

Written evidence submitted by Dr Rachel Moseley [WRH0022]

I am [Dr Rachel Moseley, principal academic in Psychology at Bournemouth University](#). My research focuses on wellbeing, mental health and suicidality in autistic people. My colleague and I conducted the first ever research on autistic experiences of the menopausal transition ([study 1](#); [study 2](#)). We have conducted three other studies on this topic which await publication.

My evidence will focus on **autistic women and autistic people with ovaries*** as a disadvantaged group in relation to reproductive health. I will focus on their **experiences of menopause**** , though I will refer to broader reproductive health in this group.

** Note: Autistic people are significantly more likely to be non-binary or transgender (see, for e.g., [Warrier et al., 2020](#)). This means that non-binary or transgender autistic people will also be affected by the kind of issues included within “Women’s reproductive health” – including menopause).*

*** Note: By ‘menopause’, I refer to the whole menopausal transition, from peri- to post-menopause.*

To contextualise my evidence, the following points are relevant:

- Menopause seems to be a time of particular difficulty and potential crisis for autistic people: described by one of our research participants as **“a dominating, incredible, awful, debilitating thing”**
- Menopause can amplify existing challenges associated with autism – e.g. it exacerbates sensory sensitivities; makes emotional dysregulation worse (such that emotions are more overwhelming and difficult to manage); intensifies pre-existing difficulties with memory, organisation and planning. Autism also amplifies symptoms of menopause, such that symptoms like hot flushes become highly disabling.
- Some autistic people who were working had to retire; others went into financial arrears; some became highly dependent on ageing parents; some became unable to manage self-care. (“It makes functioning normally very difficult. I am behind in so much stuff. My self care and cleaning of my clothes/flat etc has reduced practically to zero”; “I’d stay in bed, not be able to move, I couldn’t even have my children around, I become non-verbal”)
- Some autistic people experience extreme mental health crises, self-harm and suicidality at menopause: (“within a day I feel like I can’t live like this”; “I genuinely got to the point last year where I wanted to kill myself. I was... standing on the edge of the... on the pavement looking at the bus thinking it would be so easy just to walk out.”)

1. What disparities exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?

a) *Autistic people struggle to identify that they are experiencing menopause, hence will struggle to seek appropriate help.*

Our published and unpublished work to date suggests that autistic people often enter menopause with little knowledge and awareness of what to expect. Most participants stated that they had little understanding of what menopause was and what it might entail, and what could be done to manage the symptoms.

Many will struggle to *identify* that what they are experiencing is menopause: [“I thought I was going mad... or had some terrible disease”](#)

This means that they will struggle to identify appropriate healthcare services to approach.

To fully understand the context of this, it is important to consider several background facts:

- Autistic people have high rates of mental illness, with women most severely afflicted (see, for e.g., [Hossain et al., 2023](#); [Martini et al., 2022](#)).
- However, it is also true that autism is often under-recognised in women and people with ovaries (see, for e.g. [Lai et al., 2022](#)).
- “Diagnostic overshadowing” often occurs where autistic women and people with ovaries collect a string of other mental health diagnoses when growing up undiagnosed (see, for e.g., [Fusar-Poli et al., 2022](#); [Au-Yeung et al., 2019](#)). A particularly common misdiagnosis is borderline personality disorder ([Iversen et al., 2022](#)).
- Autistic people often have traumatic experiences in mental health services which have failed to recognise their autism and/or adapt services accordingly ([Brede et al., 2022](#); [Camm-Crosbie et al. 2019](#))
- Autistic people have higher than average rates of challenging periods and hormonal conditions which affect the regularity of periods ([Gray et al., 2023](#))

With these broader contextual facts considered, **our research suggested that many autistic people will struggle to identify that menopause is happening for them.** This is down to several reasons:

- Finding it difficult to identify their emotional and physical state; this makes it hard to know when something has changed and what that might be:
- Struggling to differentiate between menopause symptoms, pre-existing or misdiagnosed mental health conditions, and previously atypical experiences of menstruation (“Because my periods are already heavy and difficult that wasn't a clue, and because my mood has always been a bit erratic, that wasn't a clue either”)
- Being isolated and lacking close friends they might learn about menopause from; [“I had little understanding of what to expect, particularly as being autistic \(though not knowing this at the time\) I did not have a circle of female friends to empathise with. I was on my own with my body and feelings.”](#)
- Finding it hard to formulate what was happening to them in words: ““At times I can remember not being able to identify or communicate any of what I was experiencing””

People do not know where to look for help if they cannot figure out what is going on, and often have no faith in the healthcare system – see next point.

b) When they seek support with menopausal symptoms, autistic people often have experiences that are dissatisfying at best and traumatic at worst.

Our studies were not particularly interested in healthcare around the menopause. It is therefore striking that negative or difficult healthcare experiences have emerged as a strong theme throughout all of our work.

The vast majority of our participants expressed dissatisfaction with NHS services (“trauma upon trauma upon trauma”; the NHS is “just a mill” – work unpublished at present).

Autistic people will typically go into menopause with greater likelihood of past negative experiences in mental healthcare ([Brede et al., 2022](#); [Camm-Crosbie et al. 2019](#)), and past negative experiences in primary healthcare ([Weir et al., 2022](#); [Brice et al., 2021](#)). They often report barriers such as not knowing whether symptoms justify a visit, getting through the process of getting an appointment, and difficulties communicating with doctors ([Doherty et al., 2022](#)).

From their side, frontline and specialist healthcare professionals lack confidence working with autistic women ([Crane et al., 2019](#); [Unigwe et al., 2015](#)). Autistic women have high rates of mental and physical comorbidities and chronic illnesses, so will often be seen as “difficult” or “problem” patients (see, for e.g., [example 1](#), [example 2](#))

Participants in our research did not trust healthcare professionals to be knowledgeable, supportive and/or helpful.

Quotes and situational examples from our research ([study 1](#); [study 2](#)) include:

- Being laughed at, dismissed or otherwise invalidated; “the doctors did not believe me and offered little to no help”; “little to no support from my (female) doctor who thought it was all in my mind.”
- Being told they were too young to be in menopause;
- Being flatly refused HRT;
- Doctors being unable to provide information about menopause in an accessible way;
- Autistic people and doctors struggling to understand one another (“the doctor or anyone seems to completely misunderstand what I am saying”; “I find it frustrating that doctors are not more forthcoming - I have to know the questions to ask as they won't share any information unless they are prompted. So I always wonder what I should be asking that I don't know is a necessary question”)
- Doctors being poorly educated about autism in adult (women);
- Doctors have “lack of any clue . . . as to how best help . . . zero clue and zero interest” in the intersection of autistic menopause;
- Doctors failing to appreciate signs of distress (“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.”)
- Ultimately, doctors were approached as a last resort (“try to deal with it in the best way possible involving the doctors if you have to . . .”)

c) Autistic people may have less uptake of hormone replacement therapies.

There is presently no data concerning the uptake of hormone replacement therapy by people recognised to be autistic. However, given that our research shows

- a) Autistic people have low menopause knowledge and awareness, including awareness of treatment;
- b) Autistic people may struggle to identify they are in menopause;
- c) Autistic people face barriers to healthcare;

It thus seems likely that they might be less likely to seek and receive HRT.

Participants in our research expressed uncertainty and anxiety about HRT, and referred to health scares and misinformation about it. Example responses when asked whether they took it:

- “No, no, because I'd heard the side effects...”
- “I can't and won't take HRT as my mother had breast cancer as a result of HRT.”
- “I did briefly use HRT patches but did not find them particularly helpful and stopped using them before the health scare over using HRT”;
- “(My GP) advised me against HRT due to increased breast cancer risks”
- “I can't take HRT because of my autoimmune disease, although the doctors haven't suggested it either - I just know from researching the condition, it can make it much worse and vastly increase the risk of skin cancer.”

d) Autistic people are more likely to have other intersectional identities which are associated with unequal access to menopause care and support.

Autistic people are significantly more likely to be non-binary or transgender ([Warrier et al., 2020](#)).

For those who are non-binary, intersex, or trans men, menopause can be threatening, traumatic and distressing ([Glyde, 2021](#); [van Trotsenburg et al., 2023](#)). These difficult emotions are exacerbated by the barriers that transgender people face in healthcare ([Heng et al. 2018](#)): for instance, stigmatizing beliefs and lack of knowledge in healthcare providers.

Moreover, transgender and queer people are not represented in public discourse or most information or resources related to menopause (see, for e.g., [queermenopause.com](#)).

Individuals who are autistic *and* transgender suffer from the stigma of these two marginalized identities, such that they often have poorer mental health than individuals who are just autistic, or just transgender ([Strang et al., 2021](#)). These two stigmatised identities can interact: for instance, autistic people often find that their expressions of gender dysphoria are disbelieved or dismissed as ‘confusion’ or ‘obsession’ due to their autism ([Strang et al., 2018](#)). Autistic transgender people have poorer healthcare experiences ([Bruce et al., 2023](#)).

2. What barriers exist in the treatment and diagnosis of gynaecological or urogynaecological conditions?

For autistic people, these include:

a) General barriers to all healthcare access ([Doherty et al., 2022](#); [Raymaker et al., 2017](#))

- Difficulty booking appointments over telephone
- Difficulty talking to reception staff
- Anxiety making it difficult to communicate with doctors
- Uncertainty about whether a problem justifies visiting the doctor;
- Worries about being dismissed or invalidated by doctors – autistic women, especially, are more likely to suffer medical invalidation and be treated as ‘difficult patients’ ([Gosling et al., 2023](#); [Tint & Weiss, 2018](#))
- Worries about not being understood, or not knowing how to communicate one’s needs
- Sensory barriers such as in the waiting room

b) Poor understanding of adult autism in professionals

- Most frontline healthcare professionals have little to no formal autism training ([Chown et al., 2023](#))
- Knowledge and confidence of working with autistic adults, especially women, is especially poor ([Nicolaidis et al., 2020](#); [Crane et al., 2019](#); [Unigwe et al., 2015](#))

c) Infantilisation of autistic bodies by professionals

- Autistic people are often infantilised, especially if they also have an intellectual disability.
- This means that professionals are often ignorant about the needs and wants of autistic people in relation to reproductive and about sexual healthcare ([Graham Holmes et al., 2022](#)).

d) Low reproductive and sexual health literacy in autistic people

- Autistic people receive poorer sex and reproductive education at school, and have lower literacy in these subjects as adults ([Solomon et al., 2019](#))
- This may contribute to autistic people being less confident about when they should come forward to seek healthcare (as per [Doherty et al., 2022](#))