

Learning disabilities and the perimenopause and menopause: what support workers and family carers need to know



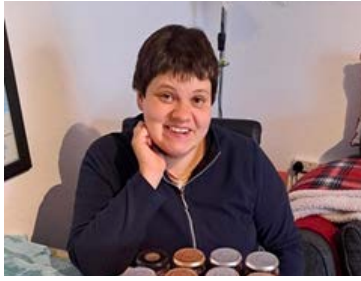
balance

by Newson Health

Produced in association with

 **dimensions**





First, let's meet Emma.

Emma Fraser is 43 years old and is currently experiencing symptoms related to perimenopause. Emma, who has a learning disability and cerebral palsy, knew something wasn't right.

'My periods became heavier and I was starting to experience mood swings. I visited my GP and got referred to a gynaecologist who asked me to create a chart tracking my moods and periods. I need to return to the clinic in a few months for a review so I haven't been offered any medication yet but I have found things that are really helping me during this time.'

Emma's top three tips

Create a traffic light system

I use three pieces of cardboard – red, amber and green – as flash cards. I show my support workers and family red when I'm feeling down in the dumps, amber for when my mood could go either way and green when I'm happy.

Talk to people you trust

I feel so much better when I talk to people, especially those who are going through it or have already been through menopause. I talk to my female support workers a lot, they reassure me and calm me down.

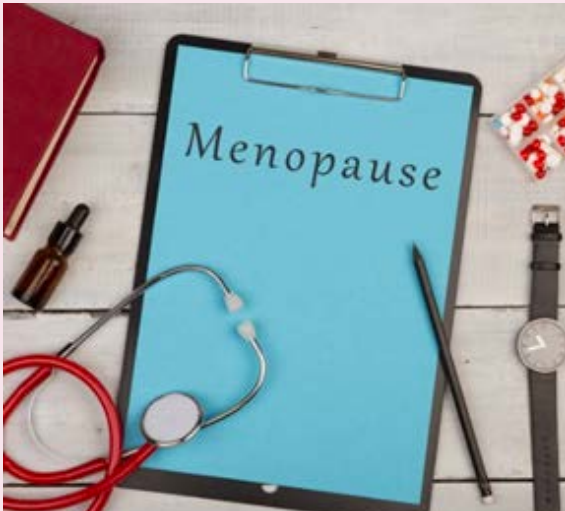
Go to your GP

This was so helpful. They referred me to a gynaecologist who gave me some great advice and is helping me now.

What is the menopause?

The menopause is something that will happen to **all women**. The menopause is **when periods have stopped** for 12-24 consecutive months, depending on your age. The ovaries stop producing eggs so pregnancy is longer possible.

Ovaries produce hormones called **oestrogen, progesterone** and **testosterone**. In the menopause the ovaries produce less of these hormones.



The average age of a woman to have the menopause is 51. Some women have it happen sooner or later than this age.

Women with learning disabilities, and especially women with Down's syndrome, tend to have **earlier menopause than other women** [1]. So, it is really important that you work with the person and their health professionals to track any changes being noticed.

The menopause can also happen if a woman has had medical treatment like having her ovaries removed, breast cancer treatment, chemotherapy or radiotherapy.

The **menopause can be different for each woman** which means there can be confusion about the symptoms and treatment.

What is the perimenopause?

Perimenopause is the **time before the menopause happens**. This can **vary in length** from a few months to up to 10 years.

During the perimenopause periods might be lighter or heavier or happen at different times. Symptoms can include:

Hot flushes

Mood swings

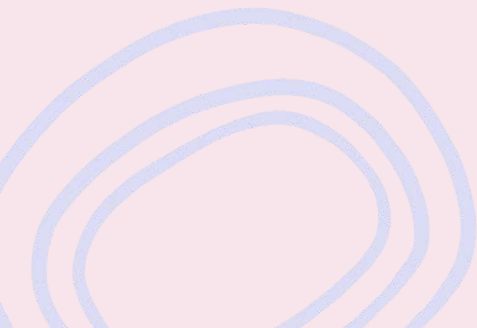
Brain fog

Fatigue

You can read more about the symptoms later in this booklet.

Some women start to have these symptoms when they are in their early 40s. Other women can be younger.

Some women do not notice that it is happening as they might think the symptoms are because of stress or being busy. If a woman has symptoms such as changes to her periods, hot flushes, mood changes, poor sleep or brain fog then a doctor or nurse can diagnose the perimenopause.



Symptoms of the perimenopause and menopause

Most women will have some or many of the symptoms of the menopause. These include:

Finding it hard to sleep: this may make you tired and irritable in the day.

Problems with remembering things and being able to concentrate.

Less interest in sex

Headaches

Palpitations: these are where you can notice your heart beating.

Having lots of **urinary tract infections**. These are infections which make it painful when you wee.

Hot flushes: these are short, sudden feelings of heat in the face, neck and chest. It can make the skin red and sweaty.

Night sweats: this is when hot flushes happen at night.

A dry and painful vulva and vagina, with itching and discomfort during sex.

Mood changes like feeling low or feeling worried.

Feeling stiff with **aches and pains**.

The menopause can cause other problems like weak bones, which is called osteoporosis and heart disease which can affect the heart and blood vessels.

Low hormones can also increase risk of type 2 diabetes and a condition affecting the way a person's brain works called dementia.

Recognising the perimenopause and menopause

It is not always easy for women, or their loved ones or carer, to spot the symptoms of menopause.

Remember yourselves as carers know the person best, you will know what is usual for someone and how they usually present. You don't need to be trained in different health topics but you do need to **help the women you are supporting to speak up** when they notice changes and to record accurately the changes they are noticing to report to health professionals. It is then the health professionals' role to notice that these symptoms may be that of the menopause and to offer support, treatment and specialist referral.

A good way to recognise the perimenopause or menopause is to **record any changes** you are noticing in the person you are supporting.



Are there any tools available to help record the changes we are seeing?

The GP or gynaecologist may provide a tracking tool or way to record the changes you are noticing. However, if not, there are a few suggestions below that have been proved to be helpful in recording changes noticed in people you are supporting:

The **balance app** is free and is all about menopause. It has a list of more than 50 symptoms that can be ticked when they are experienced. It can also track periods which is useful if they become less regular. The app can make a report of the symptoms and this can be taken to a doctor or nurse. Find the app in the App Store or on Google Play.



The **Health Calendar** (formerly Anticipatory Care Calendar) is also free and can be used in any social care setting supporting people with learning disabilities. It is a tool that records any changes a person or their carers are noticing compared to the person's usual self. It is made by the NHS Innovation Agency. Find out more at www.healthinnovationnw.nhs.uk

Restore2Mini is a tool that can be used for people with learning disabilities and their carers to help know what is usual and to identify changes. It is made by NHS Hampshire and can be found at <https://www.hantsiow.icb.nhs.uk/your-health/schemes-and-projects/restore2>

How might a learning disability be affected by the menopause?



Women with learning disabilities have similar experiences of menopausal symptoms to all women. Some conditions that are associated with a learning disability may be impacted by the menopause.

- Research shows that women with **Down's syndrome** reach the menopause five to six years earlier than other women [2]. Emotional symptoms of the menopause may be dismissed as behaviour of distress (diagnostic overshadowing) rather than being linked to changes in the person's health. Health professionals may not understand how women with learning disabilities communicate so therefore might struggle to diagnose their symptoms.
- According to the Epilepsy Society, **epilepsy** is more common in people with a learning disability compared to the general population, with about 1 in 3 people with a mild to moderate

learning disability (32%) having epilepsy [3]. Women with epilepsy might have a change in their seizure pattern during the perimenopause. It can be hard to predict how seizures will change and there could be more seizures or fewer [4]. Some studies suggest that if a woman has frequent seizures, she may go through the menopause a few years earlier than average [5,6].

- Women with **autism** may find their anxiety and sleep difficulties worsen due to the hormonal changes associated with the menopause [7]. Health professional and carers need to work together to ensure the woman's communication style is understood and that they are listened to so that they can access appropriate care and support.
- Women with **cerebral palsy** may experience menopause earlier and experience more pronounced symptoms.



How to offer support



The most important thing you can do is to **talk with the person you are supporting**. It is important that they feel they are in a safe space to have open discussions about what is usual for them and what might be changing. Be led by the person and their preferred communication style and plan a follow-up discussion to answer any further questions to ensure understanding and provide additional information if needed.

It can be frightening to not understand what is happening to your body or why you feel differently. **Women can feel embarrassed, scared or ashamed** so time to explore these feelings and reassurance can be helpful.

Give reassurance that every woman will go through the menopause and **she is not alone**. Tell her that **it is normal** just like ageing and that it happens to all women.

If you feel comfortable, and you have been through menopause yourself, tell her about your own experience. Remember, if you are the mother or a relative of the person you are supporting, their experience of menopause may not match your own. **It is different for everyone**.



Preparing for a GP appointment

When you book an appointment at the doctor's surgery, ask to see **someone with a special interest in menopause**. The person can ask for a longer appointment to make sure there is enough time to explain the situation and understand the information they are given. This is called **making reasonable adjustments**.

Consider if the person you are supporting would like privacy to talk to the GP. For example, if she is experiencing painful sex, she may feel embarrassed to talk about this in front of loved ones or support workers or she may prefer support to be present.

It's **important she feels she has control** and is part of the decision making and that we respect and follow her wishes.

When she goes to the GP appointment, support her to take a list of the changes she is experiencing. **Speak about all the symptoms even if you are unsure they are down to the menopause**. For example, some women can feel very tired, others might have changes to their skin or mood.

It will also help the GP if you can say when the symptoms were experienced, and have tracked when she had her periods.



Understanding medical terms

The GP or nurse may use terms you or the person might not be familiar with or they may need to be explained to the person you are caring for. The woman you are caring for may describe her symptoms in a slightly different way so you might need to help explain them to the GP.

Vasomotor symptoms – The most common of these is hot flushes. These can feel like a sudden burst of heat in the chest, neck and head. Skin might redden and the heat might feel like it is spreading. Some women will feel sweaty at the same time or they might feel dizzy.

Night sweats are a very hot feeling over the face and body. They can wake you up in the night and a woman may find that she is wet with sweat and so are her bedsheets.

Other vasomotor symptoms include heart palpitations which is when your beat feels more noticeable or quicker.



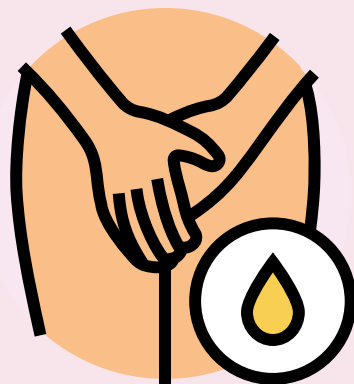
Musculoskeletal symptoms – Some women describe feeling pain all over their body. This can be joint and muscle pain, aches or stiffness which are very common.



Understanding medical terms

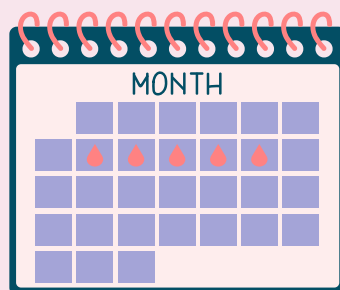
Genitourinary syndrome of the menopause (GSM) – The term genitourinary syndrome of the menopause is used to describe various symptoms. These can include genital symptoms such as vaginal dryness, burning or an itchy, uncomfortable vagina.

It also includes sexual symptoms such as pain during sex. It also includes urinary symptoms including needing to go for a wee more often, pain when weeing or getting urinary infections.



Menstrual cycle – The menstrual cycle is the time from the first day of your period to the day before the next period.

Changes to the menstrual cycle are often a sign of perimenopause. Periods may not be as regular as they were so they might happen more often or less often. Periods might change and it is common for periods to become heavier which means more blood loss.



Treatment options

If a woman's symptoms are stopping her doing everyday things then her doctor or nurse can offer treatments or suggest some changes in her life. These treatment options are the same that would be offered to all women.

Treatment options include:



Hormone replacement therapy (HRT)

This is tablets, skin patches, gels and implants that replace the hormones the woman is missing.

The dose and type will be individual to the patient and the doctor will work with her to choose the right type.



Topical oestrogen

This is cream, gel or a pessary that is applied to the skin to help vulval and vaginal dryness. Or it might be a soft flexible ring or tablet inserted into the vagina to help with dryness.



Cognitive Behavioural Therapy (CBT)

This is a type of talking therapy that can help if someone is feeling sad or worried



Diet and exercise

Being a healthy weight and staying fit and strong can make some of the symptoms better. She might receive advice on how to eat a healthy diet and types of exercise to enjoy.

Shared decision making



If it isn't explained what is happening to her body, this can be really worrying for the person you are supporting and can increase her symptoms of menopause. She may also be scared that symptoms could mean any current medical condition is getting worse.

It's important for the person you are supporting to **fully understand and be part of her treatment plan** so ensure the health professional explains things in a way that makes sense to the person in their preferred communication style.

Her **future health should also be discussed**. Women have a higher risk of some conditions once they have been through the menopause.

One example is **osteoporosis**, which is a weakening of the bones. In women over 50 years old, up to half of them will break a bone due to osteoporosis. Some medical conditions can increase the risk of osteoporosis as can some medications such as some used to treat epilepsy. HRT can help to prevent osteoporosis in the years around the menopause, especially if the woman has an early menopause [8].

Menopause myths



'I am too young to be menopausal' – MYTH

The menopause can happen at an early age. Menopause before 45 years old is known as an early menopause. Menopause before age 40 is known as premature ovarian insufficiency (POI). This affects about 3 in 100 women under the age of 40. Even girls in their teens can be perimenopausal or menopausal [9].



'Menopause is just hot flushes' – MYTH

Hot flushes are a common menopause symptom but not every woman will experience them. Some women may have few symptoms of the other menopause but others may have many.



'You just have to get through menopause' – MYTH

No woman should have to suffer with her symptoms. There are safe treatments that can help. Remember every woman's experience is different.



'HRT causes breast cancer' – MYTH

Most types of HRT do not increase the risk of breast cancer. Much of the fear about HRT and breast cancer is based on inaccurate reporting about the risks. Certain risk factors that increase your risk of developing breast cancer include getting older, being overweight, drinking alcohol, not exercising regularly and having young family relatives who have had breast cancer. Many women also develop breast cancer without these risks.

Menopause myths



'Menopause is just a natural transition' – MYTH

For some women menopause will be simple and they may not experience many symptoms. For others, especially those who go through menopause due to surgery or certain medical conditions, it doesn't feel natural. It can feel like their body is working against them and their symptoms can continue for years.



'You can't take HRT if you're a wheelchair user' – MYTH

Wheelchair users are more at risk of blood clots because they cannot move around. A reported link between HRT and risk of blood clot was based on a study over 20 years ago. This was with an older type of HRT which was an oestrogen tablet and an older synthetic progestogen.

Oestrogen given through the skin in a patch or gel or spray is much safer. There is no extra risk of clot when using this form of oestrogen, even for those with a higher risk of getting a blood clot. The newer micronised progesterone has not been shown to cause any increase in the risk of getting a clot [10].



'You need a blood test to diagnose menopause' – MYTH

If a woman is over 45 and experiencing symptoms, she won't usually need a blood test. A doctor may want to do a blood test if the woman is younger or to rule out other medical conditions.

Next steps

You can find out more about the perimenopause and menopause at
www.balance-menopause.com

You can find information and support from Dimensions at
<https://dimensions-uk.org/>

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This booklet has been written by balance and Dimensions

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by Newson Health

Balance, founded by GP and Menopause Specialist Dr Louise Newson, is on a mission to make support with the menopause inclusive and accessible to all women, and trans and non-binary people. We provide unbiased and factual information, based on the latest evidence available, to help you make a choice that's right for you. The balance website and app are unrivalled platforms that educate and empower people across the globe. We are the world's biggest menopause library, filled with medically approved content.



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dimensions

Dimensions provides person-centred support and finds the right housing for adults with learning disabilities and autism, right across the country. Our support ranges from a few hours outreach each week to intensive support for people whose behaviour is shaped by distress. We care for those with complex health needs and support many people with profound and multiple learning disabilities. We involve the people we support and their families in all aspects of their support. Everything we do is personalised to the individual and our staff are ambitious for each and every person we support.

Find out more:



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