# "I suffer in silence..."

### Menopause and Mind Research Brighton and Hove 2023





images from Menopause and Mind Creative Workshops 2023/24



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2023

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"It stops me doing things, leaves me feeling less confident, in pain, old before my time. It impacts my work and my family life. I'm often extremely tired and need to sleep, I have a lot of abdominal pain which is undiagnosed. I try and change my diet but that's hard, I've tried many different HRT treatments and that's hard as well. It's not easy at all. Some weeks are better than others and some are tough." – **Participant Feedback** 

"I don't think the life-destroying effects of menopause are taken seriously. Maybe it's ok for people in supportive relationships and/or who have had wanted children, but I've no relationship (and am autistic so there's little chance of achieving a supportive relationship) and I certainly won't be able to have one post menopause as it makes you undesirable and 'over the hill'." – **Participant Feedback** 

"I have been backwards and forwards to the doctors for many years and in the beginning did not feel like I was being taken seriously, being told I was too young and to come back in a couple of years only to have many blood tests that were inconclusive. I felt because I became a nuisance with calls and appointments that finally someone listened. I feel all doctors should be given training and have more information to signpost." – Participant Feedback

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#### **Executive Summary**

Our report provides insights from a survey conducted by Menopause and Mind in the Brighton and Hove area, focusing on the experiences of individuals during the menopausal transition, as well as providing a contextual overview.

The survey gathered data from 30 individuals between the ages of 40 and 60. The respondents expressed a significant need for better support and communication during the menopausal transition. Many reported a desire for more mental and emotional support, and a majority indicated negative impacts on work, family life, and social situations. We have entitled this report "I suffer in silence..." as the majority of respondents noted they had no one they felt they could speak with about their experiences, with many feeling let down and dismissed by medical professionals. Almost 80% said they needed more support around mental and emotional health.

The methods tried for symptom relief varied but leaned towards a holistic approach, including lifestyle change, exercise, and dietary changes, and many found medical interventions like Hormone Replacement Therapy (HRT) incredibly helpful. It is clear from the feedback that many identified solutions have been outside of the NHS and privately paid for.

The results highlight the diverse experiences of individuals with the National Health Service (NHS) during menopause. Many individuals expressed frustration and dissatisfaction with the support received, citing difficulties in diagnosing and addressing symptoms, limited mental health support, barriers to accessing HRT and concerns over anti-depressants as a first port of call. There appear to be systemic issues around being dismissed, not being listened to, or believed when presenting with menopause-related symptoms, leading to late diagnosis and delayed support. However, positive experiences were also noted, particularly with specialist nurses and the availability of HRT.

The survey respondents emphasised the need for increased knowledge and education about hormones and their mental health impact, more support from GPs, access to menopause specialists and gynaecologists, and a holistic understanding of the challenges associated with menopause. They also stressed the importance of increased awareness, education, reduced stigma, improved life and workplace support, and access to trained healthcare professionals. There is a need to understand how menopause impacts more diverse and marginalised groups, particularly around disability, neurodiversity, LGBTQIA+ and cultural differences that may impact accessing support. More detailed research is required on this to understand specific needs, and this will inform future research by Menopause and Mind.

This report emphasises the importance of comprehensive support, increased awareness, and reduced stigma surrounding menopause. There is a need to be aware of the complex nature of support needed during the menopausal transition, encompassing emotional, informational, and societal aspects and not just the medical interventions. Our findings also highlight the potential positive impact of providing support during the menopausal transition on individuals and the wider community, including reduced depression and stress, and the possibilities around building a more supportive and understanding community through practices of collective care.



#### Introduction

The current state of support for perimenopause in the UK is characterised by a growing recognition of the need for improved awareness, education, and support.<sup>1</sup> There is a rising emphasis on destigmatising conversations around menopause and enhancing workplace policies. Recent research showing the number of menopause linked absences and job losses has led to specific guidance that now aims to ensure reasonable adjustments in the workplace.<sup>2</sup>

While there has been an increase in menopause visibility, representations in the media have also deflected attention away from understanding menopause as a complex social and cultural issue as well as a medical and economic one.<sup>3</sup> There has been less interest in the impact on broader social, cultural life and relationships outside of the workplace or for those not in paid employment. Researchers are advising that we should be wary of conflating this increase in visibility of menopause with increased inclusivity, and are calling for more intersectionally-conscious accounts of menopause that reach beyond white, cis-gendered, middle-class affluence.<sup>4</sup>

The public sphere is seeing a disconnect between the broadly identified structural inequalities and the emphasis on individualised and privatised solutions.<sup>5</sup> For the majority that rely on the NHS and cannot access private care, our UK healthcare system still faces a shortage of high-quality menopausal care, with a specific lack of integrated mental health screening.<sup>6</sup> While GPs provide the majority of frontline care, most GP practices do not offer dedicated menopause services or additional training in menopause-care.<sup>7</sup>

<sup>&</sup>lt;sup>1</sup> 'Menopause (Support and Services) Bill - Parliamentary Bills - UK Parliament', accessed 16 August 2021, https://bills.parliament.uk/bills/2897; Shani Orgad and Catherine Rottenberg, 'The Menopause Moment: The Rising Visibility of "the Change" in UK News Coverage', *European Journal of Cultural Studies*, 15 April 2023, 13675494231159562, https://doi.org/10.1177/13675494231159562.

<sup>&</sup>lt;sup>2</sup> 'Menopause in the Workplace: Guidance for Employers | EHRC', accessed 20 March 2024,

https://www.equalityhumanrights.com/guidance/menopause-workplace-guidance-employers; 'Guidance on Menopause and the Workplace', accessed 9 August 2021, https://nipsa.org.uk/nipsa-in-action/equality/697-guidance-on-menopause-and-the-workplace; 'An Invisible Cohort: Why Are Workplaces Failing Women Going through Menopause? - Committees - UK Parliament', accessed 23 January 2022,

https://committees.parliament.uk/committee/328/women-and-equalities-committee/news/156760/an-

 $invisible\-cohort\-why\-are\-workplaces\-failing\-women\-going\-through\-menopause/.$ 

<sup>&</sup>lt;sup>3</sup> Orgad and Rottenberg, 'The Menopause Moment'.

<sup>&</sup>lt;sup>4</sup> Deborah Jermyn, "Everything You Need to Embrace the Change": The "Menopausal Turn" in Contemporary UK Culture', *Journal of Aging Studies* 64 (1 March 2023): 101114,

https://doi.org/10.1016/j.jaging.2023.101114.

<sup>&</sup>lt;sup>5</sup> Shani Orgad and Catherine Rottenberg, 'Mediating Menopause: Feminism, Neoliberalism, and Biomedicalisation', *Feminist Theory*, 13 July 2023, 14647001231182030,

https://doi.org/10.1177/14647001231182030.

<sup>&</sup>lt;sup>6</sup> Nayra A. Martin-Key et al., 'Perceptions of Healthcare Provision throughout the Menopause in the UK: A Mixed-Methods Study', *Npj Women's Health* 1, no. 1 (7 December 2023): 1–10,

https://doi.org/10.1038/s44294-023-00002-y.

<sup>&</sup>lt;sup>7</sup> Kanyada Koysombat et al., 'Patient and Healthcare Providers Experience of Access to Menopause-Related Information and Menopause-Care Provision across the UK: Results from a Nationwide Survey', in *Endocrine Abstracts*, vol. 94 (SfE BES 2023, Bioscientifica, 2023), https://doi.org/10.1530/endoabs.94.P116.



While slow progress is happening, there is still a need for further research, public health initiatives, and tailored healthcare services to support individuals during the peri-menopausal phase effectively. Those already marginalised and discriminated against are likely to see existing challenges to accessing healthcare extended to accessing support around menopause.

There is also a need to understand different cultural approaches to menopause, including the complexity of displaced refugee and asylum seeker experiences and the way these identities impact and restrict access to healthcare.<sup>8</sup> It is a similar story with pre-existing health conditions, disabilities, and neurodiversity.<sup>9</sup> Recently, the unmasking of neurodivergence, such as Attention Deficit (Hyperactivity) Disorder and Autism Spectrum Disorders (ASDs) during the menopause transition, has been gaining more attention.<sup>10</sup> In general, there needs to be work to generate greater understanding and perceptions of how the experience of menopause links with lived experiences of religion, sexuality, menstruation, ageing, and ethnic identities.<sup>11</sup>

There is little research on LGBTQIA+, (particularly trans, gender non-confirming and non-binary research), although national groups such as the Menopause Inclusion Collective and previously Queer Menopause have been working to rectify this.<sup>12</sup> There also needs to be research into the socio-economic disparities of menopause care that looks beyond the working community. Also, while research indicates a clear connection between trauma and difficulties around the menopause transition, there is still work needed to embed this into practice and common knowledge among GPs.<sup>13</sup> There is also little research on the impact of hormone related conditions such as

<sup>&</sup>lt;sup>8</sup> Jane M. Ussher, Alexandra J. Hawkey, and Janette Perz, "Age of Despair", or "When Life Starts": Migrant and Refugee Women Negotiate Constructions of Menopause', *Culture, Health & Sexuality* 21, no. 7 (July 2019): 741–56, https://doi.org/10.1080/13691058.2018.1514069.

<sup>&</sup>lt;sup>9</sup> Yamnia I. Cortés and Valentina Marginean, 'Key Factors in Menopause Health Disparities and Inequities: Beyond Race and Ethnicity', *Current Opinion in Endocrine and Metabolic Research* 26 (1 October 2022): 100389, https://doi.org/10.1016/j.coemr.2022.100389; Rachel L. Moseley, Tanya Druce, and Julie M. Turner-Cobb, 'Autism Research Is "All about the Blokes and the Kids": Autistic Women Breaking the Silence on Menopause', *British Journal of Health Psychology* 26, no. 3 (September 2021): 709–26,

https://doi.org/10.1111/bjhp.12477; Bettina Camara, Cintia Padoin, and Blanca Bolea, 'Relationship between Sex Hormones, Reproductive Stages and ADHD: A Systematic Review', *Archives of Women's Mental Health* 25, no. 1 (1 February 2022): 1–8, https://doi.org/10.1007/s00737-021-01181-w.

<sup>&</sup>lt;sup>10</sup> Camara, Padoin, and Bolea, 'Relationship between Sex Hormones, Reproductive Stages and ADHD'; Moseley, Druce, and Turner-Cobb, 'Autism Research Is "All about the Blokes and the Kids"'; Rachel L Moseley, Tanya Druce, and Julie M Turner-Cobb, '"When My Autism Broke": A Qualitative Study Spotlighting Autistic Voices on Menopause', *Autism* 24, no. 6 (August 2020): 1423–37, https://doi.org/10.1177/1362361319901184.
<sup>11</sup> Mwenza T. Blell, 'Menopausal Symptoms among British Pakistani Women: A Critique of the Standard Checklist Approach', *Menopause* 22, no. 1 (January 2015): 79,

https://doi.org/10.1097/GME.00000000000256; Mwenza Blell, 'The Timing and Experience of Menopause among British Pakistani Women in Bradford and Leeds, West Yorkshire, UK' (Doctoral, Durham University, 2009), https://etheses.dur.ac.uk/291/.

<sup>&</sup>lt;sup>12</sup> 'Queer / LGBTQIA+ Menopause', Queer / LGBTQIA+ Menopause, accessed 20 March 2024, https://www.queermenopause.com; 'Menopause Inclusion Collective', Menopause Inclusion Collective, accessed 20 March 2024, https://www.menopausecollective.org.

<sup>&</sup>lt;sup>13</sup> Vasiliki Michopoulos et al., 'Association between Perimenopausal Age and Greater Posttraumatic Stress Disorder and Depression Symptoms in Trauma-Exposed Women', *Menopause* 30, no. 10 (October 2023): 1038, https://doi.org/10.1097/GME.00000000002235; Joyce T. Bromberger et al., 'Does Childhood Maltreatment or Current Stress Contribute to Increased Risk for Major Depression during the Menopause Transition?', *Psychological Medicine* 52, no. 13 (October 2022): 2570–77, https://doi.org/10.1017/S0033291720004456; A.



endometriosis and Premenstrual dysphoric disorder (PMDD) on the experience of the menopausal transition.<sup>14</sup>

Organisations and healthcare providers are at the start of a journey towards providing more comprehensive information, resources, and medical support to address the physical, emotional, and psychological aspects of perimenopause. Locally, Brighton and Hove Federation note that the health service is developing a range of specialist services such as Menopause Clinics, Coil Clinics, Long-term Condition Management and group consultations.<sup>15</sup> NHS Sussex has been working with voluntary and community sector partners to get feedback from women from underrepresented communities in Sussex about healthcare experiences.<sup>16</sup> They are now working to take on board feedback about people not being listened to or believed about their experiences, menopausal misdiagnosis, calls for better information about menstrual health and the menopause. This includes better support for neurodiverse women and girls; women experiencing homelessness; the travelling community; ethnically diverse women; and trans, non-binary and intersex people.<sup>17</sup>

We hope our research will help support the move to improve services locally by adding to the diverse voices calling for improved healthcare around the menopause transition.

https://www.brightonandhovefed.co.uk/enhanced-access.

<sup>17</sup> Rayfield.

K. Shea et al., 'Depression in Midlife Women Attending a Menopause Clinic Is Associated with a History of Childhood Maltreatment', *Climacteric* 25, no. 2 (4 March 2022): 203–7, https://doi.org/10.1080/13697137.2021.1915270.

<sup>&</sup>lt;sup>14</sup> Umit Inceboz, 'Endometriosis after Menopause', *Women's Health* 11, no. 5 (1 September 2015): 711–15, https://doi.org/10.2217/whe.15.59; Cristina Secosan et al., 'Endometriosis in Menopause—Renewed Attention on a Controversial Disease', *Diagnostics* 10, no. 3 (March 2020): 134,

https://doi.org/10.3390/diagnostics10030134; Fatma Tuygar- Okutucu et al., 'Association of Menopausal Symptoms and Menopausal Quality of Life with Premenstrual Syndrome', *Malawi Medical Journal* 35, no. 2 (2 August 2023): 95–100, https://doi.org/10.4314/mmj.v35i2.4.

<sup>&</sup>lt;sup>15</sup> Designs, 'Enhanced Access', Brighton and Hove Federation, 2024,

<sup>&</sup>lt;sup>16</sup> Harriet Rayfield, 'Women's Voices Call for Improvements to Healthcare Services in Sussex', Sussex Health & Care, 8 March 2024, https://www.sussex.ics.nhs.uk/womens-voices-call-for-improvements-to-healthcare-services-in-sussex/.



#### About Menopause and Mind

Menopause and Mind are a community organisation established in March 2023 to provide inclusive support around menopause and mental health struggles in the Brighton and Hove area.<sup>18</sup> We take a trauma-informed approach, recognising that every menopause experience is different, and aim to create non-judgemental environments for sharing experiences.

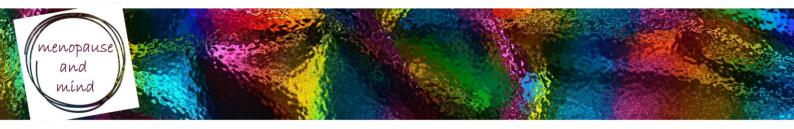
We currently have a network membership of over 80 individuals and have run around 30 events (Feb 2024). In the spring and summer of 2023, Menopause and Mind engaged in research with 30 different individuals in the Brighton and Hove area experiencing perimenopause through our detailed online survey. The survey was shared via local community mailbases, online via social media, and with partner organisations. We collated the feedback from both free text responses and Likert scales (where respondents noted what extent they agreed with a given statement). While this is only scratching the surface of menopause services and experiences, it gives a much-needed starting point to the issues and needs of those experiencing menopause-related struggles trying to access help in the local Brighton and Hove area.

We want to thank all our participants for giving so generously of their time and experiences, and for the volume of data they provided through the free text comments.

#### Accessibility Statement

Menopause and Mind embrace menodiversity and welcomes any person experiencing menopausal symptoms from any background. We recognise that the mainstream narrative of menopause does not include everyone and discriminates and excludes many marginalised voices, including (not exhaustively) LGBTQIA+, trans voices, minority ethnic voices and neuro and physical diverse groups. We also recognise the impact of trauma, and the negative impact that adverse childhood experiences have during menopause, that menopause happens at many ages, and impacts on those experiencing POI (Premature Ovarian Insufficiency) and surgical menopause can be particularly challenging. There is a lack of information of the impact of other hormone related conditions such as endometriosis and PMDD on menopause due to lack of high-quality research.

<sup>&</sup>lt;sup>18</sup> 'Menopause and Mind', Menopause and Mind, 20 June 2023, https://menoandmind.org/.



#### **Demographic Information**

The age range of survey respondents spanned from 40 – 60 plus years old, with 33% between 40 - 50, almost 60% between 50 – 60 and 7% at 60 plus. In terms of gender identity, 10% of respondents identified as a different gender from what they were assigned at birth, 53% identified as heterosexual, 17% identified as bisexual 13% as lesbian and 17% as queer or other. 21% of respondents were in receipt of state benefits. In terms of nationality the majority (77%) of Identified their nationality as British, with others identifying as American-Canadian, New Zealand, French or left the question blank.

Twelve respondents (40%) identified with conditions that are widely recognised as making the experience of the menopause transition more difficult (see the next chart). We recognise that the people completing this survey are those likely to be experiencing these conditions more intensely, looking at the number of people under 50 (the average age for menopause) that are engaging we can see many have identified with POI or early menopause, or surgical menopause, they also have co-morbidity with underlying causes such as epilepsy and autoimmune conditions.

When asked about which mental symptoms of menopause they experienced respondents identified multiple negative experiences, with 90% experiencing forgetfulness, 87% experiencing anxiety, 90% poor concentration and distraction, 83.3% experiencing low mood and feelings of sadness, and 67% identifying this as depression.

When asked about physical symptoms, most respondents identified fatigue (93%), brain fog (77%), poor tolerance to stress (77%), poor sleep quality (77%), weight gain and joint pain also ranked highly (63%). Over half of respondents noted a cessation of periods (60%), hot flushes (57%), vaginal dryness (53%), insomnia (53%), bloating, headaches (53%), and muscle aches and pains (53%). It is worth noting that these and the many other physical symptoms have an impact on mental wellbeing.

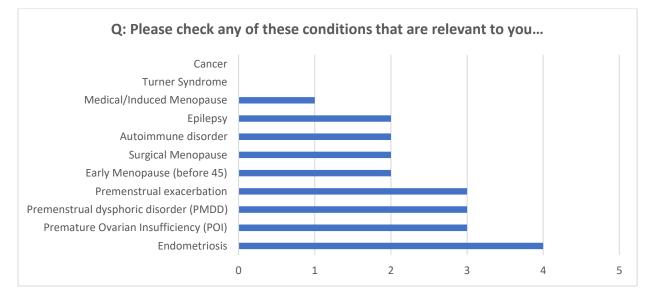
#### Impact of Menopause Symptoms and Support

It seems significant overall that only 2 respondents (7%) agreed or strongly agreed with the statement that they feel well supported with their menopause transition and only 37% of respondents agreed or strongly agreed that they had someone they could speak with about their menopause transition. Only 3 respondents (10%) agreed or strongly agreed that menopause support in the local area was inclusive, there needs to be more research to unpick what this means. 78% indicated they would like more support with their mental and emotional wellbeing.

The majority of respondents (78%) agreed or strongly agreed that menopause had impacted negatively on their ability to work. Over half (56%) agreed or strongly agreed that menopause had impacted negatively on their family life and 80% agreed or strongly agreed that they had found social situations more difficult during their menopause transition. 83% agreed or strongly agreed that they would like more mental and emotional support during their menopause transition, with only 1 person agreeing or strongly agreeing with the statement that they had easy support to mental health issues around menopause. When asked what they had tried in relation to easing menopause symptoms the majority of respondents had tried exercise (78%), HRT (74%), vitamin supplements (74%), meditation or mindfulness (70%), dietary changes (63%) and natural remedies (51%).



The data suggests a significant need for better support and communication for individuals going through menopause. Many respondents express a desire for more mental and emotional support, and a majority report negative impacts on work, family life, and social situations. The methods tried for symptom relief vary but have a strong leaning towards a holistic approach, with a focus on lifestyle changes, supplements, as well as medical interventions like HRT. It is worth noting that many of the additional types of therapies are not available on the NHS and have to be paid for privately.





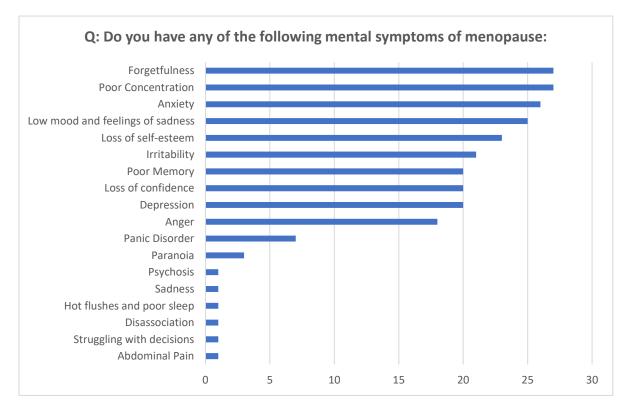


Figure 2 Question on mental conditions during menopause.



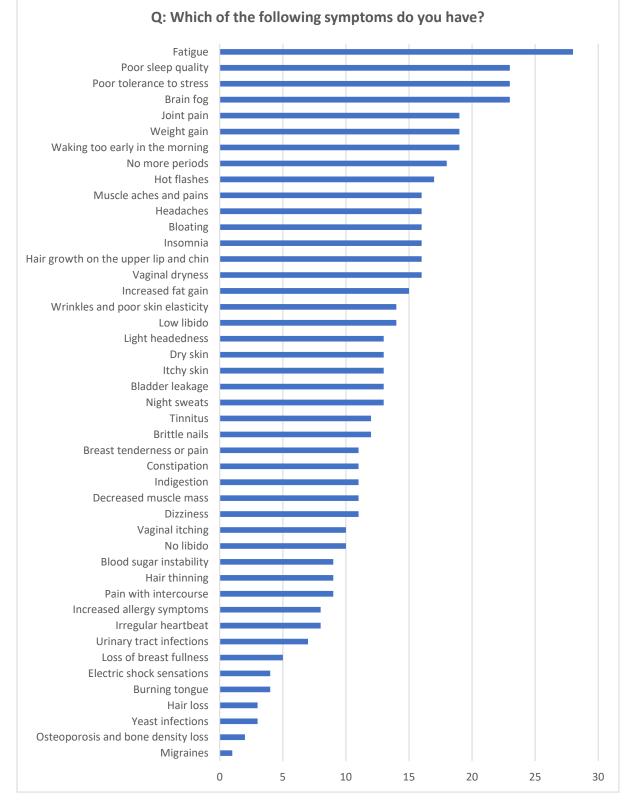
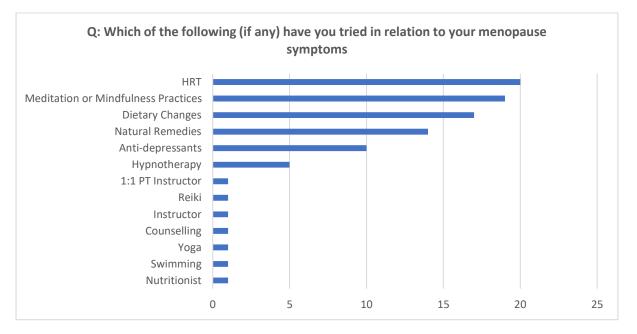


Figure 3 Physical symptoms of menopause







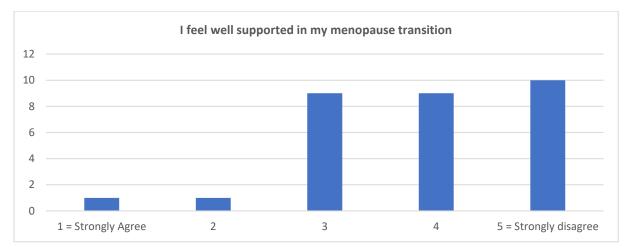


Figure 5 Support in menopause transition.

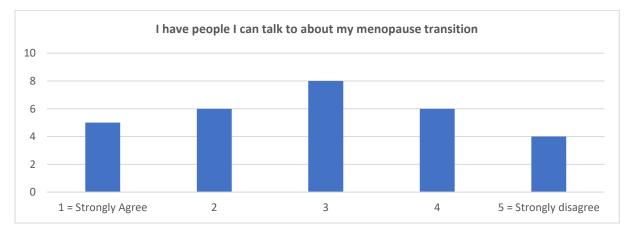
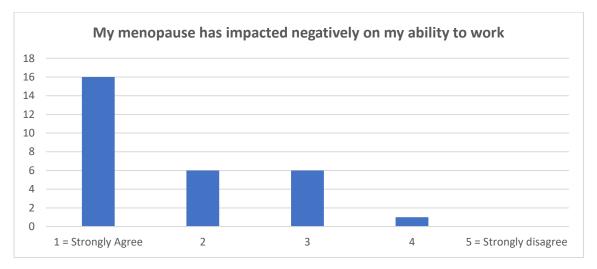


Figure 6 People to talk to about menopause.











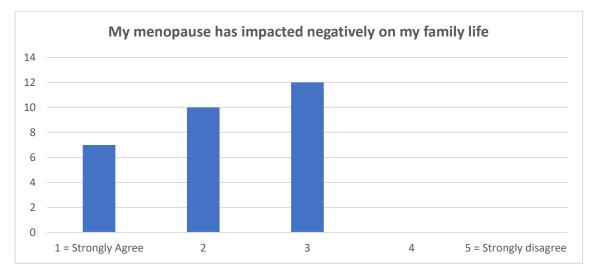
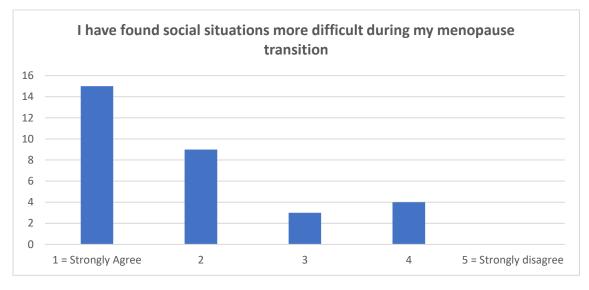
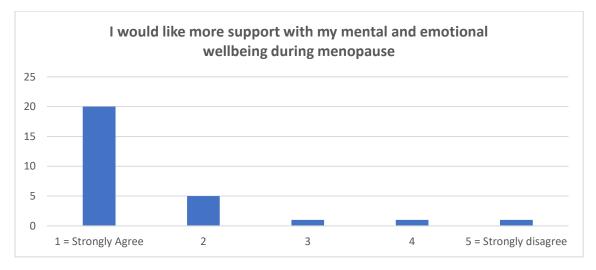


Figure 9 Menopause impact on family life.











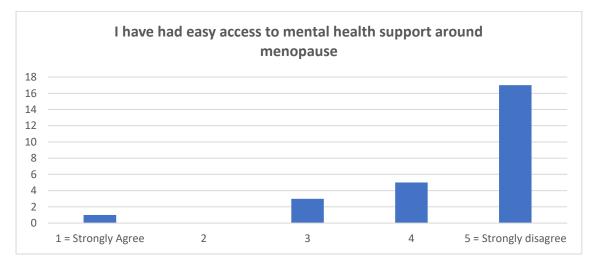


Figure 12 Access to mental health support.



#### Feedback on Local Menopause Support

"Menopause help feels disjointed - I wonder if groups could work together? I'm not sure what I'm thinking might work - maybe a publication/newsletter and advertising each other events to make it easy to find in one place? I know that's harder than it sounds." – **Feedback from Participant** 

"My doctors surgery had an online discussion about the menopause and then I was able to join a group in-person and get to explain my situation/ask questions and get HRT. That was a one-off group and it's been hard to see anyone at my surgery since. That's why going to your group was so great and needed." – **Feedback from Participant** 

We asked participants to use an open text box to describe their experiences with menopause support that was available to them in the local area. Local menopause support in Brighton and Hove varies widely among individuals, with responses ranging from limited access, lack of joined up working and knowledge, to some positive experiences. Several respondents' expressed uncertainty about available support or mentioned minimal assistance due to health conditions, such as breast cancer and epilepsy. Some reported challenges in accessing GP support, with instances of anti-depressant prescriptions offered instead of HRT and the side effects of which were not recognised.

However, a few mentioned menopause workshops provided by health centres, and others noted the initiation of menopause wellbeing clubs at their GP's office, though timing may be inconvenient. Several respondents rely on GP consultations for Hormone Replacement Therapy (HRT), while others have sought support from various sources, including social prescribers, online searches, and workshops, either free or paid. Some express satisfaction with support groups, both within and outside the NHS, and others mention the lack of awareness or availability of menopause support in rural communities.

#### The impact menopause has had on your life

"Decreased pleasure in life. Loss of self-esteem and confidence at work - reduced hours and changing job to one with less responsibilities." – Participant Feedback

"I used to be a confident person who could multitask. Now I'm constantly tired, can't concentrate, lost enthusiasm to do anything and find life in general overwhelming." – **Participant Feedback** 

"It had been devastating. Impacted on relationships, work, friendships. Struggling to make ends meet as [I] cannot keep the jobs I used to." – Participant Feedback

The responses to the question about the impact of menopause on individuals' lives reflect a range of significant challenges and negative effects. Many describe a profound negative impact on various aspects of life, including relationships, work, and overall well-being. Common themes include tiredness, sleep disturbances, anxiety, depression, and a diminished ability to enjoy life, with some feeling suicidal. Participants mention difficulties in maintaining productivity, struggles in personal relationships, and the isolation experienced due to the lack of understanding or belief from others about their menopausal experiences. Some express feelings of devastation, loss of confidence, and a sense of being overwhelmed. For some this has also been a time of 'unmasking' around ADHD and ASD symptoms becoming unmanageable, with some having a recent diagnosis of these conditions.



The impact extends to career changes, job losses, resulting financial challenges, and a significant toll on mental health. Despite the hardships, a few respondents note improvements with HRT, indicating the potential positive effects of certain interventions. The responses collectively convey the substantial negative impact of menopause on various aspects of their lives that extends to professional and personal relationships.

#### Support accessed around menopause

"I suffer in silence and look for alternative solutions which are costly and may or may not be working" – Participant Feedback

"Tried loads - it's had to get consistent ongoing support. Have had to wait a long time for an appointment, and then can't see the doctor regularly to talk through symptoms. Doctors surgery offers menopausal support group, but there is a waiting list. It's hard to just find help with HRT as regular GP's don't seem to have the skills or expertise. I've had to pay to get help with diet and more detailed support." – Participant Feedback

In the responses to the question about the support accessed around menopause, some individuals state that they have not accessed any support, while others mention specific sources. Friends and family emerge as a support network for some, despite the fact many feel they cannot speak out about their experience, there is an emphasis on the importance of interpersonal connections during this life stage. Access to information and advice from the internet, including online meetings organised by workplaces and institutions like Menopause in Mind, have been accessed by some of the participants.

Healthcare professionals, particularly GPs, are mentioned as first line sources of support, with some individuals attending menopausal support groups at their doctors' surgeries. Specialist nurses and practitioners, private hypnotherapy, and paid therapy are cited. There's a recognition of challenges in accessing consistent and ongoing support, especially with HRT, with waiting lists and the need for more specialised expertise. A few respondents' express dissatisfaction with the support available, citing difficulties in finding help with symptoms and the limitations of conventional medical approaches.

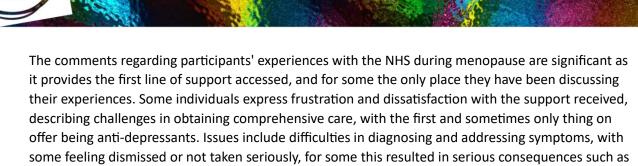
# Experience with the NHS relating to menopause and menopause symptoms

"They refused to believe me, took me two years of going back with repeat and worsening symptoms." - Participant Feedback

"I felt because I became a nuisance with calls and appointments that finally someone listened. I feel all doctors should gave more training and have more information to signpost." - Participant Feedback

*"First GP was not helpful and quite condescending, second GP I saw was helpful, third GP was brilliant." - Participant Feedback* 

"GP only offered anti-depressants, and only after significant pushing and crying!" - Participant Feedback



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some feeling dismissed or not taken seriously, for some this resulted in serious consequences such as hospitalisation. The length of time waited and having to go to different doctors or transfer surgeries to get a heard was an issue, some were told they were too young to be experiencing symptoms and dismissed several times before getting help. Several participants note a lack of holistic approaches and limited mental health support. There is a lack of support for those who have experienced breast cancer who cannot access HRT, and in general poor understanding of how menopause interacts with existing health conditions which can lead treatment that exacerbates health issues rather than helps.

Those with complex trauma often feel like they are falling between the cracks as they are too complicated for mainstream support, and that there is no other support available. Some mention barriers to accessing HRT, while others indicate positive experiences, particularly with specialist nurses and the availability of HRT-related advice through their GP's surgery. The convenience of medication access is acknowledged, although some individuals choose to seek alternative solutions independently. Instances of minimal mental health support and limited awareness training are also mentioned. Overall, the responses reflect varied encounters with the NHS during menopause, emphasising the need for improved awareness, training, and comprehensive support for individuals navigating menopausal transitions.

It is worth noting anecdotally here that how to access support through the NHS is one of the main topics discussed by participants at the Menopause and Mind Care Cafes. Participants frequently share advice on which GPs at which surgeries are likely to listen and respond to concerns around menopause and mental health, and have been using this information to switch surgeries to access much needed support.

#### What would help on your menopause journey?

"Being aware of what the perimenopause is and what this entails...... someone that would have believed me, listened, supported and signposted me." – **Participant Feedback** 

"Being able to talk about it and having information as to what would help and support to make helpful changes" – Participant Feedback

The comments on what would help individuals on their menopause journey highlight several key themes. Respondents express a desire for increased knowledge and education about hormones and their mental health impact. More support from GPs, including online meet-ups and advice on alternatives to HRT, is emphasised, recognising the diverse needs of individuals who may not be able to take HRT. There is a need to feel listened to, as many participants felt they had to fight to be heard or believed about their symptoms or medication side effects. Access to menopause specialists and gynaecologists is deemed essential, suggesting a need for more specialised care. A holistic understanding of challenges, coupled with sympathy and kindness, is identified as crucial for navigating this life stage effectively. There was a desire for a greater trauma-informed approach as many GPs do not consider the impact of Complex-PTSD and PTSD on menopause. Participants also



stress the importance of greater support in the workplace, including confidence-building measures and non-biased, medically informed options. More research in the field is suggested, alongside increased awareness, education, and reduced stigma.

Local support in the form of groups, counselling, and trauma-informed approaches is desired, emphasising the significance of community and shared experiences. Access to trained healthcare professionals, advice on vitamins, HRT, and diet, as well as the ability to openly talk about menopause and make helpful changes, are seen as valuable resources. Overall, the responses underscore the complicated nature of support needed during the menopause journey, ranging from education and medical advice to community-based networks and mental health assistance.

# How does providing support during the menopause transition make a difference in the wider community?

*"If all the menopausal women I know were supported to fire on all cylinders the world would simply be a better place"* – **Feedback from Participants** 

Providing support during the menopause transition can have a positive impact on individuals and the wider community. It is noted that with proper support, individuals would experience reduced depression and tension in the workplace, leading to increased engagement in community events and activities. The mention of tackling stigma and dispelling the feeling of going mad suggests that support contributes to mental well-being and a sense of normalcy during this life stage.

The comments highlight the potential ripple effect of support, envisioning a community with fewer emotionally distressed women and peri-menopausal people generally. The idea that a supported group of menopausal people could positively influence the world indicates a broader societal benefit. However, there is also a call for a deeper level of support, emphasising a transition to different roles in the community and questioning societal expectations placed on women at different life stages. Overall, the responses emphasise that providing support during menopause can foster a sense of connection, reduce isolation, and contribute to a more supportive and understanding community.

## What support could Menopause and Mind and other services provide?

*"I look forward to attending more events with menopause and mind to help me feel supported on my journey."* – Feedback from Participant

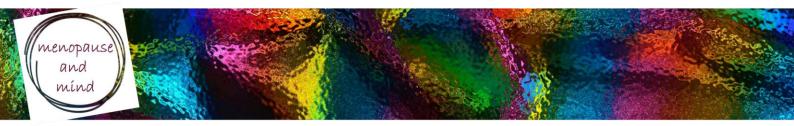
"Access to medical support, talking therapy, more regular classes to connect with women. It's nice to be able to share experiences, talk openly about embarrassing problems and feel you're not alone." – Feedback from Participant

The responses regarding the most helpful things Menopause and Mind or other services could provide to support individuals on their menopause journey highlight a diverse range of needs and preferences. Participants express a desire for understanding and compassion about the journey through menopause, emphasising the importance of specialist and peer advice. Access to medical support, talking therapy, and regular classes to connect with other women is seen as beneficial, providing a space to share experiences openly and address embarrassing problems while fostering a sense of connection.



Information about alternative options, education, and resources are deemed valuable, with some respondents expressing excitement about trying care cafes and attending expert talks. A general desire for all-encompassing support, including a network of caring individuals, information on local groups and services, and advocacy for improvements, is evident. Regular support, both virtually and through face-to-face events, is emphasised, as is expert advice and easy access to doctors with reduced waiting times.

Other needs include assistance with repositioning oneself and developing a new self, along with a space to express feelings freely. The importance of bringing people together, encouraging open conversations about menopause, reducing stigma, and facilitating the sharing of experiences is reiterated. Overall, the responses underscore the multifaceted nature of support sought during the menopause journey, encompassing emotional, informational, and societal aspects.



#### Recommendations

Based on the data from the Menopause and Mind survey, the following recommendations can be made to better support individuals during the menopausal transition in Brighton and Hove:

**1. Comprehensive Mental and Emotional Support**: There is a clear need for increased mental and emotional support for individuals going through the menopausal transition. This can be achieved through the provision of courses and groups, specialist advice, talking therapy, and regular support classes to connect with others facing similar experiences. These services need to be more inclusive of LGBTQIA+ individuals, those with disabilities and pre-existing health issues, neurodiversity and cultural differences. It also needs to be free to access.

**2. Improved Access to Medical Support:** Individuals expressed a desire for better access to medical support, including easier access to doctors with reduced waiting times. This could involve increasing the availability of menopause specialists and gynaecologists, as well as providing information about alternative options to HRT or a holistic approach that is not only HRT. The issue of miss-prescription of anti-depressants without support for negative side effects needs to be addressed.

**3. Workplace Support and Awareness**: There is a need for greater support in the workplace, including confidence-building measures and non-biased, medically informed options. Employers should be encouraged to create a supportive environment and provide flexibility to accommodate the challenges individuals may face during the menopausal transition.

**4. Community-Based Networks and Information**: Local support in the form of groups, counselling, and trauma-informed approaches is desired. It is important to reduce stigma and increase awareness through community-based networks and information about local groups and services. Peer support can be a great comfort and a source of information sharing and friendship.

**5. Increased Education and Reduced Stigma**: There is a need for increased knowledge and education about hormones and their mental health impact. Efforts should be made to reduce the stigma surrounding menopause and create a more supportive and understanding community. This is particularly important for trans and non-binary individuals where this information is particularly poor.

6. Research into Menopause, particularly into understanding diverse experiences and representation of diverse stories: There is still a need for research beyond the mainstream experience of menopause. Many people attending our groups have found the inclusive nature of our spaces key to being able to attend, but do not see themselves reflected in the narratives of mainstream menopause, and have suffered discrimination through a 'one size fits all' NHS approach. There needs to be increased sharing of diverse stories and investment into research that encompasses different cultural approaches, LGBTQIA+ experiences, disabilities, mental health issues and neurodiverse experiences. There also needs to be greater research into the socio-economic disparities of menopause care that looks beyond the working community.



#### Input to Action Planning for Menopause and Mind 2023-24

These actions aim to create a more supportive and informed community for individuals experiencing menopause in Brighton and Hove, addressing both the practical and emotional aspects of this life stage.

1. Enhance Local Support Services:

- Collaborate with healthcare providers and community organisations to enhance local menopause support services in Brighton and Hove.
- Increase awareness of available support through targeted outreach programs with partner organisations to ensure individuals are informed about the resources and workshops offered.
- Buddy schemes for NHS appointments and draft letters for GPs.

2. Improve GP and Healthcare Professional Training:

- Meet with Sussex Community NHS Foundation Trust to discuss findings.
- Work with local NHS provides to emphasise the importance of a holistic approach to menopause care, addressing both physical and mental health aspects.
- 3. Promote Workplace Awareness and Support:
  - Work with local businesses and organisations to promote awareness and understanding of menopause in the workplace.
  - Encourage the development of workplace policies that accommodate the needs of individuals experiencing menopause, fostering a supportive and inclusive environment.
- 4. Expand Mental Health Support:
  - Develop and promote accessible mental health support services such as the "Surviving Menopause" programme and care cafes specifically tailored to individuals going through the menopausal transition.
  - Collaborate with mental health professionals to create workshops, counselling services, and support groups that address the unique mental health challenges associated with menopause.

5. Community Education and Outreach:

- Implement community education programs to raise awareness about menopause, addressing common misconceptions and reducing stigma.
- Collaborate with local organisations, and community centres to provide information sessions, promoting a better understanding of menopause and its impact on individuals' lives.

6. Research and Creative Interventions:

- Giving a voice to those experiencing menopause related mental health struggles.
- Collaborate with local organisations, and community centres to provide information sessions, promoting a better understanding of menopause and its impact on individuals' lives.
- Collecting and sharing diverse stories through creative projects.



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