Resources for autistic (/neurodivergent) women and people with ovaries at menopause



© Dr Rachel Moseley and Professor Julie Gamble-Turner, Department of Psychology, Bournemouth University



# **Disclaimers:**

- Autistic people, including girls and women, come in every shape and size! Some are assigned female at birth but identify as outside the gender binary, or as trans men. Here, the focus is on women and people with ovaries (who might have varied genders).
- 2. We focus on autism here as this is our area of expertise however, there are some ADHDspecific resources here too.
- 3. At time of writing, there are no autism (/ADHD) 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 (doctors will not necessarily be aware of them) and haven't been validated on a grand scale.

# **Disclaimers:**

- Sadly, there is a lack of research and support specifically tailored for older neurodivergent people. In places, especially in relation to menopause and mental health, the links and resources provided are not specific for autistic people (or ADHDers). We apologise for this; where non-specific resources are provided, it is because there are no specific ones to our knowledge. (3)
- 5. We have done our best to screen out any links or resources which use problematic and/or pathologizing language, but cannot take responsibility for content that isn't ours.
- 6. This is not a definitive list of resources just our favourites. They are not ours unless clearly stated as such.

#### 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: podcasts on a range of mental health topics (including depression, anxiety, eating disorders and suicidality) during menopause

#### Menopause: ADHD-specific

#### resources

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 <u>here</u> and <u>here</u>, though the whole site is full of useful stuff, including an <u>app</u> <u>and menopause library</u>.

# Menopause: resources for people with learning disabilities

- The amazing Dr Louise Newson developed <u>a</u> <u>guide to menopause</u> specifically for people with learning disabilities
- In <u>this podcast</u>, a woman who identifies as disabled and with learning disabilities discusses her experience through menopause.
- <u>RockMyMenopause's page</u>.



# 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.



© the Diversity Project

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

- Information about <u>premenstrual dysphoric disorder and</u> <u>other menstrual conditions</u> which are common in neurodivergent folk.
- <u>Rock my Menopause</u> provides lots of accessible information, <u>including fact sheets</u>, <u>podcasts and videos</u>
- <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.



<u>Living well through your</u>
 <u>perimenopause and menopause</u>
 <u>booklet</u> by Dr Louise Newson

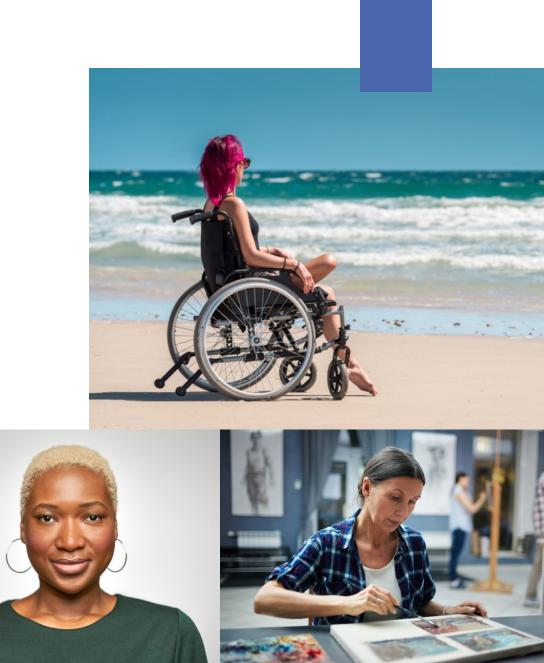
# The following resources are not directly about menopause

They relate to experiences that often co-occur with menopause. Although these are mainly autism-specific, there's some ADHD resources too.

# Resources for people who are wondering if they might be neurodivergent, or newly diagnosed

Many autistic participants in our menopause research were diagnosed as adults – some when they were struggling through menopause. This also happens to people with ADHD.

The following resources are for people who are newly diagnosed or wondering if they might be autistic/ADHDers. There are articles by people who were diagnosed as adults, and sites where 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

- <u>Screening test for adult women</u>, and <u>accompanying scientific report</u>. There is also the <u>CATI</u>, which may be more sensitive to less stereotypical presentations of autism.
   Please note that only clinicians (doctors) can actually make a formal diagnosis.
- This <u>page from the National Autistic Society</u>, 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)



# Resources for people who are wondering if they might be autistic

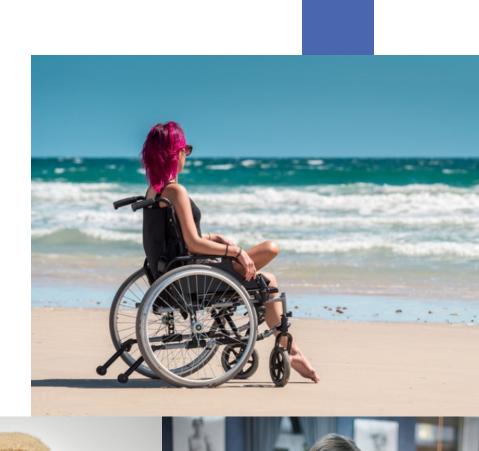
- <u>Autistic Women and Non-binary Network</u> welcome packs
- <u>Spectrum Women</u>
- <u>Embrace Autism</u> is written by neurodivergent women and very affirming
- <u>Autistic Self-Advocacy Network</u>
- <u>Society for Neurodiversity</u>
- <u>Chris Bonnello's articles</u>. This one covers the <u>diagnostic journey</u>.





# Resources for people who are wondering if they might be ADHDers (have ADHD)

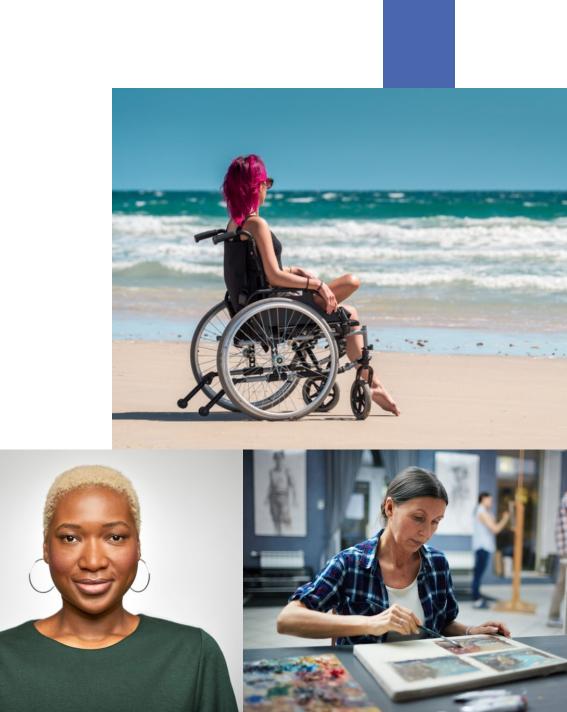
- The Adult ADHD Self-Report Scale (ASRS) is freely available through google. <u>This page explains it very well</u> – but please note that only clinicians (doctors) can actually make a formal diagnosis.
- Check out 'How to ADHD' on <u>Facebook</u> and <u>Youtube</u>; they even have their <u>own site</u>.





# What about *auDHD*? (autism and ADHD combined)

- Unfortunately, there are no screening tests specifically for people who are autistic and ADHDers, but you can still use screening tests for ADHD and autism individually.
- <u>Articles on auDHD from Embrace</u> <u>Autism</u>.



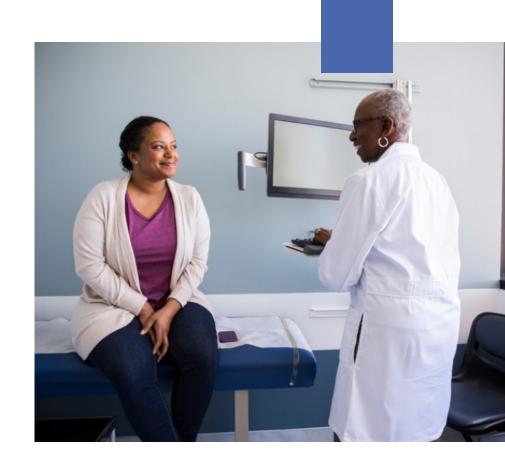
## Resources related to being

## 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.

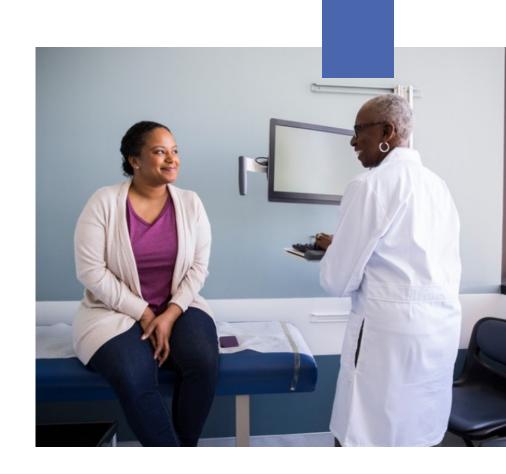
Autistic people and their loved ones may find it useful to share these with their healthcare practitioners.



## **Resources related to being**

# autistic in healthcare settings:

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

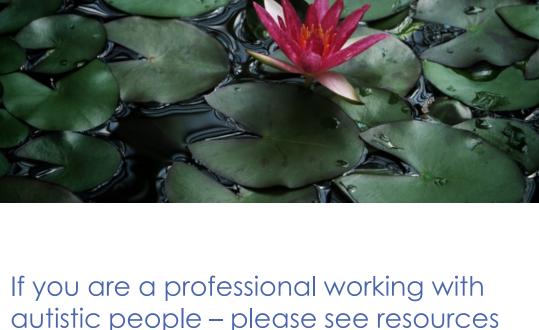


- <u>Resources for professionals from Scottish</u>
  <u>Autism</u>
- <u>Asperger Autism Support Network's advice for</u> professionals

#### **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.



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 when you're feeling calm and relatively OK. You will then have it ready at times of crisis.
- Mental Health Autism have collected <u>stories from</u> <u>autistic people</u> who have struggled with suicidal thoughts.
- You may like to look at the blogs and resources of <u>Lisa Morgan, an autistic suicide survivor and</u> <u>consultant</u>. She also writes a column in Spectrum Women – here is her article on <u>PTSD</u>, for example.
- <u>Spectrum Women</u> have written a lot of articles, many around mental health.

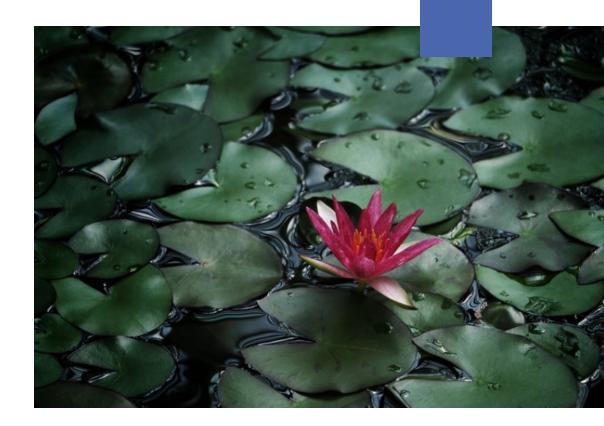


 Many people struggle to cope with overwhelming emotions. This resource for autistic people aims to help people learn <u>emotion management skills</u> to improve their mental health and wellbeing.

# Resources related to autistic

#### mental health and suicide:

- The <u>National Autistic Society's advice, guidance and</u> <u>resources</u> 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> for autistic people.
- 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.
- <u>Mind</u> have a page for autistic people

#### Non-autism specific crisis

#### helplines and resources

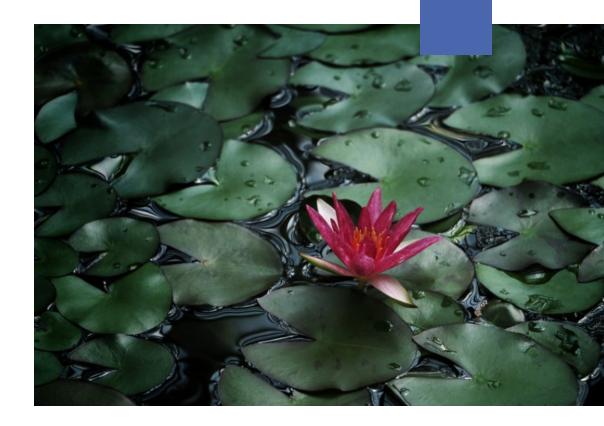
- Samaritans can be called at any time on 116 123. Their <u>page here</u> gives you some other ways of contacting them if you are having suicidal thoughts.
- <u>Rethink Mental Illness</u> have a crisis factsheet to help people who are feeling suicidal
- Mind have a crisis pipeline and resources
- <u>Shout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



 Online support forums at <u>Suicide Stop</u> and <u>Mind</u> **Resources related to self-harm** 

#### (not autism-specific):

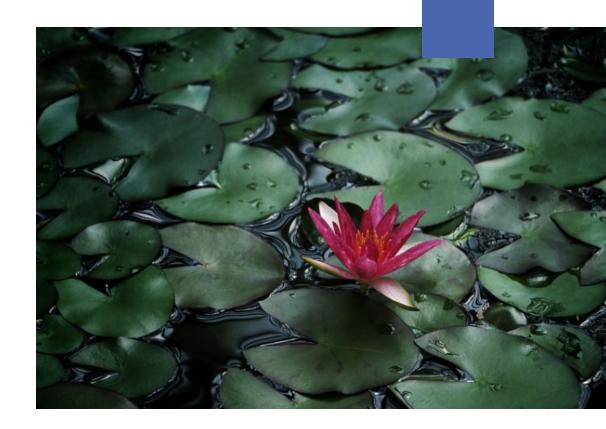
- <u>National Self-Harm Network</u> a friendly forum where you can connect with others for support.
- <u>LifeSigns</u> lots of advice around preventing self-harm and/or reducing the severity and consequences. Packed full of information and stories.
- <u>Self-Injury Support</u> is also packed full of 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.

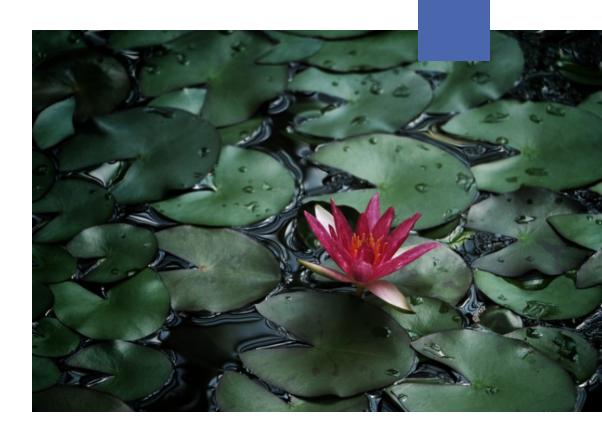
For professionals: resources related to autistic mental health and suicide

- <u>Warning signs for suicide in autistic people</u> a fantastic guide by researchers, clinicians and autistic experts. See <u>here</u> 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.
- Sue Wilgoss's (National Suicide Prevention Alliance) <u>talk and slides</u> on suicide prevention



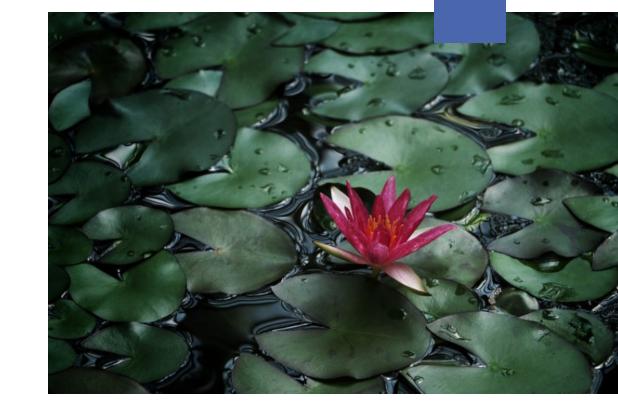
 <u>Mental Health Autism's guide for</u> <u>doctors</u> includes tools for assessing suicide risk and depression (note: not clinically validated). For professionals: resources related to autistic mental health and suicide

- Professional guide to fatigue and burnout
- Dr Rachel Moseley's <u>research on suicidality</u>
- Emotion dysregulation is a major source of psychopathology for autistic people. Here is a <u>toolkit aimed at helping autistic people</u>.
- 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.

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:

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