

# Understanding premenstrual dysphoric disorder (PMDD)

This resource explains what premenstrual dysphoric disorder (PMDD) is and explores issues around getting a diagnosis. It also provides information on self care and treatment options, and how friends and family can help.

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## What is PMDD?

Premenstrual dysphoric disorder (PMDD) is a very severe form of premenstrual syndrome (PMS), which can cause many emotional and physical symptoms every month during the week or two before you start your period. It is sometimes referred to as 'severe PMS'.

While many women may experience mild symptoms of PMS, if you have PMDD these symptoms are much worse and can have a serious impact on your life. Experiencing PMDD can make it difficult to work, socialise and have healthy relationships. In some cases, it can also lead to suicidal thoughts.

"The best way for me to describe it is that – once a month – I decided to press my own 'self-destruct' button and literally let my life (my normally very happy and satisfying life...) implode around me. Then when the dark thoughts lifted and completely cleared, I spent the next 2 weeks trying to pick up the pieces."

# What are the symptoms of PMDD?

If you have PMDD, you might find that you experience some of symptoms listed below. But it's different for different people, so you might also experience other kinds of feelings which aren't listed here.

#### **Emotional experiences:**

- mood swings
- feeling upset or tearful
- feeling angry or irritable
- feelings of <u>anxietu</u>
- feeling hopeless
- · feelings of tension or being on edge
- difficulty concentrating
- feeling overwhelmed
- lack of energy

- less interest in activities you normally enjoy
- suicidal feelings.

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#### Physical and behavioural experiences:

- breast tenderness or swelling
- pain in your muscles and joints
- headaches
- feeling bloated
- changes in your appetite such as overeating or having specific food cravings
- sleep problems
- finding it hard to avoid or resolve conflicts with people around you
- becoming very upset if you feel that others are rejecting you.

You will typically only experience these symptoms for a week or two before your period starts. The symptoms follow your menstrual cycle, so you might find they start to get better when you get your period and will usually have disappeared by the time your period is finished.

"In the depths of my PMDD I tend to just retreat to my bed – I get very depressed and my anxiety goes sky high. I get hugely fatigued and can't keep my eyes open – I sleep for about 18 hours a day."

#### PMDD and suicidal feelings

Some women find that one of their monthly symptoms is thoughts about suicide. This can feel very distressing. If you're experiencing suicidal feelings and are worried you may act on them, you can call 999, go straight to A&E or call the Samaritans for free on 116 123 to talk. (See our pages on <a href="https://doi.org/10.1001/journal.org/">how to cope with suicidal feelings</a> for more information.)

#### What are the causes of PMDD?

The exact causes are still not fully understood but some possible factors are:

- Being very sensitive to changes in hormone levels. Recent research suggests that PMDD is associated with increased sensitivity to the normal hormonal changes that occur during your monthly menstrual cycle.
- **Genetics**. Some research suggests that this increased sensitivity to changes in hormone levels may be caused by genetic variations.

Some other research has shown that in some cases PMDD may be linked to stressful and traumatic past events (such as emotional or physical abuse), but there's no evidence to explain how or why.

"It very much got worse as I went into my 30s and by my mid-30s I was losing 3 days going downhill, a week in a depression feeling like I was going through a bereavement, and then a few days to recover and feeling like I've been chewed up and spat out. It's exhausting to know that once it passes you have to brace yourself for it all to happen all over again in a couple of weeks' time."

## Is PMDD a mental health problem?

PMDD is commonly defined as an endocrine disorder, meaning that it is a hormone-related disorder. But as well as physical symptoms, people with PMDD also experience a range of different mental health symptoms such as depression and suicidal feelings. For

these reasons, it has recently been listed as a mental health problem in the DSM-5 (one of the main manuals that doctors use to categorise and diagnose mental health problems).

Ultimately, how you understand your symptoms and experiences is up to you. The most important thing is that you get the support you need and deserve to help you manage the effects that they have on your life.

# How is PMDD diagnosed?

To get a diagnosis of PMDD the best place to start is by visiting your doctor. To help them understand your symptoms your doctor may:

- Ask you to keep a detailed record of your symptoms for several months. This may
  be in your diary or they may give you some daily questionnaires to complete. You
  will need to do this for at least two months to see if your symptoms show a
  pattern over time.
- Ask you about your medical history.
- Give you a physical examination along with some blood tests (this is to rule out other medical problems).

When you're asked to keep a record of your symptoms over several months, getting a diagnosis can feel like a very slow process. This can be frustrating if you're having to wait a long time to access treatment. (Our page on <u>self care for PMDD</u> has some ideas you can try in the meantime).

## What if I am struggling to get a diagnosis?

Some people find getting a diagnosis of PMDD can be really difficult. This might be because it can take a long time to realise that your symptoms follow a cycle and that they are linked to your period. It can also be because PMDD is not very well known, even amongst health professionals. It can be really upsetting and frustrating if you feel like your doctor is overlooking something, or not taking you seriously — but there are things you could try:

- Keep your own detailed record of your symptoms over time. You could do this in a
  diary or you can download mood charts from the internet. The more information
  you collect over a long period of time, the better prepared you'll be to explain your
  symptoms to you doctor.
- Take the PMDD treatment guidelines with you to your GP appointment. The <u>National Institute for Health and Care Excellence (NICE)</u> and the <u>National Association for Premenstrual Syndrome (NAPS)</u> both provide detailed, step-by-step guidelines on the diagnosis and treatment of PMS (including severe PMS, which is another term for PMDD). You can download these from their websites.
- Ask at your GP surgery if you could speak to a doctor who specialises in mental health or gynaecology (the branch of medicine that deals specifically with women's reproductive health).
- Consider finding an advocate. An advocate is someone who can come to
  appointments with you and help make sure people listen to you (see our pages on
  advocacy for more information).

"When the suicidal feelings became unbearable, I realised I had to take action. I decided I had to explain it properly to the doctor as my life depended on it, so I brought my mum with me and told the whole story. I got referred to a gynaecologist and now I am under hormonal treatment, my symptoms are much better."

#### Misdiagnosis with other mental health problems

Sometimes people with PMDD can be wrongly diagnosed with other mental health problems such as <u>depression</u> or <u>bipolar disorder</u>. This is because they share some of the same symptoms. Also, if you have any other physical or mental health problems, experiencing PMDD at the same time can make the symptoms worse. For these reasons, it is really important to keep a clear and detailed record of how you're feeling over time, because with PMDD your symptoms will follow a regular monthly pattern.

If you're worried that a diagnosis you've been given doesn't fit your experiences, it's important to discuss it with your doctor so you can make sure you're getting the right treatment to help you.

<u>See our pages on seeking help</u> for more information on getting the most from your doctor and making your voice heard. Remember that if you feel you've been treated unfairly by a healthcare professional, you can complain.

"I saw five different (male) GPs at my medical practice before they accepted my suggestion that my problems were connected to my cycle and I eventually came away with a factsheet about 'PMS' in my hand... It wasn't until [recently] that I actually sat in front of a doctor who didn't look at me as if I was mad when I said that my menstrual cycle was driving me insane."

# How can I help myself?

There are various things you can try to reduce the impact PMDD has on your life. This section covers:

- Talk to someone you trust
- Contact a specialist organisation
- Try peer support
- Get to know your cycle
- Look after your emotional wellbeing
- Look after your physical health

Some people find these ideas useful, but remember that different things work for different people at different times. Only try what you feel comfortable with, and try not to put too much pressure on yourself. If something isn't working for you (or doesn't feel possible just now), you can try something else, or come back to it another time.

## Talk to someone you trust

It may be that just having someone listen to you and show you they care can help in itself.

- Stay in touch. If you don't feel up to seeing people in person, or talking, send a text or email to keep in touch with friends and family.
- **Keep talking**. It might feel hard at first, but many people find that sharing their experiences can help them feel better.

Unfortunately, some people feel uncomfortable discussing anything to do with women's reproductive health, as it's often considered to be something quite private, or even taboo – despite being a normal part of many people's everyday life. You may even feel this way yourself. This can make it even more difficult for you to open up about physical and

mental health problems related to your periods. But finding the words to tell others about what's going on is usually the first step you can take towards getting help and feeling better.

"Deep down I knew it was my period causing the depression, but I felt silly for admitting it. I felt like I was pathetic for being unable to deal with something that most other women have no issue with, and I didn't want to talk about it with my female friends as they just didn't get it."

## Contact a specialist organisation

You might find it useful to contact an organisation that specialises in support and advice for PMDD. Whilst there is no a specific organisation for PMDD support in the UK, you may find it useful to visit the <u>Gia Allemand Foundation website</u> (an American organisation). The <u>National Association for Premenstrual Syndrome</u> may also be useful. These organisations may be able to direct you to more sources of support.

## Try peer support

Peer support brings together people who have had similar experiences, which some people find very helpful.

- The Gia Allemand Foundation provides more information about online peer support
  available for women with PMDD around the world, including links to various online
  groups you could join if you choose to have a Facebook account.
- Mind's <u>Elefriends</u> community is a supportive online space which welcomes people with experience of all kinds of mental health problems.

See our pages on <u>peer support</u> for more information about what it involves, and how to find a peer support group to suit you. If you feel unsure about the idea of talking to people over the internet, you might find it useful to read our pages on <u>how to stay safe online</u>.

"I have suffered with PMDD for 20 years but only been diagnosed for 18 months. It can be a very lonely experience and support via peer support groups has been invaluable for me, not only just to know that I wasn't the only one going through it but to learn information about treatments."

## Get to know your cycle

If your symptoms follow a pattern, you may be able to work out when you are most likely to start to experience these symptoms in the future. For example, if you notice that over the past three months your symptoms have started seven days before your period, you could try and work out when this would be for the upcoming months. Being able to predict when your symptoms may start may help you to put things in place for that time.

For example you could:

- re-arrange stressful events and tasks for another time
- plan relaxing activities that you know improve your mood
- put in place a support plan that sets out how you would like to be supported in a particular situation.
- create a self-care box.

"I know my PMDD cycle like the back of my hand now and plan my days/ weeks/ month accordingly. On the days I know I'll be bad I never plan anything important. I try and be

positive about these days. I record TV programmes and films throughout the month and watch them in bed on these days. I save books and magazines to read and I have meditation apps for these days. I make sure I have the right foods in the house and also have meals that need just popping in the microwave."

#### Creating a self-care box (sometimes called a 'happy box')

Some people find it helpful to fill a box with things that normally cheer you up and help you to relax. You could include your favourite book or film, a notebook and pen to write down your thoughts or notes of encouragement to yourself. This can be a useful tool as it can be very difficult to come up with ideas to help you when you're feeling low.

## Look after your emotional wellbeing

- Manage stress. It can help to think of ways to manage pressure and build your
  emotional resilience (see our pages on how to manage stress for more
  information).
- Try some relaxation techniques. Learning to relax can help you look after your
  wellbeing when you are feeling stressed, anxious or busy (see our pages
  on relaxation for tips you could try).
- **Spend time in nature.** Being outside in green space can help you feel more in touch with your surroundings (see our pages on <u>ecotherapy</u> for more information)
- **Try mindfulness.** Practising mindfulness could help you manage unwanted thoughts and reduce stress (see our pages on <u>mindfulness</u> for more information).

"I made a decision that I was going to accept I have PMDD and make positive lifestyle changes to try and live as happily and stress-free as I could. It took a few years and was not an easy process... [Now] I work part-time nannying, but on my terms. A complete turnaround from my previous jobs. If I focused on the negative of these choices I might say it's not the life I had planned for myself, but I try not to dwell on this."

## Look after your physical health

- Try to get enough sleep. Sleep can give you the energy to cope with difficult feelings and experiences. (See our pages on <u>coping with sleep problems</u> for more information).
- Think about your diet. Eating regularly and keeping your blood sugar stable can make a difference to your mood and energy levels. (See our pages on food and mood for more information).
- Try and take some exercise. If you are experiencing physical symptoms you may
  find it difficult to exercise, but research has shown that exercise can help reduce
  symptoms of depression. You may also find that it might help you to relax. (See
  our pages on physical activity and exercise for more information).

"My diet has changed loads too. I gave up red meat and try to eat no sugar [and drink] hardly any alcohol. I exercise when I can and find meditation and yoga really helpful."

## What are the treatments?

There are a number of different treatments that have been found to work for some people. This section covers:

Talking treatments

- Antidepressants
- Painkillers or anti-inflammatory drugs
- Combined oral contraceptives
- GnRH analogue injections
- Surgery

"It took me two years to realise that my symptoms were cyclical – my best friend made the connection. It's then taken me another three years to get to a treatment that works. Looking back it seems like such a long haul, and I'm glad I'm this end of it for now."

#### Making healthy lifestyle changes

When you first talk to your doctor, they may suggest some lifestyle changes which could improve your physical and mental health generally. This may reduce your PMDD symptoms to a manageable level without the need for further treatment, or it may be something you try alongside another treatment.

Possible suggestions they might make are:

- · getting more regular exercise
- changes in your diet
- getting regular sleep
- trying to reduce your stress levels
- reducing the amount of alcohol you drink
- if you smoke, trying to cut down or stop entirely
- reducing the amount of caffeine you have in your diet.

This will be different for everyone, as the changes you feel able to make will depend on your personal circumstances and experiences.

## Talking treatments

To help manage the psychological symptoms you experience you may want to consider seeing a therapist for talking treatment. Your doctor may refer you to Improving Access to Psychological Therapies (IAPT). This is an NHS programme which can provide talking treatments for various mental health problems, such as <u>anxiety</u> and <u>depression</u>.

However, IAPT is not available in all areas and the waiting lists can be long. You can find out whether IAPT services are available near you through the <u>IAPT website</u>. In some cases you might be able to self-refer to a service.

(See our pages on <u>talking treatments</u> for more information about different kinds of therapu, including how to find a therapist.)

## Antidepressants

You may be offered antidepressants to help treat feelings of <u>depression</u>. In this case your doctor will likely offer you a three month trial, and then see how you are doing. Your doctor may suggest you to take them just on the run up to your period, or continuously throughout the month.

Research has shown that some SSRI (selective serotonin reuptake inhibitor) antidepressants can be effective at reducing PMS and PMDD symptoms, but they can

also cause a range of side effects, so they may not be right for everyone. (See our pages on <u>antidepressants</u> for more information).

## Painkillers or anti-inflammatory drugs

Your doctor may suggest you take painkillers or anti-inflammatory drugs (for example ibuprofen) to help you manage the physical symptoms of PMDD such as headaches, joint and muscle pains.

Although you may be able to get these without a prescription from your doctor, it's a good idea to discuss it with your doctor or pharmacist first to make sure that they're suitable for you.

## Combined oral contraceptives

Oral contraceptives (often just called 'the pill') may reduce the symptoms of PMDD by controlling or stopping your periods, but the evidence for the pill as a treatment for PMDD is mixed. Some people do find it helps to reduce their symptoms, but others find it makes their symptoms worse. The pill can also cause side effects.

If you and your doctor do think this medication might help, it is likely that you will be given a three month trial to see if the treatment is right for you. You can find more information about combined oral contraceptives on the <a href="NHS Choices website">NHS Choices website</a>.

#### Can vitamins and supplements help?

There is some evidence that certain supplements may reduce premenstrual symptoms. Some examples are:

- Calcium carbonate some research indicates that this may help to reduce the physical and psychological symptoms.
- Vitamin B6 this may help to relieve symptoms, but if you take too much it may lead to a condition called peripheral neuropathy which is a condition where you lose feeling in your arms and leas.
- **Agnus castus** (a herb known as chasteberry) some research has shown that this may help reduce symptoms of irritability, anger, headaches and breast pain.

However, these are not officially recommended as treatments as there is not enough strong evidence that they can treat PMDD specifically. If you are considering taking a supplement it's important to speak to your doctor or local pharmacist first, as **taking them alongside other medications or in the wrong dose could be dangerous**.

Before deciding to take any drug, it's important to make sure you have all the facts you need to **make an informed choice**. See our pages on <u>things to consider before taking</u> medication and your right to refuse medication for more information.

## GnRH analogue injections

Gonadotropin releasing hormone (GnRH) analogues can be helpful for some people, as they reduce the symptoms of PMDD by bringing on a temporary menopause. They typically come as injections or a nasal spray. However, they can cause side effects such as loss of bone density, which puts you at higher risk of developing osteoporosis (a condition in which your bones become weak and break more easily).

Because of this, treatment is sometimes limited to six months, and should be combined with hormone replacement therapy (HRT), which relieves symptoms of the menopause and reduces bone density loss. If you're prescribed GnRH analogues as a long-term treatment your doctor should give you an annual check-up to measure your bone mineral density.

"[My symptoms] took almost three months to settle down [after starting hormonal treatment] but now I am able to go to work every day and only have 1-2 bad days a month, which is much more manageable."

## Surgery

In very severe cases your doctor may talk to you about the possibility of a hysterectomy (an operation to remove your uterus) or a bilateral oophorectomy (an operation to remove your uterus, ovaries and fallopian tubes). All surgery carries a risk of complications — and the surgery is non-reversible — so this would only be something you and your doctor would consider when you've already tried every other possible treatment and nothing has worked.

# How can other people help?

This section is for friends and family who want to support someone they know with PMDD.

If you are supporting a friend or relative who is experiencing PMDD it can sometimes be hard to know what you can do to help. This page lists some things you could try.

## Take it seriously

Some women with PMDD find it hard to explain what they're going through, and it's particularly difficult when others dismiss their experiences as "just that time of the month" or "just something all women experience". These misconceptions are not true, but it can make it very hard for women to open up about how they're feeling. It is important to understand that PMDD can have a large effect on someone's life. The symptoms are very real, and can be very difficult to cope with.

"I still can't bring myself to tell a lot of friends and colleagues what has gone on, due to the pervading attitude of 'women's problems / it's just your period'."

## Try to understand

- Find out as much as you can about PMDD. This will help you understand what they
  are going through. Reading about people's personal experiences in blogs can help
  too.
- Ask them about their personal experience of living with PMDD. You could ask them
  how PMDD affects their life and what things can make it better or worse. Listening
  to their experience might help you to understand how they feel.

"My relationships with friends and family have suffered too. I have a terrible relationship with my sister because she just refuses to understand or acknowledge my PMDD. I'm fortunate my parents are as understanding as they can be, but for a non-PMDD sufferer PMDD is really difficult to understand."

## Ask them what helps

PMDD can affect people in different ways, so it's important to ask what things they would find most helpful. They may just want your emotional support or there may be specific practical things you could do that could help them cope. For example, they may find it helps if you offer to take some of the pressure off them by helping out with daily tasks such as household chores or food shopping.

## Be patient

Even with support, someone with PMDD may be irritable at times and act differently than they normally do. It can be hard to support someone if they do not appear to appreciate the help you are trying to offer. It's not easy, but you may find that you need to be a bit more patient than usual. Remember that this won't last forever and their symptoms should get better within a few days.

When they experience their symptoms, they might say or do things that upset you. If this happens, it can be helpful to try to wait until after the symptoms have passed before bringing it up so that they may feel more able to cope with talking about it.

#### Reassure them

When they experience symptoms, you can try to reassure them that the symptoms will soon pass, that you are there to support them and that they are not on their own. Often just knowing that there is someone around who understands helps a lot.

Some people with PMDD experience <u>suicidal feelings</u>. This can be difficult to cope with, for both of you. See our pages on <u>supporting someone with suicidal feelings</u> for information about how you can help in this situation.

"My partner is very supportive and that helps so much and really does mean the world to me. He makes my world feel very safe when I feel very lost."

# Plan around their monthly cycle

Many people only experience symptoms for one to two weeks of every month. If you can predict when the symptoms are likely to start, you may want to plan things in advance that might help. For example, you could schedule time to help out with daily chores, plan activities that may help them to <a href="relax">relax</a> or just make sure that people will be around to offer their support. It might also help to avoid planning any activities during that time that they might find difficult.

## Support them to seek help

Supporting your friend or loved one to seek help can be really important. It can help to remind them that PMDD is a recognised condition like many others, and that they deserve treatment and support. You can read our information on <u>treatment options</u> and <u>self-care</u>, and encourage them to seek help from their GP (see our pages on <u>how to support</u> someone else to seek help for more information).

Not all healthcare professionals are aware of PMDD or fully understand it, so women can sometimes face barriers to getting the treatment and support they deserve. Knowing that you're in their corner to support them could help them keep trying if they do face barriers. You could even consider becoming their advocate (see our pages on advocacy for more information).

## Look after yourself

It can sometimes be really challenging to support someone, and it's common to feel overwhelmed at times. It's important to remember to look after your own mental health too, so you have the energy, time and distance you need to be able to help your friend or family member.

#### For example:

- Set boundaries and don't take too much on. If you become unwell yourself you won't be able to offer as much support. It is also important to decide what your limits are and how much you are able to help them. (See our pages on how to manage stress for more information.)
- Share your caring role with others, if you can. It's often easier to support someone if you're not doing it alone.
- Talk to others about how you're feeling. You may want to be careful about how much information you share about the person you're supporting, but talking about your own feelings with someone you trust can help you feel supported too.

See our pages on <u>how to cope when supporting someone else</u> for more suggestions on what you can do, and where you can go for support.

## Useful contacts

#### Mind's services

- Helplines all our helplines provide information and support by phone and email.
   Our Blue Light Infoline is just for emergency service staff, volunteers and their families.
  - Mind's Infoline 0300 123 3393, info@mind
  - Mind's Legal Line 0300 466 6463, legal@mind
  - o Blue Light Infoline 0300 303 5999, bluelightinfo@mind
- Local Minds there are over 140 local Minds across England and Wales which provide services such as <u>talking treatments</u>, <u>peer support</u>, and <u>advocacy</u>. <u>Find your local Mind here</u>, and contact them directly to see how they can help.
- **Elefriends** is a supportive online community for anyone experiencing a mental health problem. See our **Elefriends** page for details.

## British Association for Counselling and Psychotherapy (BACP)

01455 883 300

bacp.co.uk

Information about counselling and therapy. See sister website <u>itsgoodtotalk.org.uk</u> for details of local practitioners.

#### Gia Allemand Foundation

giaallemandfoundation.org

An American not-for-profit organisation which provides information about PMDD and online peer support.

#### IAPT (Improved Access to Psychological Therapies)

iapt.nhs.uk/services

Information about your local NHS services.

#### National Association for Premenstrual Syndrome (NAPS)

#### pms.org.uk

Support and information for women with PMS. Although their focus is PMS, they produce treatment guidelines and information on getting the best from your doctor which may also be useful for people with PMDD.

#### **NHS Choices**

nhs.uk

Provides information on PMS and details of treatments.

#### **Samaritans**

samaritans.org
116 123 (freephone)
jo@samaritans.org
Freepost RSRB-KKBY-CYJK
PO Box 90 90
Stirling FK8 2SA
24-hour emotional support for anyone struggling to cope.

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