

Acknowledgements

We would like to thank all the people who have helped us produce this book. In particular, we would like to thank the people with lived experience of OCD who made valuable contributions to the book and the OCTET research team at the Universities of Manchester, York, Sheffield and East Anglia:

Dr Penny Bee, Dr Peter Bower, Professor Michael Barkham, Dr Sarah Byford, Ms Helen Cox, Dr Judith Gellatly, Professor Gillian Hardy, Ms Nicola Lidbetter, Dr Dean McMillan, Dr Pat Mottram, Dr Chris Roberts, Professor Simon Gilbody, Professor Shirley Reynolds

We would also like to thank all the people with OCD whom we have talked to over the years. The insights shared with us by these 'experts by experience' have been invaluable in shaping the way we have written the book. This book is much better for what we have learnt by talking to people who actually know what it is like to suffer from OCD. Thank you.



















Contents

Section One	
What is this book about?	4
Section Two	
What is Obsessive Compulsive Disorder (OCD)?	6
What causes OCD?	8
How does OCD affect you?	10
Understanding how I feel	12
Setting some goals	17
Your own goals	18
Section Three	
How to beat OCD	20
The 4 golden rules	23
Your own individual programme	24
Section Four	
Frequently asked questions	28
Section Five	
How do I prevent OCD from returning?	30
Section Six	
Stories	
Jayne	32
Paul	34
Colin	36
Section Seven	
Personal diary	38



Section One: What is this book about?

Introduction

This book has been designed to help you to manage your Obsessive Compulsive Disorder (OCD) with support from a mental health facilitator. There are seven sections to this manual and although most people will want to work through it section by section, each section can be read on its own. In some sections there are exercises which you may wish to do.

- Section 1 tells you how to use this book with support from your facilitator.
- Section 2 gives you some information about OCD and how OCD affects you.
- Section 3 explains ways of managing your OCD.
- Section 4 provides some answers to frequently asked questions.
- Section 5 is about staying well when you are managing your OCD better.
- Section 6 has three stories from people with OCD and how they overcome their difficulties.
- Section 7 provides some blank sheets if you want to keep your own personal diary.

We have tried to make this book user-friendly and helpful. We would welcome your comments on the book, so please let us know what you think.

In this book, we have included advice about using a treatment (cognitive behaviour therapy or CBT). CBT is the recommended 'talking treatment' for OCD in national UK guidelines (www.nice.org.uk/CG031). We have also included things that people who have OCD have told us they have found useful. We hope you will find all the information helpful. Most of all, we hope you will be able to put some of these suggestions into practice.

Your Team

At this point we want to reassure you that you are not on your own. We don't want you to use the book without support from other people. Managing your OCD is a team effort – a partnership. So first of all, let's meet the team. The team includes you, this book, your facilitator and your friends and family.

You are the most important person, and only you can take the steps that are needed to beat OCD. You are the only person that really knows what this feels like and are the person who knows what you want to feel like in the future.

This book: this book is divided into seven sections, most people will want to work through the book section by section, but the sections can be read on their own. The book is available in written form, electronically or audio CD. It is your choice which form you would like to use.



We have used stories to illustrate how you can use the different techniques we describe in the book. These stories are about people with OCD and show the many different forms that OCD can take. Before we wrote these stories we had talked to a lot of people who had experienced OCD about what should go in this book. We also asked doctors and other mental health workers for their advice

The people who actually wrote this book are a team of researchers working in the NHS and universities. Our group includes nurses, psychologists, doctors and health researchers. We are all committed to making life better for the many people who have OCD.

Everything we suggest in this book is something that we know someone else has found useful or something we ourselves have found personally helpful. All the exercises are things we would be glad to do ourselves. We would feel very happy recommending them to our own friends and relatives.

Your facilitator is a mental health worker who knows about OCD and how it can affect people. He or she has also had some extra training in being a self-help facilitator. Your facilitator will help you make sense of how your thoughts, feelings and behaviours maintain your OCD. Most importantly, they will help you to overcome your OCD. Overcoming OCD can be tough. So when you feel discouraged, your facilitator will give you advice and offer you support through any difficult times. If you wish, they can also speak to a friend or relative with you.

Facilitators normally see people over a three month period. They will be in contact with you weekly. They can see you face-to-face or telephone you. It is your choice how you want to organise this, although if you wish an appointment in the evening (up to 8.00pm) then this will usually be via telephone.

Think of your facilitator like a personal fitness trainer. If you go to the gym or play sports, fitness trainers don't do the actual physical work of getting you fit. That's up to you. However, the trainer will help devise a fitness plan, monitor your progress and keep encouraging you when the going gets tough. Your facilitator will act in the same way. They are there to support you.

Your friends and family: for many of us, our friends and families are usually the people we are closest to. When we suffer from OCD they are often the first to notice. They are often involved in our rituals or provide us with reassurance. Sometimes, of course, we try to hide how we feel from those closest to us. We feel embarrassed or we might want to protect them from how we feel.

We believe that families and friends are very important to overcoming OCD. Everyone must make their own choices as to what they say to whom. You can discuss this book with them; if they would like a copy of the book just ask your facilitator.



Section Two: What is OCD?

Obsessive compulsive disorder (OCD) is a common problem and affects about 1 in every 100 people. It can start at any time but most often starts in late adolescence. It affects both men and women, young and old and cuts across different social backgrounds and cultures. OCD makes people anxious and unhappy; it interferes with everyday activities and can impact on all areas of people's lives. Unlike some mental health problems, OCD rarely improves without treatment.

To understand OCD it is important to know what obsessions and compulsions actually are.

Obsessions are thoughts or images, which are intrusive, unwanted, repetitive and usually distressing and cause anxiety. These thoughts are often about dirt and contamination, accidental harm, illness, aggression, sex, orderliness and perfection. You may be interested to know that research has found that the content of thoughts is no different for people with OCD than people without OCD. This means that we all have these types of thoughts, but people with OCD have them more frequently and consider these thoughts to be more important and meaningful than other people do.

Compulsions (rituals) are acts we carry out to reduce the anxiety the thoughts provoke. Compulsions take many forms but the most common are checking, cleaning, repeating things, tidying, putting things in order, seeking reassurance. We carry out rituals for many reasons: they stop us from feeling anxious; they reassure us that nothing terrible will happen, or they become such entrenched habits that we cannot break free from them

If you feel it would be helpful then use the sheet on the next page to identify your own thoughts and rituals.



My obsessive thoughts	
My compulsions (rituals)	



What causes OCD?

There have been many explanations of why people develop OCD. Some have argued that it is inherited, whilst others have said that life events (such as bereavement or other traumatic event) can cause it. Others have suggested that it is caused by an imbalance of chemicals in the brain and some think that people with meticulous and perfectionist personalities are more prone to developing OCD. Different people find different explanations more helpful than others.

However, no one really knows what causes OCD and for many people it is often difficult to pinpoint it to one single cause. Often there are a number of factors which lead to its development. Many people like to understand why their problems started and you and your facilitator might want to discuss this. It would be helpful if you could write our own ideas in the box on the next page. about why you think your OCD started and what keeps your OCD going.



1. What do you think	k caused your OCD?		
2. What do you think	k has maintained your OCD	?	



How does OCD affect you?

Many people find that writing down the impact of their problems on their life is the first step towards managing their OCD. Although it can be distressing to list all these things, writing them down can give us something to aim for.

OCD may affect your home life, your social life, your work and your personal relationships with partners, families and friends. The things you identify now are the things you really want to change. On the next page there is a sheet where you can list all the ways in which your OCD impacts or affects your life. Write them down and try to be as specific as you can. If you find this difficult the questions below might help you.

- What exactly do you find difficult?
- Where and when is this difficult?
- Are the difficulties associated with specific situations or people?

Here is a copy of the IMPACT SHEET to help you decide what to write. Ask your facilitator to help you with this if you are not sure.

IMPACT SHEET

Home – things around your house such as housework, cooking etc. The things to do with home that I find difficult because of my OCD are:
Work – paid, self-employment, home working or caring for others The things to do with working that I find difficult because of my OCD are:
Relationships – family and close relationships with others The things to do with relationships with others that I find difficult because of my OCD are:
Social activities – being with other people The things to do with being with other people that I find difficult because of my OCD are:
Personal activities – doing things alone which you enjoy such as reading The things to do with personal activities that I find difficult because of my OCD are:



Understanding how I feel

There is no specific way a person who has OCD feels. It is an individual experience. Nonetheless, there are many common symptoms which people experience. This section describes a way of understanding OCD. We can think of OCD having three separate but related parts.

- Things we feel physically
- Things we do excessively (behaviour) or stop/avoid doing
- Things we think or imagine

Things we feel physically – these are the bodily sensations that we have when we are anxious/panicky and can include palpitations (heart racing) hyperventilating (feeling as though you are having difficulty breathing), butterflies in the stomach, sweating, shaking, trembling. Some sensations may be mental such as feeling out of control or detached from reality.

Things we do excessively include rituals such as excessive washing, checking, counting. Things we avoid doing include things or situations that we are frightened of and we are anxious about; therefore, we stop doing these things altogether or we can only do them if we have a lot of safeguards in place. We often seek reassurance from others that our fears are untrue or that our rituals have been carried out correctly.

Things we think include our obsessive thoughts or intrusive images, but you also might have thoughts about how OCD is affecting you. For example some people have unhappy thoughts such as "OCD is ruining my life."

The 'Vicious Circle' of OCD

We can think of this as a 'vicious circle' of OCD. Here is an example:

Jack had frequent obsessive thoughts that a fire might start from electrical equipment. Such thoughts made him very anxious and he found that if he checked electrical equipment over and over again his physical feelings of anxiety reduced. If we look at his anxiety using these three parts shown above (physical feelings, thoughts and behaviour) we can see how they are linked.

Physical sensations – "I feel very panicky and my stomach churns, I can feel my heart beating quickly (palpitations) and at times I have difficulty in catching my breath."

Thoughts – "If a fire started through an electrical fault, and I had not turned the appliance off it would be my fault, and I would be responsible for my own and others deaths." "I must make sure that I have turned all the electrical appliances off", "I want to be 100% sure that I won't start a fire"

Behaviour – "I check that all the appliances are off, but then I doubt that I have done it and have to do it over and over again. I also have to check in a certain order. This helps me to make sure I have checked properly. I avoid using electrical appliances if I can help it."

Your personal feelings, behaviours and thoughts

Now let's think about you. What are your feelings, behaviours and thoughts? Below is a copy of a sheet which you can use to write down how your OCD is affecting you. Just jot down your physical sensations,

the things you do excessively or have stopped or avoid, and your thoughts.

It can be quite difficult to write these things down. Make sure you talk it through with your facilitator and, if you want to, with a close friend or family member. Have a go now.

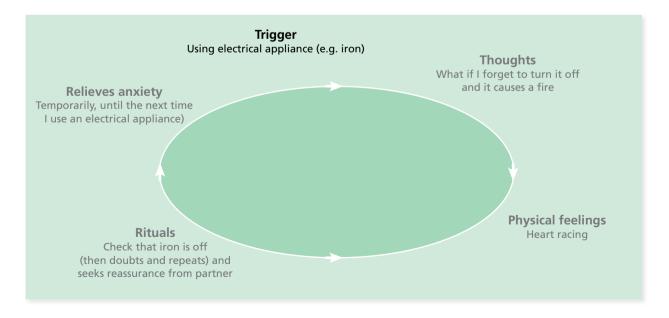
	sical sensations				
Things I do e	xcessively or hav	e stopped/avo	ided doing (be	ehaviour)	
My own thou	ughts				



Understanding how I feel

Although all three of these parts are important, it is the things that you do (behaviour) including compulsions (rituals), avoidance, escape, reassurance, etc which maintain OCD. This will be explained in more detail. For example Jack becomes anxious every time he uses electrical equipment (**triggers**) and when he leaves his home. When this happens he has thoughts such as "What if I have not turned it off and a fire occurs?" To relieve his anxiety he does lots of rituals (repeatedly checking the equipment) or he avoids using the equipment. The rituals and avoidance relieve the anxiety but interfere in his life as he spends up to three hours a day checking.

If we draw this as a diagram we can see how Jack's difficulties are maintained, i.e. he becomes anxious when he uses an electrical appliance; he then has thoughts of the fire, which may be caused if he left the appliance on. This increases his anxiety and to reduce this anxiety he checks the appliance but then doubts that he has done this correctly so goes back and checks it again and again and again. The checking relieves his anxiety for a brief period until he uses the same or another electrical appliance. Thus, as can be seen in the diagram below a 'vicious circle' is formed and it is this circle which maintains OCD.





In the space below try complete your own vicious circle You might want to do this alone or with your facilitato	r.
Trigger	
	Physical feelings
Anxiety reduces but only temporarily	
	Thoughts
Rituals	



Understanding how I feel

The vicious circle of OCD needs to be broken, where do you think the circle can be broken? You could write this down (below) – this is something you can do with your facilitator.

The next section will explain how, where and why the 'vicious circle' can be broken but before that it is helpful to look at what you want to achieve in the next three months.



Setting some goals

Now you understand how your obsessions, compulsions, physical feelings, behaviours and thoughts fit together; you can use this knowledge to help you overcome OCD. You already know how your OCD affects your life. You wrote this down a few pages ago on the impact sheet.

Many people find it a really good idea to set themselves some goals to start their recovery. You should base these goals around the areas where your life is affected by your OCD. That way you can do something really positive to overcome the impact of OCD. Remember, your facilitator will give you some advice here if you need it.

Goals in Detail

You are the person who can decide what you want out of your treatment. These will be your goals. Goals will help you to:

- keep focussed on your recovery
- be clear about what you want to achieve
- give you feedback on your progress

A goal is what you want to be able to do at the end of your programme. You should be as clear and as specific as you can. You may want 'to feel better' or 'to stop OCD' but ask yourself what 'stopping OCD' means you will be able to do.

Examples of a person's specific goals:

- to go out with my family/friend once a week for 2 hours and enjoy the time I have with them
- to do the family wash twice a week in 4 hours
- to leave the house every day and leave a lamp on
- to take my children to the park and let them play on the grass for 2 hours a week



Your own goals

What are your own goals? We have provided some sheets for you to write these down. Your facilitator will give you some advice here if you need it. Working with too many goals can be confusing. We would advise you to set between one and three goals. Here is some advice for setting your goals:

- Ask yourself what you want to be able to do
- Be as specific as you can by stating how often you want to do something, or for how long, or where you want to do it
- Set realistic goals, things you want to do in the future or used to do in the past
- State goals positively, start with 'to be able to...' rather than 'to stop...'
- Ask your facilitator or someone you know well and trust to help you

Goals are things to aim for. Pick things that your OCD is getting in the way of. Because of this, they should be things that you are struggling with at the moment. The techniques in this book are designed to help you reach your goals. So that you know how you are doing, we have written down a simple scale underneath each goal. Circle one of the numbers for each one. This will tell you how difficult you find each goal.

Re-rating them every now and then using the same scale is an excellent way to monitor your own personal progress. Aim to do this at least monthly during your recovery programme. Your facilitator will keep a copy and can give you some spare sheets if you need them.



			MY	GOALS				
Goal number 1				Т	odays D	ate:		
How difficult is this goa	to do now	? (circle a numbe	er):					
				4			7	8
Not at all		Slightly		Moderately		Very much		Extremely
Goal number 2								
How difficult is this goa	to do now	? (circle a numbe	er):					······································
0	1	2	3	4	5	6	7	8
Not at all		Slightly		Moderately		Very much		Extremely
Goal number 3								
								<u>.</u>
How difficult is this goa	to do now	? (circle a numbe	er):					
0	1	2		4		6		
Not at all		Slightly		Moderately		Very much		Extremely



Section Three: How to beat OCD

Overcoming OCD is difficult but possible. **Cognitive Behaviour Therapy (CBT)** is a 'Psychological Therapy' based on the view that the way we act (behaviour) and our thoughts (cognitions) and our physical sensations (feelings) are all interlinked and change what we do. CBT helps to identify the unhelpful and helpful feelings, behaviour and thinking that you have.

It can help you to change the way you think and act and in doing so reduce the impact that a problem has on your life. CBT is about working in partnership with you and together looking at and trying the best solutions. CBT is a broad term for a number of interventions. One CBT treatment used particularly for OCD is exposure and response prevention. Exposure and response prevention is recommended by the Department of Health as the best psychological therapy for treating OCD. Exposure means gradually facing your fear until anxiety falls. Response prevention means stopping the rituals. A way of thinking about this is that you will be gradually taking risks, but these risks are no different to the risks that people without OCD take. This will be explained in more detail by your facilitator. Write down in the space on the next page what you think would happen if you did not do your rituals or ask for reassurance.



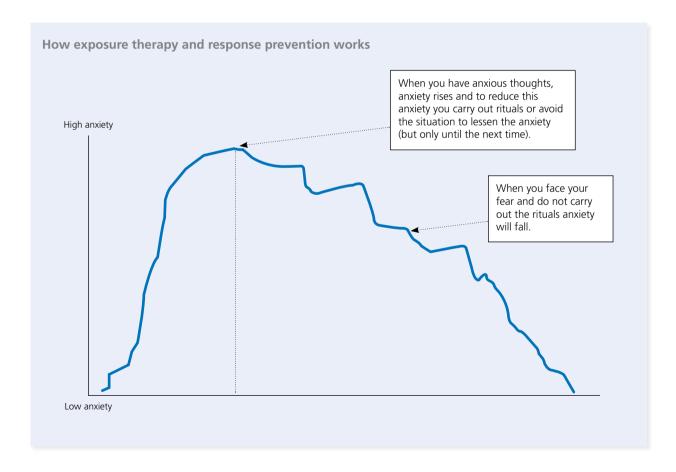
Write what you think would happen if you did not carry out your rituals?



How to beat OCD

By facing your fears and not carrying out your rituals your anxiety will fall. The diagram below may help you to understand how this works. We carry out rituals and avoid situations when our anxiety is high and

learn that this will bring relief (but only until the next time we try). Your facilitator will explain this to you in detail.



The 4 golden rules

There are 4 golden rules of exposure therapy and response prevention. The first is that it is **graded** which means that you gradually face your fears, starting with something that is manageable and slowly building up to more and more difficult situations. The second rule is that you need to **repeatedly** practise the same situation over and over again until you feel comfortable. The third rule is that when you practise you should stay in the situation (**prolonged**) until your anxiety lessens. The rule of response **prevention** is to stop the rituals.

The 4 golden rules of exposure therapy and response prevention:

- Graded Gradually facing your fears, starting with something easier and gradually building up to more difficult situations.
- Repeated Exposure must be repeated, it is important that you practise facing your fears many times until you feel comfortable in that situation.
- Prolonged Stay with your fear for long enough for your anxiety to reduce by at least 50%, which usually takes between 45 and 90 minutes.
- **Prevent** stop carrying out the ritual.

It is useful to think of therapy in the following way – At present you are getting short-term relief by escaping and avoiding your fears but this is not a long-term solution. Exposure therapy will provoke short-term anxiety but provide lasting relief.

You may find it helpful to think of exposure and response prevention as taking a risk. For example if you had a friend who would not cross any roads at all for fear of being knocked down, would you suggest that they never cross any more roads? Or would you suggest that he/she take the risk? If another friend were frightened of becoming contaminated by dirt would you suggest he/she never come into contact with it? Or would you suggest that he/she lead a usual life and take the risk? You will be taking a series of risks starting with ones you feel you can manage and working up to more difficult ones. It is important to remember that the risks you are taking are the ones we take every day. People with OCD are often trying to seek 100% assurance or guarantee that their fear will not become a reality. But the problem with this is that we can never be 100% sure. We cannot be 100% sure that we will not get run over when we cross the road. We have to either take the risk or never cross the road again, which would make everyday living impossible. Next we will describe in detail how to gradually face your own fears by taking small and gradual risks.



Your own individual programme

Setting up your own individual exposure and response prevention programme

You will have already decided on the goals you want to achieve in the longer term. With your facillitator's help you will break these goals down into smaller steps and set **weekly targets**.

Each week, with your facilitator, you will agree some daily targets. These targets need to be achievable and it is usually best to start slowly. It is helpful to make a list of your fears starting with the easiest to the most difficult. The list to the right is from a person with OCD who feared causing an accident when driving and kept going back to a particular spot to check that there was no evidence of an accident (such as blood, broken glass or a body). He also rang the traffic police to check if there had been an accident in the places where he had been driving. As you can see from the list to the right, being with someone was much easier than being alone and the more busy the road the more risk they felt that an accident would occur.

Hardest -

- ▲ Driving on the motorway alone
- ↑ Driving on town roads alone
- ↑ Driving on country roads alone
- ▲ Driving on the motorway with someone
- ▲ Driving on town roads with someone
- ↑ Driving on country roads with someone

Easiest -

In the following space (to the right) try to fill in your list of fears from the easiest to the most difficult, if you are stuck ask your facilitator for help.



Hardest –
Easiest –

You can use the list to help you set your weekly targets. From the example we used earlier Jack's weekly targets for the first two weeks might be as follows:

Week 1: drive for 1 hour daily on country roads with my partner without asking for reassurance, going back to check to see if I have caused an accident or ringing the traffic police to check whether an accident occurred on the route that I went.

Week 2: drive for 1 hour daily with my partner on town roads without going back to check to see if I have caused an accident or ringing the traffic police to check whether an accident occurred on the route that I went



Your own individual programme

Targets need to be thought out carefully, for example if someone is washing their hands every time they touch something (for fear of becoming contaminated), the target set should be to gradually face the feared contaminant. Most people will be able to determine different levels of contaminants, for example touching a 'clean' bin bag will be easier than touching a bin bag with rubbish in it. So, in this example, the target might be to touch 'clean' bin bags without the person washing their hands. But to prevent any ritualising we would suggest that each time they wash their hands (e.g. after using the toilet, cooking etc) they re-contaminate their hands by touching the 'clean' bin bag.

You can write your weekly targets in a diary like the one to the right. You will find copies of the diary in your pack. Rate your anxiety before you start exposure and afterwards. Many people find these diaries helpful to monitor their own progress.

The role of families and friends

Many people find it helpful to have support from a relative or friend. To help you they need to understand what OCD is and how exposure and response prevention can help. If you wish your facilitator can provide a copy of this book for your friend/relative. Your facilitator will also be happy to speak to them and answer any questions they have. We can only speak to a friend or relative if we have your permission and your family and friends wish to speak to us.



		WEEKL	LY GOALS		
Goal 1:	1: Goal 2:				
Anxiety: rate how anxio	ous you felt before and aft	er you did th	ne task using the	rating scale below.	
0	2		4	6	8
no anxiety	little anxiety		oderate nxiety	much anxiety	extreme anxiety
Goals I completed			Anxie	ty before	Anxiety after



Section Four: Frequently asked questions

There are some common questions that people ask about exposure and response prevention and we have tried to answer them. If you want more details or have other questions ask your facilitator.

I don't know how to cope with the level of anxiety when facing my fears?

This is common and there are a number of ways of coping with your anxiety. You may find it helpful to write some coping statements. These are statements that you say to yourself or write down on a piece of card. For example they may include things like:

"Anxiety is unpleasant but it won't harm me"

"Although I feel anxious in the short term if I face it, the fear will pass"

"The physical symptoms of anxiety are similar to those when I am excited; it is the worrying thoughts that make me feel afraid".

"These feelings will pass"

"If I achieve this, it will be the beginning of a new life and new opportunities for me"

In the space to the right write down three coping statements that you think will be helpful to you.

coping statements

My partner/friend/family do not know what to say when I ask them for reassurance

Frequently partners and friends have got into the habit of offering reassurance or carrying out our rituals. Your facilitator will be happy to speak to your family or friends (with your permission) and help them with this.

I have managed to get so far but I just cannot face the next step on my list, how do I move on?

It is usual to get 'stuck' at one point in therapy, but your facilitator will help you when this happens. One of the most common reasons is that the next step on the list is too big. When this happens it is helpful to break the step down into smaller steps. Your facilitator can help you do this.

I am much better now and I want to stop taking my antidepressants – should I?

This very much depends on how your mood has been; it is recommended that people on anti-depressants should remain on them for at least six months after the depression has lifted. If you do want to stop your antidepressants it is important that you discuss this with the health professional who prescribed them. They will help you to plan the gradual withdrawal of the medication and monitor your mood whilst you do so.

I have practised one particular task over and over again and the anxiety does not seem to be getting any better

A common reason for this is that the person is continuing to carry out another ritual within the main one. Such rituals are often subtle (it may be that you

are so used to doing it you do not recognise it as such). For example, an individual who is washing their hands repeatedly, but also saying 'clean' over and over in their head, may stop washing their hands but still continue with the 'mental ritual'. Hence it is important to monitor yourself or write down exactly what you do to see if there are any 'hidden' rituals. Ask your facilitator to help you.

I have managed to stop the ritual, but I still get the thoughts

This is common and at the beginning you will get thoughts even though you are not carrying out the rituals. The obsessional thoughts will decrease in both frequency and intensity over time. Your facilitator can discuss this with you in more detail if you wish.

I am worried that this treatment will make me lose too many standards (i.e. I will never clean my house or will not check at all).

This is a common worry about treatment in that it will make them too 'sloppy'. This is not the case and most people remain slightly more careful than people without OCD (but not to the extent that it interferes in their life). Think that if you are free from OCD, then you can clean your house or wash your hands because you want to (a choice) and not because you have to (a compulsion)!



Section Five: How do I prevent OCD from returning?

It is important that you read this section. There is a lot of evidence that the improvement you make will remain. However you do need to practise your weekly targets regularly until they become incorporated into your daily life.

If you become depressed, or experience a serious life event (such as bereavement, job loss etc.) or have a period of stress, then your OCD may recur. If you are prone to depression, you should monitor your mood on a monthly basis using the PHQ9. Your facilitator will go through this form with you to monitor your mood. It is important that you prepare for this possibility and know what to do if this happens. It is important to remember that OCD does not come back immediately, it usually recurs gradually. If you become depressed you need to be extra vigilant of the early warning signs of OCD i.e. thoughts or small rituals starting to creep back in. Setbacks can usually be nipped in the bud and relapse can often be avoided.

It is useful (particularly for the first year) to monitor yourself to ensure no thoughts or rituals are beginning. For some people keeping a weekly diary of their progress is helpful. If you have a friend or partner who has helped/supported you through your treatment it is important that they are aware of the factors associated with relapse and to ask them to tell you if they notice any rituals (however small) starting.

Your facilitator will discuss keeping well with you and will help you to develop an individualised 'staying well' plan.



Please use this section to make notes.	



Section Six: Stories Jayne

Jayne: washing and checking

Jayne is a 35-year-old woman who is married and has 2 children aged 12 and 14. She feared that she would catch an unspecified disease from other people and would pass it on to her husband and children who could become ill and die. She felt if this happened it would be all her fault. Jayne's rituals were extensive, for example if she went out she avoided touching people as much as possible, and wore a long coat so that as much of her was covered as possible. When she arrived home she would put her coat in a black bin liner and keep it in the porch. She would put her shoes in a plastic bag and then without touching anything she would wash her hands and face. She would wash her hair if she had brushed her hair against anything. Each time she used money she washed her hands (as other people would have touched this).

The weekly food shop was difficult. When Jayne brought it home newspaper was laid on the kitchen table, and everything had to be wiped over with disinfectant, before being put away (as shop workers would have touched it when it had been placed on the shelves). Nothing could be brought into the home without being wiped with disinfectant, this included milk bottles, post, newspapers etc.

Wherever possible Jayne tried to ensure that no one other than her children and husband came into the house. If this was not possible every room that the visitor had been in had to be wiped with disinfectant.

Her children were not allowed to bring friends home. Her family had become caught up in Jayne's rituals. Her children and husband had to change and wash when coming into the house. If her children went to a friend's house they were given strict instructions not to touch anything 'dirty' (i.e. handles on toilet doors, rubbish bins, floors etc) and on return home had to bath or shower

This problem severely interfered with Jayne and her family's lives. Every part of her life was hampered by these problems and she estimated that her cleaning rituals occupied at least 8-10 hours a day.

Treatment was explained to Jayne and together with the facilitator the following problem and goals were defined:

Problem – 'Fear of causing my family harm through contamination from other people which results in me avoiding touching people or handling anything that others have touched which leads to extensive washing and cleaning rituals for up to 10 hours daily. This problem severely impairs my social, family, and leisure activities.'

Jayne set the following goals:

Goal 1: to go to the local supermarket/shop every day, handle money, and bring the goods home without washing the goods or myself.

Goal 2: to have friends/family to visit on at least one occasion weekly.



Goal 3: to be able (and 'allow' my family) to go out and come into the house without washing or cleaning every day.

Goal 4: to bring in the milk everyday and put in the fridge

A list hierarchy was made of feared contaminants.

- Touching people's hands
- Touching people's skin
- Touching people's hair
- Touching people's clothes
- Touching other people's 'high contamination' items such as rubbish, using toilets outside the home, pets etc.
- Touching other peoples 'low contamination' items such as ornaments, cutlery, sitting on others' furniture etc.
- Touching own rubbish
- Touching things that had been handled by many people (e.g. money, goods on shelves, clothes)
- Handling items that had been touched by one or few people (e.g. milk bottles, newspapers, post)

Once the list had been made, weekly targets were set. What weekly targets do you think Jayne should begin with?

It is important to note that Jayne's weekly targets are graded by 'contamination' rather than a specific task. The first weekly target was to 'contaminate' her and the house with a low 'contaminant'. Jayne felt that the lowest was a milk bottle (as she believed milk bottles were touched by the least number of people). Jayne agreed to bring the bottle of milk into the kitchen

(without disinfecting it) or washing her hands and then to go from room to room touching everything from carpets, curtains, cutlery, large and small items of furniture, all towels, clothes, walls etc. Put simply Jayne was asked to take the risk (in the same way that we all take risks). To ensure that the 'contamination' continued Jayne agreed to touch the milk bottle every time she washed her hands or had a shower, she was to 're-contamination' also included everything that was normally washed in the house, thus all washed clothes, cutlery, crockery were to be touched by her 'contaminated' hands.

Each week Jayne moved up one step of the list. It was not easy and many times Jayne felt like giving up. It was Jayne's determination and hard work, which led to an improvement in her OCD. She found the anxiety difficult to cope with and wrote coping statements on a piece of card. She also kept a diary of her progress, so that when she felt like giving up she was reminded of the progress that she had made. At the end of treatment Jayne had greatly improved. She achieved all her goals and was able to go out, and have people visit without washing or wiping things with disinfectant. Her children went to their friends for tea and vice versa. Although Jayne made significant progress and no longer carried out rituals she continued to have thoughts of contamination. Her facilitator explained that these would decrease in frequency and intensity over the next few months. At 1-year follow-up Jayne had no rituals and hardly any thoughts of becoming contaminated by others.



Pau

Paul: perfection

Paul is a 24-year-old student, who lives at home with his parents. His OCD is centred on a fear of imperfection. This means that Paul wants everything to be ordered. For example when using toiletries they have to be put back in a specific order, clothes have to be hung exactly symmetrically on a coat hanger. When cooking, all bottles, cutlery, pans etc have to be put back in order. When writing, Paul is frightened that he will make a spelling mistake and checks it over and over again. When Paul writes essays, he makes sure that all paragraphs contain exactly the same words and number of lines.

The problem severely interferes with his life. Paul is taking a degree at university but failed his exams, because of his checking and difficulty in writing, he was unable to complete the exam in the allotted time. The university has agreed that he can sit the exam again but Paul feels that unless he gets his problem resolved he will fail again. His parents have become exasperated with Paul's behaviour and cannot understand why he is unable to stop this behaviour.

Problem – Paul and his facilitator defined his difficulties as 'Fear of imperfection which leads me to putting things in order and checking any work I am doing. This problem has stopped my studies and interferes with my social and leisure life'.

Paul set the following goals:

Goal 1: to write an essay in a non-symmetrical way in less than 2 hours, 3 times a week.

Goal 2: to shower in 20 minutes every day.

Goal 3: to cook a meal for my parents in 45 minutes, 2 times weekly.

Developing Paul's list was difficult as he was unable to tell the difference between things that were most and least difficult i.e. none were less or more difficult than others, so what he did was construct a list of all the things he was unable or found difficult to do. The list was as follows:

- Writing letters
- Writing essays
- Taking notes
- Posting letters
- Reading
- Having a shower (because of the bottles he uses)
- Getting dressed and undressed (because of the symmetrical way that clothes have to be hung)
- Cooking
- Ironing



Although Paul understood the rationale of treatment he felt anxious about starting exposure and response prevention.

Before moving on - try to think of some of the weekly goals you think Paul should set himself, try to be as specific as you can in terms of exactly what his weekly tasks should be.

Paul decided that he should do something that was really important to him. This was writing essays, as he felt that if he could do this, he would be able to return to university and re-sit his exams. He set himself the task of writing for 2 hours a day (1 hour in the morning and 1 hour in the afternoon), without counting the words or lines in paragraphs.

At the end of the first week, Paul had completed the task successfully. It had been difficult for him. On the first day he had tried he ripped the essay up and threw it in the bin. His parents encouraged him to try again. It remained difficult but by the end of the week his anxiety had reduced. Although delighted with his progress he was anxious that, even though he had achieved this, when it came to writing essays for university it would not work as well.

The task set for the second week was for Paul to hand in an essay to his facilitator; a topic was decided on, and Paul had to write a 750-1000 word essay in no more than 2 hours every day. Another task that Paul wanted to work on was showering and dressing. Thus the target was to wash and deliberately put the things back in 'disorder', and when dressing and undressing to deliberately put back his clothes 'unarranged'.

In the following weeks various tasks were set, and Paul continued to practice. At week 6, Paul was cooking a meal for his parents twice a week without everything being symmetrical. Outcome: at the end of 10 sessions, Paul had made a great improvement. Paul returned to university a few months later and successfully passed his exams. He still liked things neat and tidy and would still spend longer than average on letters; however the problem did not interfere in his day-to-day life.



Colin

Colin: mental rituals

Colin is a 27-year-old administrator, single and living alone. He has recurrent and persistent intrusive thoughts and images that something bad will happen to his family. He has a thought that something bad might happen to his family such as a car accident, he then worries that the thought might come true and he tries to cancel it out. To cancel the thought Colin has to have an opposing thought such as 'The family are safe – no car accident'. Colin repeats this opposing thought until he feels sure that he cancelled out the bad thought. This might take up to 5-10 minutes per thought and he has up to 30 – 40 bad thoughts a day.

He also finds it very difficult to make even small decisions (for example, whether to sign his emails to different people with "best wishes" or "kind regards" or "many thanks", etc) because he will go over and over this decision in his mind to check that what he is planning to do is right and then worrying as to whether he has said or done the right thing.

Colin said that these thoughts mean to him either that he is not normal, or that he is a bad person. The worst thing that could happen is that he has a bad thought and it might come true, he also thinks that he might be ridiculed and excluded, lose his job, or end up in hospital. He feels depressed but he cannot tell whether his depression is the result or the cause of his constant mental rituals.

Colin feels that his OCD interferes a lot in his daily life. He would like to change his job (he is over-qualified for the job that he has) but feels that a higher grade job would mean that he would have to make more decisions and doesn't feel he could cope with this. His OCD also stops him making close friends or having a relationship as the more people he is close to he would have 'bad' thoughts about them. He tries to avoid seeing the friends that he has as when he sees them he gets 'bad' thoughts.

Colin and his facilitator summarised his problems as:

Problem statement 1: "I have 'bad' thoughts about people I love and have to cancel these thoughts out. I also find minor decisions very difficult to make. I try to stop myself from having these thoughts by avoiding being in places where I may meet people who may trigger these thoughts. I also avoid making decisions where possible. This problem severely impairs my ability to form relationships and interferes with my social life, work and leisure activities."

Colin set the following goals:

Goal 1: to go out with my friends at least twice a week

Goal 2: to be able to sign at least 10 emails a day within 2 minutes.

Goal3: to spontaneously ring my friends twice a week



Colin found it impossible to write a hierarchy about his 'bad' thoughts as he felt that they were all as bad as each other. He was asked to write down his thoughts by his facilitator.

Colin was able to devise a hierarchy and he ranked his decisions in terms of their importance of 'getting them right' therefore more likely to ruminate about them for longer.

- Writing an email to my boss with questions or clarifications – ruminating about being unclear and irritating her.
- Writing an email to a colleague asking something about work – ruminating about sounding incompetent and ignorant.
- Writing an email to a colleague giving information or responding to their question – ruminating about being unhelpful or unclear.
- Calling friends (e.g. which day, what time of day, what to say) ruminating about disturbing them.
- Deciding what to wear in the morning (colour of each garment, type of clothes depending on what meetings are planned to take place, etc) – ruminating about looking odd.

Colin used exposure and response prevention to beat his OCD. He was asked to bring on the 'bad' thoughts and not cancel the thought out. To help him with this his facilitator also agreed to bring on some bad thoughts. The most difficult thing for Colin was to understand the reason behind deliberately bringing on his distressing thoughts and images. To demonstrate to Colin how pushing these thoughts away does not make them go away but has the opposite effect of making the thoughts even more powerful, his facilitator asked Colin NOT to think of

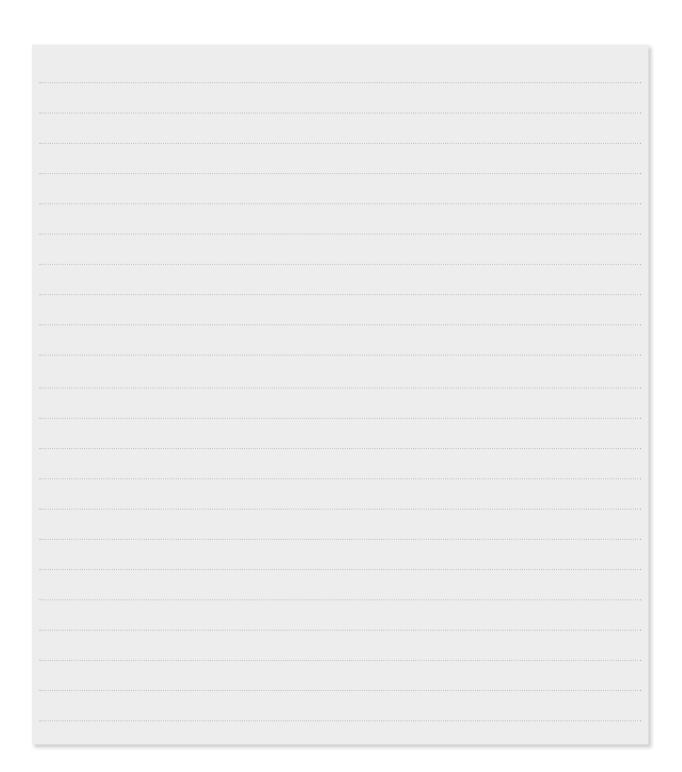
a "big blue elephant"; of course, the first thing that popped into Colin's mind was the image of a big blue elephant. Then Colin tried to hold on to this image for as long as he could and found that after 10 minutes his mind wandered off and the image faded away. Colin was asked to apply the same principles to his 'bad' thoughts. He also used exposure to help his decision making – for example to sign emails without deliberating on the wording.

Another important point in Colin's case is his depression, which is often present alongside OCD and which may need to be treated separately. On the one hand, when OCD is treated, people become more active and do things that they were not able to do before because of their OCD, and this has a positive impact on their depression. On the other hand, when depression lifts, people find that ruminations also become less severe

After 6 weeks of daily practice of exposure to his intrusive thoughts, Colin found that he literally "got bored" of them. He tested this by deliberately making a "wrong" decision, and by trying to bring on his intrusive thoughts, which he surprisingly could not hold on to for long in his mind, even if he tried to.

At 6-month follow-up, Colin said that his intrusive thoughts were few and far between but he realised he would always be prone to obsessive ruminations, especially when he was stressed. Although the content of his obsessive ruminations might change, they would always be of the same kind: intrusive, persistent and unsettling. Colin realised that whatever his intrusive thoughts, they would fade away with time if he used deliberate, repeated, prolonged and focused exposure to them rather than trying to push them away.

Section Seven: Personal diary We have left some blank pages for you here so that you can write a personal diary of your own individual journey.



OCTET

c/o The School of Nursing Midwifery and Social Work
Jean McFarlane Building
The University of Manchester
Oxford Road
Manchester
M13 9PL



