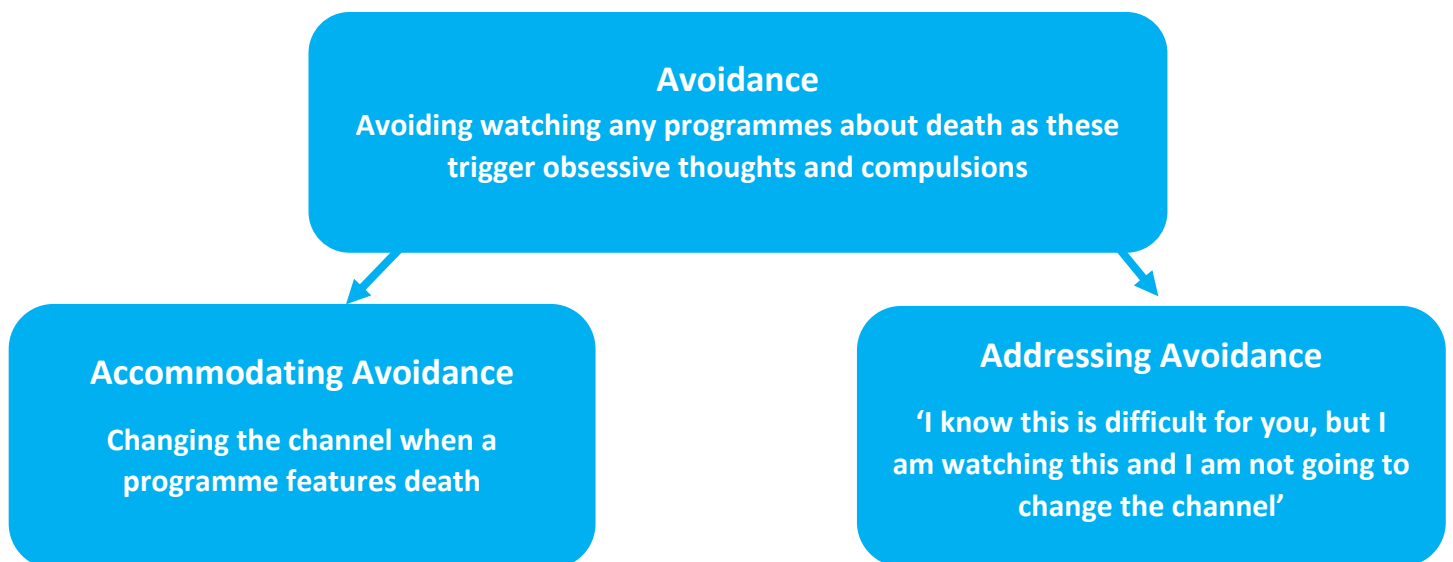


Feeling fearful or afraid doesn't always mean that we are in danger. However, avoiding things that make us feel this way can lead us to believe that we ARE in real danger. Avoiding a situation, person or place can prevent your loved one from finding out that nothing bad happens when they face their fear. Just like Clive, avoidance seems helpful at the beginning but it can spiral very quickly into a behaviour that maintains someone's experience of OCD symptoms.

## What can we do instead?

Research has found that when families stop accommodating OCD, the person experiencing OCD can become more motivated and engaged in therapy. Therefore, the best thing you can do to support your family member is to reduce, and ultimately stop, accommodating their OCD behaviours.

Once you and the person experiencing OCD have established a collaborative plan, it is time to start addressing avoidance. It might be easier for you both to start by just reducing the amount of avoidance you accommodate, then you slowly move towards completely stopping.



In this example, your family member may choose to leave the room, but this is their choice. They are taking part in an avoidance behaviour but you have not accommodated their avoidance by changing the channel. This is a small but effective way to slowly reduce your role in accommodating avoidance.

## Making Changes

Reducing accommodation can feel like an overwhelming task. Many people find that they started to accommodate avoidance in order to de-escalate tensions at home or to help the person with OCD get on with their day. However, there are some ways in which you can make the process feel more manageable for you both. We have broken the process down into 'The Three C's':

### Communication

Any changes to the way of managing OCD is going to create some anxiety and so it's important that you start by having an open and honest conversation with your family member about accommodation in your home. Together, try and identify some of the ways your family accommodate OCD behaviours and how these keep OCD going in the long term. Remember to try and help the person with OCD understand that addressing accommodation is a way of you supporting them, not to make things more difficult.

### Collaboration

Most families find that there are lots of different ways that they have changed their behaviour to accommodate OCD and attempting to change all of these behaviours at once would be overwhelming for the whole family. The most important thing is to make any changes a shared decision, so you are both working together against OCD. 'Mapping' can be a useful tool for reducing accommodation. Together you and your family member agree upon one or two areas to start targeting, you agree how you are going to do this, and what you might expect of each other. Once you have tackled this behaviour, you map out your next move.

### Consistency

One of the most important things to remember when making any kind of change is to be consistent. Once you and your family member agree a focus, it's important that you try and stick to what you have agreed as much as possible. For example, if you have agreed a particular response (such as giving a hug instead of washing your hands) it's important that you try and stick to your agreed response each time the OCD behaviour occurs.

**TIP:** In Chapter 8 of the booklet we introduce the 'Contracting Tool'; you might like to use this to help you with mapping and thinking about how you can be consistent in your approach.

## Chapter 7: Engaging in Compulsions

So far in this booklet we have explored lots of ways that families can become involved in OCD without having any involvement in carrying out compulsions. However, we know that often family members can become involved in completing OCD rituals and this often starts, as with many other accommodating behaviours, as a way to try and help your family member feel less distressed and be able to carry on with day to day life. There are two main ways that families can become a part of a compulsive ritual. This can be direct involvement by *Engaging in Compulsions* or indirectly, by *Facilitating Compulsions*:

### *Engaging in compulsions*

refers to any time when you participate in your family member's OCD behaviours alongside them or at their request

e.g.

- Saying a mantra or prayer with your family member to prevent something bad happening.

OR

- Helping your family member to complete a cleaning ritual, e.g. wiping down grocery items before bringing them into your home.

### *Facilitating Compulsions*

can be slightly more difficult to recognise, but refers to any actions which you take to enable your family member to complete an OCD behaviour. The task gets completed but with some adjustments.

e.g.

- Driving back to your home after starting a journey to allow your family member to check the doors and windows are locked.

OR

- Arranging an appointment in the afternoon so that your family member can complete their OCD behaviours before leaving the house.

## How does facilitating and engaging in compulsions maintain OCD?

As we've already seen in chapters 4 and 5, there are lots of different ways in which family accommodation can keep OCD going. Facilitating and engaging in compulsions are no exception to this. Below are some examples demonstrating how directly engaging in compulsions helps to maintain OCD:

### Reinforcing the idea that the risk is real

**Example:** Helping your family member wipe down each item of food from your shopping before putting it in the cupboard

**Belief:** Beliefs about risk are not challenged or adjusted. Instead, they are confirmed by the actions of the family, e.g. 'If my partner is doing this too, they must also think the risk is real.'

### Sharing responsibility

**Example:** Helping your family member wipe down each item of food from your shopping before putting it in the cupboard

**Belief:** Beliefs about responsibility are not challenged or adjusted because the person with OCD feels that they are SHARING responsibility for any negative consequences with the person who helped them complete the behaviour.

### Preventing the person finding out that the worst may not happen

**Example:** Helping your family member wipe down each item of food from your shopping before putting it in the cupboard

**Belief:** The person doesn't get to find out what might happen if they, or you, do not complete the compulsion. They continue to believe that the feared consequence *will* happen, e.g. someone will get ill and die, and they do not gather any evidence to the contrary.

There is another important way that these particular types of family accommodation maintain OCD, which we haven't covered yet in this booklet and that is by *Making Space for OCD*.

## What do we mean by Making Space for OCD?

When you facilitate your family member's OCD compulsions or safety behaviours within your normal daily routine, you start to make space for OCD in your daily lives. For example, you might arrange an afternoon GP appointment for your family member so that they have time to complete their rituals in the morning. By doing this, you have helped them attend their appointment, but also created designated space for the OCD ritual. When we make changes like this to our routines, it can seem helpful in the short term (enabling your family member to attend appointment). However, it can mean that

OCD is no longer stopping the person from completing an important task. Often, the reason people feel motivated to challenge OCD is because it's stopping them from doing things they want or need to do. The more space we make for OCD, the more it will grow and the less motivated your family member may feel to challenge their OCD.

### What can we do instead?

Often, families have been facilitating or engaging in OCD behaviours for such a long time that it can be difficult to remember what life looked like before this time. As you've read this chapter you might have become more aware of lots of changes you have made to your routine which allow you to facilitate or engage in an attempt to support your family member. Perhaps you feel at a loss with where to start making changes? As with other kinds of family accommodation, it would be overwhelming, for the person with OCD and families, to stop all accommodation of OCD behaviours at once. Often it can be useful for you and your family member to collaboratively agree two or three very specific goals they would like to achieve, and work through these one by one. In the next chapter, we discuss 'Contracting' which can be a useful tool when making changes with your family.

## Chapter 8: Contracting

Throughout the booklet we have discussed some tools and techniques which may be useful for you, and the person with OCD, who you are supporting. We hope that these have been helpful in developing your knowledge and understanding of what keeps OCD going. In this next chapter we focus on a template which may be useful for planning how you and your loved one might approach making some of the changes discussed in the booklet.

### What is contracting?

To help families make changes to their accommodation of OCD in and around the home, the family member's therapist might suggest that you develop a family contract. Family, or behavioural contracts are very much like a business contract. With the agreement of everyone involved, the contract sets out what is expected of each person involved in a particular situation. You and the person with OCD can use this contract as a tool to guide you through making changes.

When developing a contract, it is important to:

- Take things slowly
- Focus on one behaviour or type of accommodation at a time
- Think about a realistic and achievable goal that you would like to tackle together

On the next page you will find an example of a contract between Clive and Jayne, and you might want to use this as a template for your own contract. Alternatively, you and your family member can design a template that works for you both.

## Example Contract

**Goal:** Stop asking for reassurance that I have locked the back door when we go for a walk together.

### Clive

#### **What I can say to Jayne when I am struggling with my OCD:**

I really want to ask you for reassurance right now, I'm trying really hard not to but I'm feeling really anxious

#### **What I'd like Jayne to do when I am struggling with my OCD:**

- 1) Acknowledge that not asking for reassurance is really difficult for me and hold my hand.
- 2) Help to distract me by talking about things she's noticing on the walk.
- 3) Help me to challenge my OCD by asking 'are you trying to end the walk sooner so you can check?' if I suggest heading home early.

#### **What I need to try and resist doing when I am struggling with my OCD:**

- 1) Asking for reassurance from Jayne e.g. 'Did you see me lock the door?', 'Were you paying attention?'
- 2) Walking faster than usual or trying to end the walk early.
- 3) Asking Jayne to check the door is locked before leaving the house.

### Jayne

#### **What can I say to Clive when he is struggling with his OCD, without offering reassurance:**

I know this is really hard for you, but I know you can do this and you're doing really well.

#### **What I can do to support Clive when he is struggling with his OCD:**

- 1) Help him set a goal for the walk at the beginning and support him to stick to this e.g. let's walk for 15 minutes and then go home.
- 2) Offer words of encouragement when he's trying to challenge his OCD.
- 3) Offer alternatives to reassurance, hold hands whilst we walk, or give him a hug if he's really struggling.

#### **What I need to resist doing when Clive is struggling with his OCD:**

- 1) Saying things like 'I saw you lock the door' and 'everything's going to be fine'.
- 2) Offering to lock the door for Clive or watching him whilst he locks the door.
- 3) Getting frustrated and agreeing to go home early, no matter how much I, or he, wants to.

## Chapter 9: Helping a family member with OCD

In these final parts of the booklet we review some of our top tips for helping support a person with OCD, but also how to take care of yourself. The information builds on what we have already learnt through the booklet, but can be useful as a handy crib sheet.

The following tips are adapted from a talk by Lauren Callaghan (Clinical Psychologist) to the OCD-UK conference in 2020:

### Top tips for helping support someone with OCD:

1. **Communicate.** Communication is key. Be clear about what is happening, what you are doing and why you are doing it. This can help your family member feel safe and secure and makes it clear where the boundaries are.
2. **Define your role and how you can help.** There are many ways you can support someone with OCD. Have a conversation together and plan what you can do. Examples of the roles you can take include, but are not limited to: friend, supporter, and advocate. You may also be the occasional chef, financier, cheerleader, or comedian!
3. **Be realistic about responsibility.** Your family member has to be motivated and want treatment; you cannot force them. Anxiety and distress are at times unavoidable. Remember, it's not your fault that they have this problem, and it's not your responsibility to make them better. Sometimes things need to get bad before people can acknowledge they need to get support. There is good evidence that people who are motivated before engaging with CBT do better in treatment and maintain the treatment gains for longer.

*“You are not responsible for making your loved one better – even if you think you are, they are! But you can be supportive in a compassionate way and help them on their journey to better mental health. Remember – it is no one’s fault that your loved one has an anxiety problem [OCD]. But they can choose for their future to be different and take steps to overcome the problem.” (Dr Lauren Callaghan, Clinical Psychologist, OCD UK Conference 2020)*

4. **Set your own limits and communicate these before you put them in place.** What help can you realistically provide, emotionally and/or practically, that keeps you well and doesn't keep the problem going? Set your own boundaries in-line with your own limits and capacities, making sure you communicate these clearly.
5. **Adapt your language.** When we are stressed or frustrated, we may find ourselves being more critical towards others. This is something that we have all experienced, but it can make people feel more defensive and prevent them from hearing what you're trying to say. Have a think about how else you can say something. Using 'I' statements when you communicate can make a big difference; e.g. 'I want you to get help' versus 'you need to get help'.

The examples below may help you to alter your language in a positive way:

Criticism – ‘Can’t you see the impact this is having on me / the family? You don’t seem to care about us!’

Vs. Motivation – ‘We love you and want you to get better – you have a problem and can choose to overcome it, no matter how hard it might be.’

Criticism – ‘You don’t want to get better!’

Vs. Motivation – ‘It is hard to know how to help you, especially when you seem stuck. Let’s work it out together.’

6. **Expect some conflict – this is normal!** Difficult conversations sometimes need to happen. Take turns and let everyone express their thoughts and feelings, even if you do not agree with them. Keep the conversation simple – maybe with one or two key points- as this helps to keep the message clear. Don’t worry too much if the conversation is hard or ends badly: change often happens after periods of conflict. It is also okay to pause a conversation and pick it up later if it becomes too emotional or argumentative.
7. **Look after yourself.** It is okay to find things very difficult, this does not mean that you care any less about your loved one.
8. **Try and find non-OCD time.** This does not mean to pretend the OCD does not exist, but that it is important to schedule some time with your family member; doing something that they feel able to do without the focus being on their OCD. Sometimes the person is masked by the bully that is OCD. Remember that your loved one is still your loved one despite their mental health issues.
9. **Compassionate help.** Compassion is defined as a ‘strong feeling of sympathy and sadness for the suffering or bad luck of others and a wish to help them’. What this means is that you can sympathise with your loved one and the distress and anxiety they feel. Aim to provide care and help to your family member in a non-judgemental and non-critical way. Additionally, be fair to yourself and realistic about what you can achieve.

**Remember:**

Not getting involved in compulsions and safety behaviours is not unkind or uncaring and can actually be beneficial in the long-term for helping your loved one to live OCD-free.

## Risk and OCD

Sometimes people with OCD can present with risks such as self-neglect. In extreme cases, people with OCD, can, at times, self-harm or voice that they are suicidal. These situations can be difficult to navigate as a family member and it may be necessary to involve a professional who can assess whether your loved one is at risk of harm to themselves or others. This could include contacting your family member's GP or out of hours GP. Alternatively, if you believe that your family member is in immediate danger to themselves, then you should take steps to contact emergency services.

## Taking care of yourself

People who support others with their mental health may often find that they are affected by some or all of the following:

- Stress
- Anxiety and worry
- Feeling isolated
- Difficulties with friendships and relationships
- Lack of sleep
- Low mood
- Frustration
- Feeling angry or guilty

The following information may help you to cope with supporting someone with OCD:

- Take breaks from supporting your loved one when possible and when things feel too much.
- Talk to someone about how you are feeling or join a carers group.
- Ask others for practical support and help if you need it.
- Be realistic in your expectations of supporting your loved one.
- Keep organised – use reminders or a diary to ensure you know when or where you're meant to be and your planned time for supporting your loved one.
- Exercise regularly
- Try to eat healthy food.
- Try to encourage independence in your loved one and for them to be the driver behind their own recovery.
- Remember that your loved one is still your loved one despite their mental health issues.
- Plan positive activities to do with your loved one that do not relate to OCD.
- Ensure you have time for the things that bring you enjoyment.
- Aim for good sleep hygiene.
- Use relaxation techniques to help you rest.

## Support for Carers

The Social Services and Wellbeing (Wales) Act 2014, which came into effect in April 2016, gives people who are caring for a loved one with a physical or mental health condition legal rights to a carer's needs assessment. A carer's needs assessment looks at your emotional, practical and financial needs.

You are entitled to a carer's needs assessment regardless of the type or amount of care you provide to your loved one. You do not have to be living with the person you are caring for, and all carers involved in supporting your loved one are entitled to their own assessment of needs.

## How to access a Carer's needs assessment

Carers in Wales can request a Carer's Assessment directly from the social services departments of their local authority. There are a number of other ways you can access an assessment, these include:

- A referral from a health and social care practitioner, e.g. GP or CMHT
- As part of the care planning or assessment process for the person you are supporting
- A referral made by a friend or family member

## You can find out more information about Carer's assessments from:

Carers Wales  
<https://www.carersuk.org/WALES>

OR

Carers Trust Wales  
<https://carers.org/>

## Chapter 10: Summary

Living with OCD can be incredibly difficult, not just for the person with OCD but also for their family and close friends. Often, when someone we care about is suffering we are desperate to find ways to help. This often leads to families and friends engaging in a range of different behaviours and making significant changes to their daily lives to accommodate OCD. Throughout this booklet we have explored different types of family accommodation, and suggested some tools and techniques which you and your family may like to use to help make some changes to your daily lives.

Whether you have used this booklet to increase your understanding of OCD, start a meaningful conversation about OCD with your family member, or as a tool to make changes, we hope that this booklet has been helpful in some way for you. Ultimately, we know that a person experiencing OCD must be ready and willing to engage in change, but we hope this booklet has enabled you to work collaboratively with your family member to support their recovery from OCD and, importantly, take care of your own wellbeing along the way.

If you would like more information about OCD or the support available for friends, family and carers there are a number of national OCD charities which may be able to help. We have added the information for these below:

**OCD Action:** <https://www.ocdaction.org.uk/>

**OCD UK:** <https://www.ocduk.org/>

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