Menopause: diagnosis and management

NICE National Institute for Health and Care Excellence

Consultation on draft guideline – deadline for comments 5pm on 05/01/2024

email: Menopause@nice.org.uk

Checklist for submitting comments

- Use this comments form and submit it as a **Word document (not a PDF)**.
- **Do not submit further attachments** such as research articles, or supplementary files. We return comments forms that have attachments without reading them. You may resubmit the form without attachments, but it must be received by the deadline. You are welcome to include links to research articles or provide references to them
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include **document name, page number and line number** of the text each comment is about.
- Combine all comments from your organisation into 1 response form. **We cannot accept more than 1 comments form from each organisation**.
- **Do not** paste other tables into this table – type directly into the table.
- Ensure each comment stands alone; **do not** cross-refer within one comment to another comment.
- **Clearly mark any confidential information or other material that you do not wish to be made public with underlining and highlighting. Also, ensure you state in your email to NICE, and in the row below, that your submission includes confidential comments.**
- **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted.
- Spell out any abbreviations you use.
- **We have not reviewed the evidence for the recommendations shaded in grey. Therefore, please do not submit comments relating to these recommendations as we cannot accept comments on them.**
- **We do not accept comments submitted after the deadline stated for close of consultation.**

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate. Where comments contain confidential information, we will redact the relevant text, or may redact the entire comment as appropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

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	Please read the checklist above before submitting comments. We cannot accept forms that are not filled in correctly. We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment. In addition to your comments below on our guideline documents, we would like to hear your views on these questions. **Please include your answers to these questions with your comments in the table below.** 1. Would it be challenging to implement of any of the draft recommendations? Please say why and for whom. Please include any suggestions that could help users overcome these challenges (for example, existing practical resources or national initiatives. 2. Would implementation of any of the draft recommendations have significant cost implications? See Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.
Organisation name (if you are responding as an individual rather than a registered stakeholder please specify).	Royal College of General Practitioners
Disclosure (please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry).	No disclosures
Confidential comments (Do any of your comments contain confidential information?)	No
Name of person completing form	Michael Mulholland/ Anika Mandla

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Comment number	**Document** [e.g. guideline, evidence review A, B, C etc., methods, EIA]	**Page number** **'General'** for comments on whole document	**Line number** **'General'** for comments on whole document	**Comments** • Insert each comment in a new row. • Do not paste other tables into this table, because your comments could get lost – type directly into this table. • Include section or recommendation number in this column.
Example	Guideline	016	045	Rec 1.3.4 – We are concerned that this recommendation may imply that ……..
Example	Guideline	017	023	Question 1: This recommendation will be a challenging change in practice because ……
Example	Guideline	037	016	This rationale states that…
Example	Evidence review C	057	032	There is evidence that …
Example	Evidence review C	063	012	CONFIDENTIAL: Our unpublished study has shown that [X] is more effective than [Y]
Example	Methods	034	010	The inclusion criteria …
Example	Algorithm	General	General	The algorithm seems to imply that …
Example	EIA	010	002	We agree with the barriers to access listed, and would also like to add ….
1	Guideline	006	021	Rec 1.2.2 This recommendation should include the following: In patients with LD the menopause may present with changes of behaviour and require careful assessment particularly in non-verbal patients. In patients with neurodiversity, the menopause may be the time in their lives when the difficulties of being neurodiverse manifest themselves or are exacerbated.
2	Guideline	008	008	Rec 1.2.9 It is important that the Information available should include literature etc suitable for people with learning disability and neurodiversity including Easy read literature.eg Learning Disabilities booklet
3	Guideline	008	010	Rec 1.2.9 This recommendation should include the following: People with LD require special consideration as: - their menopause can occur prematurely. - Consultation and discussion with them and their supportive friend will require additional time and reasonable adjustment in terms of timing and location of consultation. People with neurodiversity require special consideration in their discussions about the menopause tailored to their neurocognitive profile
4	Guideline	008	024	Rec 1.3.3 This recommendation does not read very well. People with ethnic minority background could also have a white background therefore, rewording it to say "...people with predominantly white ethnicity." may read better. Additionally, it is important to include that Learning disability is associated with having menopause at an earlier age.

5	Guideline	009	012	Rec 1.3.5 It is important to include: Patients with LD can benefit, after consent or best of interests assessment of undergoing FSH measurement together with prolactin measurement if they have amenorrhoea. They are at higher risk both of early menopause and Hyperprolactinaemia which can be due to concurrent treatment with neuroleptic or tricyclic medications. Both measurements need repeating in 4-6 weeks with reasonable adjustment on both occasions to result in least distress at the time of the phlebotomy.
6	Guideline	009	015	Rec 1.3.5 The following information regarding individuals with neurodiversity should be added: - May present for the first time with distress due to neurodiversity at the time of the menopause - Are at greater risk of developing depression at the time of the menopause with risk of suicidal intent
7	Guideline	010	022	Rec 1.4.2 We suggest tailoring the information to a person's health literacy level too.
8	Guideline	010	026	Rec 1 .4.3 We believe that this recommendation should also include some information on how long it may take for medication to take effect, when to re-consult if symptoms are not improving, adjusting doses or medication depending on response, the method of application e.g. oral, transdermal etc and how to apply/take medication e.g. ensuring transdermal is on clean, dry skin, don't put near breasts etc
9	Guideline	011	009	Rec 1.4.4 It is important to extend Individual face- to- face to include that in the care of patients with LD or neurodiversity, individuals may require the presence of a supportive friend – a family member, a carer or friend.
10	Guideline	014	006	Rec 1.4.16 It is important to add that patients with neurodiversity have variable response to CBT which may, on balance, cause more harm and their vasomotor symptoms are likely to be more severe due to the risk of autonomic instability including "POTs" which has an increased prevalence in people with neurodiversity.
11	Guideline	015	007	Rec 1.4.19 We believe that it is important to include that patients known to be menopausal with LD presenting with recurrent LUTS may benefit from vaginal oestrogen preparations
12	Guideline	017	010	Rec 1.4.29 It will be beneficial to provide specific information about how the hormone receptor status of the person would have an impact on safety.
13	Guideline	018	007	Rec 1.4.33 We recommend removing "unless part of a randomised controlled trial."
14	Guideline	018	010	Rec 1.4.34 We are concerned that this recommendation does not consider moderate or severe depressive symptoms. Additionally, we think it is important to extend the recommendation to include the following: Consider HRT to alleviate mild depressive symptoms with onset in association with other menopause symptoms **particularly in people with LD or neurodiversity who may present with atypical symptoms of both menopause and depression.**
15	Guideline	018	011	Rec 1.4.35 We believe that this recommendation should be extended to include: Consider CBT for depressive symptoms associated with the menopause, **being aware of the unpredictable response of patients with neurodiversity to CBT.**

16	Guideline	018	017	Rec 1.4.36 We believe that the following information should be added to this recommendation: Consider a new diagnosis of autism presenting or associated with depression and associated with a higher risk of suicide. Consider that patients with LD can present with a new onset of behaviour problems due to menopause or depression or the two combined.
17	Guideline	019	003	Rec 1.4.37 This recommendation should be extended to include: Consider CBT for difficulties with sleep associated with the menopause **being aware of patients with neurodiversity having a variable response to CBT.**
18	Guideline	020	003	Rec 1.5.3 It is important to add details of the increased risk of endometrial hyperoestrinism and carcinoma in patients with LD and the need for increased vigilance because of this increased risk.
19	Guideline	021	015	Rec 1.5.11 It is important to extend this recommendation to the following: if needed refer them to specialist psychology services p**articularly if they are known or have recently been found to be affected by neurodiversity.**
20	Guideline	026	Table	In the section on osteoporosis, it is important to mention that any adult patient with LD is at increased risk of osteoporosis which can be exacerbated by the menopause.
21	Guideline	044	011	We are concerned that “and will standardise it.” is unclear. It will be beneficial to specify what will be standardised.
22	Guideline	General	General	This draft guideline correctly discusses the health implications of the menopause to members of several minorities but we feel that, in the interests of health equality, it should also refer to another minority – those with learning disability (at least 2.5% of the population). This minority are subject to early menopause and their presentation can be atypical and their counselling requires reasonable adjustment suitable to their needs. Relevant references: Schupf, N., Zigman, W., Kapell, D., Lee, J. H., Kline, J., & Levin, B. (1997). Early menopause in women with Down’s syndrome. *Journal of Intellectual Disability Research, 41*(3), 264–267. https://doi.org/10.1111/j.1365-2788.1997.tb00706.x Seltzer, G., Schupf, N., & Wu, H. (2001). A prospective study of menopause in women with Down’s syndrome. *Journal of Intellectual Disability Research,* 45 (pt. 1), 1–7. http://doi.org/10.1046/j.1365-2788.2001.00286.x. PMID: 11168771. Willis, D. S. (2008). A decade on: What have we learnt about supporting women with intellectual disabilities through the menopause? *Journal of Intellectual Disabilities, 12*(1), 9–23. https://doi.org/10.1177/1744629507086604

				Willis, D. S., Wishart, J. G., & Muir, W. J. (2010). Carer knowledge and experiences with menopause in women with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 42–48. *https://doi.org/10.1111/j.1741-1130.2010.00246.x* Martin, D. M., Cassidy, G., Ahmad, F., & Martin, M. S. (2001). Women with learning disabilities and the menopause. *Journal of Learning Disabilities, 5*(2), 121–132. https://doi.org/10.1177/146900470100500204 McCarthy, M. (2002a). Going through the menopause: Perceptions and experiences of women with intellectual disability. *Journal of Intellectual and Developmental Disability, 27*(4), 281–295. *https://doi.org/10.1080/1366825021000055817* McCarthy, M. (2002b). The Menopause and Women with Learning Disabilities. Updates, *The Foundation for People with Learning Disabilities. Mental Health Update 3*(14). https://www.learningdisabilities.org.uk/learning-disabilities/publications/menopause-and-women-learning-disabilities McCarthy, M. (2002c). Responses to women with learning disabilities as they go through the menopause. Tizard Learning Disability Review, 7(1), 4–12. McCarthy, M., & Millard, L. (2003). Discussing the menopause with women with learning disabilities. British Journal of Learning Disabilities, 31(1), 9–17. https://doi.org/10.1046/j.1468-3156.2003.00182.x De Almeida, E. W., & Greguol, M. (2015). Healthcare for Women with Disabilities in the Climacteric and Menopause. Sexuality and Disability, 33(2), 279–298. https://doi.org/10.1007/s11195-014-9390-4 Chou, Y.-C., Lu, Z.-Y. J., & Pu, C.-Y. (2013). Menopause experiences and attitudes in women with intellectual disability and in their family carers. Journal of Intellectual & Developmental Disability Frighi, Vet al; 2022 Incidence of fractures in people with intellectual disabilities over the life course: a retrospective matched cohort study eClinical Medicine, Volume 52, October 2022, Winterhalder R 2022 Bone health, intellectual disability and epilepsy: An observational community-based study Acta Endo Scandc 145(6): 753–761.

				Burke É, Carroll R, O'Dwyer M, et al. Quantitative examination of the bone health status of older adults with intellectual and developmental disability in Ireland: a cross-sectional nationwide study. BMJ Open 2019;9:e026939. doi:10.1136/ bmjopen-2018-026939
23	Guideline	General	General	This draft guideline correctly discusses the health implications of the menopause to members of several minorities but we feel that, in the interests of health equality, it should also refer to another minority – those with neurodiversity. This minority are subject to atypical presentation of the menopause and their counselling requires reasonable adjustment suitable to their needs. Relevant references: El Baou et al (2023) Effectiveness of primary care psychological therapy services for treating depression and anxiety in autistic adults in England: a retrospective, matched, observational cohort study of national health-care records Lancet Psychiatry 10,12, 944-954 Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2020). 'When my autism broke': A qualitative study spotlighting autistic voices on menopause. Autism, 24(6), 1423–1437. https://doi.org/10.1177/1362361319901184 Moseley, R. L., Druce, T., & Turner, C. J. M. (2021). Autism research is 'all about the blokes and the kids': Autistic women breaking the silence on menopause. British Journal of Health Psychology, 26(3), 709–726. https://doi.org/10.1111/bjhp.12477 Karavidas, M., & de Visser, R. O. (2022). "It's Not Just in My Head, and It's Not Just Irrelevant": Autistic Negotiations of Menopausal Transitions. Journal of Autism & Developmental Disorders, 52(3), 1143–1155. https://doi.org/10.1007/s10803-021-05010-y Groenman, A. P., Torenvliet, C., Radhoe, T. A., van Rentergem, J. A. A., & Geurts, H. M. (2022). Menstruation and menopause in autistic adults: Periods of importance? Autism: The International Journal of Research & Practice, 26(6), 1563–1572. https://doi.org/10.1177/13623613211059721 Spain D, Happe 2019 How to Optimise Cognitive Behaviour Therapy (CBT)for People with Autism Spectrum Disorders (ASD): A Delphi Study. Debbie Spain1 · Francesca Happé1 Journal of Rational-Emotive & Cognitive-Behavior Therapy (2020) 38:184–208 https://doi.org/10.1007/s10942-019-00335-1

				Owens A P MATHIAS C IODICE C 2021 Autonomic Dysfunction in Autism Spectrum Disorder Front Integr Neurosci. 15: 787037. Published online 2021 Dec 30. doi: 10.3389/fnint.2021.787037 PMCID: PMC8756818PMID: 35035353
24	General	General	General	It is important not to discourage the use of HRT when it can be beneficial and to view CBT as an additional option, not the primary recommendation for GPs when consulting with women about the menopause. Additionally, it is important to discuss the risks as well as the benefits of treatment options to provide a balanced understanding, allowing for informed decisions to be made based on individual needs.
25	General	General	General	We appreciate the overall direction of this guideline, but we have concerns about the exclusion of learning disabilities and neurodiversity and have therefore included comments related to these areas, alongside a few additional comments to be considered (highlighted).

Insert extra rows as needed

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