# Bridging the Silos Autistic Menopause Study

Bridging the Silos: Autistic Menopause Study is a research partnership between Autistic advocates and academics funded by an Insight Development Grant from the Social Sciences and Humanities Research Council, Canada. Previous research suggests that menopause can be a very difficult transition for some Autistic people, and we wanted to find out about the menopause experiences of Autistic people in Canada, the UK, and other parts of the world.

Summaries of our three Open Access articles are below, with hyperlinks to the full text versions.

## 1 <u>"A Perfect Storm": Autistic Experiences of Menopause and Midlife</u>

Online focus groups and interviews were conducted with 24 menopausal/postmenopausal Autistic participants who lived in Canada (n = 13) or the United Kingdom (n = 11). We found that:

- Autistic people often experienced menopause symptoms as intense and interacting.
- 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 our participants 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.
- Our participants highlighted how important it was to have knowledge about how menopause could affect Autistic people, and support from other Autistic people.

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

Acknowledging that self-expression can take many forms for Autistic people, we invited <u>creative</u> <u>submissions</u> themed around Autistic experiences of menopause, receiving works from six Autistic participants including paintings, poetry, and graphic works. Autistic Community Researchers responded creatively to these submissions with work of their own. We found that:

- Creative exploration of Autistic menopause encouraged emotional expression, selfunderstanding, and activism.
- Autistic Community Researchers noted transcendent, almost "magical" dimensions of connecting with other Autistic people's lived experiences.
- Our creative emancipatory approach enabled Autistic people to submit multimedia responses 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 factors that might make menopause harder for Autistic people, such as lack of menopause and autism awareness, and it also explored what could help them cope and even flourish during this time.

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 a more intense experience of menopause.
- Participants perceived 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 is important in helping Autistic people transition through menopause.

#### Other sources of information

#### Website and webinars

Science on the Spectrum <u>www.scienceonthespectrum.net</u> Dr Rachel Moseley's website has a menopause section, with links to her research, including: <u>"'When my autism broke': A qualitative study spotlighting autistic voices on menopause"</u>, and lots of accessible multimedia resources.

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

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

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

Autism and Menopause Autistic Girls Network YouTube webinar, with Dr Aimee Grant (57 mins).

#### Research articles

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

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

Common and unique menopause experiences among autistic and non-autistic people: A qualitative study Martha A Piper and Prof Rebecca A Charlton.

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

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

### **Guidance on providing support**

<u>Supporting autistic people through menopause</u> Choice Support, Supported Loving Toolkit. Mx Rose Matthews and Dr Rachel Moseley.