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# Perinatal OCD



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# This information is for anyone who wants to know about Perinatal Obsessive Compulsive Disorder (Perinatal OCD).

## We hope it will be helpful if:

- You are a woman who has, or thinks you have Perinatal OCD
- You are a partner, family member or friend who wants to find out more

## Disclaimer

This leaflet provides information, not advice. For further advice and guidance, please speak to your GP, midwife, health visitor, psychiatrist, psychologist or mental health practitioner.

## What is Perinatal OCD?

Obsessive Compulsive Disorder (OCD) is a relatively common mental illness. It can affect men and women at any time of life. If a woman has OCD during pregnancy or after birth (known as the perinatal period) it is called Perinatal OCD.

You may have had OCD before getting pregnant. For some women, pregnancy or birth can be the trigger for the disorder. OCD has three main parts:

1. Thoughts or images that keep coming into your mind. These are called obsessions.
2. Anxiety - usually as a result of the thoughts.
3. Thoughts or actions you keep repeating to try to reduce your anxiety. These are called compulsions.

## Acknowledgements:

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It has been adapted and adopted with their kind permission for use across the Wales Perinatal Mental Health Network.

## What does it feel like to have 'Perinatal OCD'?

Having a baby brings many changes and this can be stressful. Many pregnant women and new mothers have a normal (and probably helpful) rise in obsessive or compulsive-like symptoms<sup>1</sup>.

Most parents feel that having a baby is a huge responsibility. It is normal to worry about your child's wellbeing and to want to protect your baby. You may be more careful about avoiding risks in pregnancy or after birth.

You may worry if you have normal, but unexpected, thoughts about your baby being harmed. For most women these thoughts are not a problem.

For some, these normal worries can trigger or worsen symptoms of OCD. The symptoms can interfere with life and usually bother you for at least an hour a day, and often much more than that.

## The main symptoms of Perinatal OCD are:

### Obsessions

These are unwanted thoughts, images, urges or doubts. These happen repeatedly and can make you very distressed. Common examples are:

- **Intense fear that something is contaminated by germs or dirt.** You may find yourself worrying that your baby will be harmed due to contamination.
- **Worries about something you did or didn't do.** You may worry that you have left your doors or windows unlocked, or not sterilised your baby's bottle correctly.
- **An image (a picture in your mind), or a thought, of harming someone.** You may worry that you will accidentally or deliberately harm your baby, including sexual and violent thoughts. We know that people with OCD don't become violent or act on these thoughts.
- **Perfectionism.** You may try to get everything exactly "right".

### Anxiety and other emotions

- You may feel anxious, fearful, guilty, disgusted or depressed.
- You feel better (in the short term) if you carry out your compulsive behaviour. This doesn't help for long.

### Compulsions

These are the things you feel you need to do to reduce your anxiety, or to prevent what you fear from happening. They include:

- **Rituals** e.g. washing, cleaning or sterilising repetitively and excessively. This can take up so much time that it stops you doing other things you need to do.
- **Checking** e.g. repeatedly checking your baby throughout the night to ensure he/she is breathing.
- **Seeking reassurance** - repeatedly asking others to tell you that everything is alright.
- **Correcting obsessional thoughts** by counting, praying or saying a special word over and over again. This may feel as though it prevents bad things from happening. It can also be a way of trying to get rid of unpleasant thoughts or pictures in your mind.
- **Avoidance of feared situations or activities** is common, for if you have OCD you will often avoid things that may trigger obsessions or compulsions. If you have perinatal OCD, you may avoid nappy changing, or hide all your knives. You may not attend parent and baby groups. Some women avoid spending time alone with their baby.

**In Perinatal OCD, symptoms are often focussed on the baby. However, obsessions and compulsions can focus on many different things.**

Although mothers with OCD may fear harming their baby, they are not a risk to their babies. **There are no recorded cases of people with OCD acting on their obsessional thoughts.** However, OCD can cause problems if you have to avoid lots of things or, for example, excessively use cleaning products. Suicidal feelings are rare, but other problems such as severe depression can cause difficulties in bonding with your baby.

Perinatal OCD can be mild or severe and can affect a range of experiences and caregiving tasks. It can affect your confidence, your relationship with your partner<sup>2</sup> and your

overall quality of life.<sup>3</sup> You tend to sleep badly, feel tired and feel depressed.<sup>4</sup>

Most women with OCD can care for their baby and other children well, despite their symptoms. For some it can be very disabling and can have a major impact on them and their families. If this happens, you may need a lot of practical help and support.

Perinatal OCD may also stop you from enjoying your pregnancy and being a mother as much as you would otherwise have done. Fortunately, it is very treatable. You should see your GP as soon as possible if you think you have Perinatal OCD and are not already having treatment.

## Recognising Perinatal OCD

A woman with Perinatal OCD will often realise that her symptoms are unreasonable or excessive, although this can be harder to see if you are very anxious. You may worry that your symptoms mean that you are a bad mother, or that you are “going mad”. It can make you feel embarrassed or ashamed. You should try not to worry about this. Perinatal OCD is an illness and can be treated. **It’s not your fault.**

Sometimes Perinatal OCD is not diagnosed – but it is important that your GP or psychiatrist identifies OCD so that they can distinguish it from other disorders. These may include postnatal depression or postpartum psychosis. Once your Perinatal OCD is recognised, you can get the right treatment.

## Emotional changes after birth

Many women experience mild mood changes after having a baby. It is common to feel many different emotions.

Baby blues usually starts three to four days after birth. You may have mood swings. You may burst into tears easily. You can feel irritable, low and anxious at times. You may also over-react to things. It usually stops by the time your baby is about 10 days old. You don’t need treatment for baby blues.



## Other mental health difficulties before and after birth

Women can have many different mental disorders in pregnancy and the postpartum period, just like at other times.

Depression and anxiety are the most common mental health problems in pregnancy. They affect 10 to 15 women in every 100.<sup>5-6</sup> For further information, see our leaflet on 'Mental Health in Pregnancy'.

### Postnatal depression

This affects 10 to 15 in every 100 women after childbirth.<sup>5</sup> The symptoms are similar to those in depression at other times. These include low mood and other symptoms lasting at least two weeks. Women with depression can experience obsessional thoughts.

Perinatal OCD is quite different from depression. Many women have a sense that if the OCD improves, then any depression will also lift. Some women with Perinatal OCD may also have depression which requires treatment in its own right. For further information, see our leaflet on 'Postnatal Depression'.

#### How common is Perinatal OCD?

About one in every 50 people has OCD at some time in their lives<sup>8</sup>. At any one time about one in every 100 people has OCD.<sup>8</sup>

OCD affects ten in 100 women in pregnancy<sup>9</sup> and two to three in every 100 women in the year after giving birth.<sup>9</sup>

### Postpartum Psychosis

This is the most severe type of mental illness that happens after having a baby. It affects one to two women in every 1000<sup>7</sup> and starts within days or weeks of childbirth. It can develop in a few hours and can be life-threatening, so needs urgent treatment.

There are many symptoms that may occur. Your mood may be high or low and there are often rapid mood swings. Women often experience psychotic symptoms. They may believe things that are not true (delusions) or see or hear things that are not there (hallucinations).

The illness always needs medical help and support. You may have to go into hospital. Should you require inpatient treatment for your mental health, you should be offered admission into a specialist perinatal mental health unit with your baby where appropriate.

Although postpartum psychosis is a serious condition, the vast majority of women make a full recovery. For further information, see our leaflet on 'Postpartum Psychosis'.



## Who is most likely to get Perinatal OCD?

Perinatal OCD may be more likely in first time mothers but you can have it during or after any pregnancy. If you have had OCD before, you are more likely to get Perinatal OCD.<sup>10</sup>

There may be many factors which cause you to have Perinatal OCD. Hormones may be a factor for some women. OCD can also run in families. Perinatal OCD has also been reported in fathers.<sup>11</sup>

## What is the outlook?

For about a third of women who already have OCD, pregnancy and childbirth can make this worse.<sup>10</sup> For some women, pregnancy and birth have no impact or can even improve symptoms.

If you have OCD for the first time in pregnancy, it may get better soon after birth. However, it can continue, and keep coming back later in life, if you do not get the right treatment.

If perinatal OCD starts after your baby is born, it can happen very suddenly days or weeks after giving birth. For some women, the onset is more gradual. If you have OCD in your first pregnancy you are more likely to have it again in your second pregnancy.<sup>1</sup>



## Where to get support?

The support and treatment you need depends on how severe your perinatal OCD is. Your GP, midwife and health visitor can help you decide what kind of support you need.

Everyone can try the self-help suggestions below. If this is not enough, you may benefit from a talking therapy or medication (see below). Your GP can advise you about these treatments.

Some women with perinatal OCD will need support from mental health services, preferably specialist mental health teams. These are specialist services for women who are pregnant or in the first postnatal year. Your GP, midwife or health visitor can refer you. This is usually only needed for women with more severe illnesses.

You can access specialist perinatal mental health teams in all areas across Wales. These services can be accessed through your GP, midwife or health visitor. For more information, see our leaflet on Perinatal Mental Health Services.

If you cannot look after yourself or your baby, or if you have thoughts of harming yourself, you should be seen urgently by:

- Your GP
- Midwife
- Health Visitor
- Specialist perinatal mental health service
- Community mental health service
- Your local Accident & Emergency Department

## Self-help

**Tell someone how you feel.** It can be a huge relief to talk to someone who understands. This may be your partner, a relative or friend. If you can't talk to your family and friends, talk to your GP, midwife or health visitor. They will know what support is available in your area.

**Learn about OCD.** Become an expert on the disorder and how it makes you feel. You can learn to recognise the physical and mental symptoms common in OCD. This will help when you are feeling challenged with an OCD fear.

**Self-help workbooks.** You can use these on your

own or with professional guidance to aid your recovery.

**Maintain energy levels and general wellbeing.** Recovery requires a lot of energy. Take every opportunity to get some sleep and rest. Think about what really needs doing now and what can wait. Accept offers of support from family and friends. This will mean you focus on getting better.

**Don't blame yourself.** It's not your fault.

**Don't use alcohol or drugs** to control your anxiety.

### Which treatments are available?

The two main treatments are Cognitive Behavioural Therapy and Medication.<sup>12-16</sup> These can be used alone or in combination.

#### Cognitive Behavioural Therapy (CBT)

This is a talking therapy. CBT helps you examine patterns of thoughts and behaviour that are distressing you. You will usually see a therapist. Sometimes you can attend a full course of sessions over a shorter period.



#### Medication

Antidepressants are used to treat OCD. There are several antidepressants you can try. The ones most commonly used for OCD are called Selective Serotonin Reuptake Inhibitors (SSRIs). Sometimes other medications are added.

## Is medication safe in pregnancy and breastfeeding?

Decisions about whether or not to take medication in pregnancy, or when breastfeeding, are not straightforward. You need to decide what is best in your individual case. It is important to discuss medication with your GP or psychiatrist. They will give you information to help you decide what is best for you and your baby.

If you have OCD and are planning a pregnancy, you should talk to your doctor before you become pregnant. Sometimes, however, pregnancies are unplanned. In that case, you should see your doctor as soon as you know you are pregnant. **It is very important that you don't stop medication.** Stopping treatment suddenly can cause people to relapse quickly. It can also cause side effects.

Many women need to take medication in pregnancy and when breastfeeding. This can be for mental or physical health difficulties.

Your doctor can support you to think carefully about the advantages and disadvantages of medications in pregnancy or when breastfeeding. Some medications have been used in pregnancy for many years. In many cases, we simply do not have enough information to be absolutely sure that a treatment is safe. In order to decide what is right for you, you should think about:

- How unwell have you been in the past?
- How quickly do you become unwell when you stop medication?
- Medications you have taken before:
  - which medication has helped you most?
  - have some medicines caused side-effects?
- Up-to-date information about the safety of medications in pregnancy and breastfeeding. Discuss this with your doctor.
- How easy or difficult is it to access CBT in your area? Discuss with your doctor.
- What might happen if you are unwell during pregnancy or after birth? This may include:
  - Not taking good care of yourself.
  - Not attending antenatal appointments. This means you may not get the care you need.
  - Using more alcohol or drugs. This can be harmful to your unborn baby.
  - Needing a higher dose medication if you become ill. Sometimes you may need two or more medications to treat a relapse. This might be more risky for your unborn baby than if you take a standard dose of medication throughout pregnancy.
  - Needing in-patient treatment.
  - Finding it more difficult to care for your baby.
- If your illness is not treated, this may be more harmful for your baby than the effect of medication.

## Can CBT cause any problems?

CBT has no reported side-effects. However, it is an 'active' treatment involving tasks in, and between, sessions. This helps you to put what is learnt into practice. It does require effort and commitment. It can support with the specific and individual ways that OCD affects life with a small baby.

## Which is best for me - talking therapy or medication?

The best treatment for you will depend on the type and severity of illness you have experienced. Both antidepressants and CBT have been shown to be effective in treating OCD.

After seeing your doctor, you may find it helpful to discuss treatment options with your family and friends. Consider the impact of the treatment on yourself and your family. Think about the side-effects that you may find hard to cope with. Also think about lifestyle changes you may need to make during the treatment.

Consider how long each treatment may take to make a difference to your recovery and how accessible treatment is locally.

Understand that overcoming Perinatal OCD does take dedication and hard work. Any support will really help your recovery.



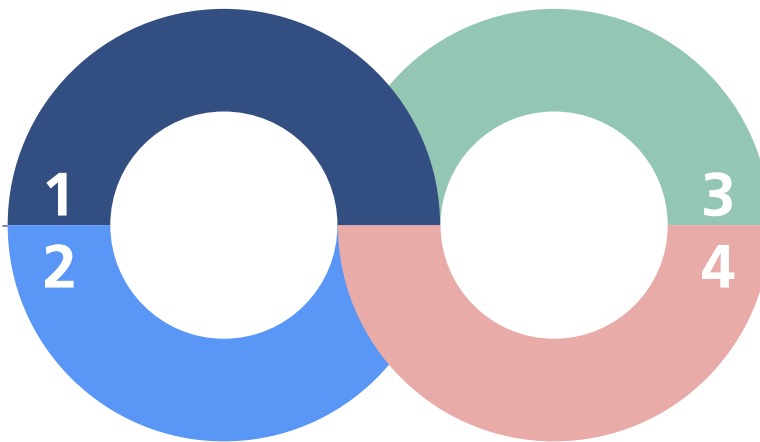
## How partners, family and friends can help

### Understand OCD.

Read about the disorder and learn about the symptoms. A mother suffering from Perinatal OCD may appear to be very rigid. However, she is just trying to get through the day.

### Be supportive.

Sometimes a mother may feel ashamed to admit she is unwell. She may worry about the stigma of having a mental illness. Support her to find more information about perinatal OCD. This will help to normalise the disorder.



### Make time for yourself.

Being around a mother with Perinatal OCD, and a baby or child too, can be exhausting. Ensure you are also looking after yourself. Be reassured: mothers with Perinatal OCD are not at risk of acting on their thoughts.

### Level of involvement.

Families often get involved in the compulsions of OCD. Having a good understanding of what is driving these can really help the mother and partner to limit this. If the mother has therapy, it may be useful to become involved in the homework tasks. Suggest attending one session so you can understand what you can do at home. This may include encouraging exposure to something the mother fears. It may mean saying 'no' to assisting compulsive rituals.

# Further Information and Support

We have extensive resources on our webpage - visit us at [executive.nhs.wales/PNMHSsupport](https://executive.nhs.wales/PNMHSsupport) or scan this QR code.



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## Contact Details

Include details for your midwife or health visitor here.

