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# Obsessive Compulsive Disorder

A guide for family, friends and loved ones



# Authors

Amy Peters (Assistant Clinical Psychologist, Cardiff and Vale University Health Board).

Dr Will Hallam (Clinical Psychologist, Cardiff and Vale University Health Board).

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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 the family members and loved ones 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 use the term 'family member' in this booklet to refer to all those people supporting a loved one with OCD.

## 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, family member desperately want to support their loved one through OCD but they are unaware of how best to help. This can sometime put a strain on family relationships and on the mental health and wellbeing of family members.

## What are we aiming to do?

The aim of this booklet is to help you understand more about OCD, the recommended treatments and ways you can support your loved one to engage in therapy and take back their life. We hope that this booklet will give you ideas around how to have useful conversations with your loved one, and with the agreement of your loved one, 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, its 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. doors not being locked)
- 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 get bigger and 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 makes us feel 'safe' or lessens anxiety in the short term. 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 baby is breathing

### Neutralising

e.g.

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

### Reassurance

e.g.

- Did you see me lock the front door?
- Shifting responsibility e.g. 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 member, may have become involved in these safety behaviours, think about the impact this could have on you loved ones recovery from OCD and think about how to make changes to you own behaviour to support your family member.

## 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 provides 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 your loved ones experience.

In the next few chapters we will explore the role of families in OCD, focusing 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 so 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 for 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 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 he becomes unsure. 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 don't have to turn 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 feel 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 loved ones experience of OCD (Steketee, 1997, Black et al. 1998). In the next part of the booklet we will explore behaviours which the wider family might engage 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 made in response to their loved ones OCD. Despite being known as 'Family' accommodation, the concept applies to anyone with whom the person with OCD has an important relationships. 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, family members become involved in one or more of these kinds of accommodation because they find it incredibly difficult to watch their loved one in distress. Some families also find that they agree to some accommodating behaviours to help them and their loved one 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 cases family members are aware that the accommodation is unhelpful but feel at a loss to know what else to do to support their loved one.

## Why is family accommodation important?

Accommodating OCD by engaging in safety behaviours often come from a place of love and compassion. It may seem helpful in the short term, but in the longer term they work to reinforce your loved ones 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;

<p>Preventing your loved one from finding out that the worst does not happen when they do not perform their compulsions</p>	<p>e.g. When Jane checks the doors are locked, It prevents Clive from finding out that nothing bad happens when they do not check the doors.</p>
<p>Taking responsibility away from your loved one or sharing it</p>	<p>e.g. When Jane checks the doors are locked at Clive's request, she takes on some of the responsibility. Clive believes that is someone did break into the house BOTH he and Jane would be responsible. This prevents Clive from adjusting his beliefs around responsibility.</p>
<p>Reinforcing doubt</p>	<p>e.g. When Jane 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 Jane checked / reassured me'</p>
<p>Reinforcing that the 'risk' is real</p>	<p>e.g. When Jane takes action by checking the door is locked, it 'proves' to Clive that his concern was valid and the 'risk' needed addressing.</p>

Often family member can experience feelings of guilt or shame when exploring family accommodate 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.

**One of the most helpful things that families can do to support their loved ones is to understand more about family accommodation, learn to recognise and name it in their day to day lives, and make some changes to their responses to their loved ones safety behaviours.**

**The focus of this chapter was to understand more about the different types of accommodation, what that might look like for you and your loved one, and some tools which might combat accommodation in your family.**

## Chapter 5: Reassurance Seeking

### What is reassurance?

Reassurance is the action of removing someone's fears or doubts, and it's 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 experience OCD their relationship with reassurance is often described as 'Excessive reassurance seeking' meaning that requests for reassurance are frequent, unrelenting and often repetitive. Your loved one might seek reassurance from; themselves e.g. mentally reviewing an activity or ritual in their mind, online information seeking e.g. researching symptoms of an illness, and seeking reassurance from other people. The evidence suggests that providing reassurance is the most common way in which family members accommodate a loved one's OCD (Halldorson, Salkovskis, Kobori and Pagdin).

### What does reassurance seeking look like?

Sometimes it is very easy to recognise when someone is seeking reassurance but other times it can be much more difficult to identify. 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 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 re-assurance, as they know that if someone collects their coat by the door, if 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 your loved one in distress and so your natural instinct may be to offer your loved one reassurance when they are for it. You might find that reassurance appears to help your loved one in the short term, however by seeking reassurance, the person 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 understanding of Excessive Reassurance Seeking in OCD. The researchers conducted interviews with 10 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 their loved one 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 loved ones '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 had 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'.***

## Making changes

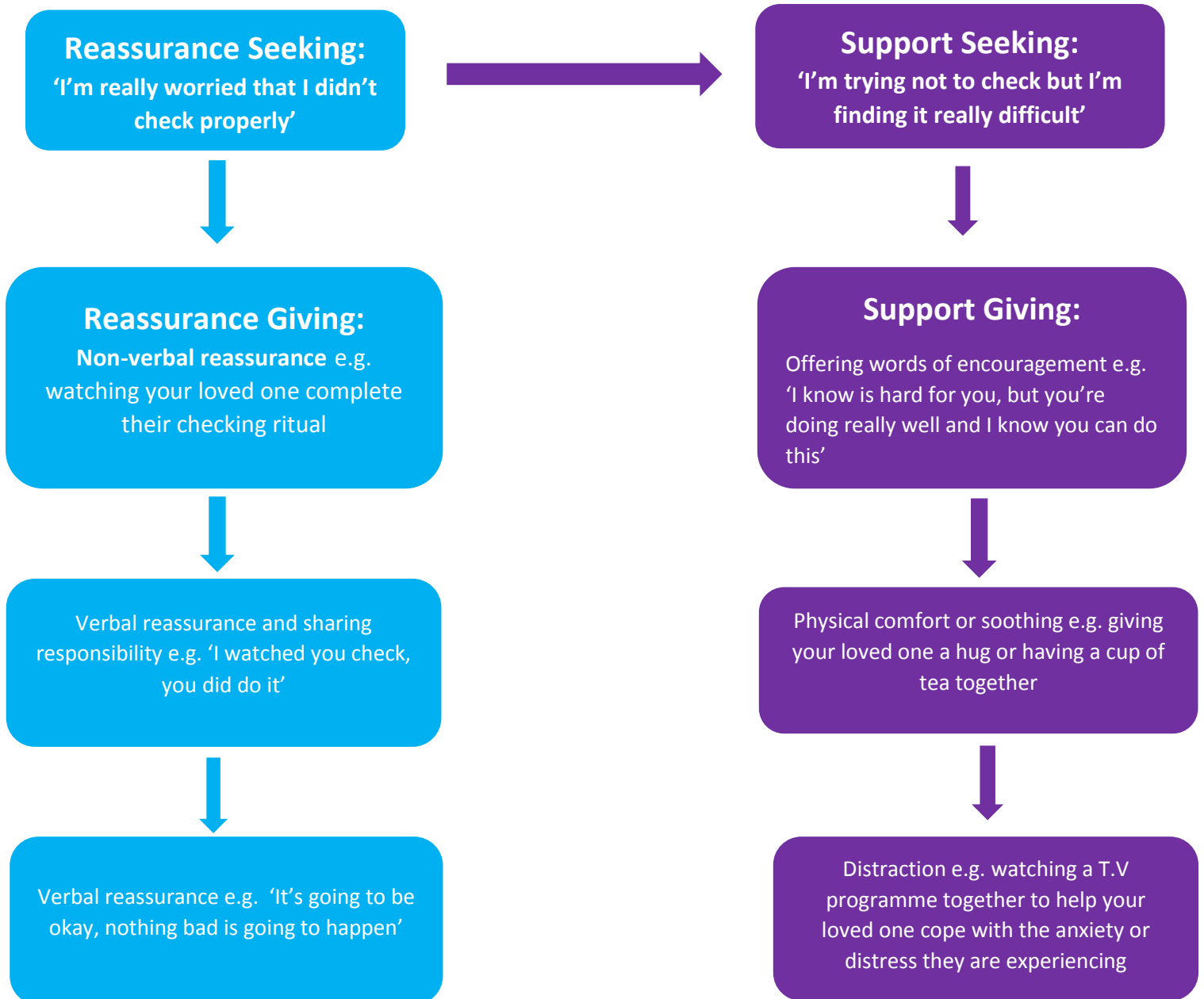
This research, and others like it, can help us to understand why is it so important that caregivers do not simply withhold all forms of reassurance at once, this could lead to both you and your loved one feeling even more distressed and emotionally disconnected from one another. Instead, the research suggests that offering an alternative to reassurance can be a helpful tool. By offering an alternative, you are still able to provide the person experiencing OCD with emotional or physical support, 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 from 'saving' the person from sitting with their anxiety or doubt, by offering reassurance, 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 with OCD 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 loved one could shift from reassurance seeking and giving, or support seeking and giving;

## Reassurance Seeking vs. Support Seeking



Making the change from Reassurance Seeking to Support seeking is likely to be a conversation that your loved one first explores with their therapist. As with all aspects of recovery from OCD, this conversation is something that the person experiencing OCD must feel empowered to lead however, It is important that you try and work together to agree a plan for moving forward with changes to you relationship with reassurance.

In chapter 6, we discuss 'Contracting' which is a useful tool to support a slow and steady approach to reducing reassurance, and in fact lots of other types of accommodating behaviours we cover in this booklet.

REMEMBER: You cannot control whether your loved one seeks reassurance from you, 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. 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 tells us that he avoids leaving the house at all on weekends so that his outings are delayed by his checking rituals. He also avoids being the last person to leave his office so that he doesn't have to lock up*

Often in an attempt to help their loved ones manage their anxiety, or even to help the whole family get on with their day, families can also engage in avoidance behaviours or facilitate their loved one 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 family members can accommodate avoidance when their loved one is experiencing OCD.

Preparing meals for your loved one so they can avoid rituals

Making small decisions for my loved one when their OCD is making decision making

Avoided going for dinner with a friend which might trigger cleaning compulsions for loved one

Make excuses for why my loved one can't attend events so that they can avoid a triggering

Avoid watching certain programs that might cause my loved one 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 your loved ones OCD. But why is it helpful to identify behaviours which accommodate avoidance?

Well, accommodating avoidance means that your loved one 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, or maintaining relationships with friends or maintaining romantic relationships. 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.

Lets think about Clive and his compulsions around locking the house as an example of this:

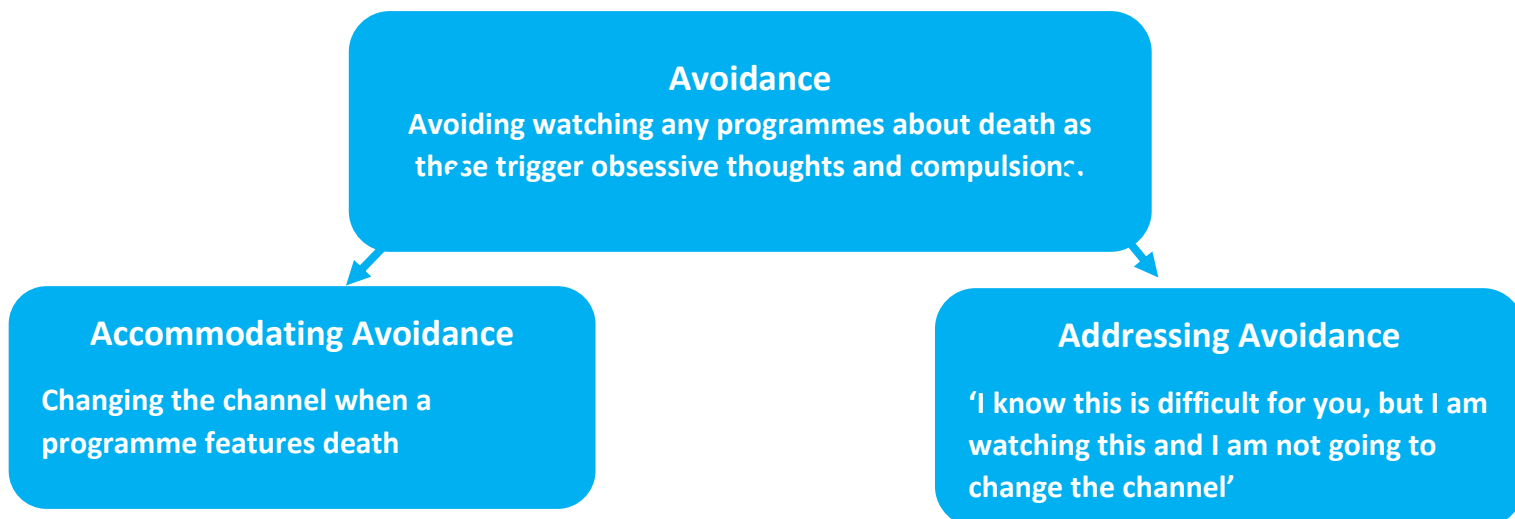


Feeling fearful or afraid doesn't always mean that we are in danger, however avoiding things that make us feel this way can lead us to believe that we ARE in real danger. Avoiding a situation, person or place can prevent your loved one from finding out that nothing bad happens when they face their fear. 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?

You can support your loved one without supporting OCD. In fact, research has found that when families stop accommodating OCD, the person experiencing OCD can become more motivated and engaged in therapy. Unfortunately, there is alternative to accommodation, the best thing you can do to support your loved one 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 you're the amount of avoidance you accommodate, then you slowly move towards completing stopping.



In this example, your loved one may choose to leave the room, but that 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 to de-escalate tensions at home or to help the person with OCD get on with their day and so it's normal to feel slightly reluctant to making changes. There are some ways which you can make the process feel more manageable for you both. We have broken the process down into the sections; The Three C's.

### Communication

Any changes to both yours and your loved ones way of managing OCD is going create some anxiety and so it's important that you start by having an open and honest conversation with your loved one 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 your loved one understand 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 loved one agree upon one or two areas to start targeting, you agree how you are going to challenge this, and what you might expect of each other. Once you have tackled this behaviour, your map out your next move.

### Consistency

One of the most important thing to remember when making any kind of change is to be consistent. Once you and your loved one agreed a focus, it is important that you try and stick to what you have agreed as much as possible. For example; if you have agreed a particular response e.g. giving a hug instead of washing your hands, it is important that you try and stick to your agreed response each time the OCD behaviour occurs.

TIP: In chapter 6 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: Facilitating Compulsions or Engaging in Compulsions

So far in this booklet we have explored lots of ways that families can become involved in their loved ones experience of 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 loved one 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 loved ones OCD behaviours alongside them or at their request

e.g.

- Saying a mantra or prayer with your loved one to prevent something bad happening

OR

- Helping your loved one to complete a cleaning ritual e.g. wiping down grocery items before bringing them in into your home

### *Facilitating Compulsions*

can be slightly more difficult to recognise, but refers to any actions which you take to enable your loved one 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 loved one to check the doors and windows are locked

OR

- Arranging an appointment in the afternoon to so that your loved one 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. We will use the examples from Chapter 3 to help up this more about the role directly engaging in compulsion plays in maintaining OCD.

### Reinforcing 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 challenge or adjusted, they are confirmed by actions of the family member e.g. 'If my partner is doing this too, they must thing 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 feels that they are SHARING responsibility for any negative consequences with the person who helped them complete the behaviour.

### Preventing them from finding out the worst does not happen

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

**Beliefs:** 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 don't 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 members 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. Even though you may have done this to avoid them missing the appointment like they usually do, by doing you have created designated and space for the OCD ritual. When we make changes like this to our routines, it can seem helpful in the short term i.e. enabling your family member to attend

appointment however it can mean that OCD is no longer stopping the person from completing 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, 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 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 family members, if the family were 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 somewhat helpful for you in depending on 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, your loved one'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 your loved one can use this contract as a tool to guide your thought making changes.

When developing a contract it is important to take things slowly, focus on one behaviour or type of accommodation at a time, and think about a realistic and achievable goal that you would like to achieve together.

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

## Example Contract

**Goal:** Stop asking for reassurance that I have locked the backdoor 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. lets 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

“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

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

1. **Communicate.** Communication is key. Be clear with 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 role you can take include, but are not limited to; friend, supporter, advocate, occasional, chef, financier, cheerleader, babysitter, chauffeur, realist and 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 they have this problem, or 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.
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 you 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!’

**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 is and we will help you.’

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

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 don’t agree with them. Keep the conversation simple – maybe with 1 or 2 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 comes too emotional or argumentative. However, if someone threatens to hurt themselves in some way, always take it seriously – even if you do not believe them.
7. **Look after yourself.** It is okay to find things 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 and 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 for helping your loved one to live ‘OCD-free’ longer term.**

## 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 organized – 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 in 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 on 6th April 2016, gives people who are caring for a loved one with a physical or mental health condition legal rights to a carers needs assessment. A carer's needs assessment looks at your current or future emotional, practical and financial needs for support as a carer.

You are entitled to a carers' 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 carers' 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 Carers 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, as a family member of someone living with OCD. 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 work collaboratively with your family member to support their recovery from OCD and 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/>

