Bridging the Silos

Menopause Resource Pack for Autistic People in the UK



Artwork by Mae Greyfrost

About our team

We are a <u>neurodiverse team</u> of academics and Community Research Associates from Canada and the UK. We conduct research on Autistic people's experiences of the menopausal transition. The Bridging the Silos study was funded by an Insight Development Grant from the Social Sciences and Humanities Research Council of Canada (SSHRC) from 2021-2023.

About our research study

We called our study <u>Bridging the Silos</u> because knowledge about autism and the menopause transition is found in many different places. Understanding of Autistic people's experiences of menopause gets held back if information isn't joined up. We want to help improve this by bringing together people and ideas.

About this resource pack

This resource pack includes a summary of the findings from the Bridging the Silos research study. We have added some general information about menopause and links

to other research and resources. We have made this pack for Autistic people, but friends, family members, support workers, and clinicians may find it useful too.

About menopause

Please note: We are not qualified to give medical advice.

<u>Menopause</u> affects anyone who has periods (menstruates) and means the time when periods stop for good. It is a normal process which usually happens when someone is in their 40s or 50s, but it can happen earlier, sometimes because of health conditions or medical interventions.

Menopause has different stages, so it is often called the menopausal transition. The first stage is perimenopause which can last for several years. During perimenopause hormone levels start to change, which can cause a wide range of symptoms such as:

- Heavier or lighter bleeding during periods (menstruation)
- Longer or shorter gaps between periods (changes in the menstrual cycle)
- Hot flushes/hot flashes and/or night sweats (vasomotor symptoms)
- Changes in thinking (memory problems, confusion, brain fog)
- Changes in emotions (mood swings, tearfulness, rage)
- Mental health problems (anxiety, depression)
- Skin problems (itching, dryness, soreness)
- Leaking urine (incontinence), urinary tract infections (UTIs)
- Tiredness and lack of energy
- Muscle pain and aching joints
- Lack of interest in sex (low libido) and/or painful sex
- Suicidal thoughts
- Loss of confidence

Some people hardly notice the changes that happen during the menopausal transition while other people have lots of problems. It is not always obvious that perimenopause has started or that hormonal changes are causing symptoms. It can be difficult to know how to ask your GP for help.

When someone has not had a period for 12 months continuously they reach the next stage of the menopausal transition, which is called menopause. This only lasts for a day, and then they go into the final stage, which is called post menopause. Importantly, menopausal symptoms typically continue into the post menopause stage, only stopping or decreasing around 4 years after a person's last period. However,

menopause is different for everyone in terms of how long it takes and what symptoms are involved.

There are <u>treatments</u> for menopausal symptoms, such as Hormone Replacement Therapy (HRT), also known as Menopause Hormone Therapy (MHT), and non-hormonal medications. Lifestyle changes can also make it easier to cope. We encourage you to look at dependable, evidence-based information. There are lots of scams, fake stories, and false claims about menopause treatments. <u>Menopause misinformation is everywhere. Here's how to detect it.</u>

Some of the changes that happen during the menopausal transition, like thinning and dryness of vaginal and vulval skin, may last for a lifetime, and require ongoing treatment.

The menopausal transition is a uniquely individual experience, influenced by personal circumstances. Even if perimenopause is disruptive and distressing, access to appropriate information and support can help to restore well-being and quality of life.

What we found out from our research

Our research study had three phases:

Phase One

Online group discussions or interviews on menopause with 24 Autistic people in Canada and the UK

Phase Two

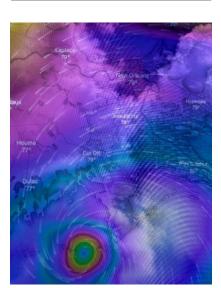
Creative work on menopause by six Autistic people and two researchers in Canada and the UK

Phase Three

An international survey completed by 508
Autistic people with experience of the menopausal transition







The titles of the next three sections link to our academic articles.

1 "A Perfect Storm": Autistic Experiences of Menopause and Midlife

We held group discussions or individual interviews with 24 Autistic people in Canada (13 people) and the UK (11 people) who were either in perimenopause or post menopause.

We found out that:

- Autistic people often experienced menopause symptoms as intense and interacting with each other.
- Autistic people had many competing demands and things going on in their lives,
 with menopause symptoms an additional burden on top of this.
- Many of the people we spoke to described stressful and traumatic experiences
 which affected them as they tried to cope with menopause. For instance, many
 had had negative healthcare encounters, and talked about the barriers they faced
 when trying to get help.
- The people we spoke to stressed how important it was to know how menopause could affect Autistic people, and to have support from other Autistic people.

We also asked the people we spoke to what questions to ask in the survey we were planning, and how to make this easy to complete. Their suggestions were very helpful.

This quote from someone who took part in our research gave us the title for our article:



"So I had a perfect storm. I had so many different balls to juggle in the air that, you know, on top of the menopause and not knowing whether I was autistic, I had a lot, a lot to deal with."

2 Stepping into Who I Fully Am: A Creative Exploration of Autistic Menopause

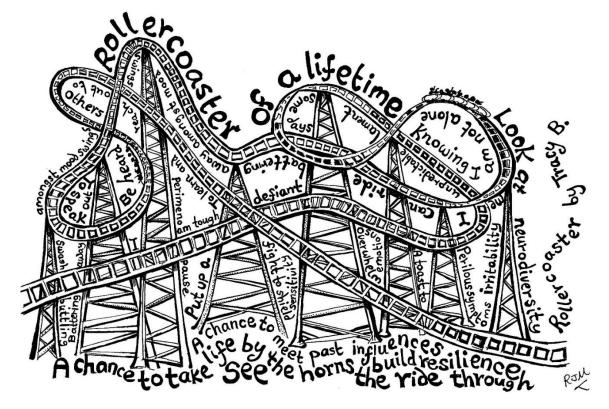
Because we knew that Autistic people like to express themselves in different ways we asked for some <u>creative submissions</u> describing what Autistic menopause was like. We received paintings, poetry, and graphic works from six Autistic people.

One of the artworks submitted to our study is included below. This is a multimedia painting on two panels placed together called "Birthday." Next to it is a brief description by the artist explaining how this relates to their experiences of autism and menopause.



"I painted these in autumn 2021. The 'Birthday' of the title refers to my autistic birthday – I was diagnosed in August 2021 aged 56. The image is deliberately ambiguous – it could be a final menstruation (though mine was six years ago) but it could also be a rocket taking off into the light. There is fire there, both of the overheating menopausal body and the fire of a new stage of life and self-discovery as an autistic person. Also anger at years of struggle because of not having this knowledge......It also relates to my non-binary identity. I am using blue as a shorthand here, with pink and white in the upper image, as a nod towards gender...Menopause has stripped away a lot of life masks that I was carrying – around how I relate in the world and about my gender. It has become much harder to mask and make everything okay for others before myself." Anonymous.

After reflecting on the six creative submissions, the two Autistic Community Research associates responded by writing journals and making creative work of their own. Rose Matthews (UK Community Research Associate) did the drawing below in response to a poem submitted by Tracy B., describing perimenopause as like being on a rollercoaster.



We found that:

- Creative exploration of Autistic menopause encouraged emotional expression, self-understanding, and activism (trying to get changes made).
- Autistic Community Researchers noted uplifting almost "magical" feelings when they connected with other Autistic people's lived experiences.
- Our creative approach allowed Autistic people to submit multimedia work, which would not have been possible if we had used traditional research methods.

3 "Struggling for Years": An International Survey on Autistic Experiences of Menopause

This international survey explored what might make menopause harder for Autistic people, such as lack of menopause and autism awareness, and what could help them cope and even flourish.

508 Autistic people completed our survey, and we found that:

- Autistic participants wanted more appropriate and Autistic-specific information about menopause.
- Participants who were unaware they were Autistic and going through menopause were more likely to report intense experiences of menopause.
- Participants saw lack of clinician awareness about both menopause and autism as barriers to care and support.
- Participants reported discovering ways to cope and even flourish during menopause through self-awareness and self-acceptance.
- Better awareness of autism and access to Autistic-specific menopause information can help Autistic people transition through menopause.

The quote below is from one of the people who completed our survey:

"My GP [General Practitioner] refused to believe my perimenopausal symptoms and also refused to believe me about the Autism as well. If I had known more, I could have been more assertive about this and provided information, instead of the long drawn-out process I had to endure" (47-year-old white woman from the UK in perimenopause who did not know she was Autistic at menopause onset, age 42).

For more information on our research please visit: www.AutisticMenopause.com

Other sources of information

Please note: We are not recommending or endorsing any treatments, services, or products offered via the links below. There are presently no evidence-based resources for Autistic people at menopause. We have included sources that we, as academics and Community Research Associates with lived experience, consider helpful.

Websites

NICE (NHS) UK Guidance on the identification and management of menopause: www.nice.org.uk/guidance/NG23 This document gives guidance on how healthcare staff are supposed to diagnose and treat menopausal symptoms.

Leicestershire Partnership NHS Trust, UK, Autism Space <u>www.leicspart.nhs.uk/autism-space</u> This website has a section on <u>Autism and menopause</u> with tips on getting support during the menopause transition and links to useful resources. Other sections which may be helpful too.

The Royal College of Obstetricians and Gynaecologists, UK has a section on Menopause and Later Life on their website: www.rcog.org.uk

Science on the Spectrum, Dr Rachel Moseley's website, has a section on <u>menopause</u> and <u>menstrual-related resources</u>, with links to research and accessible information: <u>www.scienceonthespectrum.net</u>

National Autistic Society (UK autism charity) <u>www.autism.org.uk/advice-and-guidance/topics/physical-health/menopause</u>

Autistica (UK autism research charity): What is Menopause www.autistica.org.uk/what-is-autism/autism-and-menopause

<u>The Menopause Charity</u> evidence-based menopause information and advice: https://themenopausecharity.org

Autism from Menstruation to Menopause, UK research study, based at Swansea University. Website: https://www.autismmenstruationtomenopause.com and Facebook Group with information and tips.

Rock My Menopause https://rockmy.com/menopause/ Leaflets and useful tips.

Autistic Realms: <u>Perimenopause and Menopause Resources</u> Wide range of links and resources https://autisticrealms.com

Black Health and Beyond: <u>Black Women in Menopause</u> <u>https://blackhealthandbeyond.co.uk</u>

You & Me_nopause: www.youandmenopause.org destigmatising the black menopause experience and encouraging open and honest discussions (Dr Yansie Rolston).

Menopause Inclusion Collective: www.menopausecollective.org

Queer/LGBTQIA+ Menopause: www.queermenopause.com/resources

Diversity Project: <u>Types of Menopause</u> (including Trans menopause) https://diversityproject.com

Henpicked Menopause Inclusion Collective: www.menopausecollective.org

<u>The Daisy Network</u>: Charity for Women with Premature Ovarian Insufficiency (a cause of early menopause) https://www.daisynetwork.org

Webinars, podcasts, and presentations

Bournemouth University research exploring autistic experiences of menopause You Tube video with Dr Rachel Moseley and Prof Julie Gamble-Turner (2 mins, 19 secs).

<u>Autism and menopause</u> YouTube webinar with Dr Rachel Moseley, Prof Julie Gamble-Turner, Dr Richard De Visser, and Prof Rebecca Charlton. (1 hr, 30 mins). <u>Autistica www.autistica.org.uk</u>

Neurodivergence & menopause Mindroom YouTube webinar with Dr Rachel Moseley (48 mins).

When the wheels fall off: Navigating menopause and midlife through an autistic and neurodivergent lens with Christine Jenkins Spotify (54 mins).

<u>Autism and Menopause</u> YouTube webinar, with Dr Aimee Grant (57 mins). <u>Autistic Girls Network</u>: https://autisticgirlsnetwork.org/

<u>Autism and the (peri)menopausal experience</u> YouTube, Dr Deborah Leveroy (1 hr, 16 mins). <u>Neurobox</u>: <u>https://neurobox.co.uk/</u>

<u>Neurodiversity and the Menopause</u> PowerPoint: Dr Rachel Moseley, Ms Eunhee Kim, Bournemouth University, Neurodivergence Wales: https://neurodivergencewales.org Autism and Menopause Dr Kim Sage. YouTube (9 mins, 28 secs).

<u>Transgender and Menopause</u> International Menopause Society, Mick van Trotsenburg and Maria Cristina Meriggiola (1 hr, 18 mins, 45 secs) https://imswebinars.com

<u>Q&A on ADHD and Perimenopause</u> YouTube, Dr Lotta Borg Skoglund (14 mins, 55 secs). <u>ADDitude</u>: https://www.additudemag.com/

Academic articles

Autism research is 'all about the blokes and the kids': Autistic women breaking the silence on menopause Rachel Moseley, Tanya Druce, Julie Turner-Cobb.

"'When my autism broke': A qualitative study spotlighting autistic voices on menopause" Rachel Moseley, Tanya Druce, Julie Turner-Cobb.

Unmet need for autism-aware care for gynaecological, menstrual and sexual wellbeing Richard O de Visser, Rachel Moseley, Julie Gamble-Turner, Laura Hull, Felicity Sedgewick, Charlotte Featherstone, Chella Quint OBE, Eloise Freeman, Marianna Karavidas.

"It's Not Just in My Head, and It's Not Just Irrelevant": Autistic Negotiations of Menopausal Transitions Marianna Karavidas, Richard O de Visser.

<u>Menstruation & menopause in autistic adults: Periods of importance?</u> Annabeth P Groenman, Carolien Torenvliet, Tulsi A Radhoe, Joost A Agelink van Rentergem, and Hilde M Geurts.

Common and unique menopause experiences among autistic and non-autistic people:

<u>A qualitative study</u> Martha A Piper and Rebecca A Charlton.

Self-Reported Psychological, Somatic, and Vasomotor Symptoms at Different Stages of the Menopause for Autistic and Non-autistic People Rebecca A. Charlton, Francesca Happe, Alanna Shand, Will Mandy, Gavin Stewart.

<u>Fundamental intersectionality of menopause and neurodivergence experiences at work</u> Debora Gottardello, Dr Belinda Steffan.

Being a Woman Is 100% Significant to My Experiences of Attention Deficit Hyperactivity

<u>Disorder and Autism: Exploring the Gendered Implications of an Adulthood Combined</u>

<u>Autism and Attention Deficit Hyperactivity Disorder Diagnosis</u> Emma Craddock.

<u>The Night I Lost My Freedom and Got It Back Again</u> by Rose Matthews (open access preprint of an article published in Autism in Adulthood).

Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings Mary Doherty, Sue McCowan, and Seb Shaw

Other resources

BS 30416:2023 Menstruation, menstrual health and menopause in the workplace (Guide) British Standards Institute website: https://knowledge.bsigroup.com

Menopausal and Melting Down: An Autistic Tale of Sensory Survival by Karen Noble. Reframing Autism Australia website: https://reframingautism.org.au

<u>Autism, Menopause and Reaching Breaking Point: A Hidden Crisis</u> Altogether Autism New Zealand: <u>www.altogetherautism.org.nz</u>

<u>Menopause, Hormones and ADHD Symptoms in Women: An Overview ADDitude</u> website: <u>www.additudemag.com</u>

Why Autistic Women's Experience of Menopause is Different Dr Claire Jack, Psychology Today website: www.psychologytoday.com

Auti Peri Q & A Sam Galloway, Substack: https://samgallowayaudhd.substack.com

The Hidden Truth: Exploring How Menopause Unmasks Neurodivergence in Women Donna Morgan. BACP (British Assoc for Counselling & Psychotherapy) www.bacp.co.uk

<u>Neurodiversity and Hormones – Part 3: Hormones Across the Lifespan</u> Caroline Turner. Creased Puddle website: <u>www.creasedpuddle.co.uk</u>

<u>Surviving the Storm: Autism, Menopause and Mental Health</u> Rose Matthews. Inspire the Mind website: https://www.inspirethemind.org

Autistic Menopause: A Curated Collection of Curiosities Rose Matthews. Padlet.

<u>Supporting autistic people through menopause</u> Dr Rachel Moseley, Mx Rose Matthews. Supported Loving Toolkit, Choice Support website: <u>www.choicesupport.org.uk</u>

Black and Menopausal: 3 people share their experiences of this time of transition Women's Health Magazine website: www.womenshealthmag.com

Books

Autistic Menopause: A guide to the menopausal transition for autistic people and those supporting them. Dr Rachel Moseley and Prof Julie Gamble-Turner. Due to be published by Jessica Kingsley Publishers in early 2026.

<u>'Bloody Hell! Adventures in Menopause from Around the World</u> Edited by Mona Eltahawy. ISBN 9781800183711

Black and Menopausal Yansie Rolston and Yvonne Christie. ISBN 9781839973796

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