



Young onset dementia: menopause and perimenopause



It is estimated that over 70,000 people in the UK are living with young onset dementia, where symptoms begin before the age of 65. For some women, dementia symptoms develop at the same time as perimenopause or menopause, which can bring additional challenges.

What are perimenopause and menopause?

Perimenopause is the time leading up to menopause where hormone levels begin to fluctuate and then drop. A woman will still have periods – although they may be different from usual – and many have physical and mental symptoms caused by their changing hormone levels.

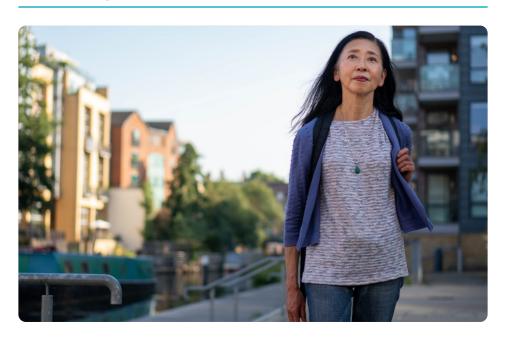
Menopause occurs when a woman has her last period. If you have not had a period for 12 consecutive months, you are post-menopause.

Menopause can happen naturally or be brought on by medical conditions such as premature ovarian insufficiency (POI), where the ovaries stop making normal levels of hormones. It can also be triggered by medication or medical treatments – for example, some cancer treatments – or by surgery, for example if the ovaries are removed.

While this leaflet refers to women, we recognise that some people who experience menopause do not identify as female. At Dementia UK we support everyone living with dementia, and the information in this leaflet applies to people of all sexual and gender identities who are affected by menopause and dementia.

When do perimenopause and menopause happen?

The average age for menopause is 51, but it can happen earlier or later. Perimenopause can begin months or even years before menopause. Women often start to notice perimenopausal



symptoms in their early 40s, or sometimes younger – there is no such thing as 'too young'.

Post-menopause describes the rest of a woman's life after menopause. They may have some symptoms for a few more years – generally they settle down, but occasionally, they can continue for decades if not treated.

Common symptoms of perimenopause and menopause

The ovaries produce hormones called oestrogen, progesterone and testosterone. They affect every system in the body, so when the ovaries start to slow down and produce fewer hormones (typically as women get older), the symptoms can be widespread.

Around 90% of women experience menopausal symptoms. They may be mild, but a quarter of women with symptoms find they are so severe that they affect their everyday lives. Common symptoms include:

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- changes in periods, including the frequency, pattern or flow
- hot flushes and/or night sweats
- fatigue and poor sleep
- mood changes, anxiety or stress
- 'brain fog' or poor concentration
- loss of interest in sex
- joint pains and/or muscle aches
- migraines and headaches
- hair loss
- dry skin
- genital symptoms, including vaginal dryness and soreness
- needing to pass urine more often, leaking urine and/or urinary tract infections (UTIs)

Brain fog is a very common symptom of menopause, and women often say that their brain feels like 'cotton wool'. This can affect every aspect of daily life at home and work. Women may find it difficult to recall words or multi-task, and they may lose or forget things. Some take time off work due to their symptoms; others reduce their hours or even resign because of the impact on their work.

It is important that women are supported in the workplace when they are going through perimenopause/menopause. Although it can be difficult, they should talk to their manager before making any decisions that will affect their career. If possible, they should ask for a referral to the Occupational Health Team for advice and support with managing their day-to-day work.



Intimate symptoms of perimenopause and menopause, such as vaginal dryness and incontinence, can also have a big impact on wellbeing. It is estimated that around 80% of post-menopausal women experience these changes but few seek help – often because of embarrassment. However, there are very effective treatments for these symptoms – for more information, please visit The Menopause Charity website (see Sources of support on p19).

How to tell if a woman is entering perimenopause

A change in menstrual cycle is a common sign of perimenopause. Periods may become more or less frequent, be longer or shorter than usual, or become heavier or lighter, but they will be different from what the woman considers 'normal'.

Other symptoms tend to start gradually and subtly. Often, women notice psychological issues like anxiety, feeling overwhelmed or a loss of confidence. These symptoms may be put down to other stresses in life, so it may take time for women to realise what is happening – often when they also develop physical symptoms.

Women over 45 do not need tests to diagnose perimenopause. Blood tests can be unreliable as hormone levels can fluctuate greatly even within a single day, so a change in periods along with one or more other symptoms is enough evidence that a woman is perimenopausal. However, if a woman is under 45, her healthcare professional may want to run some tests to rule out other conditions.

It can be helpful to track your periods and menopause symptoms over time to see if there are any patterns. You could use a The Menopause Charity's symptom questionnaire:

• themenopausecharity.org/2021/10/21/menopausesymptoms-questionnaire

Is it perimenopause, menopause or young onset dementia?

The psychological symptoms of perimenopause/menopause and dementia – such as negative thoughts, low mood and anxiety – often overlap, which can make it hard to tell them apart. Many women have difficulties with:

- low mood/anxiety
- negative thoughts
- concentration
- word-finding
- memory
- multi-tasking



- mood and emotions
- overall wellbeing

Because it can be difficult to tell whether these symptoms are being caused by perimenopause/menopause, young onset dementia or both, some women become concerned that they are showing signs of dementia – particularly if they have a family history of the condition. It is also thought that a lack of oestrogen during and after perimenopause/menopause may increase the risk of developing dementia.

However, while people with dementia do experience brain fog and memory problems, these are not usually the first symptoms to develop in younger people. There are more likely to be changes in vision and spatial awareness, language problems and changes in behaviour. Family members, friends and work colleagues may notice these changes first, often before the person themselves.

If you are concerned that you may have dementia, it is important to see your GP. There are many other conditions that can cause similar symptoms, and these should be investigated and ruled out or treated where appropriate. It is helpful to fill in a symptom questionnaire and keep a record of your periods over the course of a few months, which you can show your GP.

Your doctor should discuss the stages and symptoms of menopause, the lifestyle changes that could help, the benefits and risks of treatment and how menopause may affect your future health. They may also suggest blood tests to rule out any other causes of your symptoms, such as an infection.

If there are still concerns that you might have young onset dementia, the GP may refer you to a memory clinic for further assessment.

Perimenopausal symptoms and young onset dementia

If you have been diagnosed with dementia, it can be particularly difficult to work out whether any changes you are experiencing are due to your dementia or to perimenopause/menopause — or both. The cognitive, psychological and emotional changes associated with menopause may also have a greater impact on women with dementia.

If there have been changes to your menstrual cycle and you have at least one other symptom as outlined in this leaflet, you may be going through perimenopause/menopause. If you feel you need help with these symptoms, make an appointment with your GP.

Improving the symptoms of perimenopause/menopause

There are a number of things that can help to manage or improve some of the symptoms of perimenopause/menopause. These may also have a positive impact on brain health.



Sleep It is important to try to sleep well as this will help physical and mental health and emotional wellbeing. A lack of sleep could also make your memory and concentration worse.

Stress Anyone can experience stress, but if a person has dementia, they may find that this feeling is heightened with perimenopause/ menopause. While it may not be possible to avoid stress completely, relaxation techniques, meditation or mindfulness may help.

Movement and exercise Physical activity releases a hormone called dopamine in the brain which can help with attention, stress and anxiety, and may improve memory and thinking skills. Aim to be active for 30 minutes a day, five days a week, at a pace that increases your heart rate.

Nutrition A healthy diet with a wide variety of fruit and vegetables is important for brain health. Certain vitamins and minerals, including

vitamin D, magnesium and iron, are also particularly important during perimenopause and menopause. The NHS Eatwell guide is a useful model to follow – see Sources of support on p19.

Smoking and alcohol Aim to stop smoking if applicable and keep alcohol to a minimum as these may make symptoms worse including disrupting sleep and affecting mental wellbeing. Please see Sources of support on p19 for more information.

Making decisions about treatments

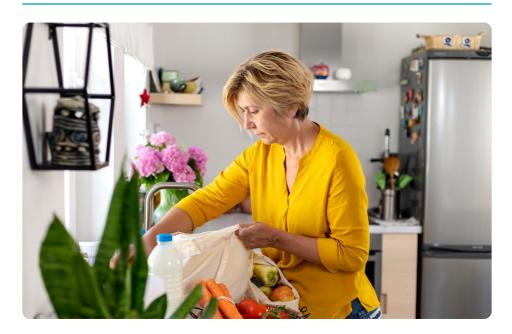
If you are experiencing perimenopausal symptoms, there are various treatment options that may be available to you. Before your GP appointment, spend some time thinking about the symptoms you are experiencing, what treatments are available, and what outcomes you would like to achieve.

Dementia can affect your ability to remember, recall or make decisions. If you have a diagnosis of dementia, your doctor may discuss your mental capacity and your ability to make an informed decision and give consent before deciding on a plan of action to help you manage the symptoms of perimenopause, particularly around medication.

Your GP should support you to come to your own decision about your treatment plan, as long as you can show that you understand the relevant information and the pros and cons of any particular treatment. If you do not agree with the GP's recommendations, you may wish to ask another healthcare professional (who could be a GP in the same practice) for a second opinion.

Hormone replacement therapy (HRT)

The most common and effective treatment for the symptoms of perimenopause/menopause is hormone replacement therapy (HRT), which can be prescribed by a GP. HRT may ease some of the



symptoms that result from falling hormone levels. There are also benefits to future health, including a reduced risk of:

- heart disease
- osteoporosis
- type 2 diabetes
- clinical depression

There are different types and doses of HRT, and different ways of taking it.

Oestrogen This is the main hormone in HRT. The best way to take it is through your skin (transdermal) via a patch, gel or spray. It also comes in tablet form, but transdermal forms are considered safer and evidence shows no risk of blood clots.

Progesterone Women who have a womb will need to take a form of

progesterone to keep the womb lining thin and healthy. The safest type of progesterone is 'micronised progesterone'. This may be prescribed in capsule form (for example, under the brand name Utrogestan), or as a 'progesterone based intrauterine coil', such as the Mirena coil brand – this is a small plastic T-shaped device that is inserted into the womb and is often used for contraception and to reduce heavy menstrual bleeding.

Testosterone The hormone testosterone also declines sharply around the time of menopause. Evidence shows that taking testosterone alongside oestrogen and progesterone may help improve energy levels and libido. Some women report improved bone and muscle strength, brain fog and sleep, although the trial evidence does not support this.

There is currently no licensed testosterone for women available in the UK, which can make it difficult to access. You may want to seek advice from a menopause specialist; you can find a specialist on the British Menopause Society website at **1** thebms.org.uk/find-amenopause-specialist

Vaginal oestrogen Vaginal oestrogen medication may improve symptoms like vaginal dryness and soreness, frequent urination, urine leakage and infections like thrush and UTIs. It comes as a pessary, tablet, cream, gel or ring that is inserted into the vagina. It is very safe and can be taken long-term and alongside HRT, so there is no need to suffer in silence with these symptoms.

Risks of HRT

For the vast majority of women, the benefits of HRT far outweigh any risks, and perimenopausal or menopausal symptoms will usually improve after several months.

Some women worry about the risk of breast cancer when taking HRT,



but most modern types of HRT do not increase the risk if taken for up to five years. It is important to continue to self-examine your breasts and attend any breast screening appointments that you are offered.

The only exception is a very slightly increased risk in women who are over 51 and taking HRT containing both oestrogen and the older, synthetic types of progestogen. It is advisable to discuss the type of HRT you take and the individual risks and benefits with your GP.

If you take oestrogen in tablet form, some preparations can very slightly increase the risk of developing a blood clot or having a stroke, especially if you smoke, are very overweight, or have had a clots or stroke in the past. But there is no increased risk of clots for women using an oestrogen patch, gel or spray.

You should discuss any possible risks of HRT with your GP or visit The Menopause Charity website for more information – see Sources of support on p19.

HRT should not interfere with medications for dementia, such as donepezil, rivastigmine, galantamine or memantine, but it is advisable to discuss any treatments you are currently taking with your GP, psychiatrist or neurologist.

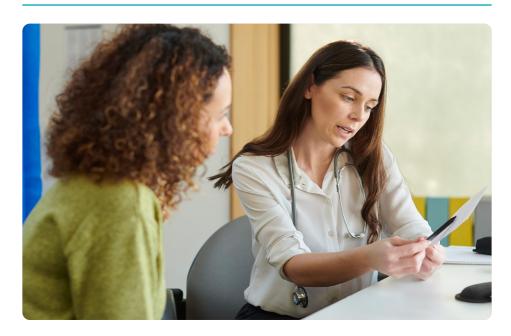
Other treatments

Although HRT is an effective treatment for perimenopausal/ menopausal symptoms, it may not be the right choice for everyone. There are lots of other things that may help manage symptoms, whether or not you choose to take HRT. These include:

- cognitive behavioural therapy (CBT): a talking therapy which can help to reduce some mental health symptoms, including depression and anxiety
- regular exercise
- prescription medicines such as antidepressants: these may help with hot flushes and night sweats, but are not usually effective in helping with mood-related changes caused by fluctuating hormone levels
- herbal medicines: these can be bought over the counter in pharmacies and health food shops. Many claim to ease menopausal symptoms but scientific evidence is mixed on how effective they are. They may also have side effects or interfere with other medicines you might be taking, so it is important to speak to your GP or another healthcare professional before using these remedies
- massage, acupuncture or aromatherapy

Supporting a person with young onset dementia to see their GP

These tips will help you support a family member or friend who lives with young onset dementia if they wish to see their GP about symptoms of perimenopause/menopause.



- If possible, help the person keep a record of their periods, if they are still having them
- Keep a record of any menopause symptoms you notice and any that the person with dementia tells you about
- Do some research about menopause symptoms, future health risks, and the pros and cons of different treatments
- At the appointment, explain the changes you and/or the person with dementia have noticed and why you think they may be due to hormonal changes
- Think about what form of treatment would suit the person best, especially if they may need support to manage the treatment successfully
- Be aware that some healthcare professionals are not fully aware of the variety of menopause symptoms – they might put changes

down to the person's dementia or another issue like depression or an infection

 Be patient but persistent – it may take several appointments to come up with a treatment plan, and you may need to see a different doctor or menopause specialist

If you have lasting power of attorney (LPA) for health and welfare for the person with dementia, which allows you to make decisions on their behalf if they lack the mental capacity to do so themselves, ensure their GP knows about this. If the person is not able to make a clear decision about treatment, you can discuss what would be in their best interests with their GP. Please see Sources of support on p18 for information about LPA and capacity and decision-making.

Managing changes in periods

During perimenopause, most women notice a change in their periods. Generally, periods will become less frequent, but for some women they can become more frequent, lighter or heavier.

If you are supporting a woman with young onset dementia, be aware that their changing menstrual cycle may cause them to experience stomach cramps, pains and mood changes. They may need your help to understand the changes they are experiencing, and assistance with using sanitary products and maintaining personal hygiene.



Sources of support

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, 'Dementia: what next?' at

dementiauk.org/dementia-what-next

To speak to an Admiral Nurse on our free Helpline, call 0800 888 6678 (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **helpline@dementiauk.org**If you prefer, you can book a phone or video call with

an Admiral Nurse at a time to suit you: please visit

dementiauk.org/book

Dementia UK information

Dementia and sleep

• dementiauk.org/dementia-and-sleep

Lasting power of attorney

dementiauk.org/lasting-power-of-attorney

Managing anxiety and depression in dementia

dementiauk.org/managing-anxiety

Mental capacity and decision-making

dementiauk.org/mental-capacity-and-decision-making

Staying healthy

dementiauk.org/staying-healthy

Understanding young onset dementia

• dementiauk.org/young-onset-dementia

Other resources

The Menopause Charity

themenopausecharity.org

NHS Eatwell guide

• nhs.uk/live-well/eat-well/food-guidelines-and-food-labels/the-eatwell-guide

NHS alcohol advice

nhs.uk/live-well/alcohol-advice

NHS information on HRT

nhs.uk/medicines/hormone-replacement-therapy-hrt

NHS stop smoking advice

nhs.uk/live-well/quit-smoking



To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline:

o8oo 888 6678 or Ohelpline@dementiauk.org

Book a virtual appointment:

dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call 0300 365 5500
- Visit odementiauk.org/donate
- Scan the QR code

Thank you.











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