Acknowledgements

Thank you firstly to the patients on Heather Ward who helped in producing ideas for this booklet. Good luck to you all for the future.

Thank you also to the staff on Heather Ward for being so helpful and answering my questions.

And finally, thank you to my tutor, Dr Lynne Drummond, for being very enthusiastic about this project and showing me some great resources – I've enjoyed working with you.

Nikki Ramskill BSc, Author
Medical Student, St. George's University of London
Contents

Introduction 4
What is Obsessive Compulsive Disorder? 5-7
Obsessions 8-9
Compulsions 10-11
What causes OCD? 12
Patient experiences 13-15
Treatment 16-17
How can carers help? 18
For your notes 19
Additional information 20-21
Sources 22-23
Acknowledgements 24

If English is not your main language, or if you would like this document in large print, Braille, or on audio tape, please call 020 8682 5532.
What is OCD?

OCD is an anxiety disorder. This means that people experiencing OCD often feel worried about things. Worrying is usually a normal coping technique when we are unsure of what will happen, or think that something bad will happen. This feeling usually subsides after a short while.

When someone experiences OCD, worried feelings are taken out of context. This means that something that will normally not cause much anxiety actually causes a lot of anxiety. In order to reduce these feelings, the person uses certain behaviours to feel calm again. The problem with doing this is that it only gives temporary relief before they start to worry again. They become trapped in a seemingly endless cycle of anxiety and rituals.

Introduction

Question
What do David Beckham and Howard Hughes (of ‘Aviator’ movie fame) have in common?

Answer
They have both experienced a condition known as Obsessive Compulsive Disorder (OCD).

How common is OCD?
OCD affects about one in every 50 men and women. This means around one million people in the UK will have experienced OCD at some point.

If you think that you are experiencing OCD, then please be assured that you are not alone – there is help out there!

This booklet will provide you with:
- information about the condition
- information about the treatments
- advice for families and carers
- further information that can help you beyond the scope of this booklet.

This is a diagram to illustrate the OCD cycle.
People with OCD do not enjoy having their condition. It can be very disabling for them because it can affect normal everyday activities. Worrying is just one example of how someone feels with this disorder. Other emotions that people experiencing OCD can feel include:
- guilt (due to what they are thinking or doing)
- disgust/shame
- depressed
- stressed/tearful.

OCD can also affect family members and carers, because they do not always know how to help to make it better. Over the next few pages, we will be looking at what OCD is...

Notice that by continuously giving in to rituals, the cycle is allowed to continue, because the feeling of calm that accompanies the rituals is often only a temporary one. Treatment works by breaking this cycle and teaching people other ways to cope and feel less worried about things.

The things that people worry about are called 'obsessions'.

The things that people do to make themselves feel better are called 'compulsions'.

This is a diagram to illustrate OCD treatment:

- Anxiety initially rises
- Breaking the cycle – self-imposed response prevention
- Anxiety eventually reduces – it falls lower than when ritualisation occurs

obsessions
compulsions
what causes OCD?
patient experiences
treatment
carers
Obsessions

As shown with the cycle diagram, when people experience OCD they often feel worried a lot of the time. The things that they worry about are known as ‘obsessions’ because they cannot help thinking about what worries them. The thoughts come into their head without them wanting them to. For example:

Unwanted thoughts that do not go away
These can be single words or short sentences that the person may repeat over and over again. They can be shocking to the person who is thinking them, and they may think that they are a bad person for thinking them, or even that they are “going mad”. These thoughts keep coming, and the more the person tries to ignore them, the more the thoughts come back.

For example, the person could be thinking that they are contaminated by germs, or that they are suffering from a terrible illness like cancer or HIV.

Unwanted pictures in the mind that do not go away
The person may see shocking images in their head instead of (or as well as) thinking about words or sentences. If they try to ignore them, the images come back even more. They can be really upsetting.

For example, the person could have an image in their head of killing their family. This is something that they would never ever do, but they worry that they might if they are left near a sharp object.

Doubts about whether they have done something or not
A person experiencing OCD may worry that they haven’t done something like lock the front door when leaving the house, or that they ran someone over when they were driving their car. They doubt that their memory has remembered what they did correctly, so they think about it until they are sure that it was ok.

Wanting to get things ‘perfect’
Everything has to be in a correct order, or lined up in a certain way (‘perfectionism’). The person may think that having ‘odd’ numbered books on a shelf is ‘bad’, and so will take one off, or put one on to make it an ‘even’ number which is ‘good’. It has to be perfect, or they will start to feel worried about it. Sometimes perfectionism is a good thing – like when you do a piece of coursework and you want to make it look the best it can be. However, perfectionism is not good when it takes over and affects everyday life. Getting ready in the morning can take a very long time!

Summary
All of these scenarios are examples of why someone with OCD is anxious a lot of the time. It is easy to see how these thoughts, if they are allowed to continue and get worse, could potentially affect someone to the point of not being able to undertake the basic activities of daily living.

A person experiencing OCD will try to cope with these unwanted thoughts by carrying out certain activities in order to reduce their anxiety. The next few pages will show what someone may do to cope.
Compulsions

‘Compulsions’ are the things that people experiencing OCD do to feel better about what is happening to them. These include:

Counting, praying and repetition
In order to feel better about thinking a ‘bad’ thought or image, a person may think ‘good’ thoughts in order to counteract the ‘bad’ ones.

For example, they may repeat a short phrase over and over until they feel better and have corrected their ‘bad’ thought.

Rituals
These are things that someone experiencing OCD will do regularly whenever they are having thoughts or feelings that are worrying them (like those described on the Obsessions page).

For example, they may wash their hands in a certain way if they are worried about germs. They could arrange objects in a particular way, or put on their clothes in a certain order. It can take them ages to do anything because they have to carry out these ‘rituals’ to make them feel better.

Although some people may always wear a ‘lucky’ piece of clothing or carry ‘good luck’ charms in order to do well in a test or a football game, this does not mean they have OCD.

Checking things
If someone is worried about not having done something (like closing the front door properly), then they may want to keep checking it until they are happy that they have carried it out well enough. It can take much longer to do anything because the person may want to check something lots of times.

For example, before leaving the house they may feel they have to check the front door is locked several times before they can leave.

Keeping things
The person may not want to throw anything away so they will keep things that most people wouldn’t. Their house may get really messy, and they might not let their family or carers throw anything away.

However, just because someone has a messy bedroom, it does not automatically mean that they have OCD.

Reassurance that everything is ok
Someone experiencing OCD may keep asking if everything is ok, and check whether they are doing anything they shouldn’t be.

For example, one person could not go out without her mum because she needed her mum to tell her that she had not knocked anyone into the middle of the road in front of a car. Of course she wouldn’t really do this to anyone, but she had an obsession that she might, so her compulsive action was to get reassurance from her mum. Her obsession was the image of knocking someone out into the road in front of a car. Her compulsion (in order to feel better about thinking the image) was to keep checking with her mum that it was ok.
What causes OCD?

This is not known for certain, although some research has suggested that OCD has a possible genetic link. In other words, if a close relative experiences OCD, there is a chance other members of the family will also develop OCD. It is also thought that having a perfectionist type of personality (where everything must be completed to a very high standard) can turn into OCD if the perfectionism is taken to extreme levels.

There are many other ideas for what causes OCD. Refer to Additional Information on page 20-21 to find out more.

People who experience OCD are not alone! On pages 13-15 are some experiences of patients currently receiving treatment for OCD.

Patient experiences

Patient ONE

I think my OCD started when I was around 15 years old. I wasn't really sure what was happening to me – I thought I was going mad! I constantly felt petrified that something awful was going to happen. I had a horrible sensation in my stomach every time I got anxious; it felt like I was ‘drowning’ in my emotions. In order to stop feeling like this I would carry out rituals in my everyday routine.

For example, I used to comb my hair so that the parting was exactly perfect. Once I had carried out a ritual successfully, I would feel calm again and carry on with my day.

The problem with doing that, however, was that once I lost that calm feeling, I felt even more anxious and scared and had to carry out rituals again to feel better. I became trapped in a vicious cycle of rituals. I even started to use alcohol and drugs in order to ‘cement’ in the calm feeling and carry on with my day. I needed to stay in hospital for treatment.

My advice to anyone with OCD would be to understand that although you feel terrible right now, and that you have no escape, there is a light at the end of the tunnel, and it will get better; you just have to work for it!
Patient TWO
Having OCD really gets me down. It stops me from going out with my friends, and from doing the things that I enjoy. With my OCD, I feel like something awful is going to happen if I step on cracks, or if I don't carry out certain rituals like counting to an even number or turning light switches on and off until I feel better again. Normal activities are really hard work when you have OCD! It makes you feel like not bothering to get out of bed in the morning because it takes so long to do anything.

Patient THREE
I thought I was going ‘mad’. I felt constantly worried that I was being contaminated with germs from all around me. I wouldn’t cook because I was terrified about making people ill with germs on the food. I felt like I was in a ‘crystal ball’ because I was convinced that someone was always watching me and checking that I did things right. If I didn’t open and close the door in the right way, or count to the right number, then I would be found out, and something bad would happen to people around me and my family. If you have OCD don’t give up wanting to get better. It does get better I promise!

Patient FOUR
Having OCD feels embarrassing sometimes. I don’t like telling people that I’ve got OCD because I’m sure they think I’m weird! I worry about germs and being contaminated by them. It does feel infuriating because I know that what I believe and what I do is irrational, but I can’t help it. It takes so much time to do anything and I get so exhausted and depressed from it all.

Patient FIVE
“Would I? No, but I’ll call my husband to make sure he thinks I’m safe enough. Help this is driving me nuts! I must look this up on the internet or my OCD book just to be sure I won’t harm anyone.” It feels like my brain is ganging up on me.

“I would love to come over,” I say to my friend. But then my OCD says, “Hmm but what if I lose control and murder everyone?” I am so gentle but the OCD part of my brain loves to tell me otherwise. I can’t say, “Sorry I’ve changed my mind because I have an obsessive thought about harming you.” So then starts the “Would I? No, but I’ll call my husband to make sure he thinks I’m safe enough. Help this is driving me nuts! I must look this up on the internet or my OCD book just to be sure I won’t harm anyone.” It feels like my brain is ganging up on me.
Treatment

Talking Therapies

Exposure Response Prevention Therapy (ERP)
According to research, ERP is one of the most effective treatments for OCD. It is thought to be effective for around eight out of every 10 people who experience OCD.

The patient is required to make a list of all the things that set off their compulsive behaviours, and then to rank them in order from least stressful to most stressful.

The list could look something like:
- leaving dirty clothes on the floor (least stressful)
- touching toilet handles
- touching dirty clothes on the floor (most stressful).

The idea of the therapy is then for the patient to carry out the tasks on the list without using compulsive behaviours to make themselves feel better. These tasks are repeated until they cause a reduced amount of stress.

The ideal outcome of the therapy would be for all of the items to be worked through successfully in this way, and for the patient to learn other ways of keeping calm instead of using rituals. The length of time it takes varies between people, because it depends on how bad their symptoms are, and how long they have suffered from OCD.

Cognitive Behavioural Therapy (CBT)
This therapy is sometimes used in addition to ERP but can be used without it. The idea is to work on the thoughts or beliefs that cause someone to respond in the way they do (rituals, tapping or counting for instance). For example, the therapist might ask a patient to assess why they think that their family will die if they do not carry out the correct rituals, and then show them that this belief is unrealistic.

Medication

Selective Serotonin Reuptake Inhibitors (SSRIs)
These are known as ‘antidepressants’ because they affect how someone feels. Although not everyone with OCD is depressed, SSRIs are shown to be useful in treating OCD too. They increase the activity and amount of a chemical called serotonin in the brain, which has the effect of improving a person’s mood. Examples of this type of drug include: Fluoxetine (Prozac) and Paroxetine (Seroxat). Medication is usually used in combination with a ‘talking therapy’.
How can carers help?

If you are a carer you can help in lots of ways! Here are a few suggestions:

- Do not take part in ritualistic behaviours. Carrying out rituals does not help someone experiencing OCD, so you must try to discourage it.

- Contact your GP as soon as possible. Your doctor should be able to refer the patient on for other treatments such as Cognitive Behavioural Therapy or Therapist Guided Exposure Therapy, or provide medication if required. The longer you leave contacting a health care professional, the worse the problem may get.

- Get hold of self help books and use internet resources (there are some listed in this booklet for you). The more knowledge you have about the condition, the more it will help you to help them.

- Talk. It can be a tremendous benefit to someone if they can talk through what troubles them. Support is extremely important.

- If the person experiencing OCD must stay in hospital for treatment, get involved with their treatment. It is much better to know how to help them than to be unsure of what to do and potentially reverse the effects of therapy.

- Stay positive! OCD is difficult to beat, but be assured that it can be done. There is light at the end of the tunnel!

Notes

Use this page to write down any notes or questions that you may want to remember to ask your therapist or doctor.
Additional Information

This list is not exhaustive. Searches on the internet bring up lots of websites about OCD. Contact your local library or bookshop for books on OCD, and get in touch with your GP.

Books
Fineberg N, Marazziti D, Stein DJ, eds.  
*Obsessive Compulsive Disorder: A Practical Guide.*  

Marks, I. M.  
*Living with Fear.*  

Tallis, F.  

Veale D, Willson R.  
Constable & Robinson, 2005.

Websites
www.ocdyouth.info  
A really informative website aimed at young people. It is easy to use and has video-clips of young people talking about their experiences with OCD.

www.ocfoundation.org  
This website contains lots of information, and has a link to a 'webzine' written by teenagers experiencing OCD.

www.rcpsych.ac.uk  
The Royal College of Psychiatrists website. An informative website on all aspects of mental health. Highly recommended.

www.nice.org.uk/CG031  
National Institute for Health and Clinical Excellence. This website is informative and as well as OCD, contains information on many other conditions as well. Highly recommended, but beware – there is a lot to read!

www.babcp.com  
The British Association for Behavioural and Cognitive Psychotherapies offers CBT both inside and outside of the NHS. Contact them for more information.

www.ocfoundation.org/organizedchaos  
Highly recommended.

Support Organisations
OCD Action  
22/24 Highbury Grove,  
Suite 107, London N5 2EA  
Telephone: 0845 390 6232  
Email: info@ocdaction.org.uk  
Web: www.ocdaction.org.uk

OCD UK  
Po Box 8115,  
Nottingham NG7 1YT  
Telephone: 0845 120 3778  
Web: www.ocduk.org
Sources

Patient information leaflets
British Association for Behavioural and Cognitive Psychotherapies (BABCP)
Obsessive Compulsive Disorder (July 2005)

The Royal College of Psychiatrists (RCPSYCH)
Obsessive Compulsive Disorder (November 2006)

National Institute for Health and Clinical Excellence (NICE)
Treating Obsessive Compulsive Disorder and Body Dysmorphic Disorder in Adults, Children and Young People (November 2005)

Journal articles
Drummond, L.M. Fineberg, N.

Drummond, L.M.
The Management of Obsessive Compulsive Disorder
Current Opinion in Psychiatry. 6: 201-204 (1993)

Websites
Daily Mail Online (www.dailymail.co.uk)
Obsessive Compulsive Disorder: The Facts

Books
Treatment Plans and Interventions for Depression and Anxiety Disorders Forms: 2.4, 4.3, 5.5 (2000)

Grabe, J.H. Ruhrmann, S. Ettelt, S. Buhtz, F. et al.

Heyman, I. Mataix-Cols, D. Fineberg, N.A.

Whittal, M.L. Thordarson, D.S. McLean, P.D.

Chapters

Drummond, L.M. Obsessive Compulsive Disorder