

# Autistic people during ageing and the menopause

Dr Rachel Moseley

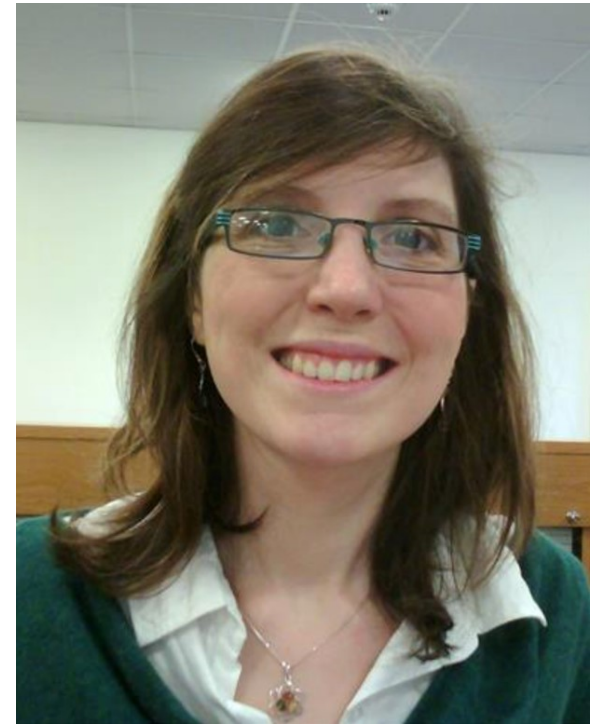


Who am I?

Principal academic,  
Bournemouth University

Research focus:

Mental health, self-injury,  
suicide, ageing, sex  
differences, female  
presentation, late  
diagnosis.



Who am I?





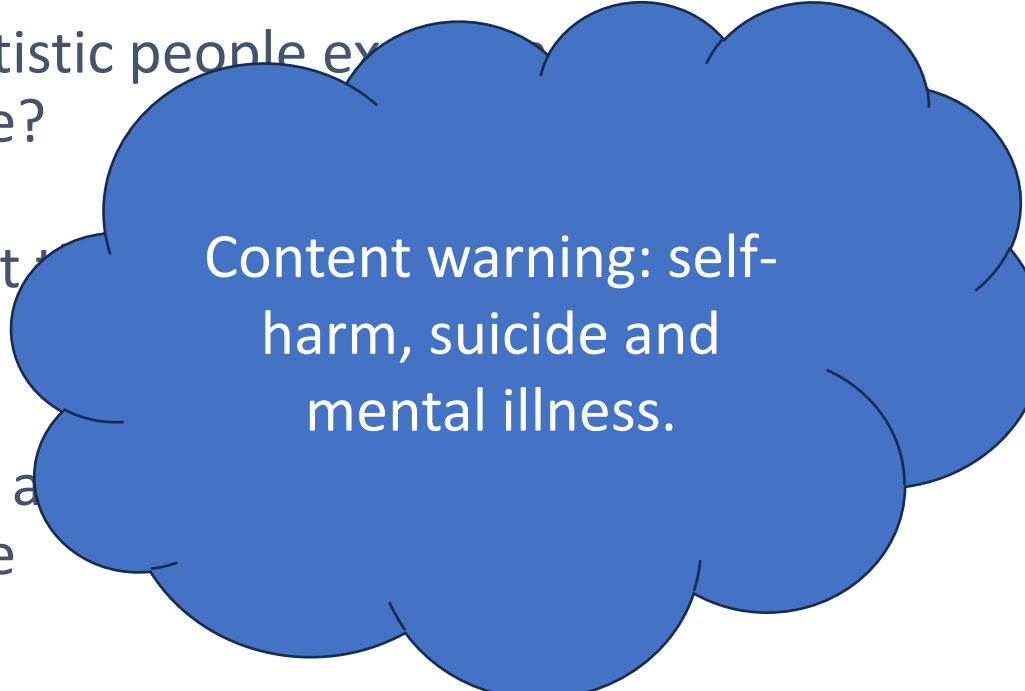
## This talk will cover:

- The significance of ageing as an autistic person
- What is menopause, and why does it matter?
- Why might menopause be especially hard for autistic people?
- How do autistic people experience menopause?
- What about the bigger picture: midlife and beyond?
- Supporting autistic people through menopause

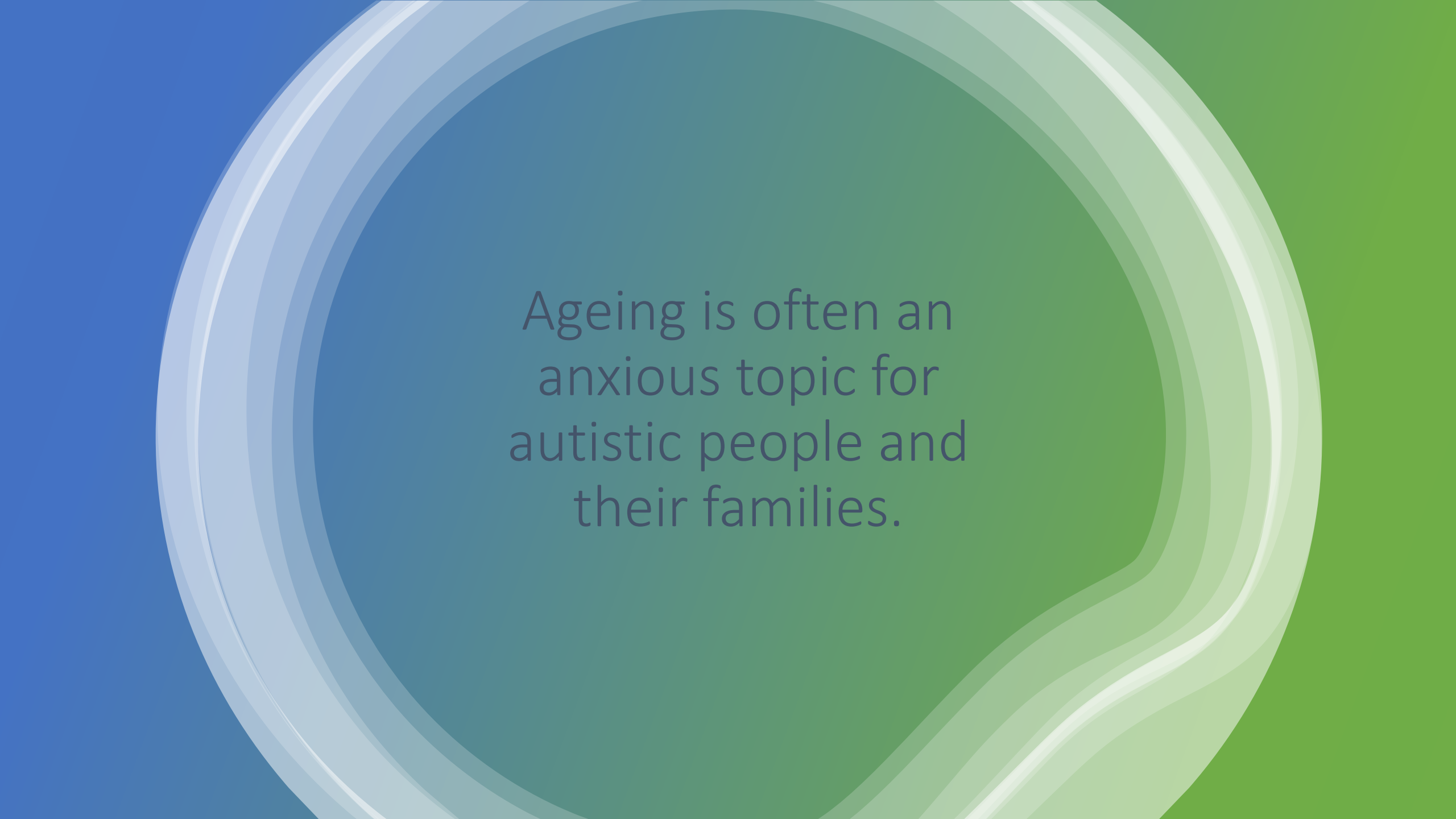


## This talk will cover:


- The significance of ageing as an autistic person
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- How do autistic people experience menopause?
- What about trans and non-binary people beyond?
- Supporting autistic people through menopause



Content warning: self-harm, suicide and mental illness.



Ageing is often an  
anxious topic for  
autistic people and  
their families.




**“I suddenly realised, oh shit, my husband could die, in fact my husband IS going to die before me probably, and I'm going to be on my own”**

*Moseley (2021)*

**“Many of us, autistic people, wonder how our old age will look like... I ask, who will look after me if I need care?”**

*Cos Michaels (2016): Why we need research about autism and ageing.*



*Priority #3: 'The importance of continued support **throughout the autistic person's life**, not just focusing on autistic youth'.*

"How can services be designed or adapted to be more person-centred and high quality for autistic people **across the lifespan**...?"

Cage et al. (2024)

1. Understanding co-occurring conditions
2. Adult transition
- 3. Lifespan issues**
4. Health and wellbeing

Frazier et al. (2018)

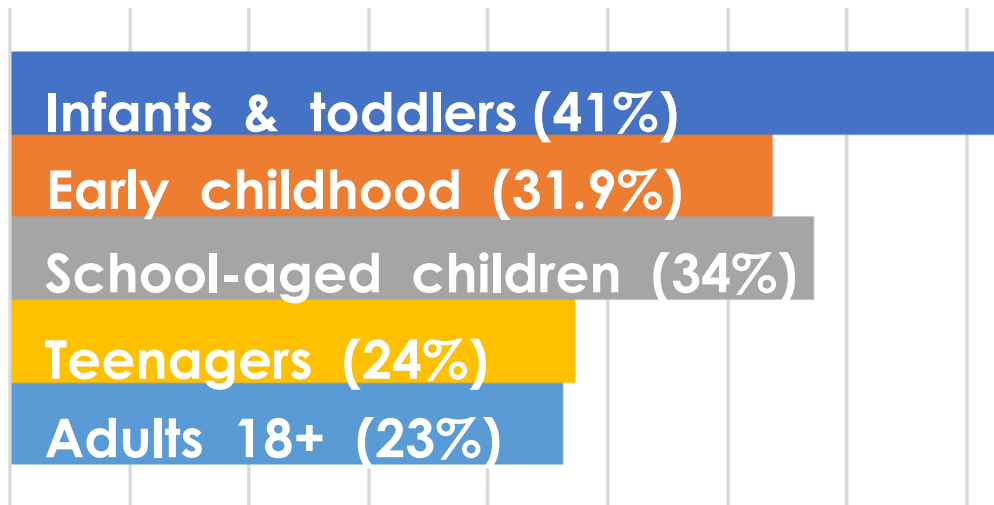
1. Skills development & training **from childhood into adult employment**
2. Physical and mental health & wellbeing
3. Availability and accessibility of services **across the lifespan**

Roche et al. (2021)

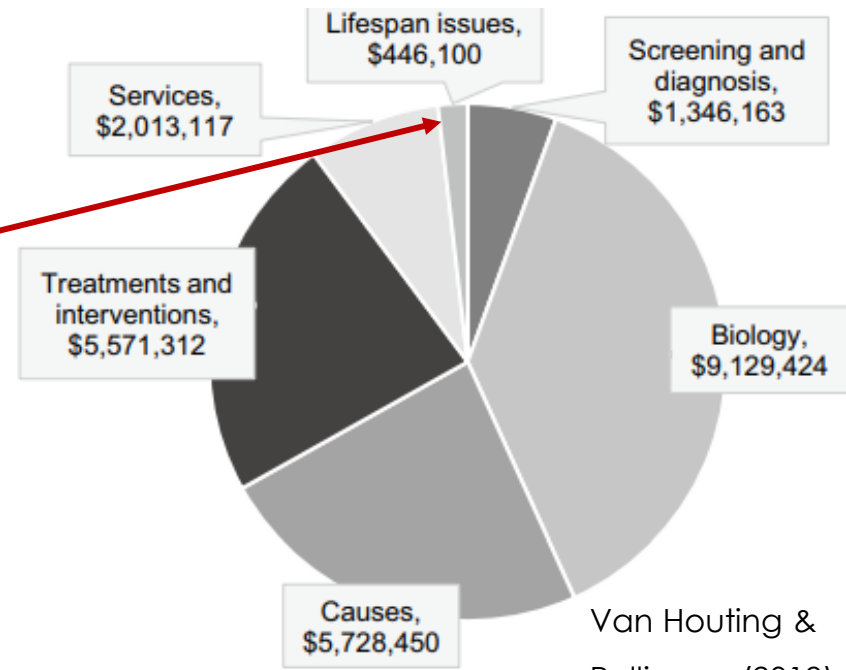


**And yet...**

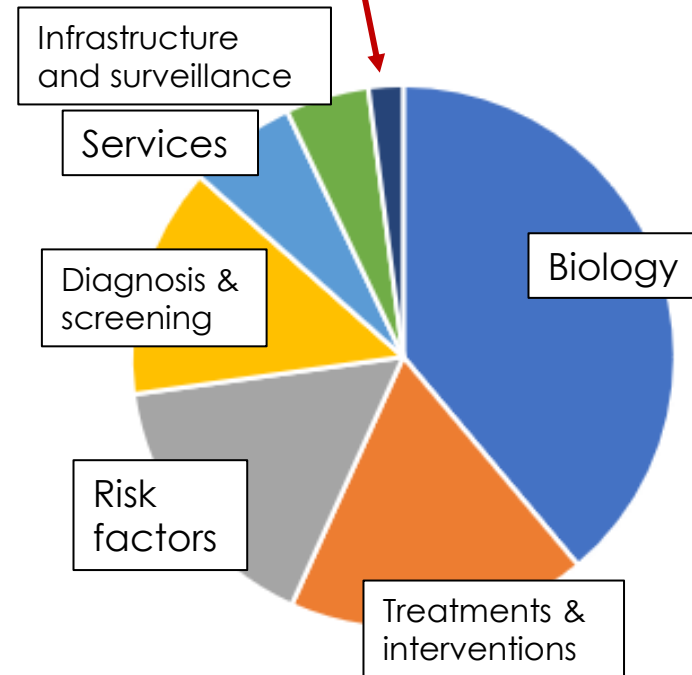
Cervantes et al. (2021): NIH funding across 2008-2018




**Lifespan issues**



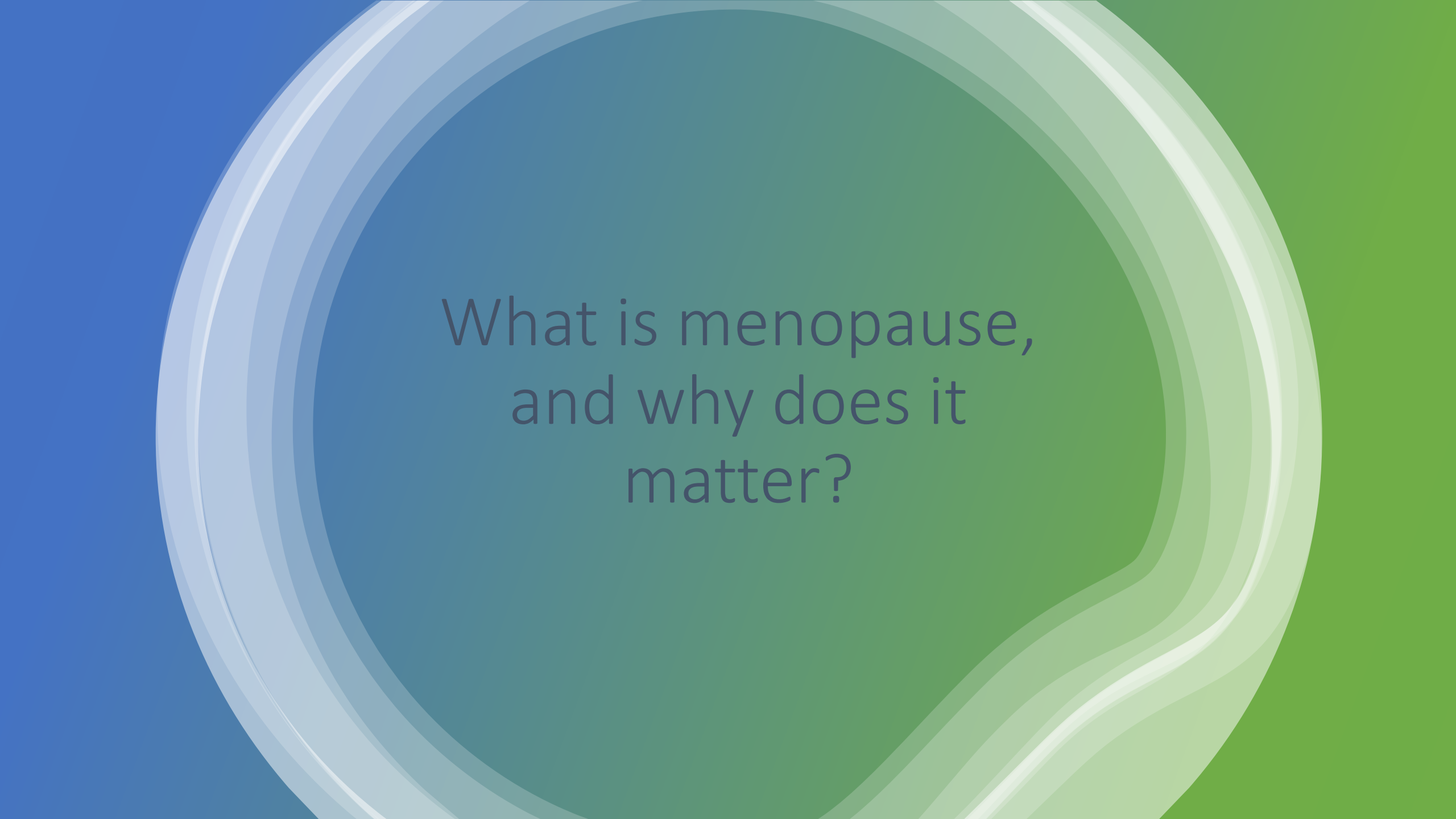
Van Houfing & Pellicano (2019): research funding in AUS 2008-2017



Harris et al. (2021): number of US-funded studies 2017-2019

The image features two decorative curved bars, one in the top-left corner and one in the bottom-right corner. Each bar is composed of two segments: a darker blue segment on the outer edge and a green segment on the inner edge, both curving towards the center of the page. The text is centered in the white space between these bars.

We really need services  
and research to keep up  
with us as we age.



What is menopause,  
and why does it  
matter?

# Audience participation time

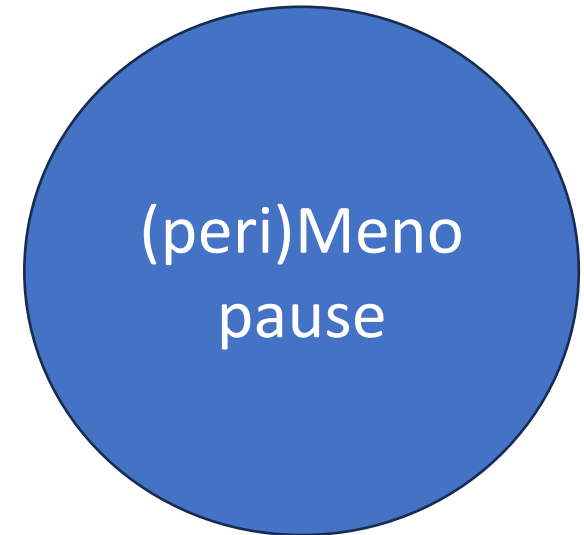
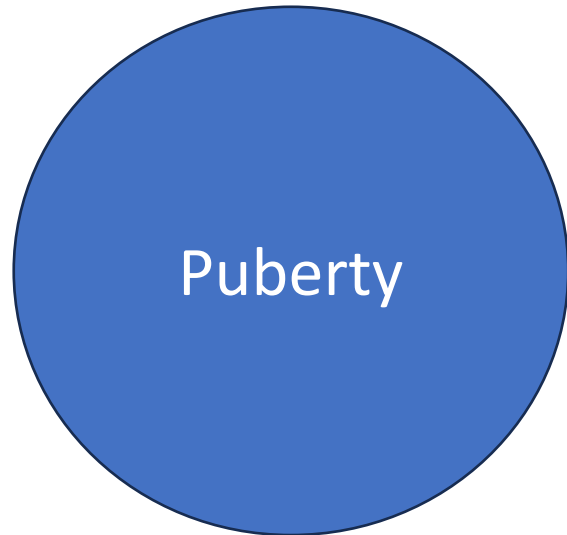
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the code:

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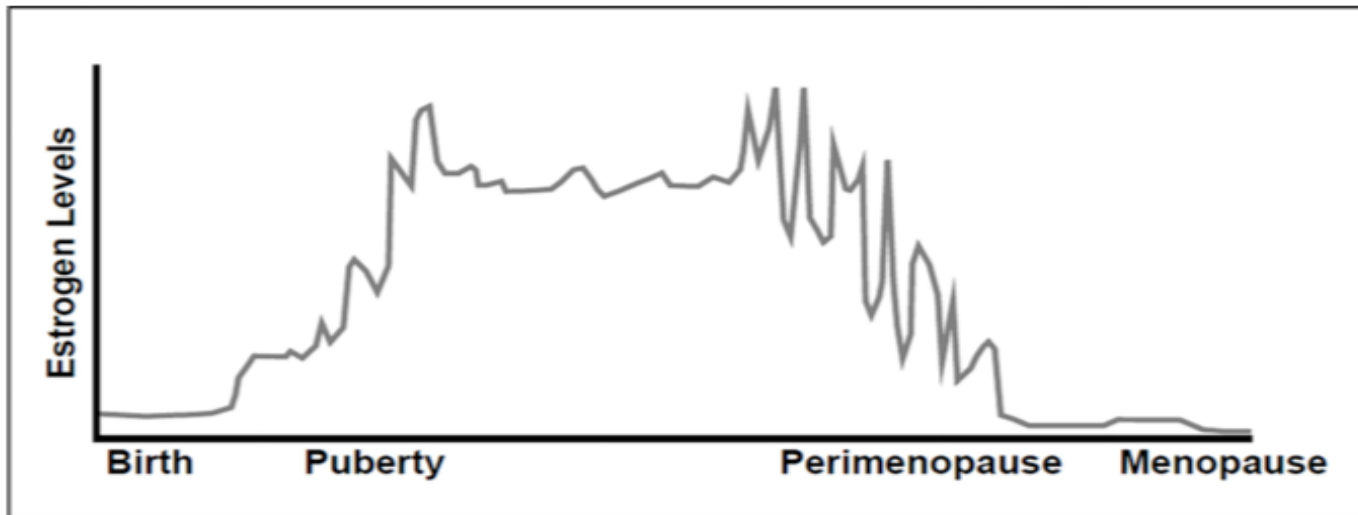
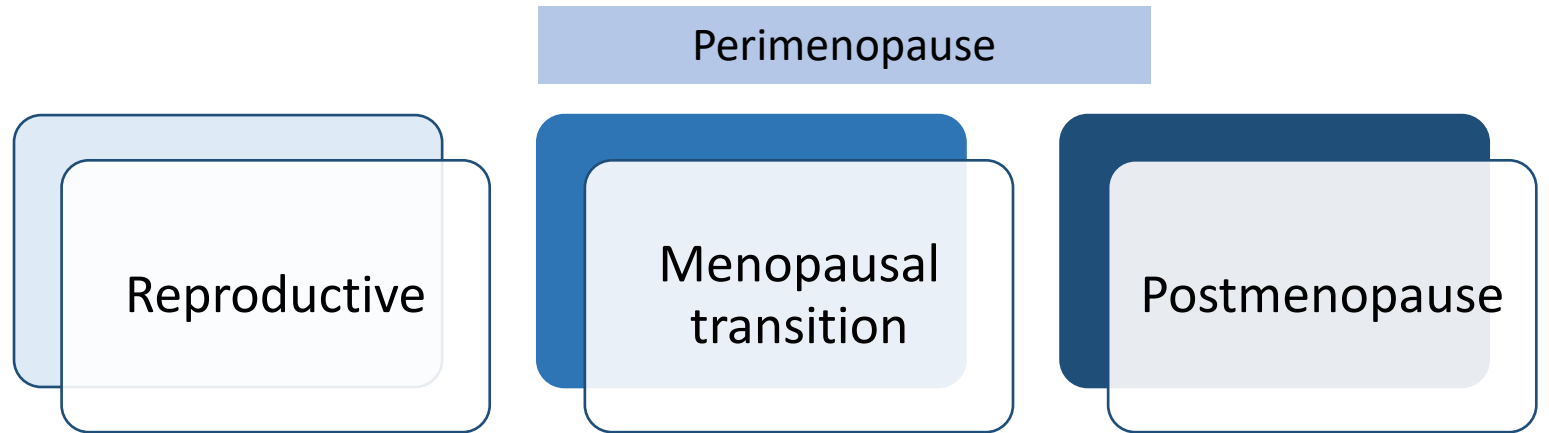


Menopause is *one of several* critical stages in lifespan development...

... sensitive phases of increased vulnerability to stress, mental and physical ill-health



# Three epochs of the reproductive cycle for people assigned female at birth...



*Oestrogen levels across the lifecourse in people assigned female at birth (Hoyt & Falconi, 2015)*

## And those symptoms...?

- Symptoms start a few months or years before periods stop
- On average, most symptoms stop about 4 years after last period
- 1 out of 10 women experience symptoms for up to 12 years

Change in normal pattern of periods

Hot flushes/flushes

Night sweats - night-time hot flushes

Difficulty sleeping – daytime tiredness & irritability

Reduced libido (sex drive)

Problems with memory and concentration

Vaginal dryness

Headaches

Mood changes – low mood or anxiety

Palpitations

Joint stiffness, aches and pains

Reduced muscle mass

Urinary tract infections

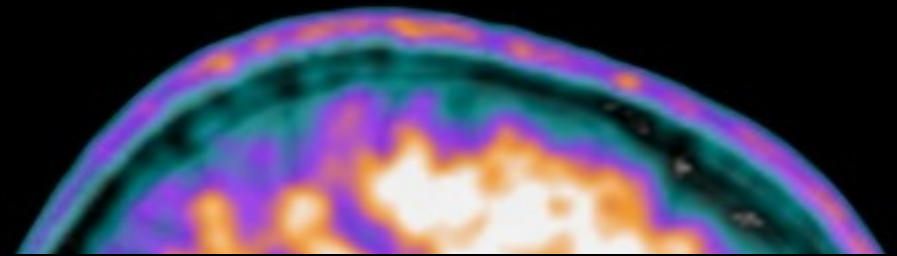
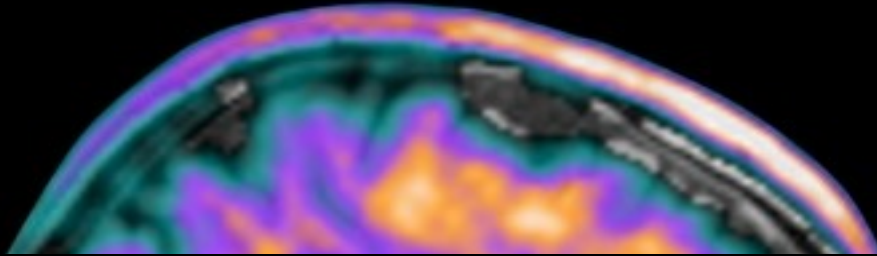


BEFORE MENOPAUSE

AFTER MENOPAUSE

Estrogen receptor  
density

HIGH 



Menopause as a *neurological* transition



How does it *feel*?

please go to [menti.com](https://menti.com) and  
enter the code:

**7815 8635**

# How does it *feel*?

*"I had to leave a well-paid position due to no support. I lost my house, my confidence and my self-worth. I felt like a failure."*

*"I was just a shell"*

*"It didn't really stop my social life as such, but it definitely had an impact on relationships, on my self-worth. Feeling of not being worth – they were definitely really strong"*

**1/2**

said menopause  
had a **negative**  
impact on  
their home life

**1/2**

said menopause  
had a **negative**  
impact on  
their sex life

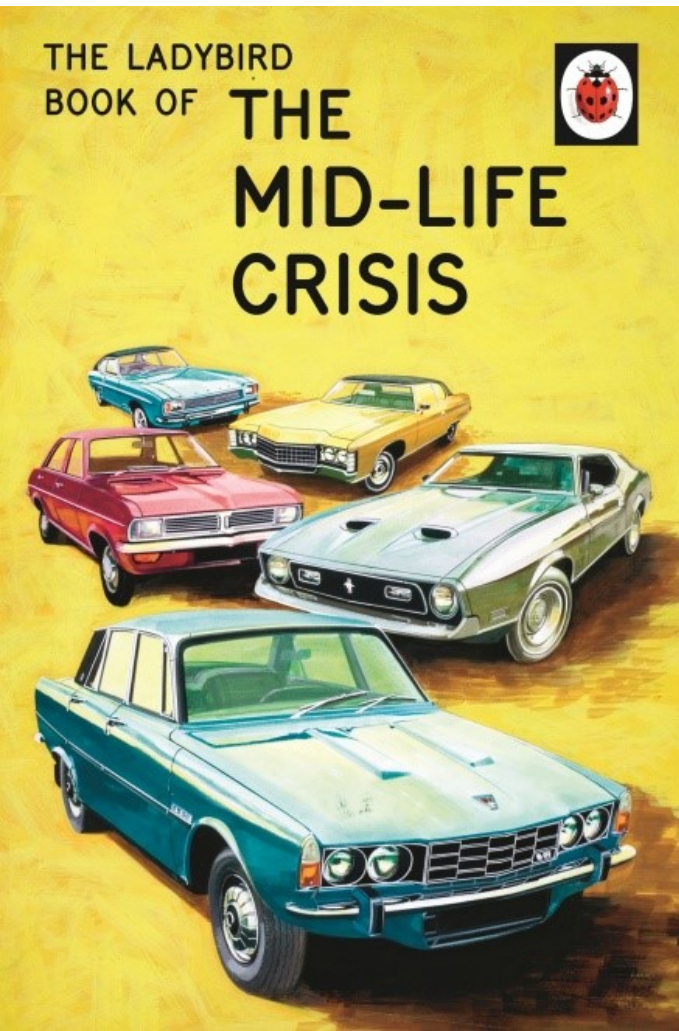
**4 in 10**

said menopause  
had a **negative**  
impact on their  
work life

**3 in 10**

said menopause  
had a **negative**  
impact on their  
social life

This reminds us of the wider backdrop  
of menopause... *midlife*



- Multiple role demands
- Financial pressures
- Redundancy
- Divorce
- Age discrimination




Our past affects how we experience menopause (and midlife)... and how we experience menopause affects our future health and wellbeing



Our past affects how we experience menopause (and midlife)... and how we experience menopause affects health

Note these are population-level trends: we're not yet at precision-level medicine which could let us predict difficulties before menopause begins



Why might menopause be  
difficult for autistic  
people?

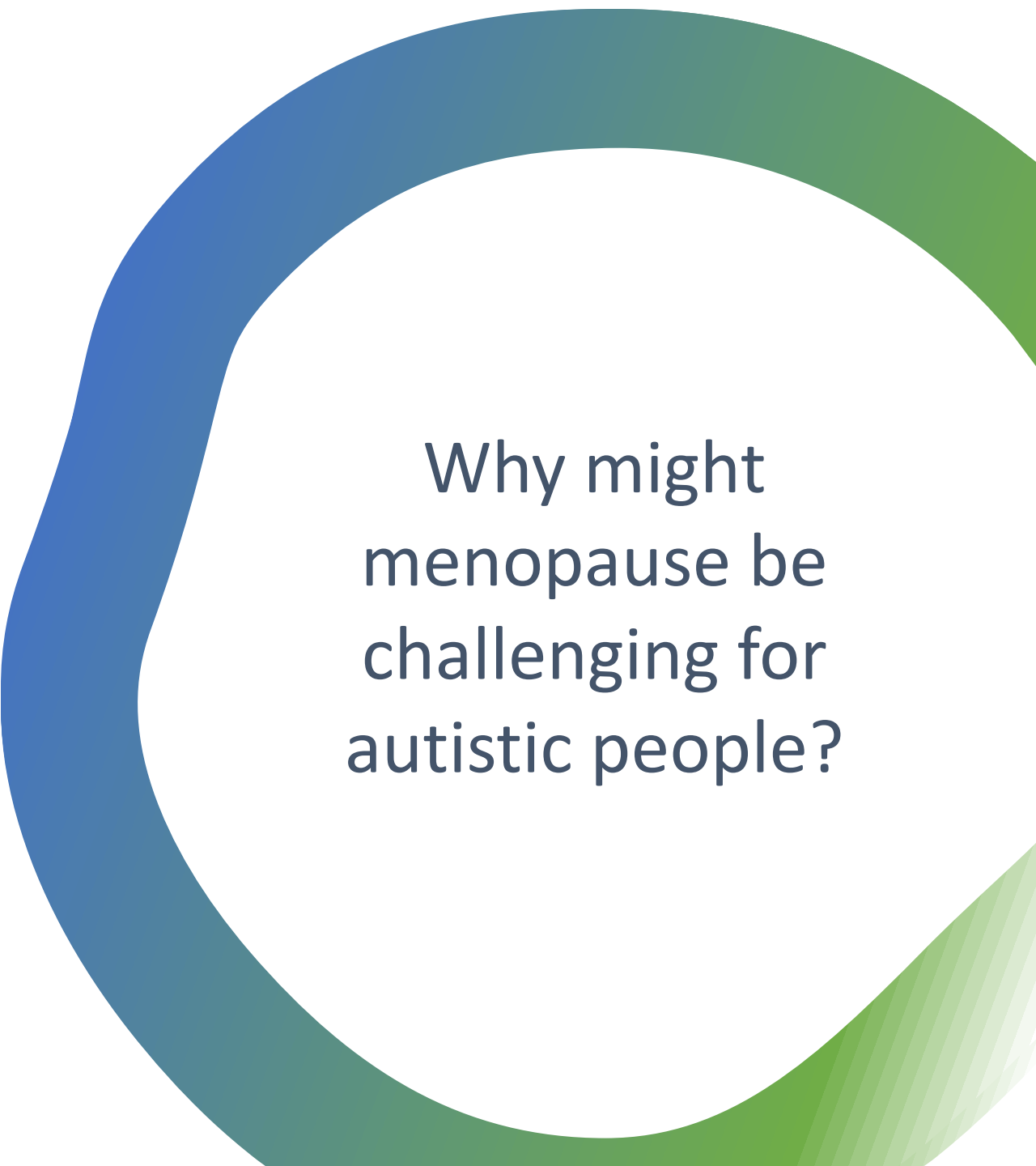


Research tells us that reproductive transitions are really difficult for autistic people

- Hormone sensitivity
- Menarche, puberty and monthly menstrual cycles are *tough*
- Pregnancy, childbirth and the post-natal period hold their own challenges

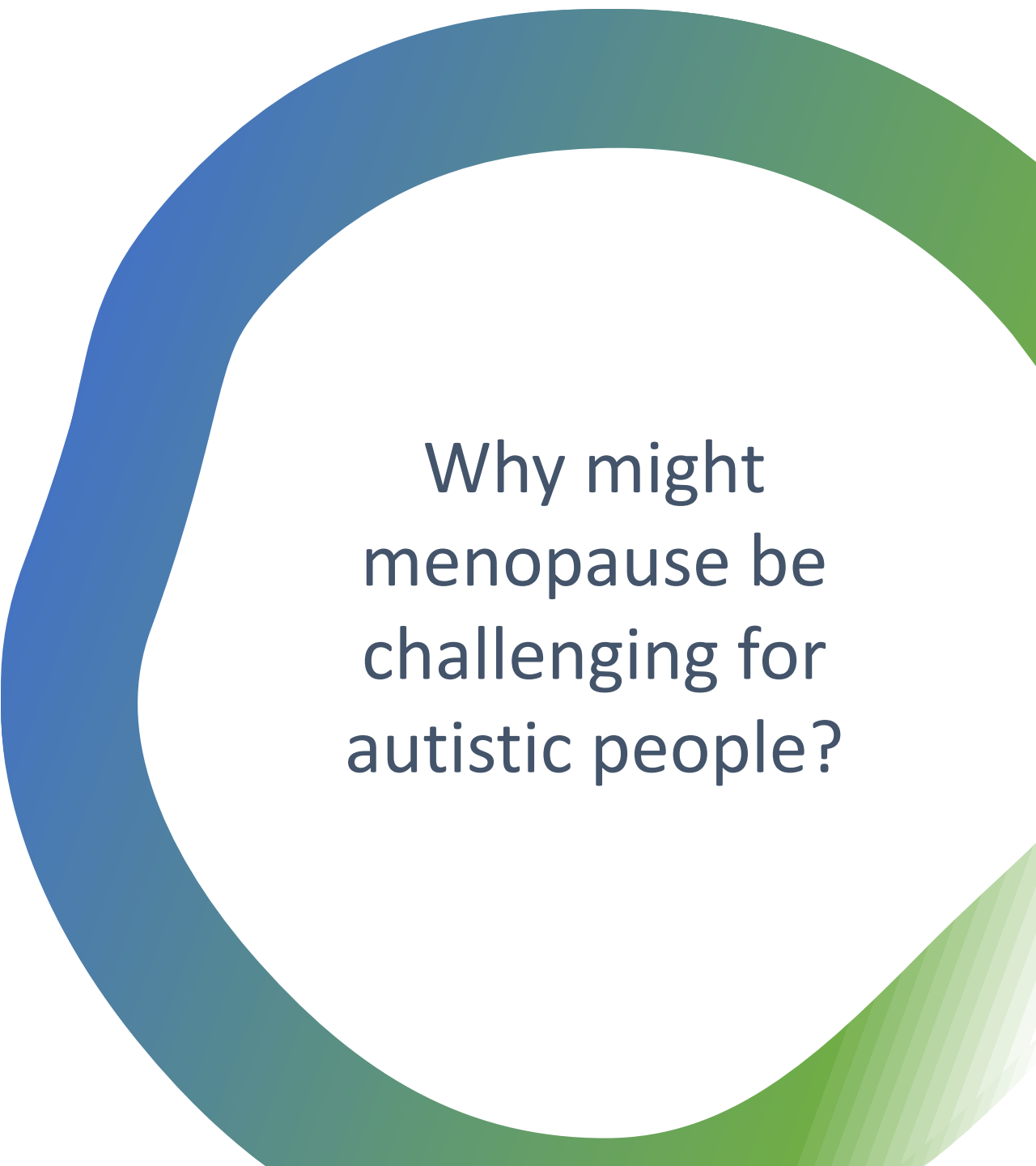


1. Your body and mind change in *unpredictable* and often *uncontrollable* ways



Why might  
menopause be  
challenging for  
autistic people?

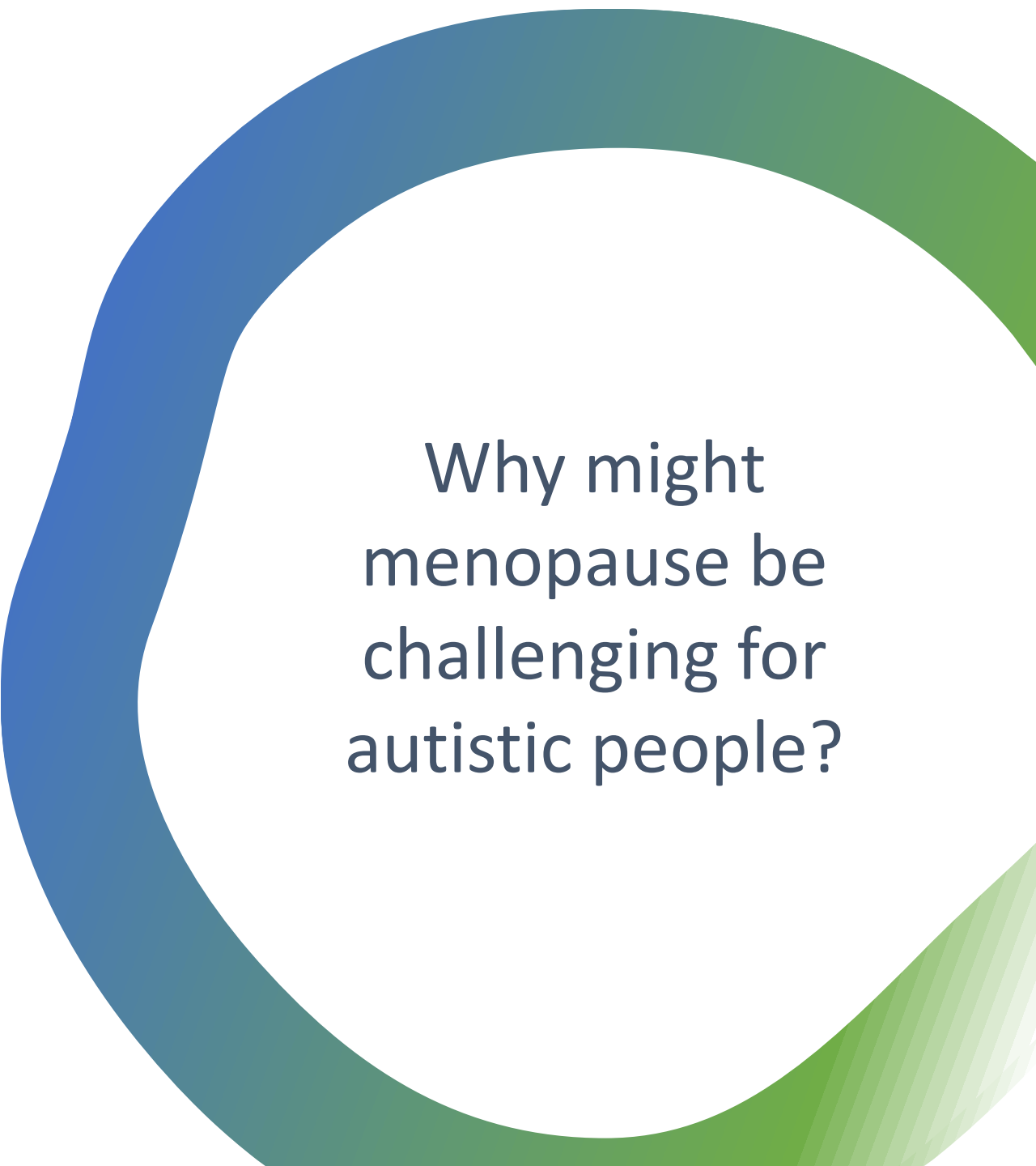
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2. Menopause affects your *thought processes, emotions, mental health* and *sensory experiences*.



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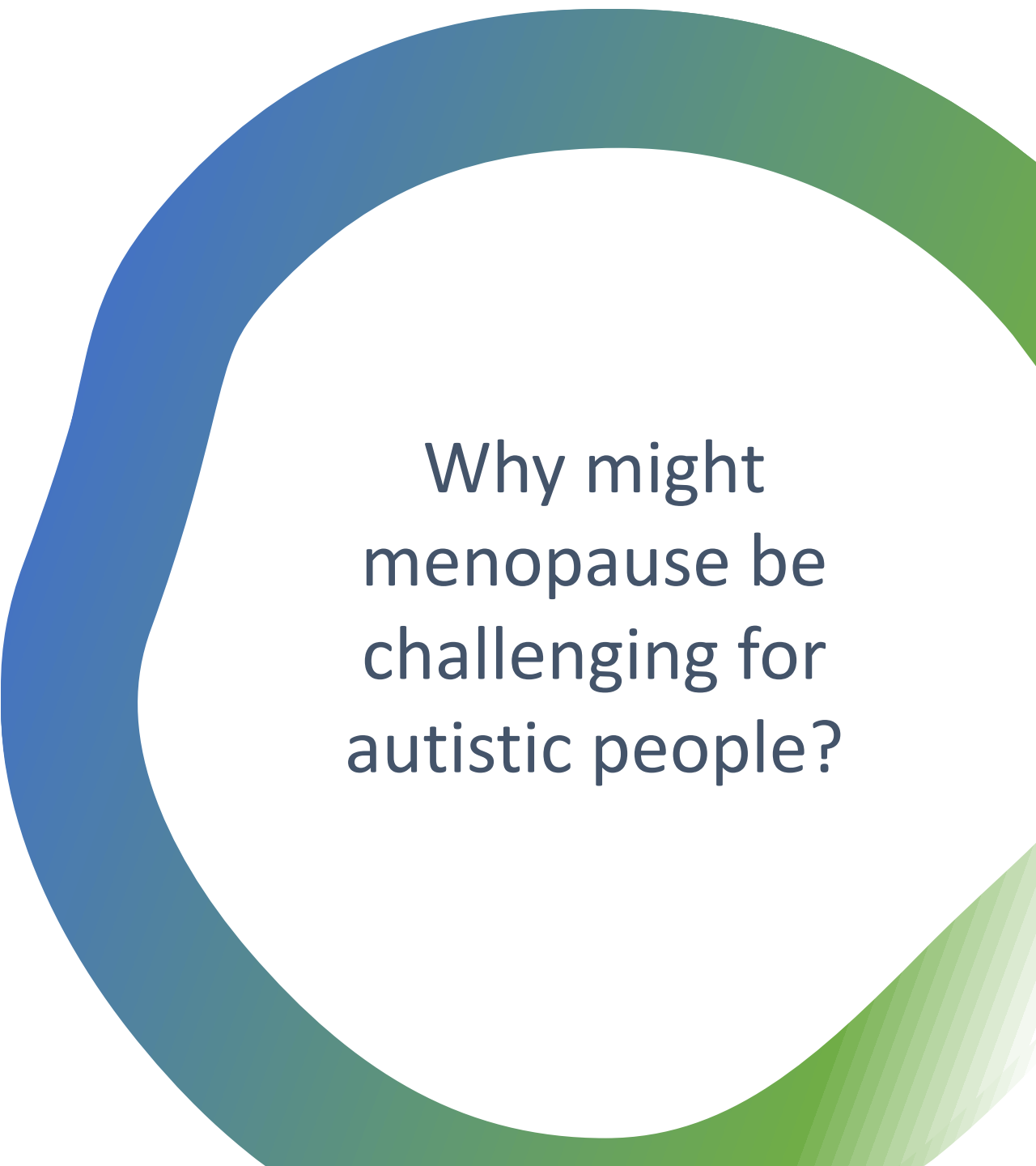
1. Your body and mind change in *unpredictable* and often *uncontrollable* ways
2. Menopause affects your *thought processes, emotions, mental health* and *sensory experiences*.
3. Autistic people may enter menopause **less well-prepared** and with **less social and professional support**.

They may also be less able to communicate their experience to the people they *do* have around them.



Why might menopause be challenging for autistic people?

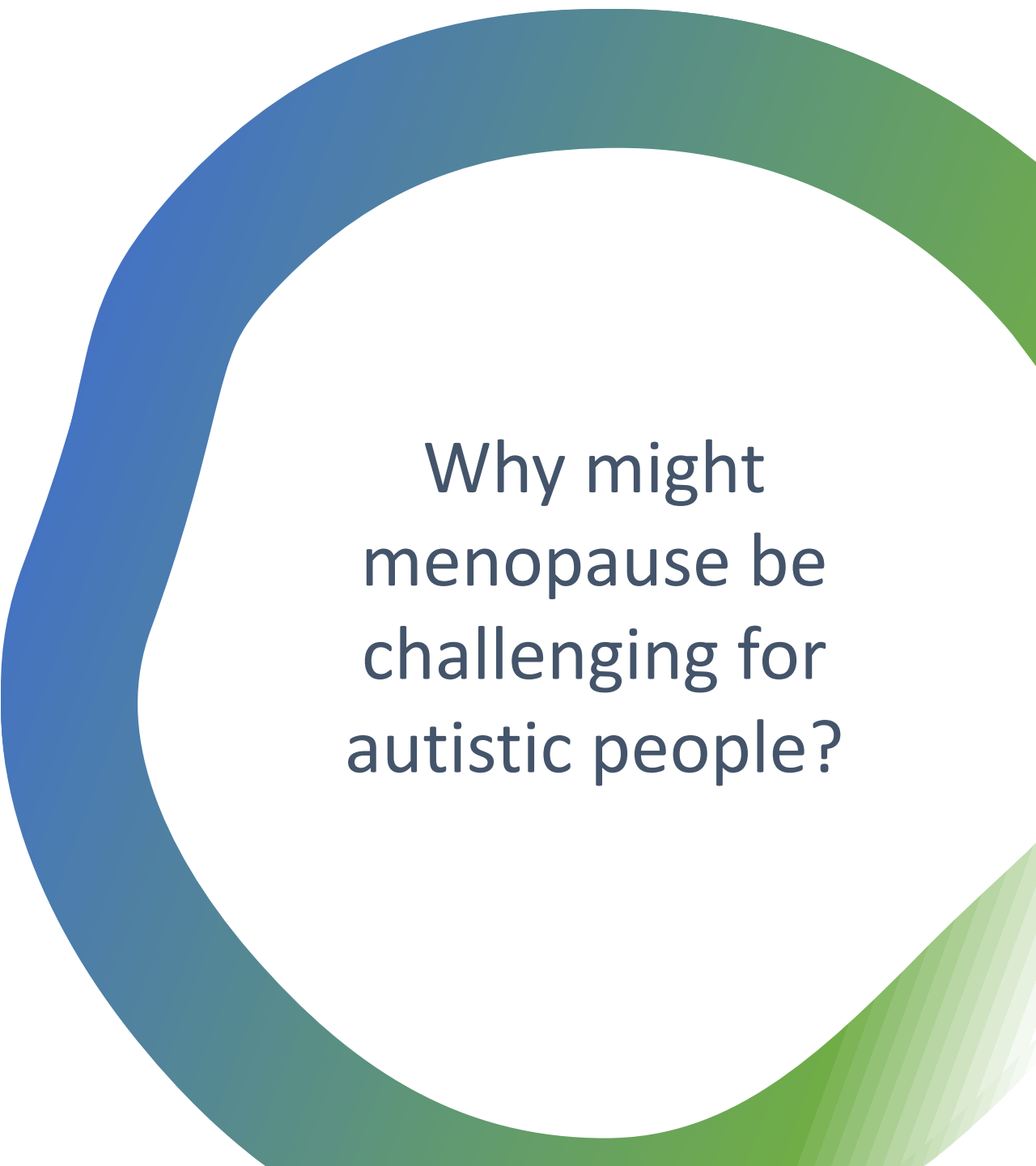
4. They are more likely to have experienced *past trauma*, which affects how you experience menopause.
5. They are more likely to be trans or gender-divergent.



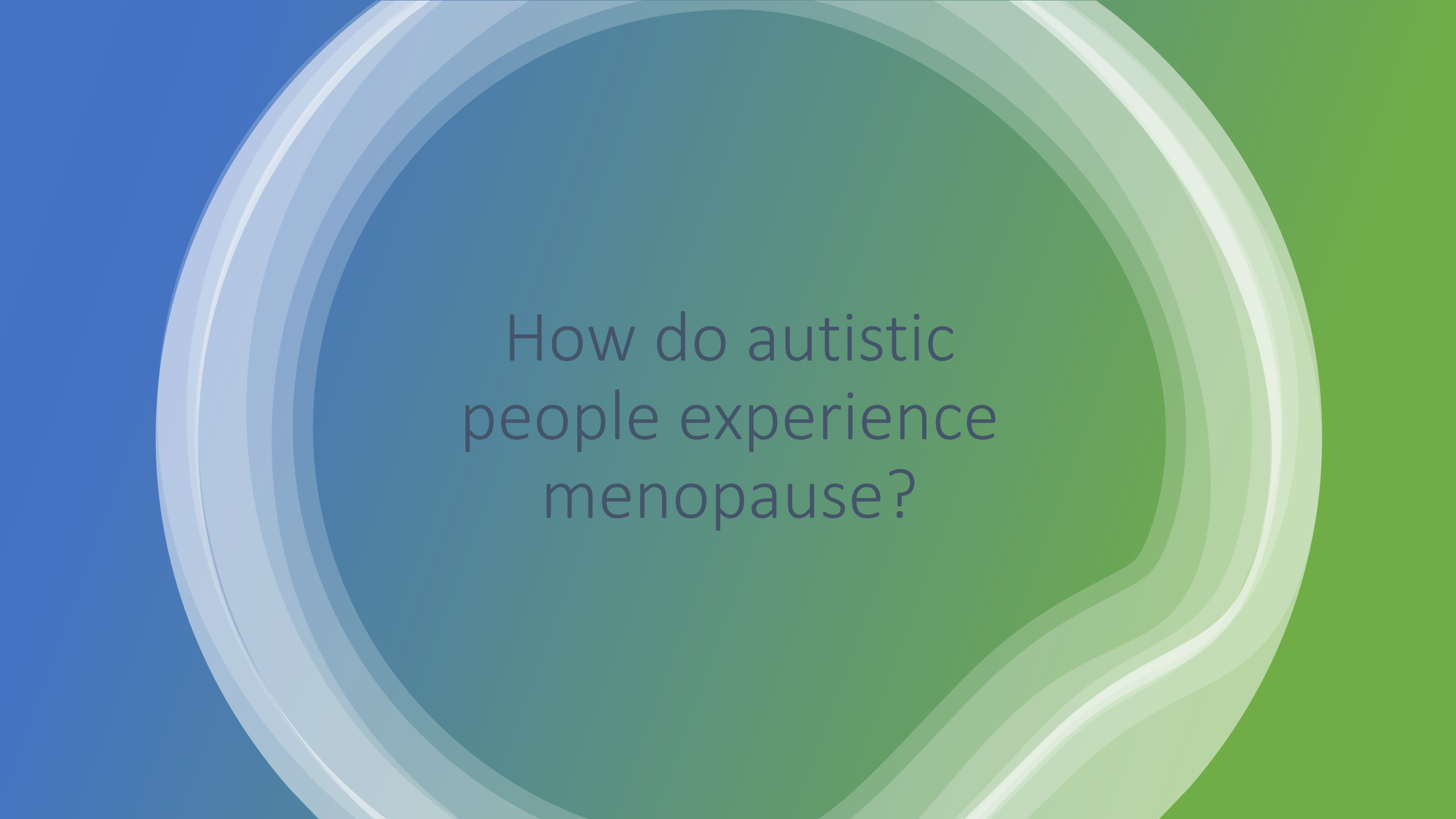
Why might  
menopause be  
challenging for  
autistic people?

6. They may not know they are autistic (especially millennials and older).

That means they cannot get appropriate support or be kind to themselves if they're struggling.



**Why might  
menopause be  
challenging for  
autistic people?**




How do autistic  
people experience  
menopause?

Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2020). 'When my autism broke': A qualitative study spotlighting autistic voices on menopause. *Autism*, 24(6), 1423-1437.

Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2021). Autism research is 'all about the blokes and the kids': Autistic women breaking the silence on menopause. *British Journal of Health Psychology*, 26(3), 709-726.

Brady, M. J., Jenkins, C. A., Gamble-Turner, J. M., Moseley, R. L., Janse van Rensburg, M., & Matthews, R. J. (2024). "A perfect storm": Autistic experiences of menopause and midlife. *Autism*, 28(6), 1405-1418.

Jenkins, C. A., Moseley, R.L., Matthews, R.J., Janse van Rensburg, M., Gamble-Turner, J.M., & Brady, M.J. "Struggling for Years": An International Survey on Autistic Experiences of Menopause. Under review, *Neurodiversity*.



We've focused  
on it from the  
autism angle...

If you could describe your experience of menopause in one word:



A word cloud of various terms used to describe the experience of menopause. The words are arranged in a roughly circular pattern, with 'change' being the largest and most central word. Other prominent words include 'anxiety', 'hell', 'sweat', 'crazy', 'nightmare', 'challenging', 'awful', 'traumatic', 'overwhelming', 'bewildering', 'enlightening', 'soul-destroying', 'exhausting', 'confusing', 'bloody', and 'confusing'.

change

anxiety

hell

sweat

crazy

nightmare

challenging

awful

traumatic

overwhelming

bewildering

enlightening

soul-destroying

exhausting

confusing

bloody

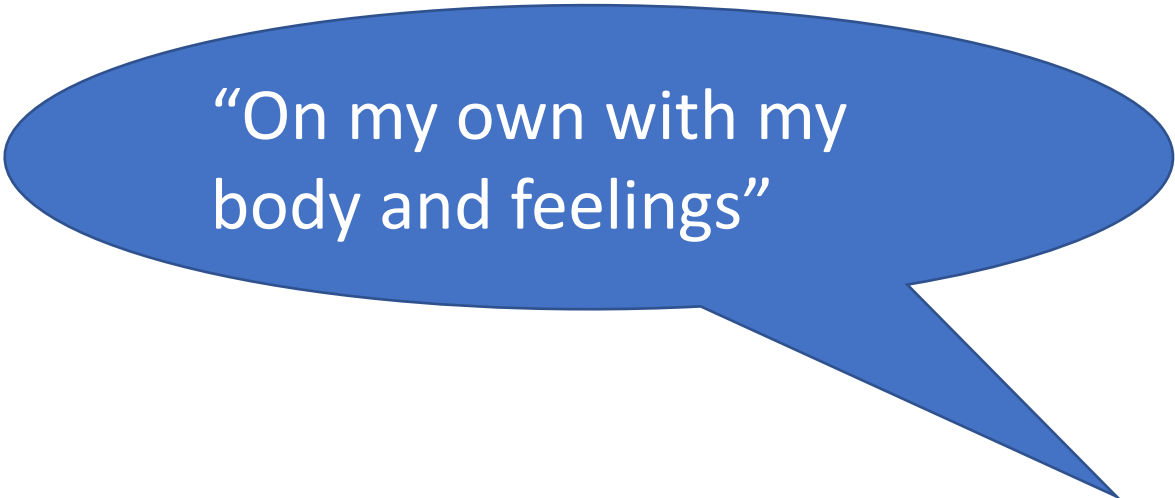
confusing



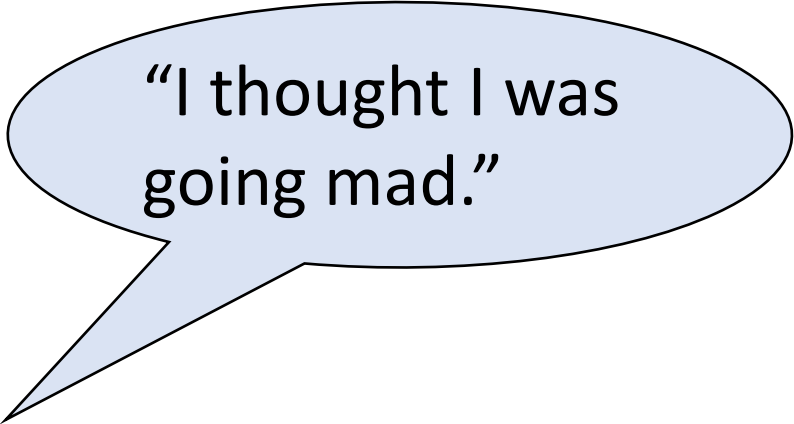


We found that:

1. People often go in unprepared.



“On my own with my  
body and feelings”



“I thought I was  
going mad.”

# We found that:

2. Menopause amplifies *neurodivergent difficulties*, and *neurodivergence* amplifies menopause.

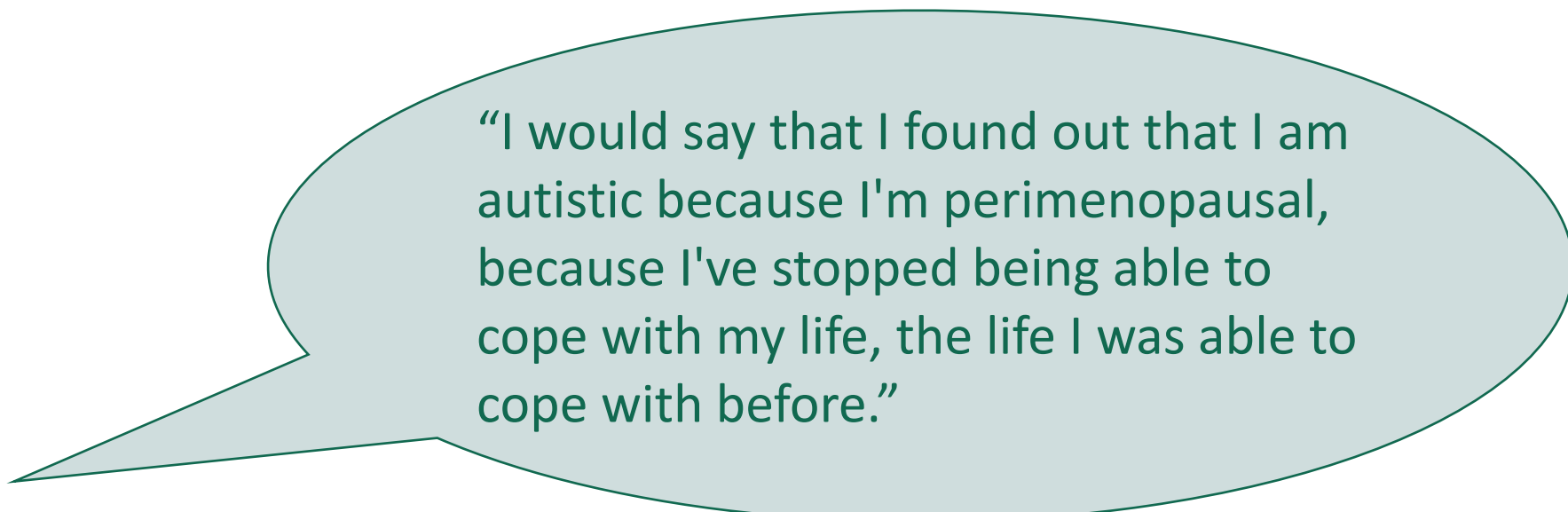
“The experience I had was very abrupt from being quite capable... to being unrecognisable as that person... being autistic can be a challenge but it does give us skills... My most noticeable thing was that I lost my skills [at menopause]... [how do others cope with] being robbed of their skills?”

“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.”



We found that:

2. Menopause amplifies *neurodivergent difficulties*, and *neurodivergence* amplifies menopause.

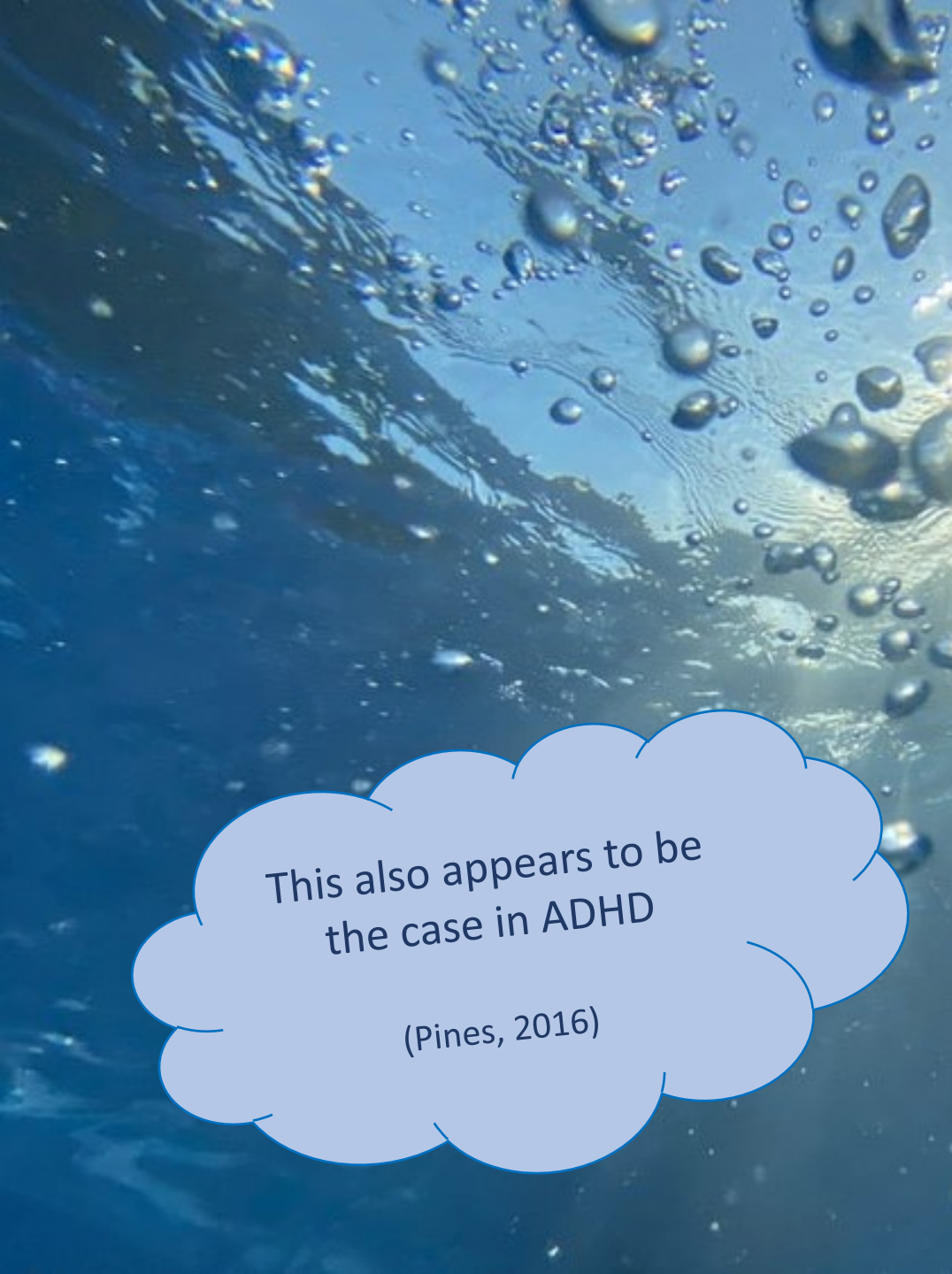


“I would say that I found out that I am autistic because I'm perimenopausal, because I've stopped being able to cope with my life, the life I was able to cope with before.”



“There is something in those hormonal shifts that brings [autism] to the surface ... that makes it more prominent”

(Participant,  
Karavidas & de Visser, 2021)

An underwater photograph showing a large number of bubbles of various sizes rising from the bottom towards the surface. The water is clear and blue, with light filtering through from above, creating a shimmering effect on the bubbles.

This also appears to be  
the case in ADHD

(Pines, 2016)

“Life felt like a gargantuan juggling act. Since childhood I have had on loop in my head the question, ‘what is wrong with me?’

[at menopause] I felt I was deteriorating cognitively... [many] women say peri/menopause is the period in which ADHD had the greatest overall impact on their lives. For a lot of women with ADHD, perimenopause is a brutal and life changing experience.”

([Margaret’s story](#), [balance-menopause.com](http://balance-menopause.com))



We found that:

3. Menopausal symptoms have wide-reaching impacts.

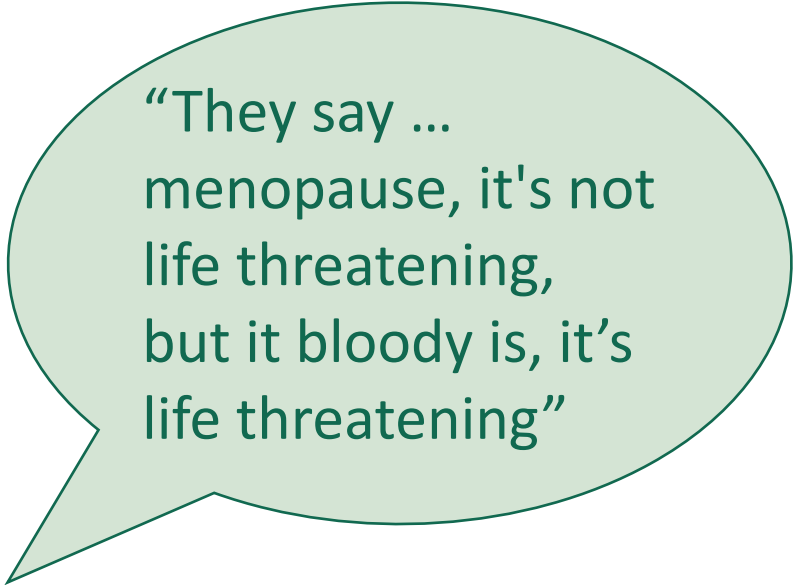
“...a head full of cotton wool and a body which just isn't going to behave.”

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

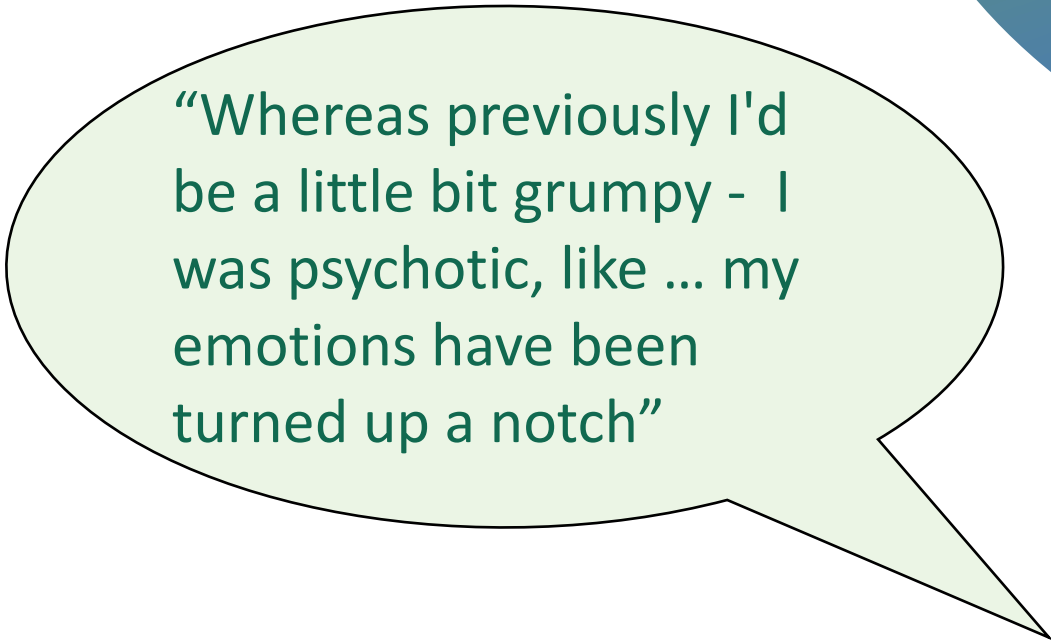


We found that:

3. Menopausal symptoms have wide-reaching impacts.



“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”



We found that:

3. Menopausal symptoms have wide-reaching impacts.

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

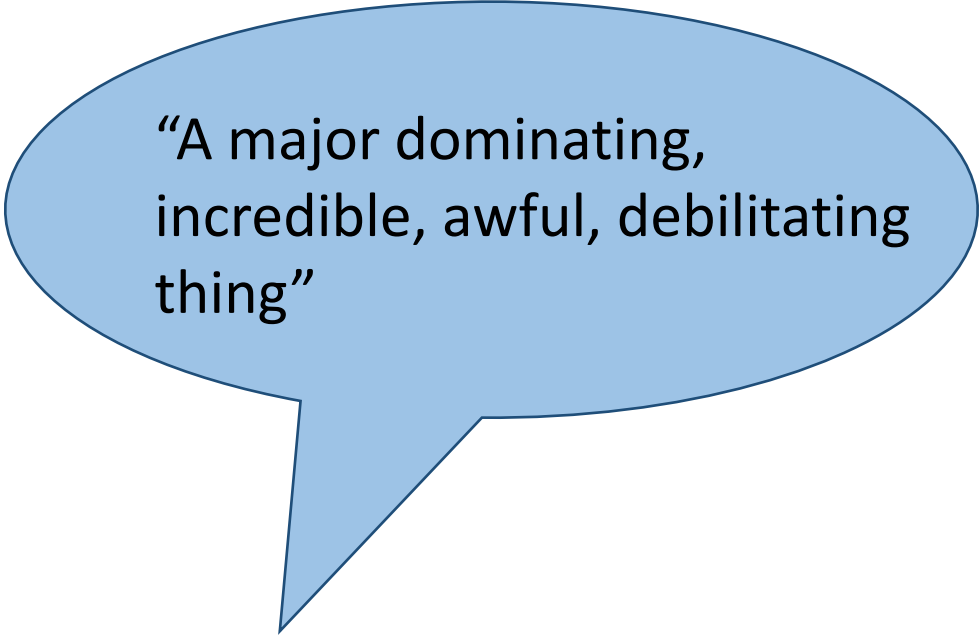
“I couldn't talk to him about it because I just didn't have words for these things”



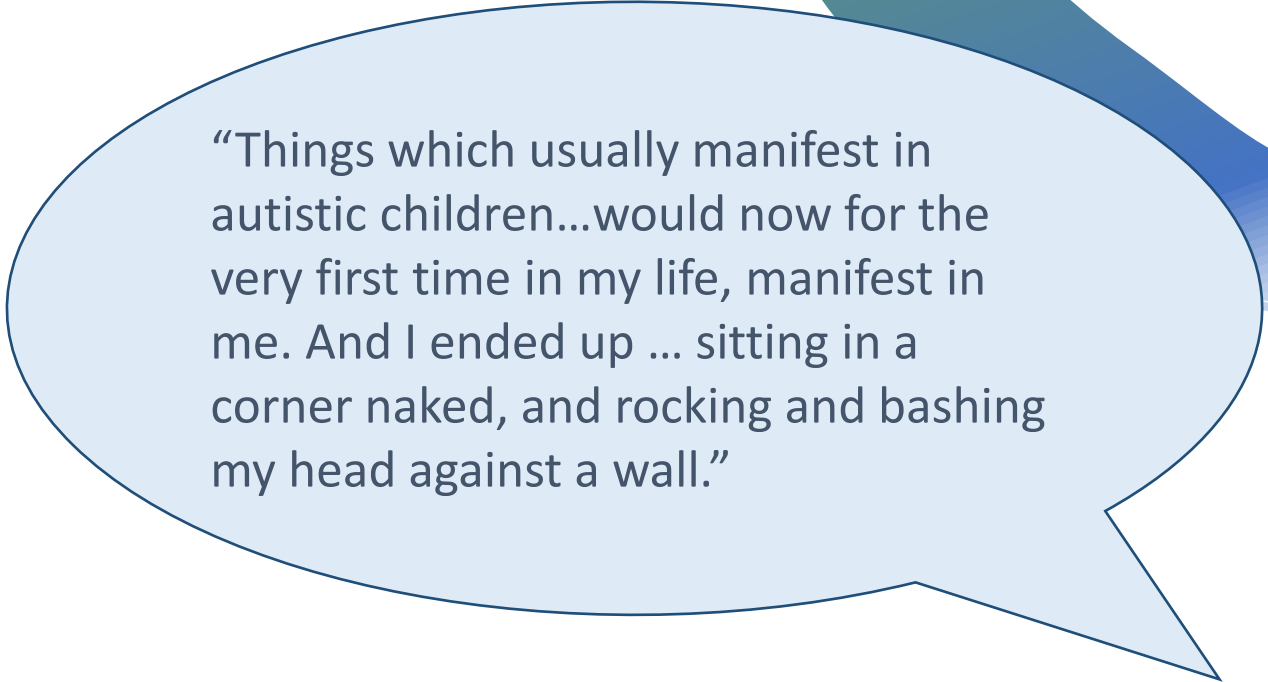


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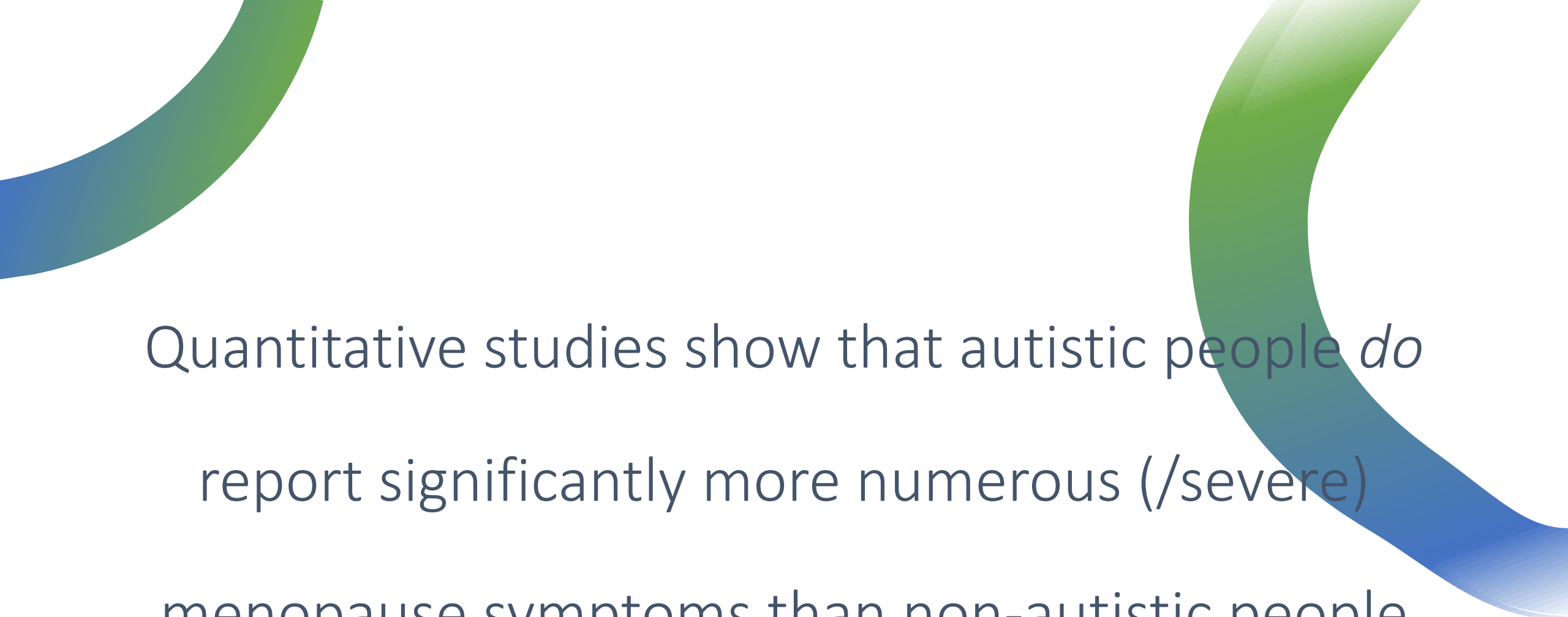
3. Menopausal symptoms have wide-reaching impacts.



“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. And I ended up ... sitting in a corner naked, and rocking and bashing my head against a wall.”




Quantitative studies show that autistic people *do*  
report significantly more numerous (/severe)  
menopause symptoms than non-autistic people

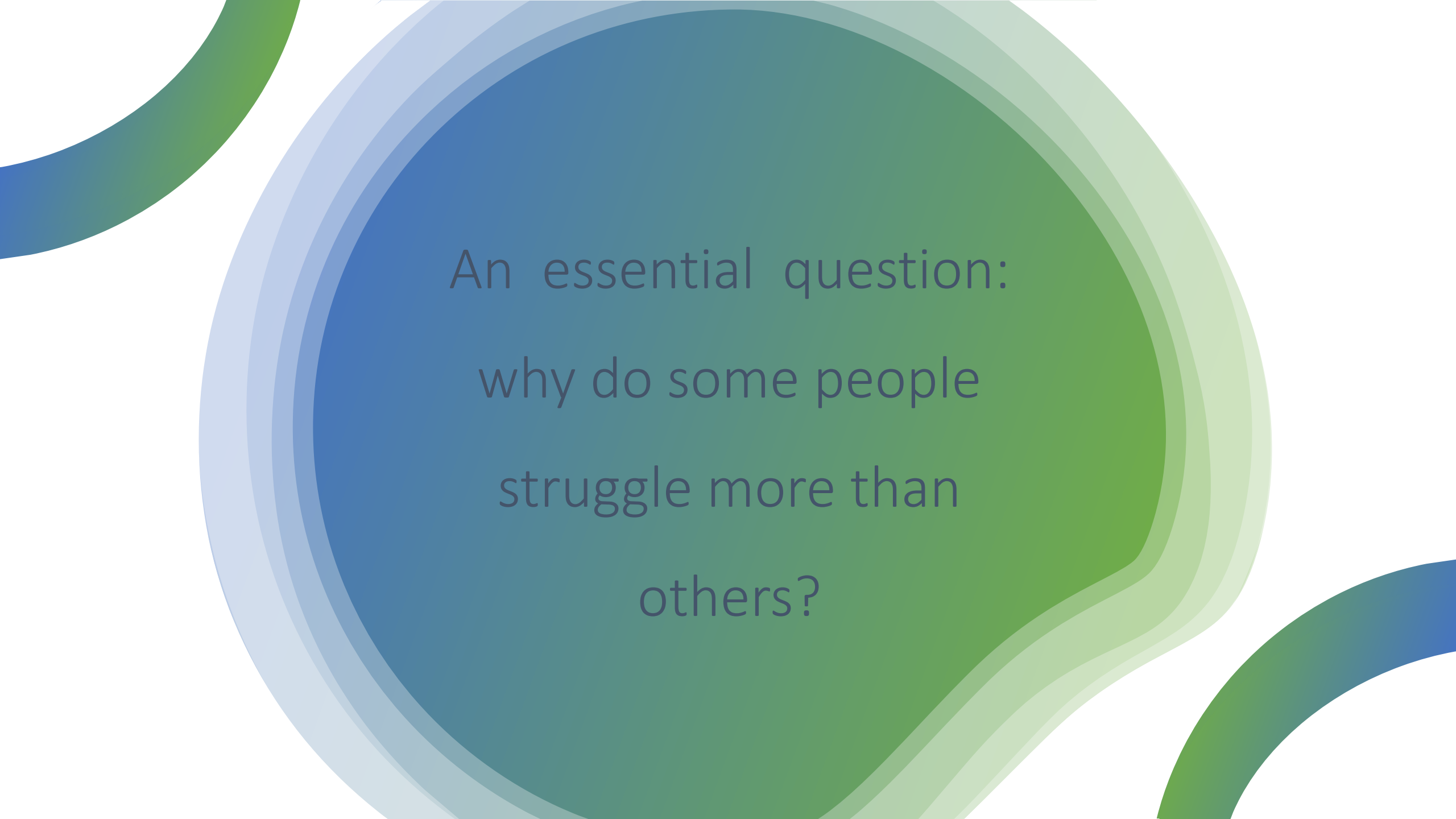
“I didn't really know what was happening”

“Will it happen today? ... It feels like, is it gonna come back?”

“I think I've felt more happier today because I've talked about it”



What about those  
whose voices  
haven't been  
represented?



An essential question:  
why do some people  
struggle more than  
others?

“A Venn diagram of  
chaos”:  
The bigger picture of  
midlife... and beyond

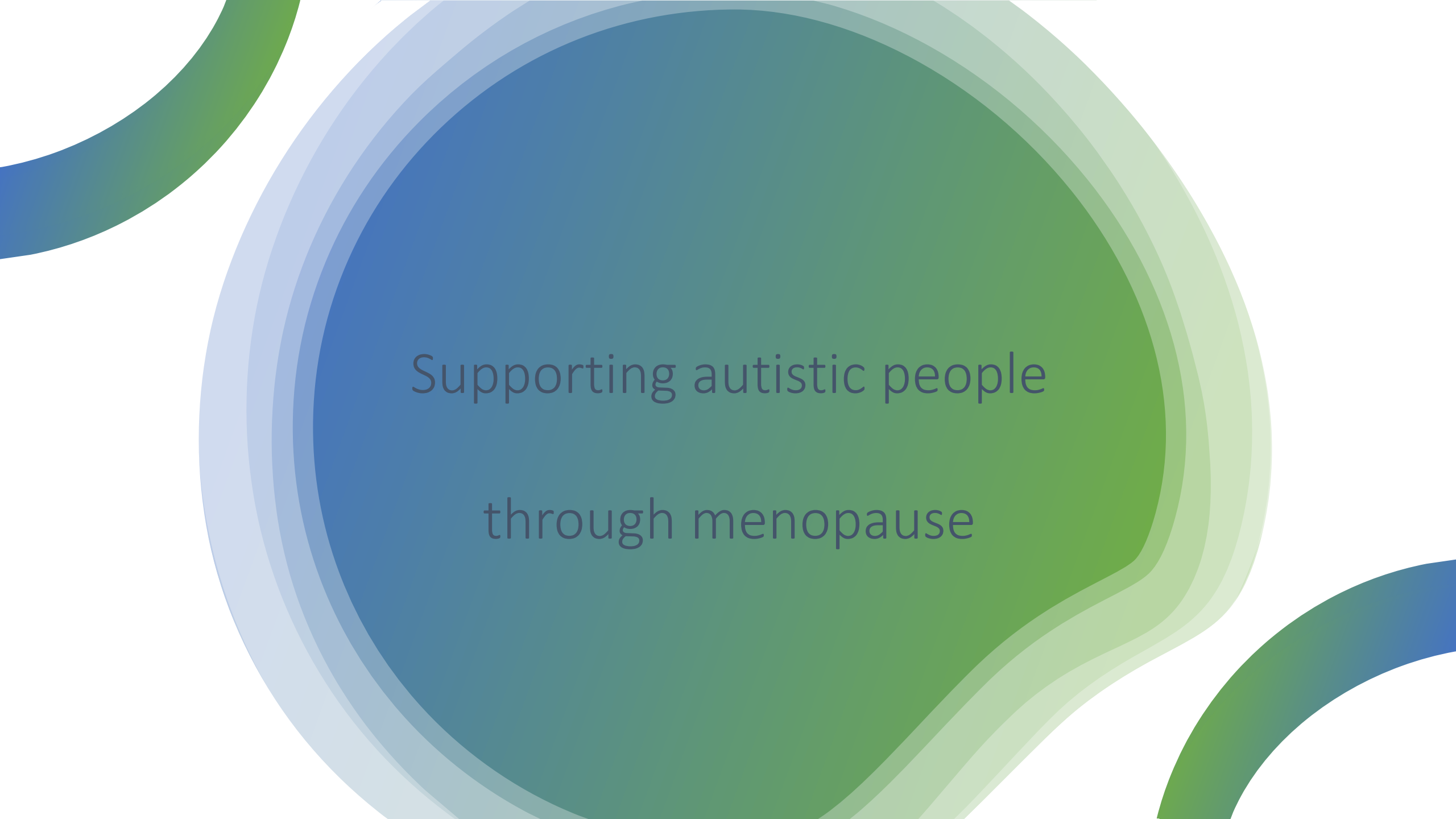


# What do later years look like for autistic people?

*“There are not very many over 50s who even have diagnosis and very few over 70. So how are we even supposed to know what happens when we get older?” (Aitken et al.)*

## What do autistic people need to age well?

- Knowledge about what to expect (autistic role models)
- Understanding your autism
- Having adaptive coping strategies
- Independence and autonomy (“first time in my life I can actually do what I want to do”)
- Peer support
- Social relationships
- Formal/informal support: “practical solutions to sensory needs, emotional recognition, and support with proactiveness”



Supporting autistic people  
through menopause






1. Be aware of reproductive transition points.

Prepare yourself and/or the autistic person you support.



2. Ensure they (and you!) know that

- a) Menopause is different for everyone - they might have very few symptoms;
  - b) If they are struggling, it is not their fault; it is not because they are weak or in any way deficient. There are valid reasons why autistic people might have a harder time;
  - c) Menopause passes;
  - d) There are treatments that can help.
- 




3. Connect them with healthcare or other professionals - but be ready to advocate/support them.

Remember difficulties communicating their experience, 'taking off the mask', asking for help – and that distress may look different.



4. Encourage and support social connections.  
Autistic peer support may be especially helpful.

5. Encourage self-care, sufficient alone time and indulgence in interests/passions.



# Thank you for listening

I have put together a PDF of my favourite resources.

You can find it on my site, along with these slides.

<https://www.scienceonthespectrum.net/talknotes>

*Feedback form on the same page – I'd hugely appreciate it!*

