



Exploring the impact of menopause and neurodiversity





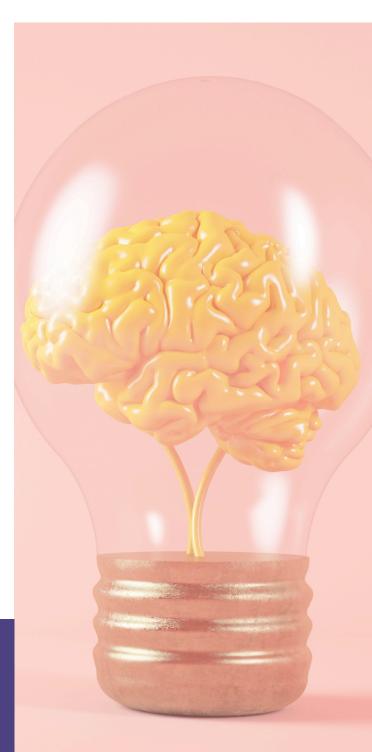
Introduction:

Groundbreaking studies being carried out by researchers at Bournemouth University in the UK are seeking to find how menopause could impact neurodivergent people. Funded by The Menopause Friendly Employer Awards, the research is an extremely welcome part of our understanding of menopause, as we continue to plug gaps in knowledge and better ways to support every individual.

The team at Bournemouth University, Professor Julie Gamble-Turner, Dr Rachel Moseley and Ms Eunhee Kim, explain more about why they're conducting the research, their findings so far and where they are taking it next.

Menopause is a highly individual experience. When we consider it in terms of lifespan, we look at past experiences and health combined with present experiences to enable us to consider each individual's future health trajectory. We wanted to explore the little-understood aspects of how neurodivergent people (e.g. autistic people and people with ADHD [ADHDers]) manage their menopause transition, how their symptoms may differ, and importantly, to gain further insights into how we can support them better.

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Menopause and midlife

On average, menopause occurs in midlife around 51 years of age. This can often be an extremely stressful time with lots of demands. Caring responsibilities for children or parents, financial pressures, redundancy, relationship breakdowns... all these potential events are more likely to occur in midlife.

Ageing brings its own set of losses and gains. On one hand, we might see declines in our functional health, speed of processing and memory. On the other, we gain in knowledge and experience, as well as the ability to regulate emotions. And midlife really sits at the crossroads of these losses and gains.

In terms of ageing for neurodivergent people, there may be particular vulnerabilities around this time, in relation to both aspects of decline and growth. For instance, neurodivergent people are often especially dependent on their parents and siblings for practical and emotional support, which might become problematic as they age.

The process of maturing and developing is driven by our hormonal systems, and there are certain sensitive points in our lifespan. These can result in changes to our physical appearance, reproductive ability and social and emotional development.

Life stages where hormone changes happen are sometimes referred to the three Ps'

- Puberty
- Pregnancy
- Perimenopause

What happens at each of these stages can affect our subsequent health development. As there is an increased vulnerability to physical and mental ill health during these stages these are critical transition points.

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- Perimenopause





Our research

- Our research is focusing on the menopausal transition, from perimenopause to postmenopause. During this time, oestrogen and progesterone levels fluctuate and ultimately decline, while follicle stimulating hormone (FSH) increases.
- These changes can result in a wide range of symptoms during perimenopause, which can be physical, cognitive and emotional. We also see changes in our stress hormones and stress built up over a lifetime could mean certain people are particularly vulnerable at this point in their life.
- This is indeed another indicator that menopause could present difficulties to neurodivergent adults, because they appear to carry a greater degree of accumulated life stress and may experience further stress during their menopause transition. This is why our research is particularly interested in autistic people, although we are keen to hear from non-autistic people too and those with other forms of neurodivergence (like ADHD).

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What does 'neurodivergent' mean?

It's a good idea to clarify exactly what we mean by neurodivergent, as it's such a commonly used word now. Essentially, neurodiversity means there are many different types of human brains and environments which suit certain brains. A bit like biodiversity!

None of us are exactly the same but for the most part our brains and minds are similar enough we can easily relate to each other. But some brains work in markedly different ways and these people find that they communicate, think, experience and interact with the world very differently. We call these people neurodivergent.

These conditions can often go undiagnosed, and it can be difficult to live in the world as a neurodivergent person. ADHD is characterised by the way in which a person controls their attention. ADHDers can often find it difficult to focus, or conversely become hyperfocused. Other examples of neurodivergence include specific learning difficulties, such as dyslexia, dyspraxia and dyscalculia – people with these diagnoses chiefly struggle with reading and writing, motor coordination, and maths, respectively. These conditions are what we call neurodevelopmental – they have a basis in the brain and are lifelong. There is nothing 'wrong' with neurodivergent people – their brains are just wired differently.

Autism is another one of these neurodevelopmental conditions or another form of neurodivergence. The key features are differences in the way a person communicates verbally and non-verbally, such as gestures, eye contact and body language. Generally, autistic and non-autistic people read each other differently and it can be hard for them to understand each other. In autism, we see a preference for sameness, liking things to be done the same way again and again, struggling with uncertainty and unpredictability.

There can also be differences in the way the person experiences their senses. All these differences can affect autistic people at school, in adult life and in the workplace. Autistic people and other neurodivergent people can feel ostracised or victimised by their peers. They can often have very low self-worth and struggle with their mental health, spending a lot of time trying to hide their differences and fit in.





Why menopause might be difficult for neurodivergent people

Studies tell us that reproductive and life-stage transitions can be more difficult for autistic people and ADHDers. They seem to be sensitive to monthly hormonal fluctuations as well as the hormonal changes which accompany the "Three Ps". At these times, features of autism and ADHD can be heightened, with people finding it harder than usual to control their attention, regulate their emotions, and cope with overwhelming sensory sensitivities.

We also know from research that people can find it hard to get the right healthcare during this time, which makes these significant life stages even more traumatic and potentially damaging. When neurodivergent people arrive at menopause they might have had a hard time moving through previous transition points like puberty and pregnancy. Menopause is very unpredictable and largely uncontrollable, and as a key feature of autism is struggling with change and uncertainty, this can also add to the impact.

Menopause can also affect several areas of life which are already hard for autistic people and ADHDers, such as memory and attention and extreme emotions. They often already struggle with mental health so can be vulnerable to another hit there, too.

Also, neurodivergent people might enter menopause less well prepared and tend to have a poorer education, since so many struggle in school with insufficient support. We know that they often become increasingly isolated with age so might miss out on the social transmission of information about menopause and the support that comes from a friendship group.

There can sometimes also be a struggle to access healthcare, so they might not be getting support from their doctor. Being neurodivergent typically comes alongside complex physical and mental health conditions, and people can often feel invalidated when they try to seek help and so are less likely to do so again.

In addition to all of this, neurodivergent people are more likely to have other marginalised identities, such as being transgender or gender-divergent – and it can be hard to get gender-affirmative healthcare during menopause.





The diagnosis issue

Many people actually don't know about their autism or ADHD when they go through menopause. Both autism and ADHD are historically underdiagnosed in people assigned female at birth due to traditional diagnosis criteria that had been mainly focusing on male autistic traits. In addition, camouflaging (i.e. masking), a characteristic of "hiding" their autistic traits to live within the neurotypical social world, have largely impacted autistic people assigned female at birth to live in the blind spot of autism diagnosis.

Growing up undiagnosed is difficult – you know that you're different and so does everyone else, but no one knows why. Individuals can struggle through school, struggle to get into employment and maintain a job, as well as often having trouble with friendships and relationships.

Because they don't know they're neurodivergent they often label themselves – or are labelled by others – as a mess, a failure, stupid, broken.





What we've discovered in our research...

So far, we have published three papers on this topic (links included in further reading). We found that autistic people often enter menopause with little knowledge about what to expect. Across our studies people frequently used the phrase 'I thought I was going mad.'

They know and understood about certain symptoms, such as hot flushes, but didn't anticipate what these would feel like or how intense they would be. This led to some people being extremely frightened or confused about what was happening to them.

In many cases, it can be something of a vicious circle. Autism affects how a person experiences menopause and menopause exacerbates how they experience autism. Some people said that menopause "floored" them. They couldn't function or leave the house. Some people said they lost the positive aspects of their neurodivergence, such as the hyperfocus of ADHD, and were just left with the more disabling aspects. And, alarmingly, some told us that menopause was life-threatening to them in terms of its impact on their quality of life or mental health: some attempted suicide during this time.

Something of a silver lining in the extreme turbulence of menopause was that for some people, it led to their finally realising that they were neurodivergent. Many of our undiagnosed participants had struggled throughout their lives, but menopause derailed their lives tosuch an extent that they were no longer able to cope and were finally diagnosed with autism or ADHD during this time.

Since we've published this work, we and other researchers have found similar stories reported by independent groups of autistic people and ADHDers. Across these studies, people are suggesting that menopause is more difficult when you're neurodivergent and undiagnosed. And some felt that knowing beforehand about their neurodivergence would have helped them put more coping strategies in place, and be more self-compassionate.





What we've discovered in our research...

We also found that menopause symptoms have wide-reaching impacts. Autistic people seem to have a lot of the same physical menopause symptoms as non-autistic people but experience them much more intensely. These can include things like night sweats, hot flushes, irregular periods, insomnia, fatigue and flare ups in chronic illnesses.

There are also broader challenges in terms of cognitive, emotional, social and sensory changes. These can include losing the ability to manage multiple tasks, meet deadlines, plan ahead or pay full attention. Some people we spoke to lost jobs or fell into financial arrears, or became highly dependent on elderly parents, to the detriment of their self-esteem and mental health. Others reported being utterly exhausted, with extreme fatigue and burnout.

Coping strategies which might have previously worked often failed during menopause, with people becoming much more prone to stress, meltdowns, and in some, self-injury and suicide attempts. They felt much less capable of social interaction, finding it impossible to maintain the 'mask', with communication much more difficult. Many also struggled to communicate their distress to doctors and loved ones, leading to increased isolation.

Our participants pointed out that menopause was happening at the same time as many other changes in their lives. They were experiencing changes in their social networks, with parents ageing, becoming ill or dying, marital relationships breaking down, or supporting partners and children through their own health issues or neurodivergence.

It's important to clarify that not all autistic people struggle at menopause, and some we spoke to had relatively few symptoms. But we don't tend to hear from people who have had an easier time, and those who struggle tend to participate more in research. Reassuringly, although we did not have many post-menopausal participants, those who did speak to us suggested that their symptoms did abate on the other side. Though they might not have felt the same as they did prior to menopause, things got considerably better than how they had been at their worst point. Moreover, some experienced menopause as a springboard to living a happier and more authentic life, finally aware of the crucial fact of their neurodivergence.





Our next steps

We've answered many questions so far in our research, but important questions still remain. We've launched some follow-up work to explore these, so that we can improve understanding of health and wellbeing during menopause and start to help people find the support they need. In this new work, we want to understand why some autistic (and non-autistic!) people have such a hard time at menopause; for instance, might this be related to mental health symptoms and stress, or to features like sensory sensitivity?

We want to understand how autistic and non-autistic symptoms of menopause might differ, and explore the factors that might impact people's quality of life and mental and physical health?

We're collecting data now and will have some more findings to share over the coming months and years. The more we can do to raise awareness of the impact of menopause on neurodivergent people, the better we can start to understand how to support them through the transition.

Links to our research

- <u>'When my autism broke': A qualitative study spotlighting autistic voices on menopause</u>
- Autism research is 'all about the blokes and the kids': Autistic women breaking the silence on <u>menopause</u>
- <u>"A perfect storm": Autistic experiences of menopause and midlife</u>



<u>Article summarising the research</u>

