Resources for autistic women and people with ovaries at menopause







Disclaimers:

- 1. Autistic people, including girls and women, come in every shape and size! Some are assigned female at birth but once they can tell us their gender, they could be non-binary, agender, genderfluid or a range of gender-variant identities, or could be trans men. Here, the focus is on women and people with ovaries (who might have varied genders).
- 2. Unfortunately, at time of writing (March 2023) there are no autism diagnostic tests that are designed for girls, women or people with marginalised genders or sexes. A few screening tests exist for women, some of which are provided here, but they are not widely used (practitioners will not necessarily be aware of them) and are still quite experimental i.e. not validated on a grand scale.
- 3. This is not a definitive list of resources just our *unofficial* favourites, out of the things we're aware of.

 They are not ours unless clearly stated as such.

Disclaimers:

- 4. Sadly, autistic people become more invisible as they age. There is a lack of research and support specifically tailored for older autistic girls, women and people with ovaries. In places, especially in relation to menopause and mental health, the links and resources provided are not autism specific. We apologise for this; where non-autism-specific resources are provided, it is because there are no autism-specific ones, to our knowledge. ®
- 5. We have done our best to screen out any links or resources which use problematic and/or pathologizing language about autism and autistic people. We cannot take responsibility for the content on these links and resources, though, unless they are our own (clearly marked out).

Menopause: autism-specific resources

- Our research around autistic menopause is available <u>here</u>, and <u>here</u>
- Other articles by researchers talking about autistic menopause can be found <u>here</u>, <u>here</u>, <u>here</u>.
- Podcasts where autistic people talk about their experiences of menopause can be found <u>here</u> and <u>here</u>
- Results from an ongoing study on autistic menopause, as they become available, can be found <u>here</u>



 Actually not autism-specific, but will be relevant to many: <u>podcasts on a range</u> <u>of mental health topics (including</u> <u>depression, anxiety, eating disorders</u> <u>and suicidality) during menopause</u>

Menopause: resources from our neuro-kin

ADHD'ers share a lot in common with autistic folk, and often struggle with menopause too. Some autistic people in our research found that menopause brought ADHD features and struggles to the fore.

- Podcasts on ADHD experiences of menopause and late-diagnosis are <u>here</u>, <u>here</u> and <u>here</u>.
- There are also some great podcasts on the impact of hormones on emotion, thought processes and attention, things that autistic people can also struggle with, <u>here</u> and <u>here</u>. These cover a range of hormone changes across the lifespan for people with ovaries, including monthly cycles and events like pregnancy.



 Dr Louise Newson developed resources for ADHD'ers going through menopause, which are likely to help autistic people too. Find her work here and here, though the whole site is full of useful stuff, including an app and menopause library.

Menopause and menstrual disorders resources that aren't autism-specific

- Information about <u>premenstrual dysphoric disorder and</u> <u>other menstrual conditions</u> which are common in neurodivergent folk.
- Rock my Menopause provides lots of accessible information, including fact sheets, podcasts and videos
- <u>Henpicked</u> is another great site for information and stories around menopause. Their <u>resources</u> include advice about talking to doctors, as well as lots of other content.
- The <u>Diversity Project's information pack</u> for people experiencing different kinds of menopause, such as medical menopause.



Living well through your perimenopause and menopause booklet by Dr Louise Newson

For those navigating a queer or transgender menopause

- For menopausal people who are trans, queer, non-binary or have other intersectional identities, the <u>Menopause Inclusive Collective</u> has a great list of resources.
- The Diversity Project developed this brilliant information pack.
- An <u>informative webinar</u> from the International Menopause Society.



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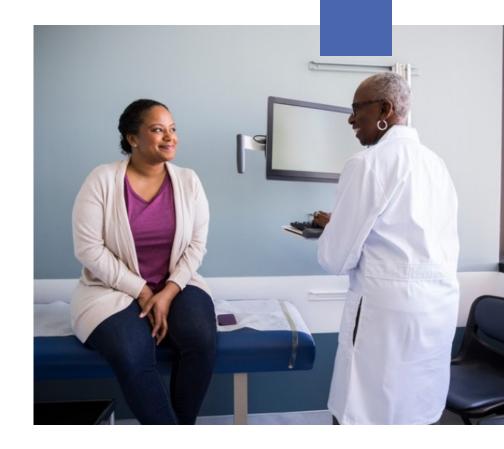
They relate to experiences that often co-occur with menopause.

Resources related to being autistic in healthcare settings:

Autistic people going through menopause have often told us that they struggle in healthcare settings.

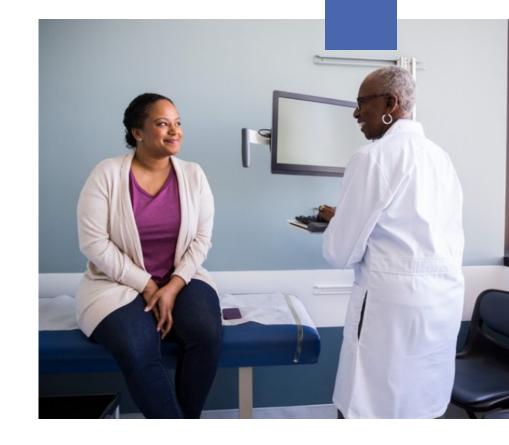
Here are some resources that may help you advocate for yourself in healthcare settings, and some resources that may be helpful for healthcare practitioners who want to support autistic patients.

Autistic people and their loved ones may find it useful to share these with their healthcare practitioners.



Resources related to being autistic in healthcare settings:

- AASPIRE Healthcare Toolkit
- Know your normal toolkit
- The National Autistic Society's advice about conversations about medication.
- Advice from Ambitious About Autism in relation to <u>meetings with psychiatrists</u>
- Scottish Women's Autism Network provide advice, training and resources for autistic patients and healthcare professionals

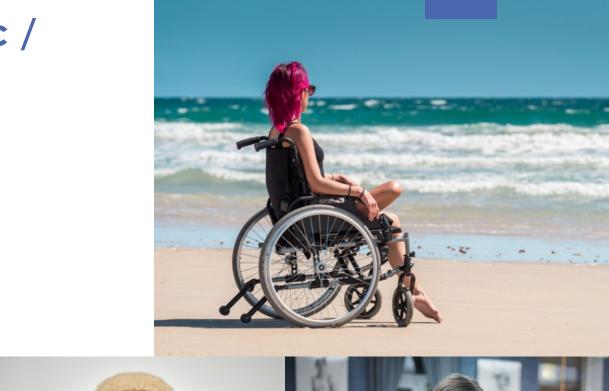


- Resources for professionals from Scottish Autism
- Asperger Autism Support Network's advice for professionals

Resources for people who are wondering if they might be autistic / newly diagnosed

Many autistic participants in our menopause research were diagnosed as adults – some were only diagnosed when they entered menopause.

The following resources are for people who are newly diagnosed or wondering if they might be autistic. On the next few pages you will find articles by people who were diagnosed as adults, recommended sites where we hope you might find a sense of community. There are also some screening tests which you might find useful if you are seeking a formal diagnosis.





Resources for people who are wondering if they might be autistic / newly diagnosed

- <u>Screening test for adult women</u>, and <u>accompanying scientific report</u>
- This page from the National Autistic Society, including their 'Now I Know' campaign and 'Stories from the spectrum'.
- BBC article, <u>'It all made sense when we</u> <u>found out we were autistic'</u> (note problematic language in places)
- The Thinking Person's Guide to Autism





Resources for people who are wondering if they might be autistic / newly diagnosed

- Autistic Women and Non-binary Network welcome packs
- Spectrum Women
- Autistic Self-Advocacy Network
- Society for Neurodiversity
- Just found out you are autistic? <u>Chris</u>
 <u>Bonnello's articles</u>. This one covers the <u>diagnostic journey</u>.

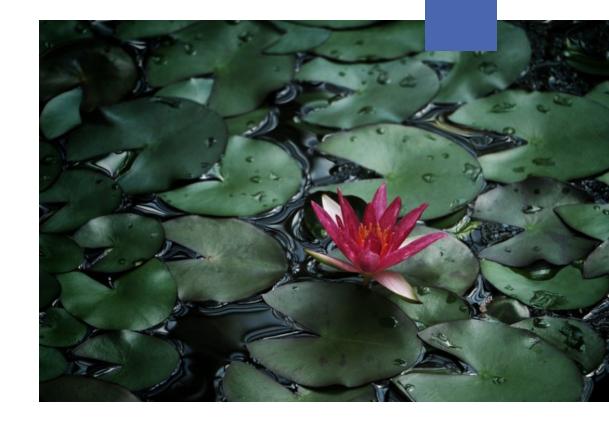




Resources related to autistic mental health and suicide:

In our research, we often hear that autistic people are struggling with their mental health. Some also report experiencing suicidal thoughts and feelings. For some, these kind of mental health struggles are amplified by menopause.

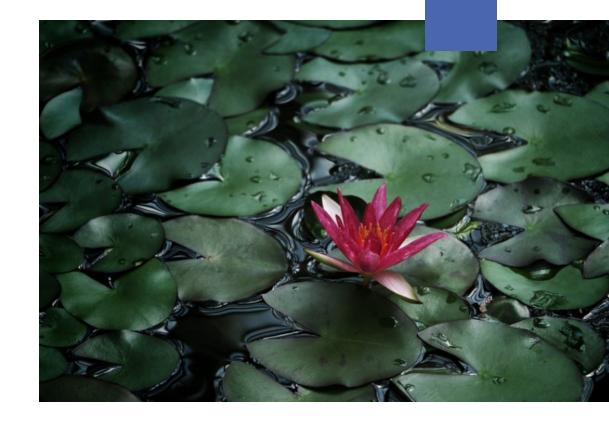
For this reason, we have provided some of the resources we're aware of over the next pages. There are also resources that you can pass on to any professionals who are working with you, like doctors.



If you are a professional working with autistic people – please see resources around assessing suicide risk.

Resources related to autistic mental health and suicide:

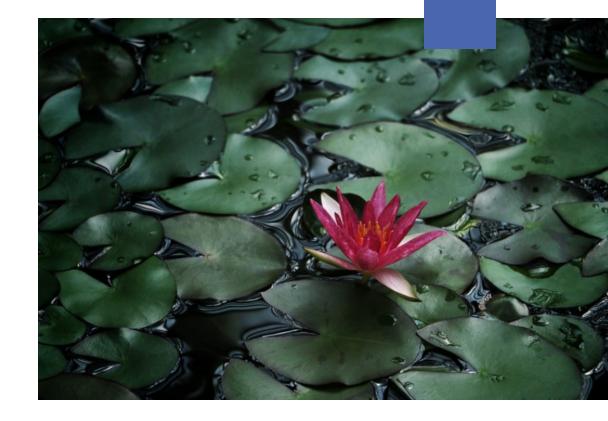
- If you're someone who experiences suicidal thoughts, <u>Mental Health Autism's safety plan</u> is worth completing at a time when you're feeling calm and relatively OK. That way, you'll have it ready to turn to at times of crisis.
- Mental Health Autism have collected <u>stories from</u> <u>autistic people</u> who have struggled with suicidal thoughts.
- Spectrum Women have written a lot of articles, many around mental health matters.



•You may like to look at the blogs and resources of <u>Lisa Morgan</u>, an autistic suicide <u>survivor and consultant</u>. She also writes a column in Spectrum Women – here is her article on <u>PTSD</u>, for example.

Resources related to autistic mental health and suicide:

- The <u>National Autistic Society's advice</u>, <u>guidance and</u>
 resources page on mental health, including advice
 around seeking-help. Here is their <u>directory</u>, where you
 can find autism-friendly professionals.
- We know that mental health is linked to things going on in your life, such as housing or legal issues. The National Autistic Society have <u>advice on a whole range of issues</u>, and <u>this page</u> advertises their different services.
- Autistica have pages on common mental health difficulties like <u>anxiety</u> and <u>depression</u>, as well as <u>suicide</u> and <u>self-injury</u>. They also produced <u>mental health advice</u> <u>for autistic people</u>.
- Ambitious about Autism's page on self-regulation

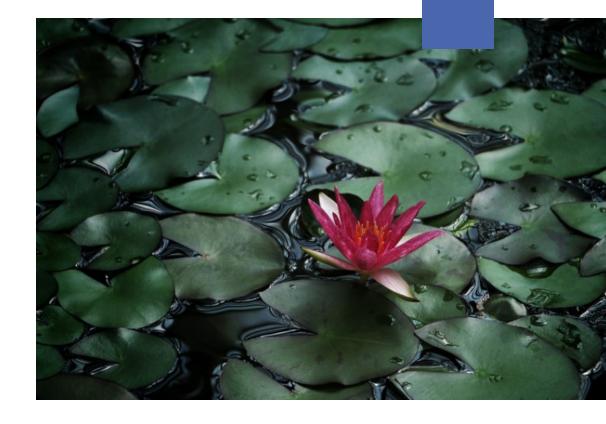


- The National Autistic Society have a <u>page on</u> <u>burnout</u>, with lots of links to useful content.
 There's a <u>short video</u> on the same topic from Spectrum Women.
- Mind have a page for autistic people

For professionals: resources related to autistic mental health and suicide

Warning signs for suicide in autistic people –
 a fantastic guide by researchers, clinicians
 and autistic experts. See here for a talk by
 the authors, demonstrating example
 scenarios.

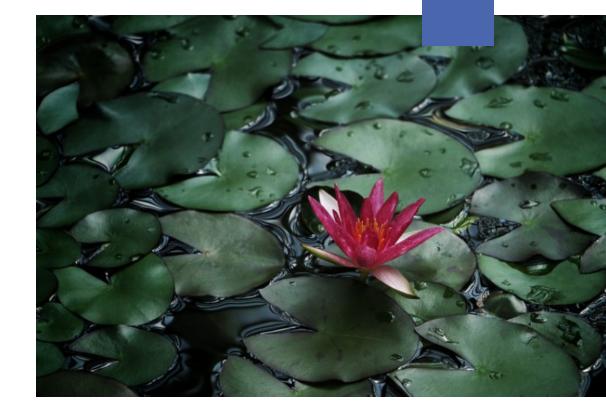
 <u>Identifying crisis in autistic people</u> - a range of resources for professionals, created by Lisa Morgan, autistic expert by experience.



Mental Health Autism's guide for doctors includes tools for assessing suicide risk and depression (note: not clinically validated).

For professionals: resources related to autistic mental health and suicide

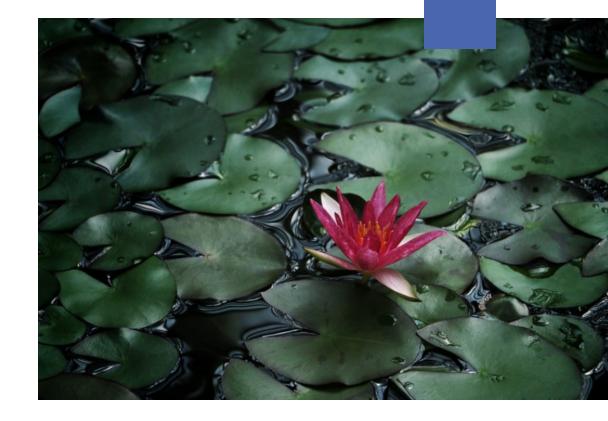
- Professional guide to fatigue and burnout
- Dr Rachel Moseley's <u>research around</u> <u>suicidality</u>
- Sue Wilgoss's (National Suicide Prevention Alliance) <u>talk and slides</u> on suicide prevention
- With researchers and autistic people, Dr Moseley contributed to some policy recommendations for suicide prevention



Autistica's <u>guide for professionals</u>
 <u>supporting autistic people</u>
 <u>through crisis</u>: pitched at young
 people, but relevant to many.

Non-autism specific crisis helplines and resources

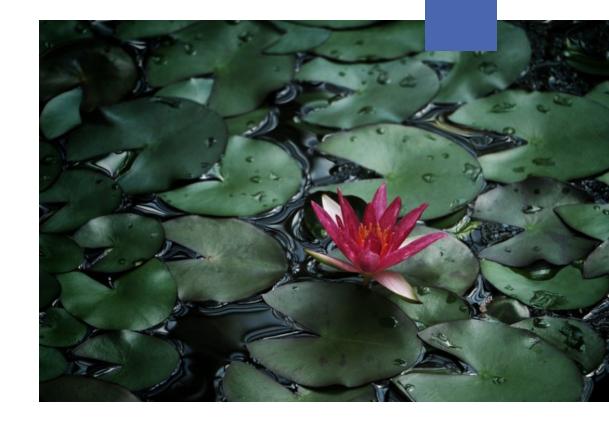
- Samaritans can be called at any time on 116
 123. Their <u>page here</u> gives you some other
 ways of contacting them if you are having
 suicidal thoughts.
- <u>Rethink Mental Illness</u> have a crisis factsheet to help people who are feeling suicidal
- Mind have a <u>crisis pipeline and resources</u>
- Shout crisis textline can be contacted by texting 85258 – they have created this page specifically for autistic people to show how the service works. They also have a lot of online information and advice.



 Online support forums at <u>Suicide Stop</u> and <u>Mind</u>

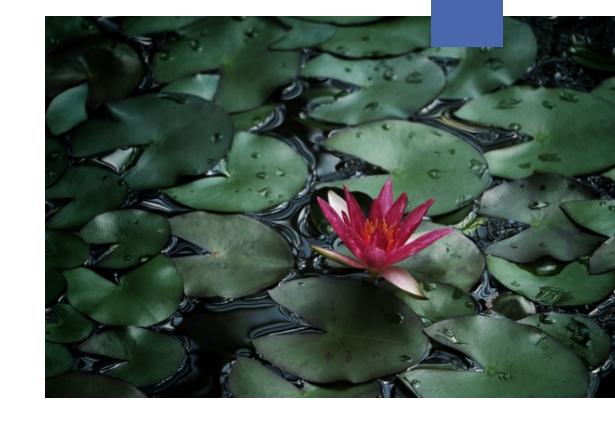
Resources related to self-harm (not autism-specific):

- <u>National Self-Harm Network</u> a friendly forum where you can connect with others for support.
- <u>LifeSigns</u> lots of advice around preventing self-harm and/or reducing the severity and consequences. Packed full of information and stories.
- <u>Self-Injury Support</u> is also packed full of information and resources – you can ignore the sign saying it's only for women and girls!



Some people find the <u>CalmHalm</u> <u>app</u> helpful.

Please see Dr Moseley's website for these and other resources



www.scienceonthespectrum.net

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Please note that we are research psychologists, not the kind that treats or diagnoses people. While we will always try to share our knowledge and any information and resources we're aware of, we are afraid that we are not able to provide individual diagnostic assessment or mental health support.

You can read more about the kind of research we do on our institutional pages:

https://staffprofiles.bournemouth.ac.uk/display/rmoseley
https://staffprofiles.bournemouth.ac.uk/display/jgambleturner



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If you would like to give feedback on this PDF of resources, please leave a message on Dr Moseley's site:

Get in touch | Science On The Spectrum

You can also contact us by email:

Dr Rachel Moseley: rmoseley@bournemouth.ac.uk

Professor Julie Gamble-Turner:

jgambleturner@bournemouth.ac.uk



