How is menstruation experienced by adolescents with Down syndrome in the UK?



This ethically-approved research was conducted by a team from the **International Centre for Evidence in Disability** at the **London School of Hygiene & Tropical Medicine (LSHTM)**: Dr Katie Greenland, Dr Sarah Polack, & Dr Jane Wilbur.

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If you would like further information, you can also find more detailed results here:

01 THE ISSUE

- **Adolescents with intellectual disabilities** often face challenges understanding, managing, & communicating menstrual health needs, affecting wellbeing & dignity.
- **Caregivers** play a key role in supporting menstrual health, especially at menarche.
- **Menstrual symptoms** are often overlooked or attributed to disability; evidence is limited & outdated.

"The managing the period itself is... not onerous... But it can have an impact, that pain. It's hard to watch"

"When I get a lot of pain I have to stop helping mum in the kitchen. I relax and watch TV."

02 WHAT WE DID

- **What we wanted to learn about:** Menstruation experiences & needs of adolescents with Down syndrome
- **Who we worked with:** An Advisory Group including young women with Down syndrome & family caregivers helped shape all aspects of the study.
- **What we did:** A mixed-methods study, involving a national online survey with caregivers & interviews with girls 13-19 years with Down syndrome & their family & professional caregivers.
- **Where it happened:** Across the UK, with interviews conducted in London & surrounding areas.

03 WHAT WE FOUND

Caregivers often felt anxious about menarche, but adolescents generally coped better than expected

- 96% of caregivers reported concerns ahead of first periods, particularly around menstrual products, self-care, & reactions to blood.
- Adolescents often managed well.

Period underwear and other products made a clear difference

- Period underwear or "magic pants" were "game changers" for improving independence & simplified care.

Heavy periods and communication of pain were a concern

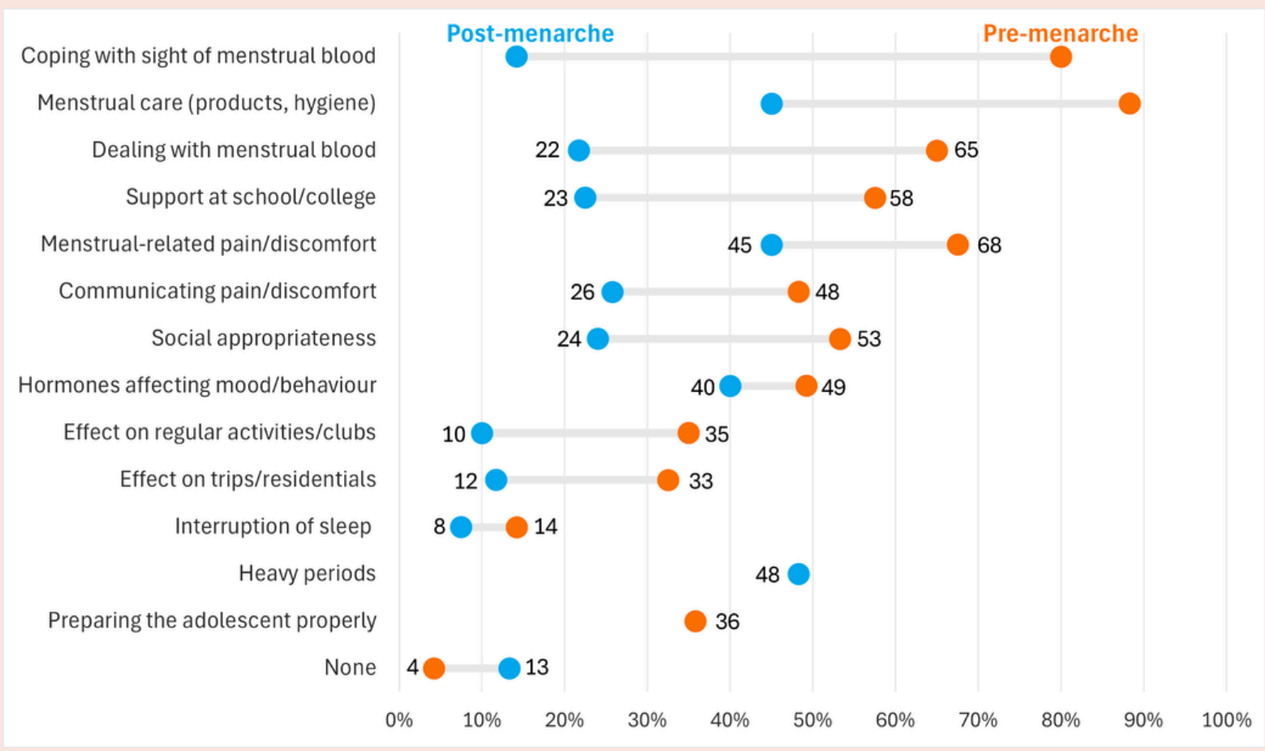
- Communicating & managing pain were concerns for 71% of caregivers
- Over a third of adolescents could not communicate pain; caregivers relied on physical signs & behaviours.
- Nearly one-quarter of caregivers felt pain was not effectively managed
- Hormonal medication brought *"peace"* by reducing symptoms, but caused worry over long-term health effects

"[She] is a visual learner... So it's doing the same thing... talking her through the process whilst I'm doing it. It is this repetition [and] you have to be very patient as well."

04 ANALYSIS

Caregiver concerns often decrease as periods establish, **but challenges remain**

Nicole worried that her daughter would "freak out", or "think that she's going to die", when she got her first period, but she "just seems to take it in her stride."



05 WHAT SHOULD HAPPEN NEXT?

- **Develop** tailored menstrual health educational resources for different cognitive abilities about periods, body changes & building confidence/independence.
- **Provide** practical guidance on menstrual care & responding to heavy periods and pain, including pain communication & hormonal options.
- **Train** clinicians to have proactive, holistic conversations about menstrual health.
- **Create** supportive networks for caregivers to reduce isolation & share knowledge and resources.

Safe and dignified menstruation for adolescents with Down syndrome requires **accessible support, informed caregivers,** & **resources that promote independence, choice, and autonomy.**

ACKNOWLEDGEMENTS

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