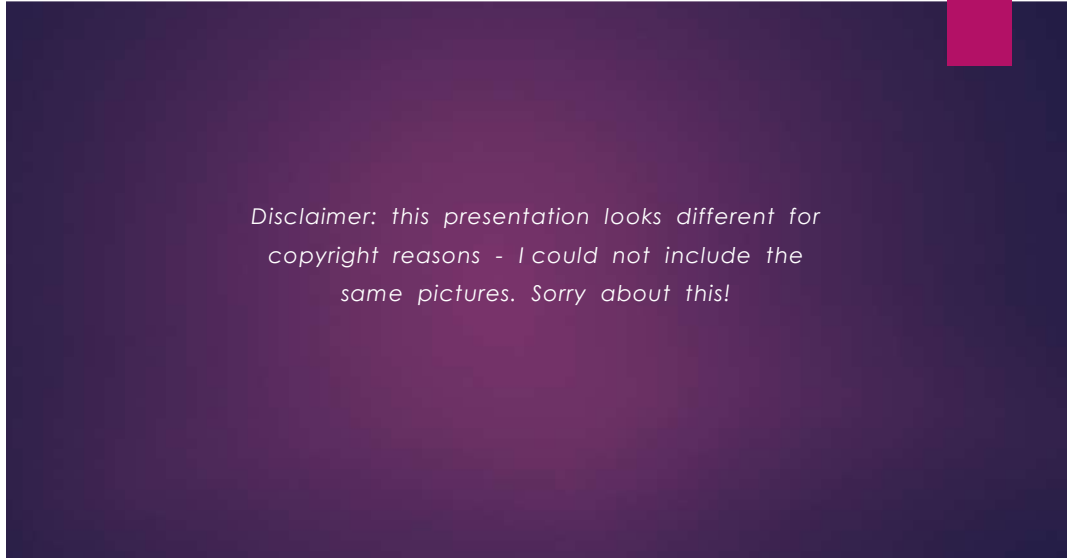


Let's talk about menopause:
what people with ovaries
should know

By Dr Rachel Moseley



*Disclaimer: this presentation looks different for
copyright reasons - I could not include the
same pictures. Sorry about this!*



“I thought I was
going mad”

(Words
spoken by a
number of
autistic
people at
menopause)

A quick introduction to me: Dr Rachel Moseley

Research psychologist, Bournemouth University

Specialist areas: suicidality, mental health, ageing, late diagnosis

Late-diagnosed at age 28 :)



Today's talk will cover:

What is menopause, and who's affected?

How do autistic people experience menopause?

Take away messages for those in menopause,
and those who might experience it in future

Why do we
need to
talk about
menopause?



Very bad, would not recommend.

Let me remind you of a time in your life that you might not want to remember – puberty. Your body changing in ways beyond your control. Your mind changing, with hormonal mood swings. Let's face it – it sucked, didn't it?

Well, menopause matters because it's kind of like a second puberty. Both puberty, and menopause, are what doctors call reproductive transition points.

As humans, our bodies change throughout our lives. If you're someone with ovaries, certain points of the lifespan are marked by more intense, accelerated changes in the body and brain. At puberty and menopause, there are huge changes in the brain's hormonal systems, which of course results in massive changes in our physical appearance, in our reproductive ability, our emotional and social development, and so forth.

We psychologists call these points biopsychosocial transition points, because your body is changing, but so is your mind and social environment. Interestingly, we're more vulnerable to physical and mental illness at these times, and we're more impacted by things affecting our bodies, like stress.

What is menopause?

Brought on by declining *oestrogen* and *progesterone*... key sex hormones for people with ovaries

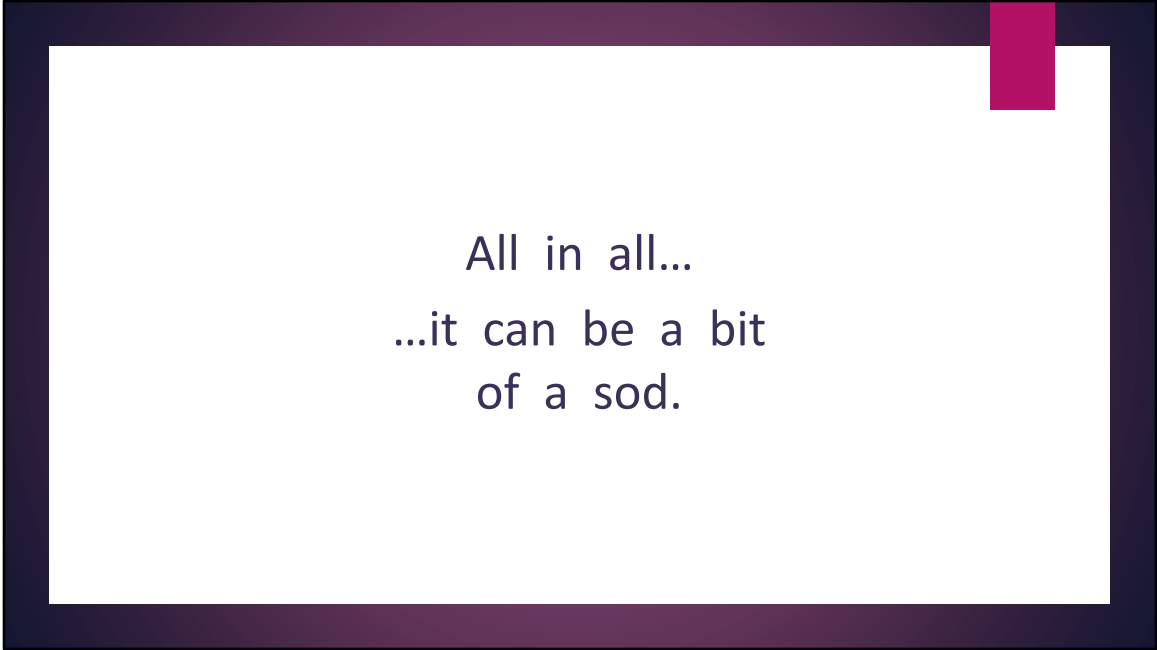
Women and people with ovaries, when they reach their 40s-50s on average, enter a stage where they no longer produce enough oestrogen and progesterone to maintain a normal menstrual cycle. Now, oestrogen and progesterone are sex hormones, but they actually do all kinds of things. They are important for physical health, such as keeping your bones strong. In terms of mental processes, they're part of a very delicate balance. They work to regulate the other chemicals in the brain which affect learning and memory, which is why people can be more forgetful and struggle with thought processes at menopause. These sex hormones also affect chemicals involved in mood, like serotonin, which is why people often experience greater anxiety and depression at menopause.

What is menopause?

Change in periods	Hot flushes (or flashes)	Night sweats - (night-time hot flushes)
Difficulty sleeping	Reduced libido (sex drive)	Urinary tract infections
Vaginal dryness, or itching, pain during sex	Palpitations	Joint stiffness, aches and pains
Problems with memory and concentration	Emotions more intense and changeable	Heightened depression or anxiety

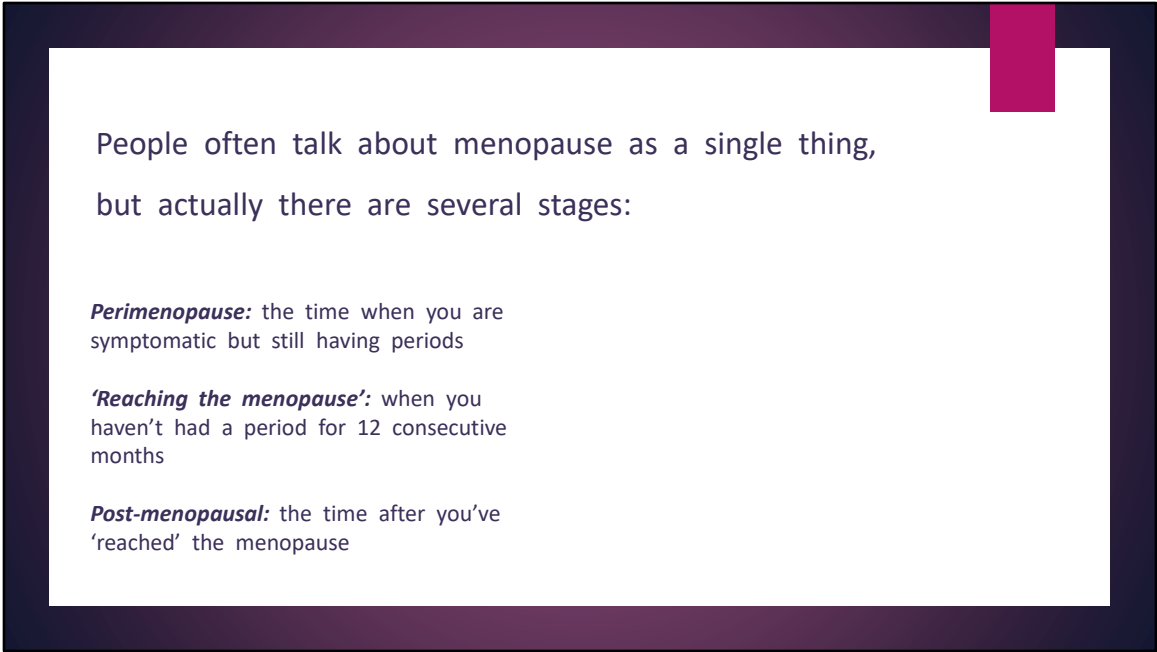
So it's actually a bit of a chain reaction – changes in these sex hormones affect a whole host of other chemicals in the brain, giving rise to physical symptoms. The most common ones are your periods becoming more irregular, changing in consistency and heaviness; hot flushes, also known as hot flashes; night sweats, which are essentially hot flushes when you're asleep. Naturally, this also makes it hard to get a good night's sleep! People also experience changes in sexual desire, vaginal dryness or itching and pain during sex, urinary tract infections, headaches, palpitations like when your heart feels like it's racing, and just generally more aches and pains across the body.

On top of that, there are changes in your thought processes, like your memory and concentration getting poorer, and changes in your emotions, which can become more extreme and changeable. People often experience more anxiety and depression at this time.



All in all...
...it can be a bit
of a sod.

All of this really affects your relationships, your sense of self and your place in the world. All in all – a sod really.



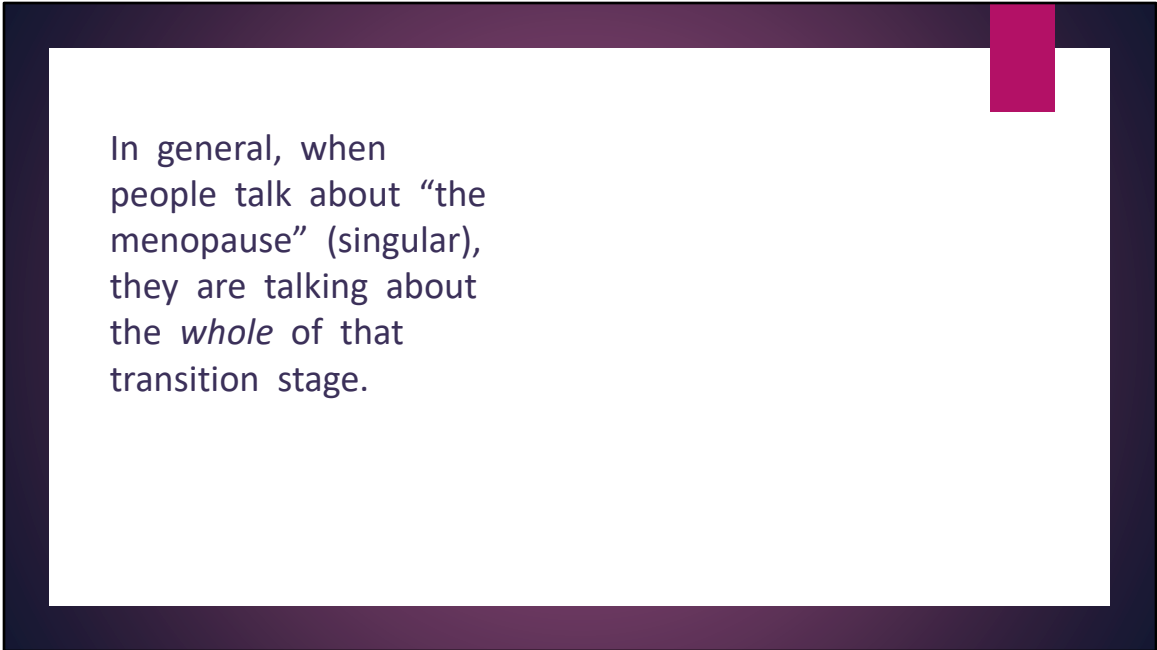
People often talk about menopause as a single thing,
but actually there are several stages:

Perimenopause: the time when you are symptomatic but still having periods

'Reaching the menopause': when you haven't had a period for 12 consecutive months

Post-menopausal: the time after you've 'reached' the menopause

Confusingly, people often talk about menopause in a slightly incorrect way. People often talk about 'menopause' as a single thing, but actually there are several stages:



In general, when people talk about “the menopause” (singular), they are talking about the *whole* of that transition stage.

When does the menopausal transition happen?

Typically starts in 40s, lasts approximately 4-5 years, though can be longer.

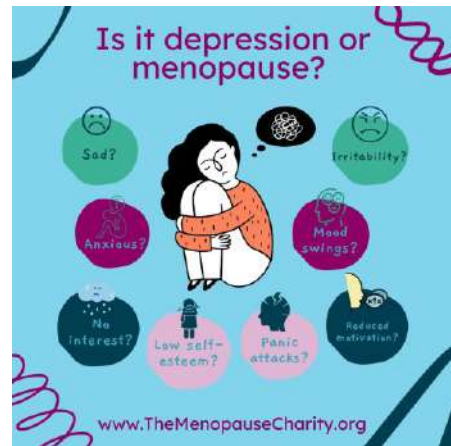
Symptoms start a few months/years before periods stop. On average, symptoms stop around 4 years after your last period.

The menopausal transition usually starts when a person is in their 40s to 50s – on average, it lasts 4-5 years, but people can experience symptoms for quite a bit longer.


The symptoms of the menopausal transition usually begin a few months or years before you have your last ever period... and keep going until a few years after that. Importantly, symptoms can be more or less intense during that time period.

By the time a person is post menopausal, i.e. hasn't had a period for 12 consecutive months, the worst of the symptoms tends to have passed. On average, most symptoms stop around 4 years after the last period.

It's difficult to diagnose menopause... diagnosis is normally made on symptoms alone.



This can make it difficult to identify that menopause is happening.



People are affected
differently, and to different
degrees.

Now, a really important thing about menopause is that it affects people very differently. People will have different symptoms. Some will have hardly any symptoms at all, or they might be just mildly irritating. Some people will struggle more. But even within a single individual, symptoms might vary in how difficult they are across the whole of the menopause.

It can be especially difficult if you are transgender or do not identify as female.



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Menopause affects everyone with ovaries – whether or not you identify as a woman. It can be especially difficult if you are trans or non-binary, though, since people tend to assume menopause is only experienced by women.

[Types of Menopause - Diversity Project](#)



When it comes to menopause... why might it be more challenging for us?

- Your body and mind change in *unpredictable* and often *uncontrollable* ways
- Menopause affects your *emotions, thought processes,* and *sensory experiences*

Menopause is essentially a process of change, largely uncontrollable and unpredictable, changes in your body, changes in your emotions and cognitive processes, and it's hard to even 'diagnose' whether menopause is occurring. Medical practitioners can't give you much of a roadmap, even if you're experiencing a non-autistic, 'average' menopause. We know that autistic people struggle with change and unpredictability at the best of times!

Menopause affects your emotions, which are already difficult for autistic people to regulate. It also affects executive function, which is likewise an area of difficulty already.

It's also worth noting that the changes to an individual's body can be distressing, especially if they are already vulnerable to conditions like eating disorders, which affect many autistic people.



When it comes to menopause... why might it be more challenging for us?

- We often struggle with *hormonal shifts*
- We have *poorer access to healthcare*
- And during menopause... we might struggle to *communicate* our experiences

Autistic people tend to be very sensitive to hormonal shifts – so they often already struggle with the changing hormones related to monthly periods, and can struggle during other transitions like pregnancy.

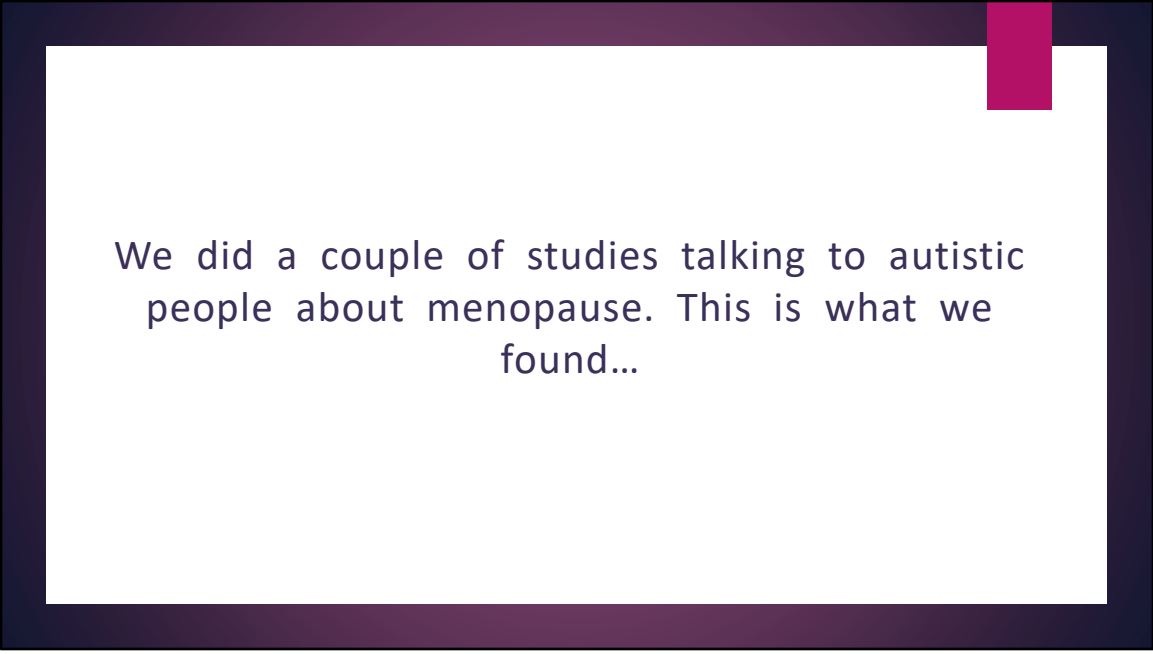
They also tend to have poorer access to healthcare, including preventative healthcare, reducing likelihood of discussing menopause before it happens.

And when menopause happens – it might be harder for autistic people to have the conversations they need to have in order to get support from their loved ones and healthcare professionals. This is to the greatest extreme if they have an intellectual disability and minimal spoken language – they might really struggle to express their distress.



When it comes to menopause... why might it be more challenging for us?

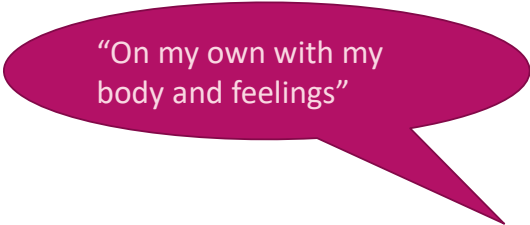
- **Past trauma** affects how you experience menopause
- We are more likely to be **gender-divergent** or **trans**
- We might have less **social support** to help us cope



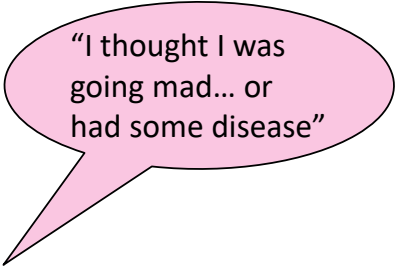
We did a couple of studies talking to autistic people about menopause. This is what we found...

We found that:

1. People often go in unprepared.



“On my own with my
body and feelings”



“I thought I was
going mad... or
had some disease”

We found that autistic people did often enter menopause with very little knowledge of what to expect – they expected certain symptoms, like hot flushes, but don't anticipate how these will feel or what wider repercussions they'll experience. Some people were extremely frightened and confused about what was happening to them, as it didn't resemble stories about menopause they'd heard – what they were experiencing just didn't resemble a normal 'neurotypical' menopause. That meant they couldn't read or hear a description of menopause and understand, 'oh OK, that's what's happening to me'.

We found that:

2. Menopausal symptoms have wide-reaching impacts, e.g. on cognition

“...a head full of cotton wool and a body which just isn't going to behave.”

“crushing tiredness and executive function of a 12-year-old”

Autistic people seem to experience a lot of the same physical experiences as non-autistic people, but they may experience them more intensely. That includes night sweats, hot flushes, irregular periods, insomnia, fatigue, but also perhaps some less common ones – like flare-ups in chronic illnesses. However, menopause also seems to create broader challenges that we could categorise as cognitive, emotional, social and sensory – though difficulties in each area very much impact on the others.

Changes in executive function – in their ability to manage multiple tasks, meet deadlines, plan, pay attention – one participant described it as “walking through life with a head full of cotton wool and a body that refuses to behave”. People found it much harder to look after themselves, be independent, and manage daily life. Some people lost jobs, others fell into financial arrears; some became highly dependent on partners and elderly parents for self-care, which was very damaging to their self-worth and mental health. People who had co-occurring ADHD found themselves much less able to control their attention and manage their daily lives.

Some participants reported being utterly exhausted – suffering extreme fatigue and burn-out. This was very much linked to other symptoms, too, like insomnia.

We found that:

2. Menopausal symptoms have wide-reaching impacts, e.g. on emotion

“They say ...
menopause, it's not
life threatening,
but it bloody is, it's
life threatening”

“Whereas previously I'd
be a little bit grumpy - I
was psychotic, like ... my
emotions have been
turned up a notch”

Coping strategies failed during menopause, and they were much more reactive to environmental stress. Some reported extreme meltdowns, severe depression, greater self-injury and suicide attempts.

We found that:

2. Menopausal symptoms have wide-reaching impacts, e.g. on communication

“I suspect GPs thought that the symptoms weren't that bad because I wasn't breaking down and crying ... When you can't describe what's going on, you can't ask for help.”

“I couldn't talk to him about it because I just didn't have words for these things”

Some people reported feeling much less capable of social interaction, and feeling far more overwhelmed by it. People report that it's much more exhausting and in some cases impossible to 'maintain the mask' – that existing difficulties with verbal communication, eye contact, understanding non-literal language and so forth, became that much more problematic.

It's also worth recognising alexithymia, interoceptive and communication difficulties. Alexithymia is really common in autistic people – a difficulty identifying and communicating your emotions; autistic people also really struggle with interoceptive awareness, with identifying their internal bodily signals, like temperature, thirst, hunger, pain and so forth. This makes it very difficult to understand what you're experiencing – sometimes, people will just feel an “overwhelming mass of bad”, that's sort of impossible to pick apart and define. People can therefore find it really hard to fill in apps like period trackers and menopause symptom apps, as they struggle to read a list of symptoms and understand whether what's written there is the same as what they're experiencing. It also means that they can struggle to explain what's happening with them, to convey how much they are struggling, such that sometimes they don't get the help they need.

We found that:

2. Menopausal symptoms have wide-reaching impacts, e.g. on sensory experiences

“A major dominating, incredible, awful, debilitating thing”

“Things which usually manifest in autistic children...would now for the very first time in my life, manifest in me. I ended up ... sitting in a corner naked, and rocking and bashing my head against a wall.”

Heightened sensory difficulties, or sensory difficulties which were entirely new. Can interact with physical symptoms of menopause (e.g. hot flushes), making the person feel very uncomfortable and self-conscious, and affecting their ability to function socially and in daily tasks.

We found that:

3. Menopause can amplify *neurodivergence*, and neurodivergence can amplify menopause.

“The experience I had was very abrupt from being quite capable... to being unrecognisable as that person... Being autistic can be a challenge but it does give us skills... My most noticeable thing was that I lost my skills ...”

“My ADHD is broken, it's got lots of D's in it, the deficit and the disorder. Before that I didn't feel it to be that way ... you could have these wonderful gifts.”

Autistic people function in the world on a precarious tipping point, with so many existing struggles and balanced coping strategies, such that hormonal changes seem to just really knock them.

Other major reproductive transitions – like starting periods, pregnancy, postnatal hormonal changes – these are hard enough in of themselves, but autistic people tell us that they make autism-related challenges even greater. This is also true of monthly hormonal cycles, for people who have periods – life becomes harder to manage, with sensory sensitivities amplified, greater difficulties with coping and self-care, and heightened emotions.

Menopause is emerging as another such time where pre-existing autistic features and difficulties can be amplified; furthermore, being autistic also seems to affect how menopausal symptoms are experienced. Autism affects how a person experiences menopause, and menopause affects how they experience their autism: some autistic people said that the experience of menopause absolutely “floored them”; that in some cases, they just couldn't function, they couldn't leave the house, that the combination of being autistic while experiencing menopause makes both

“intolerable”. Some described it as “life-threatening” in terms of its impact on their quality of life and mental health.

We found that:

3. Menopause can amplify *neurodivergence*, and neurodivergence can amplify menopause.

“I would say that I found out that I am autistic because I'm perimenopausal, because I've stopped being able to cope with my life, the life I was able to cope with before.”

For some, menopause derailed their health and their lives so greatly that they were diagnosed as autistic at this time –many had grown up undiagnosed, perhaps fitting into the world as people who struggle with jobs, social and romantic lives, chronically unemployed, chronically unwell physically and mentally, people who see themselves as “broken” or “weird” – and so with the turbulence and the amplification of autistic features by menopause, some of those individuals realised that there's a word to describe their experiences, and that's autism.

We found that:

4. There are silver linings to menopause. People can experience it as a time of challenge but also growth.

“reduced the ‘female’ pressures to look good and be sexy, etc”

“This has been an absolute springboard for me, to... do amazing things”

“a maturing process”

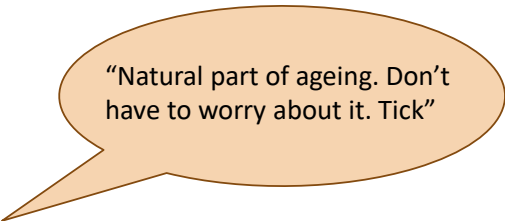
Some people see silver linings in menopause – all of our participants were happy to say goodbye to periods. Others felt that at menopause, there was less pressure to perform femininity – to be “sexy”, submissive and so forth. Some people found that getting through menopause had taught them important life lessons, new ways of coping and resilience – especially if they came to their autism diagnosis through the turmoil of these years.

People talking to us from the other side of menopause reported that their menopause symptoms had abated – they didn’t feel exactly the same as they did before menopause, as their bodies had gone through this transition, but it wasn’t entirely bad on the other side.



REALLY IMPORTANT
MESSAGE:

Some people had a *really
easy menopause!*



“Natural part of ageing. Don’t
have to worry about it. Tick”

Now, it’s really important to say that some of the autistic people we spoke to had a REALLY smooth, easy menopause. They had minimal symptoms, and they coped with them really well. It didn’t shake them.

This is one of the tricky things – we don’t really know why some people struggle, and why some sail through. But it’s why I wanted to talk to you today; it’s worth being aware of this life stage.



© the Diversity Project: depiction of mood changes and hot flashes

Take home messages



© the Diversity Project: depiction of mood changes and hot flushes

If you've not yet started menopause:

- ▶ It's worth chatting about it with your sources of support - and hopefully your GP. You can direct them to reading on the subject - see following links!
- ▶ Discuss or explore treatment options.



© the Diversity Project: depiction of mood changes and hot flashes

If you've not yet started menopause:

- ▶ Think about what is 'normal' to you in terms of how your body feels and functions, so that you are more aware and can tell your doctor when something changes.



© the Diversity Project: depiction of mood changes and hot flashes

If you've not yet started menopause:

▶ Remember that

- 1) Menopause is different for everyone - some people have a really easy time
- 2) Menopause passes.



© the Diversity Project: depiction of mood changes and hot flushes

If you're going through it now:

- ▶ We see you. You are not alone if you are struggling.



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If you're going through it now:

- ▶ If you are struggling, do not blame yourself. ***It is not your fault.***

You are not weak or in any way deficient. It can be harder for us.



© the Diversity Project: depiction of mood changes and hot flashes

If you're going through it now:

- ▶ Connect with other autistic people if you can.
- ▶ Discuss treatment options with your supporters and GP. HRT is not to everyone's taste, but it can really help.



Thank
you for
listening!

Please feel free to get in touch with
me if you have any questions:

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