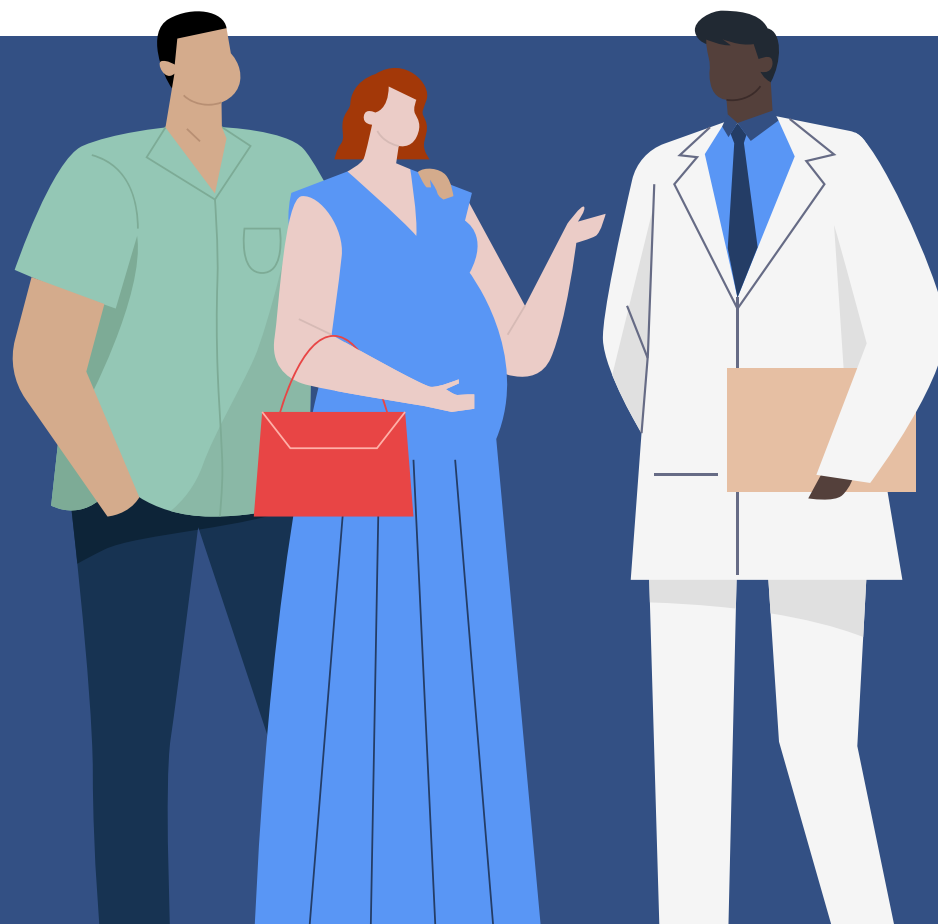




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Perinatal OCD for Carers



Visit our website executive.nhs.wales/PNMHSupport or scan this QR code for more information and resources.



This information is for anyone who would like to know more about Perinatal Obsessive-Compulsive Disorder (OCD) and how they can support their partner, family member or friend.

We hope it will be helpful if:

- You have a partner, family member or friend who has Perinatal OCD
- You are looking for further sources of help, information, and support for your partner, family member or friend, or for yourself as a carer
- You are looking for information about the treatments available.

What is Perinatal OCD?

Obsessive Compulsive Disorder (OCD) is a fairly common mental health difficulty. It can affect women and men at any time of life³.

It is called Perinatal OCD when a woman develops OCD during pregnancy or after having a baby (the perinatal period) and it affects at least two in every 100 women¹.



Acknowledgements

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.

Acknowledgements

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Perinatal OCD has three main parts:

1. Obsessions - frequent unpleasant thoughts, images, urges or doubts
2. Anxiety - distress caused by these unpleasant thoughts
3. Compulsions – behaviours like washing hands or mental acts such as counting, that the person keeps repeating, to try to reduce their anxiety or to prevent bad things from happening.

In Perinatal OCD, symptoms are often (but not always) focussed on the baby. These could be:

Intense fear that the baby will be contaminated with germs, dirt or poison, and will die as a result. Women may go to great lengths to prevent contamination by excessive hand-washing or sterilising, or not using public nappy changing facilities.

Thoughts or images (pictures in their mind) of the baby coming to harm (for example, cot death). They may find themselves repeatedly checking on the baby's breathing during the night.

Thoughts or images of harming the baby, either accidentally or deliberately. Sometimes these thoughts can be sexual or violent. Women often feel deeply distressed and ashamed by these thoughts. We know that those with OCD do not become violent or act on these thoughts, but, as a result, they may start to avoid sharp objects, like kitchen knives, or situations such as nappy changing.

They may worry too much about doing things or not doing things in a particular way, for example, not sterilising the baby's bottles correctly.

They may ask for reassurance again and again from others, for example, about whether something is clean enough.

It is very common for mothers to have occasional unpleasant thoughts about their baby being harmed² and these can be frightening, but for women with Perinatal OCD, these thoughts occur so often and are so upsetting that it becomes difficult to do everyday tasks.

These thoughts can also lead to a woman thinking that she is a bad mother and becoming depressed. This is not only difficult for the woman, it can also be hard for you as the supportive partner, family member or friend to see. For more information see our leaflet on Perinatal OCD.



Treatment

Perinatal OCD is very treatable^{3,7}. Your GP, midwife and health visitor can advise you and your partner, relative or friend about what kind of support to access.

The two main treatments for Perinatal OCD are:

- Cognitive Behavioural Therapy (CBT) - a talking therapy.
- Antidepressant medication – medications can be taken when pregnant or breastfeeding⁴. Your GP or specialist perinatal mental health team can discuss the risks and benefits of medication with you and your partner, relative or friend.

CBT and medication can be used alone or together^{3, 6}.

For more information take a look at our leaflets Mental Health in Pregnancy (this has information about weighing up the risks and benefits of medication in pregnancy and breastfeeding) and Perinatal OCD (this has details of CBT for OCD).

After making a diagnosis, or if the diagnosis is unclear, the GP may refer your partner, relative or friend to another service. This could be:

Psychological (talking) therapies services

These can offer CBT for people with Perinatal OCD. NICE⁵ recommends that women in the perinatal period should be assessed within two weeks and receive therapy within four weeks of assessment.

Specialist Perinatal Mental Health Teams

For more moderate to severe Perinatal OCD, your partner, relative or friend may be referred to a specialist perinatal mental health team. They carry out an assessment and work with her to decide what care, support and treatment may be best for her.

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.



How you can offer support

There are lots of things you can do to support your partner, relative or friend. These include:

Practical support

- **Help out around the house**, for example, cook healthy meals, manage children's bedtimes, share the housework, make sure there are small healthy snacks around
- **Encourage time for rest.** OCD can be mentally exhausting, on top of the demands of looking after a baby
- **Agree in advance when people will visit** and space out visits so they are not too tiring.
- **Support your partner, relative or friend** to understand that she can say 'no' to requests.

Emotional support

- **Everyone needs different types of support at different times.** You will know from experience what helps your partner, relative or friend. For example, some people like affection at times of stress, whereas others prefer to be left alone until they feel calmer
- **Perinatal OCD can make women question their parenting ability.** Offer encouragement and remind her of what she is doing well. Support her to feel that she is doing the best she can
- **When she has OCD-free moments, use these as beacons of hope and praise her.** If she feels worthless, or that she cannot do anything, work with her to support her to feel that she can
- **Give her hope** and remind her that she can recover.

Recovery focused support

- **Notice** when your partner, relative or friend might be avoiding something because of her thoughts - but do not criticise her for not trying
- Instead, **encourage her** to make time each day for her therapy homework
- Find local support groups that she can go to - either by herself or with you
- **Work together** to understand what helps her through an OCD moment, so you can help her control their own recovery
- During therapy, **support her** to challenge her thoughts and beliefs and see OCD thoughts for what they are – bullying and unreasonable
- **Regularly check in** with her to see what is helpful or not
- **Understand what you need to do.** Sometimes this means not reassuring her because we know that this does not help. You may have to support her to not ask for reassurance.

Increase your understanding of OCD

- **Find out as much as you can about OCD** and how treatment works. This can help you to support your partner, relative or friend to make changes. It can also help you to understand her beliefs and behaviour, which can seem quite irrational
- **Encourage her to seek support** – you are not a therapist, and whilst you can support her in recovery, she will need professional support too
- **Understand how OCD can affect her as a mother**, and the process of getting better
- **Remember** - Perinatal OCD and Postnatal Depression/Anxiety are different
- Your partner, relative or friend may seem to be very rigid, stuck in unhelpful ways of thinking and doing things - this is common in OCD and it can feel overwhelming
- **Understanding this will support you both to get through the process of recovery**
- **Having OCD can mean that she finds it difficult to be intimate.** Do not take this personally or as a sign that she does not care about you
- **She will also have normal worries** which are common for all parents – not all worries are caused by OCD!

Communication

- It is important that you **keep listening and talking**
- **It can be very frustrating to see someone you care about in the grip of OCD.** If you feel this, tell your partner, relative or friend that it is the OCD you are frustrated with, not her. Remember that with help and support, she can get through this
- **Try to agree together** to have some conversations that are not about OCD
- **Be aware of body language (yours and hers).** For example, you might start to notice a particular posture or look, such as standing still and staring, as a sign that your partner, relative or friend is experiencing obsessional thoughts. She may misinterpret the way you look at her as meaning that she has not cleaned or checked something properly
- **Some women with Perinatal OCD find it helpful to choose a simple word** that they can say to let you know that they are feeling distressed and need support when they are in a social situation.



Understand common feelings

At times you may feel:

- Frustrated and helpless
- Shocked at, disappointed or angry with your partner, relative or friend
- Scared and/or ashamed about admitting there is a difficulty
- Scared to seek support, maybe because you fear the baby will be taken away
- Worried about the effect the illness might have on the baby
- That the baby is to blame
- Worried about the responsibility of caring for them and/or baby and scared to leave them alone
- Exhausted by your caring responsibilities
- Resentful that your needs have been pushed to one side.

These are all common feelings. It is important that you have somewhere you can talk to about how you feel and get support for yourself.

Look after yourself

It can be stressful and exhausting (for you and others) to look after someone with Perinatal OCD. You need to take good care of yourself. **There are many ways to do this:**

- Get some rest when you can
- Try to get regular exercise, meals and sleep
- Don't be afraid to ask for support - ask friends, family members or your midwife, GP or health visitor for information about support in your local area or check out our resource page below
- Explain to your employer why you may need extra time off
- Share your worries with trusted friends or family members
- Look after your own health - see your doctor if you are feeling exhausted or depressed
- As the OCD improves, try to have some fun - get a baby-sitter or go out together
- Do not feel that you are solely responsible for your partner, relative or friend's recovery - you are an important part of this, but you may also need support from professionals who should support the whole family.

Work in partnership with doctors and other professionals

Good communication between everyone involved is very important. This can take time and effort and there are many questions you may want to ask.

The following checklist includes some suggestions.

Useful questions:

- Is the diagnosis Perinatal OCD?
- Is there any other diagnosis as well, for example depression?
- Is medication being prescribed?
 - Is this safe to use in pregnancy?
 - Can they breastfeed and take the medication?
 - How long might they need to stay on the medication after recovery?
- Is my partner, relative or friend being offered psychological therapies? If so,
 - When will this start?
 - How many sessions will they need?
 - Can you tell me how it works?
- Are there other things we can do to help ourselves?
- What can we expect in the near future and over time?
- How often should we see you and other professionals?
- Will anyone visit us at home?
- Who is our main contact for guidance and advice?
- What else is in my partner, relative or friend's care plan?
- Are there any other organisations or services that can offer support?
- Is there anything we can change at home to make things easier or safer?
- Will the baby be affected?
- Does this mean we should not have another baby?
- Who can we contact and what should we do in an emergency?

If your partner, relative or friend needs another appointment, remember to arrange this before you leave. Regular, well prepared visits will support you all to get the best care for you, her and your baby.

Preparing for follow-up appointments

Before your visit:

- Keep track of changes in your partner, relative or friend's symptoms and the impact these have on daily activities. Try to notice any problems with medication. Keep note of any concerns or questions that may have cropped up since your last visit. It may help to write these down.

- It may be helpful to sit together and decide what concerns you both want to discuss. Writing these down means that you do not have to worry about remembering them. You can be sure to talk about the things that matter most. These might include questions about:
 - changes in symptoms or behaviour
 - your own health
 - side-effects of medications
 - the baby's health
 - general health
 - support needed

During your visit:

- If you do not understand something, ask questions until you do understand. Do not be afraid to speak up.
- Take notes during the visit. At the end, look over your notes and share what you have understood. This gives them a chance to correct any misunderstandings, or to repeat anything that has been missed.

Tips for dealing with healthcare professionals

You may find that healthcare professionals will be cautious about discussing your partner, relative or friend's diagnosis with you. This is because they have a duty of confidentiality towards her.

However, if your partner, relative or friend gives consent there should be no problem with this and healthcare professionals usually appreciate your involvement.

You can often provide useful information as you will notice changes and can report on how your partner, relative or friend is doing. You will also provide important support and practical help.

Even if your partner, relative or friend does not consent to personal information being shared with you, professionals can still discuss the condition more generally and give you information about the kind of treatments and support that are available. The duty of confidentiality means that more personal information and the details of specific treatment may not be shared without consent.

Although many professionals will be happy to see you together, it may be important for your partner, relative or friend to be seen on her own too.

However close you are, she may put on a brave face in front of you and feel more able to discuss her feelings about her illness, her relationship with you, her baby and other family members if alone with the health care professional.

You can ask to come in for part of the appointment and ask for some time to talk to the healthcare professionals on your own if needed. You may also be hesitant to discuss your worries in front of your partner, family member or friend for fear of making her feel worse.

Further Information and Support

We have extensive resources on our webpage - visit us at executive.nhs.wales/PNMHSsupport or scan this QR code.



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Contact Details

Include details for your midwife or health visitor here:

A large, empty white rounded rectangle intended for entering contact details for a midwife or health visitor.

