

# Experiences of peri/menopause at work from neurodivergent women: suggestions for inclusive workplace practices

Speakers:

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**Nothing has impacted me as much as perimenopause has. Perimenopause absolutely being the killer of my career.**

- *interviewee*



# Agenda

- Introductions
- EDICa and the menstrual health study
- Setting the scene: peri/menopause and neurodiversity
- Menstrual health and the 'social model of disability'
- Some notes on literature
- Neurodiversity and peri/menopause at work: insights from our study
- Suggestions and take-aways

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# Equality, Diversity and Inclusion Caucus (EDICa)

- Create ***inclusive*** research and innovation cultures
- ***Access*** and ***thrive*** in chosen careers
- ***Remove barriers*** experienced by ***marginalised groups***
- ***Interdisciplinary*** research
- Create national and international ***communities of practice*** (CoP)
- ***A co-design approach*** with stakeholders and people with lived experience

# Overview of our study

- Drawing on Sang's previous work on menstrual health in research careers, including data from over 700 people
- Extensive interviews with **56** workers in the research & innovation sector;
- focus on wide range of **job settings**, including non-desk-based settings;
- qualitative insights into workplace **lived experiences** of managing periods, problematic menstruation and peri/menopause;
- **co-design** workshops with key stakeholders to propose interventions to improve the workplace.
- visiting places where research & innovation takes place.



Scottish National Galleries stores

# Main findings

- **Specific challenges** to manage menstrual health in R&I workplaces (e.g., lab, fieldwork)
- Lack of accommodations resulted in researchers with problematic menstruation and peri/menopause to **leave their careers**
- **Neurodivergent** people and those with **long-term conditions or disability** face additional barriers in managing periods at work;
- **Researchers of colour and from other ethnic groups** further marginalised due to cultural bias and racism with relation to menstrual health
- Overall **distrust** in the sector to implement change



*Fashion students' projects on display, School of Textiles & Design*

# You can read more about our study here



Heriot-Watt University  
Research Gateway

## Recommendations for improving support for researchers managing menstrual health

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Cocco, C, Sang, K, Morgan, C, Wedgwood, B & Ali, N 2024, *Recommendations for improving support for researchers managing menstrual health*. Heriot-Watt University. <https://doi.org/10.17861/ZPJJ-N584>

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Research Gateway

## Improving the workplace support for neurodivergent women managing their menstrual health

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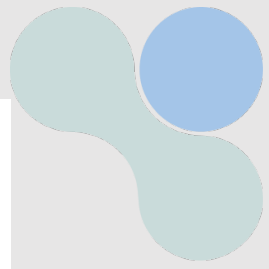
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# Understanding the perimenopause

- Menopausal transition
- Hormonal changes resulting in substantial drop of estrogen and egg release
- Physical changes
- Mental health might be affected
- Age range between 30s – 50s
- People experience it differently and often symptoms are not recognised







# What are the indicators of perimenopause?

Irregular, unpredictable or heavy periods

Joint pain

Fuzzy memory

Shorter or lighter periods

Hair loss or other changes to hair

Changes to sex drive

Dental problems

Bladder issues e.g. loss of bladder control

Anxiety

Low mood

Hot flushes

Insomnia

Weight gain

Night sweats

Headaches



# Understanding the menopause



- Reached after one year with no period
- Average menopause age in UK is 51 **BUT**  
Fluctuates
- Often perceived as liberating
- Often happens when career is established
- Might coincide with other major circumstances
- Surgically or medically induced  
**NOT** necessarily a natural event

# The peri/menopause can be problematic



- **Symptoms and signs**

- Vary widely

- Unrecognised or ignored

- Misdiagnosed (e.g. depression)

- Mask other serious conditions (e.g. thyroid)

- **Poor understanding**

- Clinicians - only 50% of GPs have training

- Employers

- Those affected

# Definitions and terminology

**Neurodiversity** – This is the idea that cognitive conditions, such as autism, ADHD, dyslexia and dyspraxia, are natural variations in the way people think and process information. The term recognises both the difficulties that people who have these conditions may encounter in the workplace and the unique strengths that can derive from thinking differently.

**Neurodivergence** – Workers may be described as neurodivergent if they have a cognitive profile that is different to that of the average or typical person. For example, a dyslexic person may be said to be neurodivergent.

**Neurotypical** – This is a term sometimes used to describe people who are not neurodivergent.



# Menstrual health and the ‘social model of disability’

- Discrimination
- Isolated individual
- Inaccessible toilets
- Poor career advancement opportunities
- Badly designed policies
- Inaccessible workplaces (e.g., **fieldwork**)





# Existing literature

Some examples of literature exploring the experiences of neurodivergent women managing menstrual health and peri/menopause:

- **Brady, M. J., Jenkins, C. A., Gamble-Turner, J. M., Moseley, R. L., Janse van Rensburg, M., & Matthews, R. J. (2024) “A perfect storm”: Autistic experiences of menopause and midlife’**
- **de Jong, M., Wynchank, D.S.M.R., van Andel, E., Beekman, A.T.F. and Kooij, J.J.S. (2023) ‘Female-specific pharmacotherapy in ADHD: premenstrual adjustment of psychostimulant dosage’**
- **Varshney, M. and Nalvarte, I. (2017) ‘Genes, gender, environment, and novel functions of estrogen receptor beta in the susceptibility to neurodevelopmental disorders’**



# Some notes on existing literature

- Autistic women and girls may experience particular challenges in managing menstrual blood, and other sensory issues as well as emotion regulation
- ADHD symptoms may be exacerbated at certain points of the menstrual cycle
- There is a growing (but limited) body of research which suggests that neurodiversity can impact the experiences of perimenopause

- 56 total
- 27 ltc/disability
- 16 ND

	Long term condition / disability	Long term condition/disability disclosed during interview	ND	ND disclosed during interview
1				
2	Yes	Hashimoto's autoimmune thyroiditis	no	
3	Yes		No	
4	No		Yes	
5	No		Yes	
6	Yes	Yes - multiple sclerosis and chronic heart condition		
7	Yes	Does not normally tick yes but this time felt that MH affects her day-to-day life	No	
8	No	Yes - iron and B12 deficiency because of heavy	No	
9	Yes	Yes menstrual pain is a long-term condition for me	No	
10	No	Depression and anxiety which have been amplified with contraceptive pills	No	
11	Yes	Endometriosis although not diagnosed	No	no
12	Yes		Yes	
13	Yes	I would call PMDD a disability.'	Yes	ADHD although not diagnosed yet but clash with the ADHD
14	Yes		Yes	clashing with PMS. Going through a formal diagnosis for Autism and ADHD
15	Yes	Endo and PMDD defined as disability	Yes	

16	Yes	Long-term depression, anxiety	Yes	ADHD interacts with perimenopausal symptoms
17	Yes	Functional Neurological Disorder (FND) whose symptoms interact with the menopause symptoms	No	
18	No	Anxiety exacerbated by perimenopause	No	
19	Yes		Yes	Neurodivergent experience of perimenopause
20	Yes	Depression and panic attacks that intensify with PMS	Yes	Autistic
21	Yes			
22	Yes	Migraine	No	
23	Yes	mental health and autism disclosed as disability at work PCOS affects day-to-day life although would have never classed it as disability	Yes	Autistic
24	Yes	Periods affect daily life	No	
25	Yes	Induced menopause (before her 40s) to treat endometriosis symptoms	No	
26	Yes		No	
27	Yes		Prefer not to say	
28	Yes		No	
29	Yes			
30	Yes	Endometriosis	Yes	ADHD

31	No		Yes	Dyslexia and ADHD symptoms exacerbated by hormonal fluctuations
32	Yes	Fibroids and endo - although when asked about long term condition responded 'no'	No	
33	Yes	adenomyosis, endometriosis and polycystic ovaries	No	
34	No		Yes	
35	Yes	Perimenopause had an effect on disability	Yes	Dyslexic
36	Yes		Yes	
37	No	Low level depression and anxiety (perimenopause exacerbated the mood swings), migraines	No	
38	Yes		Yes	



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# Neurodiversity and Menstrual Health

- Challenges in the stage before onset of menstruation (enhanced PMS and PMDD)
- Neurodivergent women may find the menopausal transition particularly problematic due to:
  - Loss of regular cycle (related to **lack of control**)
  - Loss of ability to 'mask'
- Some autistic women do not relate with normative experiences of womanhood, while not feeling represented in current work-wide initiatives and support networks
- Participants reported clinicians' lack of awareness about the interaction between menstrual health and neurodivergence



# ND and perimenopause

**'as a neurodivergent person, when you go through perimenopause, your symptoms, your neurodivergent attributes and struggles heighten... perimenopause hormonal stage impacts what the body is already dealing with.'**



# ND and PMS

**'I've got this crossover of mental health, ADHD, and being a woman, PMS. My PMS is quite a strong one. She's really got the reins during that time of the month, and so, I'm quite regular in terms of actual menstruating, the actual bleeding, but the mood-swings are hefty...I am sure there is a kind of co-morbidity with the ADHD there'**



# Masking

**'I am diagnosed with dyslexia and possibly I have some ADHD symptoms, which feel a lot worse when my hormones are not doing very well. And so, kind of feel that my organisation becomes more chaotic...I've always been able to mask my ADHD to the point where nobody would know, and probably that's still true. But I feel out of control if my hormones aren't under control.'**



# Masking (I)

**'I'm autistic, so I'm very familiar with masking. And that does help me to function in society, because certainly with teaching, that is a mask I enjoy wearing. It is where I can sort of put on the professional face.'**



# What can help?

- Include diversity of voices when planning to introduce interventions
- Avoid assumptions on experiences of womanhood and menstrual health
- Some women do not identify with normative gendered socialised behaviours
- Create workplaces where employees can be their true selves without the need to 'mask' who they are to abide by neurotypical and inaccessible structures
- Interactions between neurodiversity and menstrual health
- Design any policies and practices in relation to menstrual health **with** those most affected



# Get in touch

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Subscribe to our mailing list:  
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**I just feel I could have done so much more with the opportunities I had, and I feel that they were squandered**  
**- *interviewee***

