

Young onset dementia: perimenopause and menopause



An estimated 70,800 people in the UK are living with young onset dementia, where symptoms begin before the age of 65. For some women, dementia symptoms may 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 postmenopausal. It 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.

When do perimenopause and menopause happen?

The average age for menopause is 51, but it can happen earlier or later – there is no such thing as ‘too young’ for menopause to happen.

Perimenopause can last for months or even years before menopause. Women often start to notice perimenopausal symptoms in their early 40s, or sometimes younger.

Post-menopause describes the time women live after menopause. They may have some symptoms for a few more years – generally they settle down, but occasionally, symptoms can continue for decades without treatment.

Common symptoms of perimenopause and menopause

The hormones produced by the ovaries are called oestrogen, progesterone and testosterone. They affect every system in the



body, so when the ovaries start to slow down and produce fewer hormones, the symptoms can be widespread.

Around 90% of women experience menopausal symptoms. Some only have mild symptoms, but a quarter of women with symptoms find they are so severe that they affect their everyday lives.

Common symptoms include:

- 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)

The symptoms of perimenopause/menopause can impact on many areas of life.

Brain fog is a very common symptom of menopause, and women often say that their brains feel like ‘cotton wool’. This can affect every aspect of daily life at home and work; it may be difficult to recall words, lose items or complete multiple tasks. This may affect their performance at work. Some take time off due to their symptoms; others reduce their hours or even decide to 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, such as genital and urinary changes, 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 p15).

How to tell if a woman is entering perimenopause

A change in menstrual cycle is a common sign. 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 to 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 periods and menopause symptoms over time to see if there are any patterns. You could use a

menopause app like balance-menopause.com/balance-app or a menopause symptom questionnaire such as the one on The Menopause Charity website: visit themenopausecharity.org/2021/10/21/menopause-symptoms-questionnaire. The information recorded can then be shared with a doctor or nurse.

Is it perimenopause, menopause or young onset dementia?

The psychological symptoms of perimenopause and menopause – such as negative thoughts, low mood and anxiety – are often unexpected and can have a big impact on someone's life.

It is also thought that a lack of oestrogen during and after perimenopause/menopause may increase the risk of developing dementia.

Brain fog – caused by hormonal changes – is a very common symptom of menopause. Many women have difficulties with:

- concentration
- word-finding

- memory
- multi-tasking
- mood and emotions
- overall wellbeing

Because these issues may also occur in dementia, some women become concerned that they are showing signs of young onset dementia. This fear may be more pronounced if they have a family history of dementia.

However, while people with young onset dementia do experience memory problems, this is not usually the first symptom. 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.

It can be difficult to tell whether these symptoms are being caused by perimenopause/menopause, young onset dementia or both, so it is important to see a GP if you have any concerns.

There are also many other conditions that can cause dementia-like symptoms, and

these should be investigated and ruled out or treated where appropriate. It is advisable to complete a symptom questionnaire and keep a record of periods over the course of a few months.

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

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's important to try to sleep well as this will help physical and mental health and emotional wellbeing. A lack of sleep can also make a person's memory and concentration worse.

Stress

Anyone can experience stress, but if a person has dementia, they may



find that this feeling is heightened with the perimenopause/ menopause. While it may not be possible to avoid stress completely, relaxation techniques, meditation or mindfulness may help.

Movement and exercise

Exercise 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 exercise for 30 minutes a day, five days a week, at a pace that increases 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 important during perimenopause and menopause. The NHS Eatwell guide is a useful model to follow – see Sources of support on p15.

Smoking and alcohol

Aim to stop smoking 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 page 15 for more information.

Living with young onset dementia and perimenopause or menopause

If you are living with young onset 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.

This is why it is important to understand how perimenopause and menopause can affect you. 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 your symptoms could relate to perimenopause or menopause and you need help with them, make an appointment with your GP. It can be helpful to complete a symptom questionnaire and

keep a record of your menstrual cycle over the last few months.

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.

Making decisions about treatments

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.

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.

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.

Sometimes, if there is a mismatch of expectations and outcomes, you may wish to ask

another healthcare professional (which could be a GP in the same practice) for a second opinion.

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



Hormone replacement therapy (HRT)

The most common and effective treatment for perimenopause/ menopause is hormone replacement therapy (HRT), which can be prescribed by a GP. HRT replaces or tops up the hormones that fall during this time.

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 safer as evidence shows no risk of blood clots.

Progesterone

Women who still have a womb will need to take a form of progesterone to keep the womb lining thin and healthy. The safest types of progesterone are Utrogestan, which comes in capsule form, or the Mirena coil, which 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

Testosterone also declines sharply around the time of menopause. Taking a testosterone replacement alongside oestrogen and progesterone, may help improve energy levels, sex drive, bone and muscle strength, brain fog and sleep. It comes as a cream or gel. There is currently no female licensed testosterone for women available in the UK. Many GPs do not prescribe testosterone and this can make accessing it difficult. You may want to seek advice from a menopause specialist. You can search for menopause specialists across the UK on the British Menopause Society website:

visit thebms.org.uk/find-a-menopause-specialist

Vaginal oestrogen

Vaginal oestrogen medication is used to improve symptoms like vaginal dryness and soreness, frequent urination, urine leakage and infections like thrush and UTIs. 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. It is important to continue to self-examine your breasts and attend your breast-screening appointment when called.

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 a woman takes oestrogen in tablet form, there is a very small increased risk of developing a blood clot or having a stroke, especially if she smokes, is very overweight, or has had a clot or stroke in the past. But there is no increased risk of clot 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 p15.

Alternatives to HRT

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.

These include:

- regular exercise
- prescription medicines such as antidepressants may help with hot flushes and night sweats, but are not usually effective in helping with mood-related changes if they are caused by fluctuating hormone levels
- cognitive behavioural therapy (CBT): a talking therapy which can help to reduce some mental health symptoms, including depression and anxiety
- 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 someone living with young onset dementia

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, support the person to keep a record of their periods if they are still happening
- 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 p15 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

To speak to a dementia specialist Admiral Nurse about young onset dementia and perimenopause or menopause or any other aspect of dementia, please call our free Helpline on **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 appointment at a time to suit you at dementiauk.org/closer-to-home

Dementia UK information

Capacity and decision making
dementiauk.org/capacity

Managing anxiety and depression in dementia
dementiauk.org/managing-anxiety

Staying healthy
dementiauk.org/staying-healthy

Lasting power of attorney
dementiauk.org/lasting-power-of-attorney

Dementia and sleep
dementiauk.org/good-habits-for-bedtime

Young onset dementia
dementiauk.org/young-onset-dementia

Other resources

Balance app and website
balance-menopause.com/balance-app

The Menopause Charity
For information and symptom questionnaire
themenopausecharity.org

The British Menopause Society
thebms.org.uk

NHS Eatwell guide
[nhs.uk/live-well/food-guidelines-and-food-labels/the-eatwell-guide](https://nhs.uk/live-well/eat-well/food-guidelines-and-food-labels/the-eatwell-guide)

NHS alcohol advice
nhs.uk/live-well/alcohol-advice

NHS stop smoking advice
nhs.uk/live-well/quit-smoking

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm



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