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Menopause in women with intellectual disabilities

International Day of Action for Women's Health



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IDS-TILDA Wave 5 Findings

What did we find out about menopause from IDS-TILDA



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Age

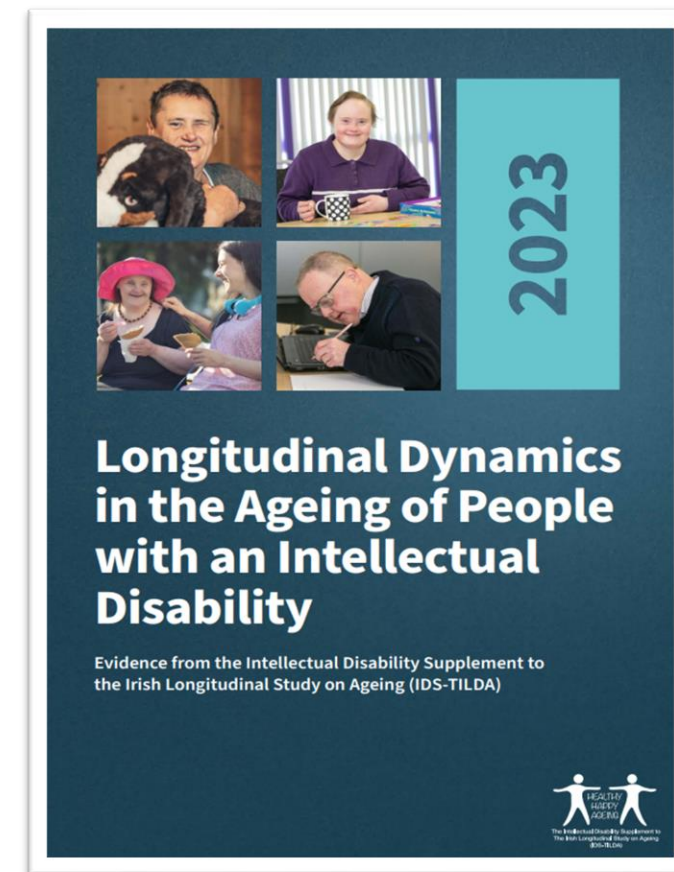
- **Earlier** age at menopause - **48 vs 51**.
- **Even earlier** for women with Down syndrome - **44 vs 48**.

Awareness

- **48.8%** of women knew what menopause was
- **37.9%** of women said they discussed menopause with someone
- **16.2%** received easy-to-read materials on the topic.

Hormone Replacement Therapy (HRT)

- **18%** on **HRT** in the general population (*Alsugeir et al., 2022*)
- ONLY **3.3%** of Menopausal women from IDS-TILDA were reported to take **any kind** of hormonal medication





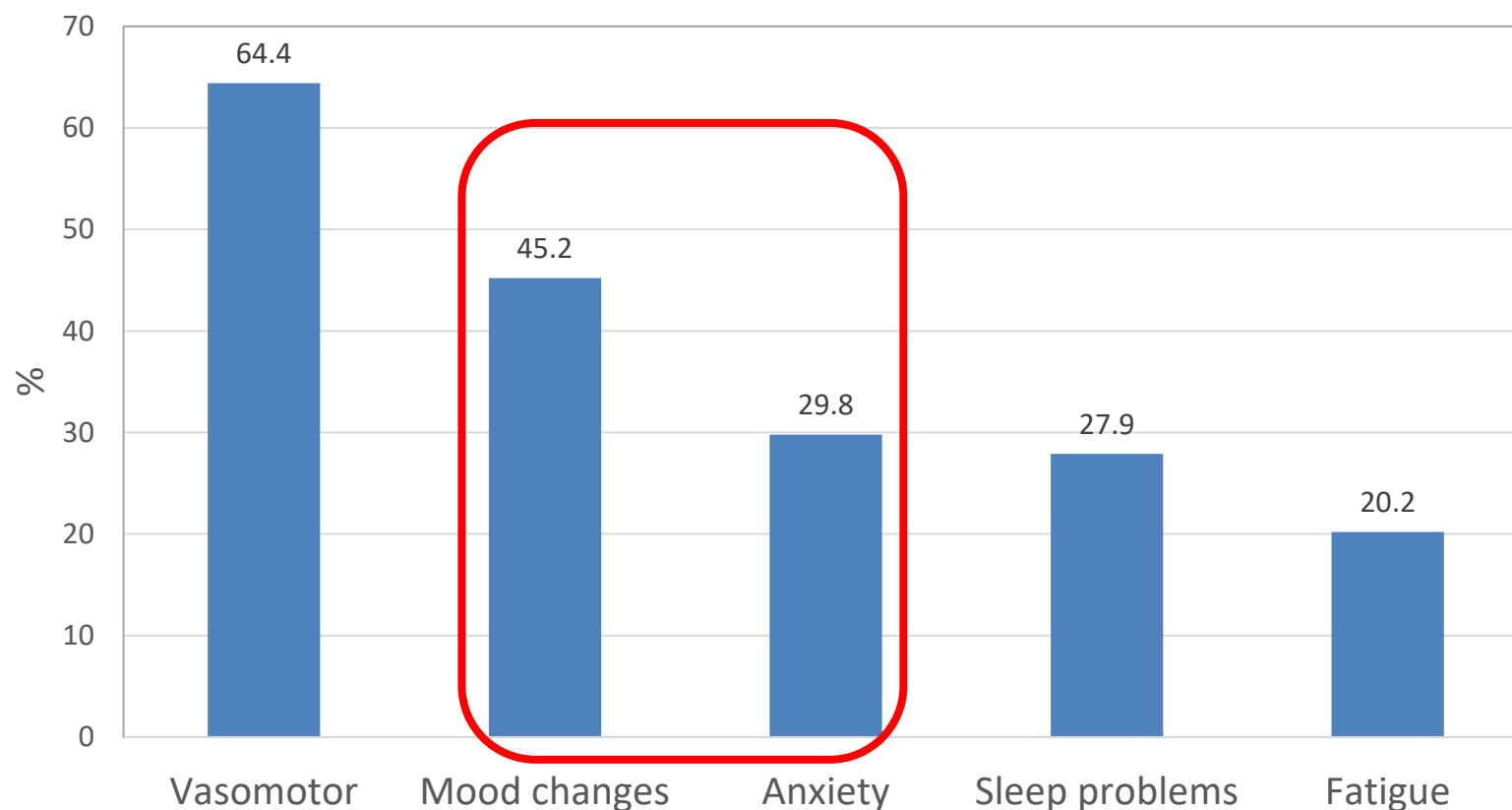
Menopausal symptoms

Most frequently reported symptoms



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Only **41.2%** of menopausal women reported menopausal symptoms vs **90%** in the general population.





Scoping Review

Thematic findings



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REVIEW OPEN ACCESS

The Impact of Menopause on the Mental Health of Women With an Intellectual Disability: A Scoping Review

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ABSTRACT

Background: Negative mental health implications of menopause found in the general population, combined with high rates of mental health conditions found in women with intellectual disabilities, provide rationale to examine the existing literature to determine the impact of menopause on women with intellectual disabilities.

Methods: The review was conducted using scoping review methodology by Arksey and O'Malley. A systematic search was conducted across multiple databases. Relevant articles were screened according to inclusion/exclusion criteria. Braun and Clarke's thematic analysis was utilised to identify themes.

Results: After screening, eight articles satisfied the inclusion/exclusion criteria, and after thematic analysis, themes found were: *changes in mood, lack of reporting of psychological symptoms and difficulty attributing psychological symptoms to menopause.*

Conclusions: Findings indicate the paucity of literature and the lack of attention paid to examining the impact of menopause on the experiences and mental health of women with intellectual disabilities.

1 | Introduction

Major health inequalities exist between individuals with intellectual disabilities and the general population (O'Leary, Cooper, and Hughes-McCormack 2018; Taggart, McMillan, and Lawson 2010). In general, people with intellectual disabilities suffer poorer health outcomes (van Schrojenstein Lantman-de Valk and Walsh 2008) and die younger than the general population (Doyle et al. 2020; McCarron et al. 2015). Women from this population are excluded from mainstream research dedicated to sexual and reproductive health—including studies on menopause (Earle et al. 2024; McCarthy and Millard 2003). This omission from research implies a paucity of knowledge of menopause in this population (Powell et al. 2020) which can impact delivery and quality of health care (Greenwood and Wilkinson 2013; Servais 2006). Such omission from research and limited access to healthcare can affect overall physical and

mental health (Wiseman and Ferrie 2020) and has been identified as a factor for premature mortality in this population (Robertson et al. 2021).

Menopause can be defined as the complete cessation of menstruation for 12 months, in the absence of any pathologic cause for amenorrhoea (World Health Organisation [WHO] 2022). Individuals with intellectual disabilities typically have problems with general abilities that affect both intellectual and adaptive functioning, which manifest before age 18 years (WHO 2019). As such, without appropriate education and support, their ability to comprehend more complex ideas surrounding their sexual and reproductive health may be limited. In addition, predictors of menopausal symptoms found in the general population such as socioeconomic status and negative perceptions of menopause (Langer-Shapland, Minton, and Richards 2023) may not be mirrored in this population, thus necessitating more specialised,

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Findings from scoping review

Mood changes

Lack of psychological symptoms reported

Difficulty attributing psychological symptoms to menopause

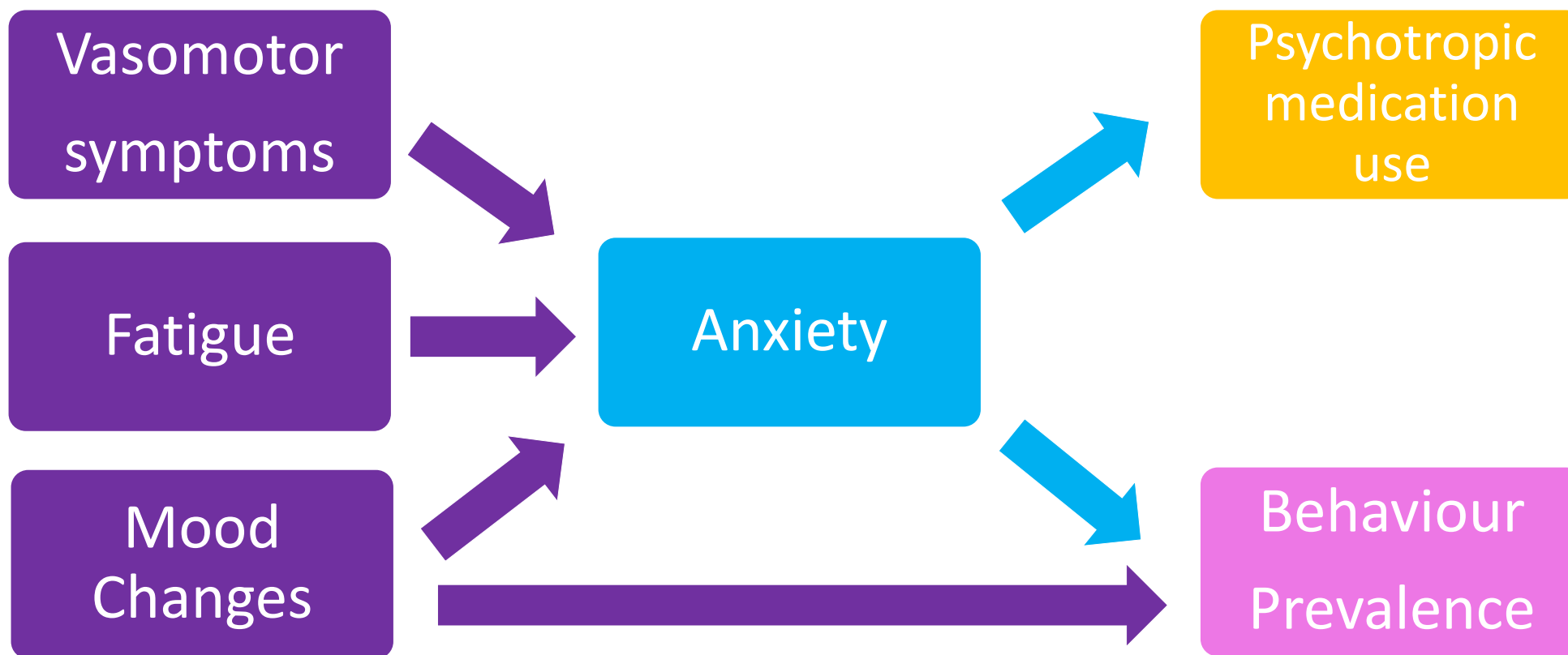


Impact of menopausal symptoms on mental health

Quantitative findings



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Quotes from participants

Qualitative findings



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“It’s for one thing being a woman for almost my life and being [like as] an adult, that I never knew [about] that women had these eggs inside them. I never knew anything about that. All my life.”

“Like you’re on edge, [...] you get annoyed very quick, you have mood swings. It [menopause] also gives you anxiety, it gives you stress, you can’t control it.”



Menopause in women with intellectual disabilities

Recommendations



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- Need for **education**.
- Need for **menopause-specific** treatments, for example;
 - Cycle-tracking (*Earle et al., 2024*)
 - Hormone replacement therapy (*Earle et al., 2024*)
 - Cognitive behavioural therapy (CBT) for vasomotor symptoms (*NICE, 2024*)
- Representation at **policy** level (*Department of Health, 2022*).





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Thank You

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Accessible Summary



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Menopause



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- Menopause is when a woman stops getting her monthly periods.
- It usually happens between the ages of 45-55.
- Sometimes menopause can happen **earlier** in women with an intellectual disability.

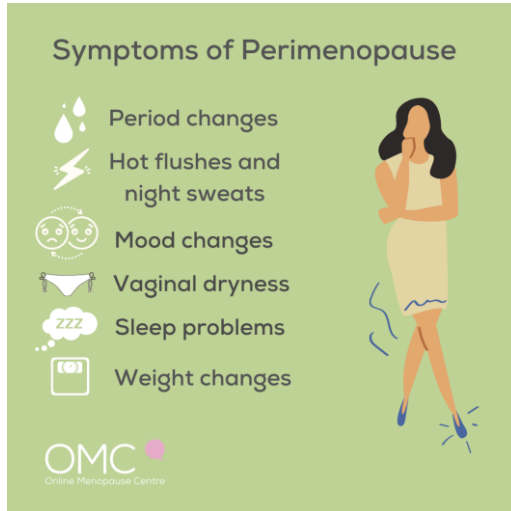




Menopause



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- Perimenopause is the time before your period stops completely.



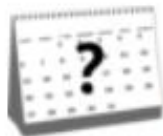
- There are lots of changes that can happen around the time of perimenopause...



Menopause



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- Periods may start to **change**. They may be shorter or longer. They can become heavier or lighter.



- Women can have hot flushes. This is when you suddenly feel very hot. It can feel uncomfortable.



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- Women can also experience night sweats which means they might find it hard to sleep and feel tired.



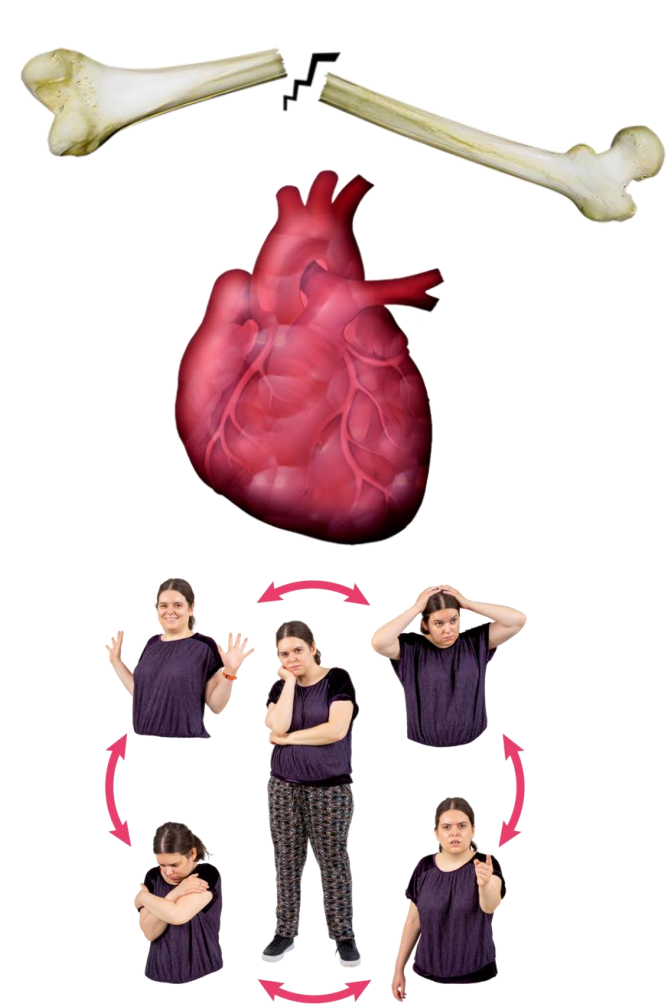
- Sometimes changes in your body can make it more likely to get other health problems like dementia...



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- Weaker bones or...
- Heart problems.
- Sometimes women experience mood changes and they can feel sad, angry, emotional or anxious.



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- Menopause can be stressful and can cause changes in behaviour.



- If you think you might be going through it, it is important to talk about it with your friends, family, carers, nurses and doctors.



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- Sometimes nurses and doctors don't realise that women with intellectual disabilities are going through menopause, and they are not given the right treatments.



- It is important for you to learn about menopause so that you know when you are going through it. This will make sure you get the help you need.



Menopause



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- There are special medicines like Hormone Replacement Therapy or HRT that can help to treat menopausal symptoms
- It is important to get the right treatments and medicines to help you to feel better.
- All women go through menopause. Let's talk more about it!



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Thank You

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