

# Forgotten Women: Lived Experiences of Menopause from People with a Learning Disability

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North East and  
North Cumbria



South Yorkshire

# Introduction

1.2m adults  
with a  
learning  
disability in  
UK

- NE England and South Yorkshire are areas of low SES and the populations experience health inequalities and low SES

PWLD die 20  
years earlier  
than wider  
population

- Menopause in people with a learning disability (PWLD) is an under-researched area.

Average age  
of  
menopause  
is 51 years

- Overlap between menopausal and LD symptomology.
- For certain ethnic groups, those with autoimmune disorders and PWLD, menopause can begin in their early 40s or even their late 30s.

Menopause  
symptoms  
experienced  
by 80% of  
females and  
last > 7 years

**AIM: To explore the perspectives of pre/post-menopausal individuals with a learning disability and the barriers to their effective care/support.**



To examine the current level of understanding of menopause for people with a learning disability



To identify the impact of menopause on learning disabilities



To examine barriers for people with a learning disability in key settings such as healthcare, social interactions, family and the community



To ascertain the key sources of support and recommendations to improve the transition of menopause for people with a learning disability

# Methodology

- **Participants:** 23 PWLDs
- **Location:** 8 South Yorkshire, 15 North-East North Cumbria
- **Age range:** 38 to 54 (mean: 45)
- **Ethnicity:** 20 Black, Black African or Black Caribbean, 1 Arabian, 1 Mixed Race, 1 white British
- **Learning Disability:** Language-based learning, visual and auditory processing, neurodevelopmental conditions
- **Carer:** 18 had a professional/relative carer, 5 had no carer
- **Menopause Stage:** 6 pre/peri-menopausal, 5 menopausal, 12 postmenopausal

# Methodology

- **Recruitment:** October 2025 - February 2026
- **Semi-structured interviews:** lasting up to 56 minutes (mean: 35 minutes 03 seconds)
- **Questions:**
  - (i) their knowledge of menopause
  - (ii) their menopausal symptoms and the impact on their learning disability
  - (iii) the barriers they experience in different settings such as the home, community, social and healthcare
  - (iv) recommendations for ways to effectively support them and carers when managing their disability and the menopause.
- **Data Analysis:** Thematic
- **Themes:**
  - (1) Understanding and Biopsychosocial impact of menopause
  - (2) Situational Contexts- Home
  - (3) Situational Contexts- Social and Community
  - (4) Situational Contexts- Medical

# Understanding and Biopsychosocial impact of menopause

*nobody prepared me for the way it made me feel, the way my body just changes within a short period of time  
(PWLD18)*

*I was always anxious of what else is going to happen. What are the symptoms I am yet to experience? That was just the feelings I had.  
(PWLD15)*

*I wake up sometimes happy, and at the end of the day, I end up, you know I see myself sometimes crying, but I don't know why. I sometimes find myself in the situation where I feel like I'm all alone, and the world is coming down... sometimes I always wonder what is going on with me. I feel sometimes like I'm going crazy. (PWLD20)*

*My confidence took a real knock. I, sort of, pulled back from socially engaging because conversations just left me embarrassed about how I could get lost, and people would feel like, "Oh, we know she is challenged, so you've got to go easy on her," not knowing that it was something different. (PWLD2)*

# Situational Context – home settings

*Some days it gets me really anxious. You know, I get nervous when I try to focus on something I know how to do. I end up not concentrating, so that really spoils my [day]... yeah, it spoils a lot of things for me. Some days, I do not get motivated to do anything at all. That's when maybe, probably, I'm depressed or maybe I'm feeling a little bit sad or maybe I'm down at that moment and there's definitely nothing to cheer me up because it's actually something that is happening within me. It's within my body and I can't remove that, there's no way I can actually stop it from happening. (PWLD3)*

*I told her [mum], "Please, you have to go back to your house, because I don't want someone around. I feel like I'm a burden to someone and I don't want that feeling." (PWLD9)*

*when the menopause symptoms came, I couldn't even leave my house... because trying to go out and coming back, I feel like I'm very tired, even if I just did a very tedious walk outside. So I've just been inside for the past months and it's not really good for me. (PWLD10)*

# Situational Context - social and community settings

*[friend] offered to start working out with me and, I mean, that is one thing that's really supportive, is keeping me going, because it can be so draining to do that alone in the midst of people that you have to, you know, talk to and they won't understand you. (PWLD8)*

*Even though I have people around to help me, I feel like me doing things by myself makes me more worthy. (PWLD11)*

*I felt tired and I had a problem concentrating during the day so it was making it harder to do my daily walks... because the lack of sleep can really worsen the mood swings. Imagine if you are not able to sleep and you're also struggling to stay asleep. It led me to a very depressional and irritable state. (PWLD6)*

*I normally can't sit down and relax [with friends], but I will try to do them, just to prove a point, so it's now like I'm hurting myself just not to make people think otherwise about my situation (PWLD13)*

# Situational Context - medical settings

*I saw a GP who just dismissed my fatigue and brain fog, he said, "It's part of getting older, or maybe it's just stress." He didn't talk to me about it being connected to the menopause or consider how it might interact with my learning disability. He just handed me a leaflet about relaxation techniques, which was really unhelpful for me because it honestly made me feel invisible. (PWLD2)*

*when I say something, they [GP] only read the meaning from ...how this is going to affect my health, so it's not like they think about how.. I am trying to deal with this. (PWLD13)*

*I only go in an emergency... I've taken up all the time, explained me disability, and then it's time to go. Then I make another appointment to go back to find out what the problem is to get me sorted. Yeah, because not all the doctors are qualified to work with adults with disability (PWLD23)*

*It's not that easy for me to understand, because he has to break down what he's actually saying to me to get my own understanding. (PWLD1)*

*Sometimes they don't know about it [learning disability], and you have to tell them, and you might be ashamed to tell them. Sometimes they don't have the training, they don't know how to [communicate with me]. (PWLD4)*

# Recommendations

Mandatory  
Menopause and  
Learning Disability  
Training for all  
practitioners and  
carers who work  
with women

Training in  
Communication  
Skills for carers,  
healthcare  
practitioners and  
medical support  
staff

Access to  
community  
groups for  
knowledge  
exchange and  
peer support

Educational  
Resources  
provided in a  
range of  
formats

Menopause  
Healthcare  
Services to  
include PWLDs  
from late 30s

# Thank you!

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As part of this project, we also interviewed carers for their perspectives  
- please contact Ellen for more information



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