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Treating obsessive- compulsive disorder (OCD) and body dysmorphic disorder (BDD) in adults, children and young people

Understanding NICE guidance – information
for people with OCD or BDD, their families
and carers, and the public

Ordering information

You can download the following documents from www.nice.org.uk/CG031

- This booklet.
- The NICE guideline – all the recommendations on treating OCD and BDD.
- A quick reference guide, which has been distributed to healthcare professionals working in the NHS in England.
- The full guideline – all the recommendations, details of how they were developed, and summaries of the evidence on which they were based.

For printed copies of the quick reference guide or information for the public, phone the NHS Response Line on 0870 1555 455 and quote:

- N0919 (quick reference guide)
- N0920 (information for the public).

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Contents

About this information	4
What is obsessive-compulsive disorder (OCD)?	7
What is body dysmorphic disorder (BDD)?	9
What happens when I first see a healthcare professional?	11
What treatments are helpful for adults with OCD or BDD?	15
What treatments are best for me?	18
What should I know about SSRIs?	20
What happens if I try the treatments and they do not help me?	26
What should I know about clomipramine?	28
Will I need to stay in hospital for treatment?	29
What happens when the treatment is completed?	30
Treatments for children and young people with OCD or BDD	31
Information for families and carers	40
Where you can find more information	42

About this information

This information describes the guidance that the National Institute for Health and Clinical Excellence (called NICE for short) has issued to the NHS on obsessive-compulsive disorder (OCD) and body dysmorphic disorder (BDD). It is based on 'Obsessive-compulsive disorder: core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder' (*NICE Clinical Guideline No. 31*), which is a clinical guideline produced by NICE for doctors, nurses and others working in the NHS in England and Wales (called healthcare professionals in this booklet).

Although this information has been written mainly for adults and children and young people with OCD or BDD, it may also be useful for family members, those who care for people with OCD or BDD and anyone interested in OCD or BDD or in healthcare in general.

There is a section on the specific treatment and care for children and young people on pages 31–39 of this booklet.

Clinical guidelines

Clinical guidelines are recommendations for good practice. The recommendations in NICE guidelines are prepared by groups of healthcare professionals, people representing the views of those who have or care for someone with the condition, and scientists. The groups look at the evidence available on the best way of treating or managing the condition and make recommendations based on this evidence.

What the recommendations cover

NICE clinical guidelines can look at different areas of diagnosis, treatment, care, self-help or a combination of these. The areas that a guideline covers depend on the topic. They are laid out in a document called the scope at the start of guideline development.

The recommendations in 'Obsessive-compulsive disorder: core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder' (*NICE Clinical Guideline No. 31*) cover:

- the care you can expect to receive from your GP or other healthcare professional
- what treatment you can expect to be offered, including psychological therapies and medication
- the services that may help you with OCD or BDD, including specialist mental health services
- how families and carers may be able to support you, and get support themselves.

This booklet tells you about the NICE guideline on OCD and BDD. It doesn't attempt to explain OCD or BDD or their treatments in detail, but there are brief explanations of the conditions on pages 7–8 and 9–10. For suggestions of starting points to find out more, see pages 42–43.

If you have questions about the specific treatments and options covered, talk to your doctor or nurse, or another healthcare professional. There are examples of questions you could ask throughout this booklet.

How guidelines are used in the NHS

In general, healthcare professionals in the NHS are expected to follow NICE's clinical guidelines. But there will be times when the recommendations won't be suitable for someone because of his or her specific medical condition, general health, wishes or a combination of these. If you think that the treatment or care you receive does not match the treatment or care described on the pages that follow, you should talk to your doctor, nurse or other healthcare professional involved in your treatment.

You have the right to be fully informed and to share in making decisions about your healthcare, and the care you receive should take account of your individual needs.

What is obsessive-compulsive disorder (OCD)?

Obsessive-compulsive disorder (or OCD for short) is the name given to a condition in which a person has obsessions and/or compulsions, but usually both.

An obsession is a thought, image or impulse that keeps coming into a person's mind and is difficult to get rid of. There are lots of different obsessions that can affect someone with OCD, but a few examples are:

- being afraid of contamination by dirt and germs
- worrying that something is not safe, such as an electrical appliance
- thoughts and fears of harming someone else
- wanting to have things in a particular order or arrangement (such as in a symmetrical fashion).

A compulsion is a feeling that a person has that they must repeat physical actions or mental acts. Usually people do this in response to an obsessive thought (for example, if a person is worried about dirt they might clean something repeatedly). People with OCD may use these actions to help deal with an obsessive thought or 'neutralise' it. There are lots of different compulsions that can affect someone with OCD (sometimes called 'rituals'), but a few examples are:

- excessive washing and cleaning
- checking things repeatedly (for example, that a door is locked or that an electrical appliance is switched off)
- keeping objects that other people might throw away (called 'hoarding')
- repeating acts
- repeating words or numbers in a pattern.

From time to time, almost everyone has a disturbing thought or checks more than once they have locked the door. For most people these thoughts and actions can be forgotten. But if a person has OCD, the thoughts and feelings of discomfort can take over and they will feel anxious until they have done something to help them to deal with the thought. People with OCD may realise that their thoughts and actions are irrational or excessive, but they will not be able to help themselves from thinking the obsessive thoughts and carrying out compulsions.

OCD can affect people in different ways. Some people may spend much of their day carrying out various compulsions and be unable to get out of the house or manage normal activities. Others may appear to be coping with day-to-day life while still suffering a huge amount of distress from obsessive thoughts. Some people with OCD may carry out their rituals and compulsions in secret or make excuses about why they are doing something. People with OCD may not realise that repeated thoughts, such as a fear of harming other people, are common symptoms of OCD and do not mean that they will carry out these thoughts.

When someone seeks help for their OCD, healthcare professionals will consider how distressing the symptoms are for that person and how much their life is affected. This will help them work out whether someone has mild OCD (symptoms are distressing but manageable and the person seems able to carry on with everyday life) or more severe or very severe OCD (symptoms are very distressing and seriously restrict the person's everyday life). It will also help the healthcare professional work with the person with OCD to identify the most suitable treatment.

It is thought that about 1–2% of the population in the UK may have OCD and it can affect people of any age, from young children to older adults. Some people with OCD also have depression.

What is body dysmorphic disorder (BDD)?

Body dysmorphic disorder (BDD) is the name given to a condition in which a person spends a lot of time concerned about their appearance. They may compare their looks with other people's, worry that they are physically flawed and spend a long time in front of a mirror concealing what they believe is a defect.

At some time or another, almost everybody feels unhappy about the way they look, but these thoughts usually come and go and can be forgotten. However, for a person with BDD, the thought of a flaw is very distressing and does not go away, even though other people may think that there is nothing wrong with the way that person looks.

Although BDD is not exactly the same as OCD, there are similarities. For instance, a person with BDD may feel that they have to repeat certain acts. A few examples are:

- checking how they look
- repeatedly combing their hair or applying make-up
- picking their skin to make it 'smooth'.

A person with BDD may feel that they cannot go out in public unless they have hidden the problem area in some way, with clothing or make-up. This can seriously affect the person's daily life. Some people with BDD occasionally also have depression.

When someone seeks help for their BDD, healthcare professionals will consider how distressing the symptoms are for that person and how much their life is affected. This will help them work out whether someone has mild BDD (symptoms are distressing but manageable and the person seems able to carry on with everyday life) or more severe or very severe BDD (symptoms are very distressing and

seriously restrict the person's everyday life). It will also help the healthcare professional work with the person with BDD to identify the most suitable treatment.

The treatments for BDD are very similar to those for OCD and are explained in the sections on treatment for OCD.

It is not known exactly how many people in the UK have BDD because people who have it often hide it from others, but it could be around 0.5%. The condition can affect all age groups from adults to young people and children.

What happens when I first see a healthcare professional?

When you first see a healthcare professional about your symptoms, he or she will want to consider whether you have OCD or BDD, so he or she may ask you the following questions (this is called an assessment).

For OCD

- Do you wash or clean a lot?
- Do you check things a lot?
- Is there any thought that keeps bothering you that you'd like to get rid of but can't?
- Do your activities take a long time to finish?
- Are you concerned about putting things in a special order or are you very upset by mess?
- Do these problems trouble you?

For BDD

- Do you worry a lot about the way you look and wish you could think about it less?
- What specific concerns do you have about your appearance?
- On a typical day, how many hours do you worry about your appearance?
- What effect does it have on your life?
- Does it make it hard to do your work or be with friends?

If you have arranged to see a healthcare professional about having cosmetic surgery or treatment for any skin conditions, and you have or are thought to have BDD, you should be offered an assessment by a mental health professional with specific expertise in BDD.

If you have OCD or BDD, your healthcare professional should ask you if you have thoughts about harming yourself or about suicide, especially if you also have depression, and if you have any other problems or conditions.

You may find it very difficult to talk about your symptoms, but your healthcare professional should understand about how distressing OCD or BDD can be. They should explain that the obsessive thoughts and compulsions are caused by OCD or BDD and can be very difficult to control.

If you have OCD and have very unpleasant or disturbing thoughts, healthcare professionals should talk to you about these and explain how they are connected to the condition.

Your healthcare professional should give you full and clear information about OCD or BDD and the treatments offered. If you have any additional needs (for example, you have a learning difficulty, a disability or your first language is not English), the information and any treatments or care that you receive should be adapted to suit your particular needs.

Your healthcare professional should discuss the treatment options with you so you can decide if you want to have a particular treatment or not, and which treatment you might prefer. Your own preference is important and after a full discussion your healthcare professional should support your choice where possible.

Your healthcare professional should, where appropriate, tell you about self-help and support groups for OCD or BDD in your area.

If you need to see more than one healthcare professional about your OCD or BDD, they should make sure that there is a written agreement about who is responsible for various aspects of your care. This agreement should be discussed with you and, if appropriate, your family or carer. You should be given a copy of this agreement.

OCD and BDD can be successfully treated, but the symptoms can come back again and for some people the conditions can last for many years. If your symptoms do come back, where possible you should be able to carry on with your treatment with the same healthcare professional(s), without having to see many different ones before receiving treatment.

OCD: religious and cultural practices

If you have OCD and you have obsessions that may be related to your religion, or that are specific to your culture, healthcare professionals may ask for advice and support from local religious and community leaders in order to assess what is reasonable for your religion or culture. This can help the treatment process. You should be asked for your permission first.

Will my family or carer be involved in my treatment?

When you have an assessment (see page 11), your healthcare professional should involve your family or carer if this is appropriate, but your permission is needed before any conversation takes place.

If you live with a family member or carer, it can help if they are involved in your treatment, but this does depend on your wishes and your individual circumstances (for instance, your age and your ability to make decisions). A family member or carer may be able to help and support you by doing some of the psychological treatment exercises with you (see pages 15 and 16).

Questions you may want to ask healthcare professionals

Many people can feel anxious when talking to a healthcare professional. Although they should try to explain things clearly, you may need something explaining to you again or in more detail. In the box below and throughout this booklet are examples of questions you could ask. It might be helpful to take this booklet with you when you go to see someone.

Questions you may want to ask healthcare professionals about OCD or BDD

- What makes you think that I have OCD (or BDD)?
- Is OCD (or BDD) common?
- Are all of my symptoms caused by OCD (or BDD)?

Questions you may want to ask healthcare professionals about treatment

- What treatment will I need?
- What choices do I have about treatment?
- How long will I need treatment for?
- How will having treatment for OCD (or BDD) affect my daily life/work, etc?
- Can you provide any information for my family/carer?

What treatments are helpful for adults with OCD or BDD?

There are a number of treatments for adults with OCD or BDD that are helpful, including psychological therapies and medication. These are outlined below.

Psychological treatments

The main psychological treatment for OCD or BDD is cognitive behavioural therapy (CBT) including exposure and response prevention (ERP). In this booklet it is called 'CBT with ERP' for short. But if you have OCD, another treatment called cognitive therapy may be used (see page 16).

Cognitive behavioural therapy with exposure and response prevention (CBT with ERP)

CBT is a psychological treatment based on the idea that the way we feel is affected by our thoughts (or 'cognitions') and beliefs, and by how we behave. If we have a negative thought, for example, this can lead to negative behaviour, which can affect the way we feel. CBT helps people to reassess the meaning of their thoughts and actions.

ERP helps people deal with situations or things that make them anxious or frightened. With the support of the therapist, the patient is 'exposed' to whatever makes them frightened or anxious (for example, dirt or germs). Rather than avoiding the situation or repeating a compulsion, the patient is taught other ways of coping with the anxiety or fear. This process is repeated until the patient no longer feels as anxious or afraid.

If you have obsessive thoughts but do not have any obvious compulsions, you can still have CBT with ERP. However the ERP will focus on mental rituals and any methods you may use to deal with obsessive thoughts.

Cognitive therapy for OCD

Most psychological treatment for OCD consists of CBT with ERP, but if you do not feel comfortable starting ERP, or it has not helped you, then your healthcare professional may offer you cognitive therapy that has been adapted for people with OCD. Cognitive therapy can help people change their beliefs about things they may find distressing, but it does not usually involve being 'exposed' to what makes them frightened or anxious as in ERP.

But if you are having ERP, your healthcare professional may consider offering you cognitive therapy in addition to your current treatment because this can help you to stay well in the future.

General information about psychological treatments

If you agree, your family or carer can help you with some of the treatment exercises in ERP.

Towards the end of psychological treatment, healthcare professionals should advise you about how you can carry on using the techniques you have learnt if symptoms come back.

Are there any other psychological treatments than can help me?

You should be advised by your healthcare professional that other than the treatments described above, there is no evidence that other psychological treatments or therapies can help improve your OCD. These include psychoanalysis, transactional analysis, hypnosis and marital or couple therapy.

Where can I have psychological treatment?

Most meetings with therapists take place at a clinic or hospital, or sometimes at your local GP's practice. If your symptoms are seriously affecting your everyday life, you should be offered practical and financial support for travel if you have difficulty getting to and from the meetings. You may be able to receive treatment in your home if:

- your symptoms prevent you from leaving your house
- you would find it very difficult being in a clinic, or
- you have severe problems with hoarding.

You may be able to have CBT over the phone if you are unable to leave your house and you feel unable to have other people in your home.

Medication

Research has shown that medication used for treating depression (called 'antidepressants') can also help people with OCD or BDD. Antidepressants work by increasing the activity and amount of certain chemicals in the brain that affect mood (such as one called serotonin). There are different types of antidepressants, but ones called selective serotonin re-uptake inhibitors (or SSRIs for short) often work best for people with OCD or BDD.

See page 20 for important information about SSRIs.

What treatments are best for me?

If you have OCD and your symptoms are mild, you should first be offered a psychological treatment involving ERP. This may be one of the following:

- up to 10 hours of CBT with ERP using self-help materials, such as a book, with help from a healthcare professional
- up to 10 hours of CBT with ERP by telephone with a healthcare professional
- a course of CBT with ERP in a group with a healthcare professional and other people with OCD.

If these treatments do not help or do not suit you, you should be offered the choice of either:

- an SSRI
- more than 10 hours of CBT with ERP (usually a one-to-one meeting with a therapist).

If you have OCD and your symptoms are more severe, you should be offered the choice of either:

- an SSRI
- more than 10 hours of CBT with ERP (usually a one-to-one meeting with a therapist).

If you have OCD and your symptoms are very severe, you should be offered combined treatment of CBT with ERP, together with an SSRI.

If you have BDD and your symptoms are mild, you should be offered CBT with ERP to address the symptoms, either on your own or in a group with other people with BDD (you and your healthcare professional should decide which would be best for you).

If you have BDD and your symptoms are more severe, you should be offered a choice of:

- an SSRI
- CBT with ERP to address the symptoms of BDD (you should have this treatment on your own, rather than in a group of other people with BDD).

If you have BDD and your symptoms are very severe, you should be offered combined treatment of CBT with ERP to address the symptoms of BDD, together with an SSRI.

See pages 31–39 for information about treatments for children and young people.

Questions you could ask about psychological treatments

If you are offered a particular psychological treatment, you might want to know more about it, so you could ask one or more of the following questions.

- Can you tell me in more detail what the treatment will involve?
- Can you tell me why you have decided to offer me this type of treatment?
- How long will the treatment last?
- Who will do this treatment with me?
- What improvements might I expect to experience?

What should I know about SSRIs?

Starting the treatment

Your healthcare professional should tell you, and should give you written information, about concerns people may have about taking medication. You should be informed about the following.

- You will not crave antidepressants or need to take more of the medication to feel the same effect as time goes on.
- People can sometimes have unpleasant symptoms (called 'side effects') when taking antidepressants, which can include feeling very anxious or agitated, or thinking about harming themselves or about suicide, especially in the first few weeks of taking the medication.
- People can also have side effects if they stop the medication, forget to take it, or reduce the amount of medication. These symptoms are called discontinuation (or withdrawal) symptoms, and they can include dizziness, feeling nauseous, unusual body sensations, anxiety and headaches. These symptoms are usually mild, but can sometimes be severe, especially if the antidepressant is stopped abruptly.
- The medication may take up to 12 weeks to work (but if you have depression, this may get better more quickly).
- Taking antidepressants does not mean that you are a weak person.

Making sure you are OK

Your healthcare professional should arrange to see you regularly so that he or she can check whether the medication is causing any side effects. This arrangement should be agreed with you and written in your medical notes. Your healthcare professional should check whether you are very anxious, agitated, feel restless or you can't sit or stand still (called 'akathisia'). He or she should also ask you if you have any thoughts about suicide, especially at the start of treatment. He or she should tell you to seek help immediately if you are at all distressed.

If you are a young adult (under 30) you should be seen more often. If you are depressed or have thoughts about suicide, you should also be seen frequently, especially in the first few weeks of starting an SSRI, and you may be given further support over the phone. If it is appropriate, your healthcare professional may ask you if you would like a family member or carer to help in watching out for any side effects. This should also be written in your medical notes.

If you have thoughts about suicide and you are offered an antidepressant you should only be prescribed a small amount of medication.

If the dose of your medication is changed, your healthcare professional should check to see whether you have any new symptoms or are feeling worse.

Choice of SSRIs

If you are an adult with OCD, you should be offered one of the following SSRIs first:

- fluoxetine
- fluvoxamine
- paroxetine
- sertraline
- citalopram¹.

If you are an adult with BDD you should first be offered fluoxetine², because research has shown that this works better for people with BDD than other SSRIs.

Because some medicines can react badly with other medicines, your healthcare professional should ask you about any other medication that you are taking. If you have significant and/or persistent side effects while taking an SSRI, your healthcare professional may offer you a different SSRI.

If an SSRI has not helped you after 4–6 weeks and you have not experienced a lot of side effects, your healthcare professional may discuss with you the need to increase your dose. He or she should tell you about possible side effects and should check for these when the dose is increased.

If treatment with an SSRI has not helped you at all, your healthcare professional should make sure that you took the medication regularly, that you took the correct amount, and check if any alcohol or other drugs you were taking at the time affected your treatment.

^{1, 2} At the date of publication (November 2005) citalopram for use in OCD in adults, and fluoxetine for use in BDD, do not have a UK Marketing Authorisation.

If treatment with an SSRI has helped you, you should continue to take the medication for at least 12 months because this will help your symptoms to improve and help to prevent you becoming unwell again. Your healthcare professional should see you again after the 12 months to see whether you should continue to take the medication (this usually depends on how severe your OCD or BDD symptoms were, how long you had the condition and whether you still have any symptoms or have any other problems). If you continue to take an SSRI, your healthcare professional should arrange to see you regularly. This arrangement should be agreed by you both and written in your medical notes.

When reducing your dose or stopping the medication altogether, your healthcare professional should make sure that this is done gradually over several weeks and to suit your needs.

When you stop treatment with an SSRI, your healthcare professional should encourage you to go back and see him or her if you have severe symptoms caused by stopping the medication.

Is there any medication I should not be offered?

The following drugs should not normally be offered to you if you have OCD or BDD because there is little evidence that they can help:

- tricyclic antidepressants (other than clomipramine, see page 28), such as amitriptyline, nortriptyline and desipramine
- tricyclic-related antidepressants, such as trazodone
- serotonin and noradrenaline re-uptake inhibitors (SNRIs), including venlafaxine
- monoamine oxidase inhibitors (MAOIs), such as phenelzine
- anxiolytics, such as clonazepam (except buspirone very occasionally for some adults with BDD also taking an SSRI)
- antipsychotics on their own, such as haloperidol and sulpiride.

See pages 31–39 for information about treatments for children and young people.

Questions you could ask about medication

If you are offered medication, you might want to know more about it, so you could ask one or more of these questions.

- How will the medication help me?
- How long will it take before I start to feel better?
- How long will I have to take it for?
- Will it be easy to stop taking it?
- Is there a leaflet or other written material about the medication that I can have?

You should be informed about the side effects associated with antidepressants. If you are unsure, you might consider asking the following questions before agreeing to treatment.

- Does this medication have any side effects?
- Will the side effects affect my daily life, or physical or psychological health?
- What should I do if I get any of these side effects?
- How long do these side effects last?
- Are there any long-term side effects of taking this medication?

What happens if I try the treatments and they do not help me?

If you have OCD or BDD and have taken an SSRI for 12 weeks, or have had CBT with ERP for more than 10 hours, and these have not helped, you should be seen by a range of healthcare professionals who will look at all the treatment you have had so far and reassess your symptoms. You should then be offered treatment with an SSRI, together with CBT with ERP.

If you continue this combined treatment for 12 weeks and you don't feel any better, you should be offered an antidepressant on its own. This should be a different SSRI or another antidepressant called clomipramine (see page 28 for important information about this medication). If you have been taking an SSRI without CBT for whatever reason and you don't feel any better, you should also be offered a different SSRI or clomipramine.

If these further treatments have not helped you, then your healthcare professional should suggest that you see a range of other healthcare professionals who are experts in OCD/BDD. They will look at the following:

- your symptoms
- all the treatment you have had so far (including whether medication has helped you and if you have had side effects)
- if you have other conditions such as depression
- whether you have thoughts about suicide
- things that make you feel anxious or stressed
- your relationship with your family or carers.

You may be offered further treatment, such as additional psychological therapy and additional medication.

For OCD such treatments might include:

- having additional CBT with ERP or cognitive therapy
- taking an antipsychotic drug in addition to an SSRI or clomipramine
- taking clomipramine and a drug called citalopram at the same time.

For BDD such treatments might include:

- having additional CBT with ERP or cognitive therapy with a different team who are specialists in BDD
- taking a drug called buspirone³ in addition to an SSRI.

You will usually have this treatment in a clinic or in hospital where it will be provided by a specialist mental health professional.

If you have BDD and treatments are not helping you feel better, your healthcare professional should check on you regularly and check to see if you are having thoughts about suicide.

Questions you could ask if you do not feel better after having treatment

- I had expected to feel differently from how I am feeling now. Can we discuss how I am getting on?
- Do we need to look at different types of treatment or do we need to extend the period of treatment?

³ At the date of publication (November 2005) buspirone for use in BDD does not have a UK Marketing Authorisation.

What should I know about clomipramine?

If the treatment described on pages 15–25 has not helped you, you may be offered another type of antidepressant called a 'tricyclic'. There are different tricyclics, but only one called clomipramine is recommended for people with OCD or BDD. This should only be offered to you after you have tried at least one SSRI, if you would prefer clomipramine, or if you have tried clomipramine before and it has helped you.

If you are at high risk of heart disease, your healthcare professional should take your blood pressure and check your heart with a machine called an ECG before you start taking clomipramine.

If you have thoughts about suicide, your healthcare professional should give you only a small amount of clomipramine at a time. He or she should check on you regularly until these thoughts have gone away.

If treatment with clomipramine has not helped you, and you have not had severe side effects, your healthcare professional may discuss with you the need to increase your dose.

If the treatment has helped you, you should continue taking the medication for at least 12 months because your symptoms may improve more.

When you no longer need to take clomipramine, your healthcare professional should reduce the dose gradually.

Will I need to stay in hospital for treatment?

Most people with OCD or BDD do not have to stay in hospital for treatment. But if your symptoms are very severe, and/or you cannot look after yourself properly, or you have thoughts about suicide, your healthcare professional may think that you will benefit by staying in hospital for treatment (this is called inpatient treatment). Inpatient treatment may also be suitable for you if you are not able to get to a clinic during the day time.

Your healthcare professional may also consider inpatient treatment if you have had OCD or BDD for a long time and lots of different treatments have not made you feel any better.

Inpatient treatment may sometimes help if you have other problems or conditions, such as an eating disorder, severe depression or schizophrenia as well as OCD or BDD.

In hospital you should be able to receive treatments that are more in-depth and you will be treated by experts in OCD/BDD.

If you have had OCD or BDD for a very long time and have difficulty living on your own, you should be helped to find suitable accommodation with people who can help you become more independent.

What happens when the treatment is completed?

Once you feel better, a mental healthcare professional should see you regularly for the next 12 months to see how you are getting on. The healthcare professional should agree with you in advance how often this should be and write this in your notes. At the end of the 12 months, if you are still feeling OK, your GP or others in the local healthcare team can provide any further care or support you need, but this may depend on your circumstances.

If your symptoms do not get much better after a course of treatment(s), your healthcare professional should make sure all of your continuing needs are met.

What happens if my OCD or BDD comes back?

If you have been treated successfully for OCD or BDD but your symptoms come back, you should be seen as soon as possible by a healthcare professional rather than be put on a waiting list.

Treatments for children and young people with OCD or BDD

What should happen when I first see a healthcare professional?

When you first see a healthcare professional about your OCD or BDD, they will ask you some questions, like the ones on page 11. If you have BDD you should also be asked if you have thoughts about suicide.

What treatments can help me?

Treatments for children and young people are like those for adults, but there are some special things that healthcare professionals (doctors and therapists) need to think about when offering them to you.

Because it can help you get better, your family or the people who care for you (and sometimes other people such as teachers) should be involved in your treatment.

If you have other illnesses or problems, you should also be able to get help for these while getting help for OCD or BDD.

Can I choose what treatments I get?

Yes, you can usually choose what treatments you get. But this does depend on your age and whether or not you are able to fully understand all the information that your healthcare professional should give you about treatments. If you are over 16 you can give your own agreement; if you are under 16 and you fully understand all the information you may also be able to give your own agreement.

Once your healthcare professional has talked with you about the treatments, and you understand about what might be helpful for you and what might not be, you might like to tell him or her which treatment you would prefer. If there are possible treatments that you do not want you should tell your healthcare professional.

If you are too young or have not fully understood the information about treatments, your parents or carers may also need to agree to your treatment. Sometimes parents and healthcare professionals will think that you need a treatment you don't particularly want and may go against your decision if they think this is best for you.

Psychological treatments

The main treatments for children and young people include talking to someone and getting help if you are feeling anxious or nervous because of your thoughts or actions (this is called psychological treatment or therapy).

If you have OCD and your symptoms are mild (they do not trouble you very much and you are mostly able to get on with school work and with other activities), healthcare professionals may first give you a book to help you with your thoughts and actions. Your healthcare professional should help you to follow some of the exercises in the book. At the same time, your family or carers may also be given information about OCD and the treatments you can have.

If the exercises do not help you, or you don't want to try them, you should be offered a special type of treatment called cognitive behavioural therapy including exposure and response prevention (we will call this 'CBT with ERP' for short; see the explanation of this on page 15). Your family or carers should be involved in the treatment and you should all be offered the choice of having the treatment alone, or with a group of other people with OCD.

If you have OCD and your symptoms are more severe (they trouble you a lot and you are not able to get on with school work and other activities), you should be offered CBT with ERP.

If you have BDD you should be offered CBT with ERP. Your family or carers should be involved in your treatment.

When you have therapy, your healthcare professional should be understanding and should support you. He or she should talk to you and your family or carers about what the treatment will involve. Depending on your age, your agreement will be needed for the healthcare professional to talk to them about your treatment.

After finishing a course of therapy, your healthcare professional may offer you one or two more sessions if you need them.

If therapy has not helped you after 12 weeks, your healthcare professional should suggest that you see a range of other healthcare professionals who are experts in OCD/BDD. They will look at all the treatment you have had so far.

They may then offer you medicine in addition to therapy if your OCD or BDD is severe (see page 34). If you do not want to have therapy, your healthcare professional may also consider offering you medicine.

Medicines

Medicines can help children and young people with OCD or BDD, but you should be offered therapy before you are offered medicine.

Medicines called SSRIs often work best for people with OCD or BDD. These medicines are also used for people with depression and so are called antidepressants.

You should only be offered medicines after you have seen a psychiatrist (a doctor who is an expert in mental health problems such as OCD or BDD) who specialises in treating children and young people. You should usually be having CBT with ERP while taking medicine. If for some reason you are not having therapy, your healthcare professional should take extra care while you are taking medicines on their own. Whether you are offered medicines also depends on your age (very young children are less likely to be offered medicines) and how you are feeling.

If CBT with ERP and medicines have not helped you, your healthcare professional may offer you another type of SSRI or other medicines, but this may depend on your age.

What should I know about medicines?

If you start taking an SSRI your healthcare professional should arrange with you and your family or carers to see you regularly so that he or she can see how you are feeling. This should be agreed between you and your family or carers and your healthcare professional and written in your medical notes.

If you are offered medicines, your healthcare professional should tell you and your parents or carers the following before you and/or your parents or carers agree:

- about why you have been offered medicines
- that the medicine may take some time to work
- how long the treatment should take, and how it might help you
- about any possible unpleasant reactions (called side effects) to the medicine
- that you must follow the instructions in the packet about taking the medicine.

You should also be given written information about the medicine you are taking.

If you have OCD and have been offered medicine it should be one of the following SSRI antidepressants:

- sertraline⁴
- fluvoxamine⁵.

^{4, 5} At the date of publication (November 2005) sertraline for use in OCD has a UK Marketing Authorisation for children aged 6 years and older; fluvoxamine for use in OCD has a UK Marketing Authorisation for children aged 8 years and older. Doctors can legally prescribe unlicensed medicines where there are no suitable alternatives and where the use is justified by a responsible body of professional opinion (Royal College of Paediatrics and Child Health, 2000).

If you have OCD and you also have depression, and you have been offered a medicine, it should be an SSRI called fluoxetine⁶. You should also be given help for depression (your healthcare professional should follow the NICE guideline on depression in children and young people⁷).

If you have BDD you should be offered fluoxetine⁸.

The amount of medicine you are given (the dose) should be small, but you can be given more gradually if a small amount has not helped you feel better.

If you start taking an SSRI your healthcare professional should check regularly to see whether you are having serious side effects (for example feeling very anxious or angry, hurting yourself or having thoughts about suicide). You and your family should be told to get in contact with your healthcare professional straight away if you start to feel like this.

^{6, 8} At the date of publication (November 2005) fluoxetine does not have a UK Marketing Authorisation for use in OCD in children and young people or for use in BDD. Doctors can legally prescribe unlicensed medicines where there are no suitable alternatives and where the use is justified by a responsible body of professional opinion (Royal College of Paediatrics and Child Health, 2000).

⁷ Depression in children and young people: identification and management of depression in children and young people in primary care and specialist services. *NICE Clinical Guideline* No. 28. Available from www.nice.org.uk/CG028

If you do not feel better after taking the medicine, or you feel worse, your healthcare professional may think about offering you a different SSRI or an antidepressant called clomipramine⁹. Before you and/or your parents agree, you should be told, however, that clomipramine can also have side effects and, if you take too many tablets by accident, it can be very dangerous.

If you are offered clomipramine your healthcare professional should first check your heart by using a machine called an ECG.

If clomipramine is not helping you to feel any better, and you have not had any unpleasant side effects, your healthcare professional may give you a bit more of the medicine gradually.

If an SSRI or clomipramine has helped you to feel better, you should carry on taking the medicine for at least 6 months **after** you get well because this can help you to stay well in the future. If you stay well, the medicine can be gradually stopped (your healthcare professional should give you less of it slowly over several weeks). Your healthcare professional should tell you and your family or carers that you may feel unwell while stopping taking an antidepressant and that your symptoms may come back. You should be told that if you do feel unwell while coming off your medicine, you should contact your healthcare professional.

While you are stopping taking an antidepressant you should also have therapy because this can help you to stay well in the future.

The following medicines should **not** be offered to you:

- a group of antidepressants called tricyclics (other than clomipramine)
- groups of antidepressants called MAOIs and SNRIs.

Medicines called antipsychotics should not usually be offered to you on their own. If one is offered, it should be with an antidepressant.

⁹ At the date of publication (November 2005) clomipramine for use in OCD and BDD in children and young people does not have a UK Marketing Authorisation. Doctors can legally prescribe unlicensed medicines where there are no suitable alternatives and where the use is justified by a responsible body of professional opinion (Royal College of Paediatrics and Child Health, 2000).

Will I need to stay in hospital for treatment?

Most people with OCD or BDD do not have to stay in hospital for treatment. But your healthcare professional may think that this will help you if:

- your symptoms are causing you a lot of worry
- you are not going to school or doing other activities because of your symptoms
- treatments have not helped you so far
- you are not looking after yourself or you have thoughts about suicide.

What happens when the treatment is completed?

Once you feel better, a mental healthcare professional should see you regularly for the next 12 months to see how you are getting on. The healthcare professional should agree with you in advance how often this should be and write this in your notes. After the 12 months, if you are still feeling OK, your family doctor or others in your local healthcare team can provide any support or care you need, but this may depend on your circumstances.

If you do not feel better after a course of treatment(s), your healthcare professional should make sure that you continue to receive the support and care you need.

What happens if my OCD or BDD comes back?

If you have been treated successfully for OCD or BDD but your symptoms come back, you should be seen as soon as possible by a healthcare professional rather than be put on a waiting list.

When you reach the age of 18 you may need help and treatment from another group of healthcare professionals who treat adults. If this happens your healthcare professional should make sure that you receive all the help and support you need after you turn 18.

Information for families and carers

How can I support a person with OCD or BDD?

Some people may not even know that their relative or friend has OCD or BDD because sometimes people with these conditions can keep their obsessions to themselves, and carry out their compulsions in private. However, some people with OCD or BDD may carry out their compulsions more openly, which can be alarming for those around them, especially if they do not understand what is happening.

Where possible and suitable, it can be helpful for everyone if healthcare professionals work with both the person with OCD or BDD and their family or carers.

As a family member or carer, you can have an important role in giving practical and emotional support to someone with OCD or BDD. In order to help you with this, healthcare professionals should tell you about OCD or BDD, how it develops and about the treatments that can help. They should also give you written information.

When your relative or friend with OCD or BDD first sees a healthcare professional, the healthcare professional will ask them questions about their condition (this is called an assessment). If it is appropriate and the person with OCD or BDD has agreed, the healthcare professional might involve you in the assessment.

If the healthcare professional thinks it will help, they should ask you how you are dealing with the person's OCD or BDD. You may feel, for instance, that you have to take part in your relative or friend's compulsions or rituals, even though you may not want to. If this is the case, it is important to tell healthcare professionals so that they can help you not to do this, while still continuing to support the person with OCD or BDD.

If it is appropriate, and the person with OCD or BDD agrees, you may also be involved in certain aspects of their assessment and treatment plan. For instance, some psychological treatments for children and young people involve families or carers (see page 16) to help the person with OCD confront their fears as part of ERP treatment (see page 15 for explanation of this treatment). Families and carers can also continue to offer support after treatment has ended to help the person stay well.

How can I find support?

Supporting a person with OCD or BDD can be distressing and demanding. Healthcare professionals should tell you about any support groups for families and carers in your area. As part of the assessment of your relative or friend, especially if they have severe OCD or BDD or have had the condition for a long time, healthcare professionals should offer you an assessment of your circumstances, needs and health.

If children are thought to be seriously affected by a parent's OCD or BDD, healthcare professionals should arrange for them to be assessed for any emotional or psychological problems. Parents should be kept fully informed of what happens at this assessment.

Questions for families and carers to ask

Families and carers need to be well informed and supported. If you are unsure about your role in helping and supporting a person with OCD or BDD, consider asking one or more of the following questions.

- What can I/we do to help and support the person with OCD or BDD?
- Is there any additional support which I/we, as carers, might benefit from?

Where you can find more information

If you need further information about any aspects of OCD or BDD or the care that you are receiving, ask your doctor, nurse or other member of your healthcare team. You can talk to them about the NICE guideline on OCD and BDD, or the information in this booklet.

If you want to read the other versions of this guideline

There are four versions of this guideline:

- this one
- the full guideline, which contains all the recommendations on OCD and BDD, details of how they were developed, and summaries of the evidence on which they were based
- a version called the NICE guideline, which lists all the recommendations on OCD and BDD
- the quick reference guide, which is a summary of the NICE guideline for healthcare professionals.

All versions of the guideline are available from the NICE website (www.nice.org.uk/CG031). Printed copies of this booklet and the quick reference guide are also available. Phone the NHS Response Line on 0870 1555 455 and quote N0919 (quick reference guide) or N0920 (information for the public).

If you want more information about OCD or BDD

NHS Direct may be a good starting point for finding out more about OCD. You can call NHS Direct on 0845 46 47 or visit the website (www.nhsdirect.nhs.uk).

There may be support groups for people with OCD or BDD in your area and your doctor or nurse may be able to give you details of these. Information about local groups may also be available from NHS Direct or your local library or Citizens Advice Bureau.

If you want to know more about NICE

There is more about NICE and the way that the NICE guidelines are developed on the NICE website (www.nice.org.uk). You can download the booklet 'The guideline development process – an overview for stakeholders, the public and the NHS' from the website, or you can order a copy by phoning the NHS Response Line on 0870 1555 455 (quote reference number N0472).

These can also be ordered from the NHS Response Line on 0870 1555 455.

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