WHITE PAPER

Recommendations for Menopause Policy Change in the UK

EQUALITY COUNTS

GLOBAL MENOPAUSE INCLUSION COLLECTIVE

PAUSE ACE'S

Authors Dr Helen Douglas, Sarah Williams

Executive Summary

By the year 2025, it is estimated that one billion of us will be going through the menopause(2). And yet, until recently, it was a topic hardly ever spoken about publicly. 2021 saw the pendulum swing the other way, with a virtually continuous stream of menopause-related content across all types of media, from peer-reviewed journals, reputable newspapers, TV documentaries, webinars, podcasts, to glossy magazines. The previous paucity of debate/content may give the impression that people have, up until very recently, simply not encountered difficulties during the menopausal transition.
However, it is worth remembering that absence of evidence is not evidence of absence. The issues making the headlines now have, we suggest, largely been hidden in plain sight for generations. "Menopause is one of the most toxic combinations of taboos that exists, because its sexism and ageism all rolled into one"(3). 2022 continues to spotlight louder voices in the mainstream, but we are mindful this is at the risk of drowning out valuable perspectives from those preferring to stay quiet in their disruption.

Focus Areas

Impact of Menopause

Diversity & Inclusion

Quality of Support

Preparation

Whilst we knew to expect the vasomotor symptoms invariably inherent to peri/menopause, we were totally unprepared for the significant negative impact on our emotional and mental wellbeing. It has been established that the so-called 'perimenopause years' can be a particularly vulnerable time of life for many(4). Anxiety, paranoia, mood swings, heavy and/or erratic periods, migraines, depression, insomnia, nausea, to name but a few issues, halted us in our tracks and reduced our quality of life significantly. Furthermore, we believe:

"..these are not insubstantial barriers to growth and development, good health and basic wellness"(5)

Impact

Both emotional and physical issues were compounded by familial, work-based and societal expectations and obligations.

Is it any wonder the highest rate of suicides amongst women in England & Wales falls within the 50-54 age-bracket?(6). Likewise, the high rates of divorce, and/or premature (and often abrupt) curtailment of employment and flourishing careers(7).

HRT

Supply

It continues to be increasingly difficult to consistently source the same product (for example Estraderm MX and Elleste Solo* patches). We have already undertaken lengthy (i.e., years) 'trial and error' approaches to finding which preparation in terms of dose and method of delivery works for us. We are exquisitely sensitive to even the slightest of changes in our hormone levels, and quite understandably, when we find a solution that works, the preference is to stick with that effective regime. Not being able to reliably source HRT merely adds to our background levels of anxiety.

Equitable Access

Where HRT has been chosen for symptom management, there should be no disparity of cost across the devolved nations.
Cost barriers to accessing HRT which can be in the form of a dual prescription, should be removed without delay and treatment freely available as it is already in Northern Ireland, Scotland and Wales.

Testosterone

We believe testosterone should be widely available through the NHS and prescribed where appropriate - without the need for a referral to a specialist NHS menopause clinic. Too many of us, particularly those with an early menopause or premature ovarian insufficiency, end up resorting to accessing testosterone via a consultation with a practitioner based in the private sector. It's hard to imagine that being necessary for medication to manage COPD or diabetes.

Surgical Menopause

. From our experiences, there is evidence of inadequate provision of support with regards to the aftercare of those undergoing surgery that will result in immediate menopause. We left hospital without any follow-up whatsoever, other than instructions to arrange a visit to our GP surgeries for stitch/clip removal. How is it we can leave hospital, after major surgery, with only 2 pieces of advice: refrain from sex for 6 weeks, and lift nothing heavier than a kettle of water, for the same duration?

We also have to ask, why have guidelines in place if they are largely ignored?

"women who are likely to go through menopause because of medial or surgical treatment are given information about menopause and fertility before they have their treatment" [Menopause Quality Standard QS143](9)

"I lost 5 years of my life to unnecessarily prolonged and protracted issues primarily as a result of a failure to provide HRT following a surgical menopause aged 41. I was actively suicidal on many occasions and walked away from my career of 20 years. I couldn't have cared less about myself. My life became about getting through each day so I could just go to sleep. And yes, I frequently hoped I would not wake up"(8).

For those whose surgery involved the removal of the cervix, a post-operative internal examination to check the healing and thus integrity of the vaginal cuff at 6 weeks should be considered standard practice. Equally, a revision of the pre-operative patient information leaflets provided to those undergoing a bilateral salpingo-oophorectomy, would be greatly welcomed.

DIVERSITY & INCLUSION

"Nothing about us, without us"(10)

There is a worrying trend, in that the current discourse around menopause is becoming increasingly polarised.

We recognise that BAME people, LGBTQIA+ people, care experienced, sex-workers, migrants, refugee & asylum seekers, prisoners & ex-offenders, those living with HIV, the homeless, neurodiverse people, as well as those with other developmental impairments and learning difficulties, are rarely included in conversations on matters that will, by definition, impact their lives, directly or indirectly.

We are committed to passionately advocating for marginalised voices by sharing knowledge and opportunities.

Trauma Informed Care

It is an unfortunate fact that we entered the healthcare system with significant trauma histories. It was not, and to a lesser extent, still is not unusual for us to be retraumatised by subsequent medical interventions, be they routine vaginal vault examinations, gynaecological surgery, or by having our experiences invalidated by medical professionals during consultations. The term 'gaslighting' springs to mind.

We're fully cognisant of the fact there is no one golden solution to this issue. It's complex. However, the application of trauma-informed (TI) practices can help. Embedding TI architecture within the healthcare system is not overly onerous. Much can be achieved by ensuring key interventions embrace the 5 key TI tenets of: choice, collaboration, trust, safety, and empowerment(11-14). Afterall, healthcare should be healing, not harmful.

Pause, ACE's

Pause is a safe, supportive space to share experiences, discuss coping skills, offer compassion and connection.

Supporting organisations to uncover and embed themes of inclusion and health through a range of bespoke and standard education, training, consultancy and research services.

Global Menopause Inclusion Collective

the Global Menopause Inclusion Collective(1) (MIC) brings together advocates, allies, activists, researchers, and academics.

REGULATION OF MENOPAUSE EXPERTS

QUALITY

Whilst we acknowledge lived experience has an important role to play in informal peer-to-peer support, as well as feeding valuable input into the development of training programmes, we are concerned at the seemingly exponential increase in what appears to be broadly best described as “menopause coaches”.

We perceive risks associated with menopause becoming the new ‘cash cow’. We feel it likely that the most vulnerable in society will be at greatest risk of exploitation by a largely unregulated sector whose practices are not governed by the Hippocratic Oath (or similar) and/or where there is a lack of transparency and a potential for a lack of accountability with regard to accreditation processes and procedures.

By way of an analogy, we may know how to drive a car, but that doesn’t by default make us qualified car mechanics. We suggest a centrally held register of ‘lay experts’, whose expertise has been appropriately assessed and certified.

Perhaps membership of the British Menopause Society(15) should be the new regulatory minimum ‘standard’ for those engaging in menopause coaching

SUMMARY

To summarise, too many people are failed, and failed repeatedly by the current diagnosis and management of menopause. And, whilst HRT is not the answer for everyone, nor for every menopause-related symptom, quite often the simple application of a patch and/or blob of gel can significantly improve quality of life. The current provision of healthcare with respect to menopause can surely no longer be considered fit for purpose, if indeed it ever was. That may sound unduly harsh, but some of us have tried to end our lives as a result of unmanaged / poorly managed menopausal transitions. Let’s be the last generation to accept that as simply par for the course. One life lost, is one too many.

Our recommendations are clear, we are calling for a paradigm shift in the way menopause is dealt with within the healthcare system. Without timely and effective changes being embedded within and throughout the full medic & nurse training trajectories and subsequent CPD framework, it makes it exceptionally challenging to ensure such improvements are translated into tangible improvements in the provision of healthcare, not least in primary care settings, and that such improvements are maintained. One only has to look at the lack of adherence to the NICE guidelines on menopause to see previous evidence of the “paper-tiger effect”.

“I cannot honestly think of any other guidelines that are ignored as much as the NICE guidelines on the diagnosis and management of menopause. This has to change”(9,16)

We very much welcome opportunities to connect with individuals and organisations with like values and vison for menopause care. If we can be of any assistance, or if additional clarification is required from this White Paper, please do not hesitate to contact us.

info@menopausecollective.org

REFERENCES

[1]*https://www.menopausecollective.org*

[2]*Hill K. Maturitas. 1996 Mar;23(2): The demography of menopause 113-27. doi: 10.1016/0378-5122(95)00968-x*

[3]*Maclean, R. 2021 MP for Redditch and Parliamentary Under Secretary of State in the Department for Transport in Moving On Wellbeing Radio Podcast: S1 Ep4.*

[4]*Kulkarni J. (2018). Perimenopausal depression - an under-recognised entity. Australian prescriber, 41(6), 183–185.*

https://doi.org/10.18773/austprescr.2018.060

[5]*Douglas H, 2021 Communiqué MIC to CSW United Nations – State of Women [copy available on request]*

[6]*https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesintheunitedk ingdom/2019registrations*

[7]*https://gen-m.com/invisibility-report/*

[8]*Douglas H., 2020 Personal communication*

[9]*https://www.nice.org.uk/guidance/qs143/chapter/quality-statements*

[10]*Charlton, J.I., 2000 Nothing about us without us - Disability Oppression and Empowerment. University of California Press.*

[11]*Trauma Informed Clinical Neuropsychiatry Ardino V., 2014. 11, (1), 45-51 Trauma-informed care: is cultural competence a viable solution for efficient policy strategies?*

[12]*Trauma-Informed Project Team. 2013. Trauma-informed practice guide. Vancouver, BC: BC Provincial Mental Health and Substance Use Planning Council. Available from: http://bccewh.bc.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf.*

[13]*Purkey E., Patel R., and Phillips S.P., 2018. 64, (3), 170-172.Trauma-informed care Better care for everyone.*

Canadian Family Physician.

[14]*Treisman, K., 2020. Trauma-Inducing and Trauma-Reducing Health and Medical Experiences: drawing on stories from 390 people and some of the values of trauma-informed practice. http://www.safehandsthinkingminds.co.uk/wpcontent/uploads/2020/12/trauma-inducing-or-trauma-reduci.pdf* [15]*https://thebms.org.uk/join-us/benefits-of-membership*

[16]*Newson L.R., 2017 In GP View [cached www.gpview.co.uk]*

*has since been discontinued, with existing supplies expected to run out by October 2021

Conflict of interests:

Sarah Williams is an Independent Advisor on Inclusion and Menopause Standards, Founder of Equality Counts and the GMIC.

Dr Helen Douglas also writes as Dr Helen Kemp, and published a book on surgical menopause under that name, Founder of Pause and the GMIC.