

## Menopause APPG Inquiry into the Impact of Menopause Session 1: Experiences and Perceptions of Menopause

Date: Thursday 15<sup>th</sup> July 2021

Time: 14:30pm – 15:30 pm

Location: Virtual, Zoom

Minutes taken by: Erza Llumnica, Interel UK

### Members Present:

- Carolyn Harris MP – Chair of the APPG
- Caroline Nokes MP
- Sarah Champion MP
- Judith Cummins MP
- William Wragg MP
- Rosie Duffield MP
- Peter Dowd MP

### External Speakers:

- Elizabeth Carr- Ellis – Guest speaker, Pausitivity #KnowYourMenopause
- Davina McCall – Guest speaker, TV Presenter
- Kate Evans – Guest speaker, Writer and expert by experience
- Diane Danzebrink – Guest speaker, Founder of Menopausesupport.co.uk and #MakeMenopauseMatter campaign
- Nina Kuypers – Guest speaker, Founder of Black Women in Menopause

### External Guests:

- Clare Shepherd – YourNewLifePlan
- Yuko Parker, NHK
- Jo Lloyd - Office of Carolyn Harris MP
- Sarah Swinglehurst – Office of Carolyn Harris MP
- Angus Bugg-Millar – Office of Judith Cummins MP
- Katherine Morgan – Interel UK
- Sarina Kiayani – Interel UK
- Erza Llumnica – Interel UK
- Holly Ramsey – Interel UK

Minutes of the Meeting – 14:30pm – 15:40pm

**Carolyn Harris MP** welcomed everyone to the meeting and announced that it was the first official APPG menopause session. She explained the agenda for free HRT to be made available from the Private Members Bill and spoke of the wider plan for what the APPG aims to achieve. She went on to introduce the guest speakers, and invited Davina McCall to speak first.

**Davina McCall** stated there is not enough correct information accessible and available to people and pointed out there are still misconceptions around the necessity and use around HRT treatment. She said that the way information is dated online means perimenopausal women and menopausal women searching for answers are being given incorrect/ poor information. She emphasised that there is not one solid place for women to go to for information, saying it would be effective to organise a place women can access correct information easily.

**Davina McCall** went on to say that testosterone should be licensed for women in the UK – women should not be embarrassed and it shouldn't be denied. She highlighted that further education for GPs

is necessary as they do not learn enough about perimenopause and menopause to help women. She stated that she aims to de-demonize HRT in order to make it more accessible and offered in GPs.

**Carolyn Harris MP** thanked **Davina McCall** for her contribution and invited Elizabeth Carr-Ellis to speak.

**Elizabeth Carr - Ellis** began by speaking about her personal experience with menopause. She explained her struggle with menopause, particularly her battle with GPs and their inability to diagnose her as menopausal which meant she had to endure many visits to the GP for over 3 years as well as the numerous symptoms she faced. This included physical hormonal and mental symptoms. She explained that not knowing she was menopausal led her to a state of constant self-doubt, worrying, paranoia and strong mood swings as GPs would find nothing wrong with her which only added to her lack of control over her emotions. She explained that experiencing menopausal symptoms not only affected her personal home life but also drastically affected her productivity in her work life.

**Elizabeth Carr – Ellis** explained how she lost faith in GPs and that, once she began experiencing hot flushes, her husband researched her symptoms himself and found on the NHS website that what she was experiencing menopausal symptoms. She added that on discovering this she went back to the GP for menopause but left feeling worse as she said the GP had nothing to give her, only providing her with four printed out sheets of information on menopause. She explained that women were not getting the help they needed and there was a lack of information available around menopause which led her to write about her experience in her blog and in doing so it brought back a lot of responses from other women who too had their own experiences with menopause and its symptoms.

**Elizabeth Carr – Ellis** stated that, from reading the replies from women on her blog post, she saw the need for a poster for menopause and followed with this idea to create Pausitivity and the “Know Your Menopause” campaign. She went on to speak about the success of the poster as so many women were downloading the poster and supporting their cause. She explained the need for this poster saying that there was a necessity for more information to be accessible, visible and available around and at GPs as before the information was not there.

**Carolyn Harris MP** introduced and invited **Kate Evans** to speak.

**Kate Evans** began by giving a brief explanation of menopause and introduced the term perimenopause: the stage before menopause. She spoke about her personal experience and the symptoms she faced during perimenopause – some of which included: heavy menstrual bleeding which would go on for days and led to chronic anaemia which led to fatigue and headaches. She went on to speak about her treatment and stated that her GP was excellent. She had numerous internal exams, blood tests, ultrasounds and drug interventions and said that HRT does not help with the perimenopause. She stated she had a hysteroscopy, a colonoscopy, a gastroscopy, she spoke about her coil implant and the complications that followed, that she had an endometrial ablation and finally a hysterectomy. She explained this all took place over five years, which left her permanently exhausted and was left shocked with the amount of blood loss she had experienced. She went on to explain how this affected her work and her day to day routine.

**Kate Evans** stated the need for education for everyone. She explained the lack of information online around perimenopause and named the common symptoms of menopause found online and that there was not a lot of information on the amount of bleeding which she had experienced.

**Kate Evans** spoke about her holistic treatment, describing herself as feeling like ‘a womb on a conveyor belt’ at times. She explained she felt as if people were not communicating with each other during her treatment. She touched upon the struggle to find clean public toilets which left her restricted to go out. Kate stated she was able to negotiate her time at work but pointed out the fact that if her work were not as understanding there would have been no way for her to function and work when enduring these symptoms. She went on to speak about research and that, despite her having several ultrasounds, the size of her fibroids that were causing her to bleed were not picked up. She explained if the size of them had been picked up sooner perhaps the treatment would have taken it into account. She stated that research into the perimenopause is quite basic and is seen as a normal

transition in a woman's life. She ends by stating that since her hysterectomy she has her life back, her energy back, her confidence and the ability to socialise, work and do the things she used to enjoy .

**Carolyn Harris MP** thanks **Kate Evans** for her contribution and welcomed **Diane Danzebrink** to speak.

**Diane Danzebrink** introduced herself and began by describing her personal experience. She stated that back in 2012 she had a hysterectomy which put her into a surgical menopause. She said the medical professionals that had been dealing with her hadn't bothered to talk to her about the effects of being in surgical menopause other than informing her she would no longer be able to have children. She stated she knew she would experience hot flushes but had no idea about the other symptoms. She explained how she had a lack of information around HRT which meant she decided against having HRT and stated she was not informed about the importance of hormone replacement treatment after she had her ovaries removed. She stated that after a couple of months it had a huge impact on her mental health. She said she started to withdraw more from life, it affected her work, she started becoming anxious to the extent where she wouldn't leave the house or answer the post. She described the effect this all had on her life, the toll it took over her to the extent where she had suicidal thoughts. After experiencing these symptoms she visited the GP who prescribed her with HRT.

**Diane Danzebrink** stated that HRT really helped her. From the treatment she said it led her to wonder whether others had experienced these symptoms of menopause and through her research she found forums online of women who were too suffering and had a similar experience to hers. She explained that as she recovered she did much research around menopause and in 2015 when she began to feel like herself again she launched Menopause Support. She spoke about an email she received in 2018 which highlighted the need for further support around menopause and the lack of services available to do so. She explained that this need for more information and services encouraged and led her to launch the Make Menopause Matter Campaign which received much support and signatures after launching. Diane mentioned the cross-party support they have received and noted that, in July 2019 they were successful in their aim to have menopause included in the secondary school curriculum. She said this has only been achieved in England but wishes to have it be achieved globally. She stated the other two aims of the campaign which are to have mandatory menopause education for all general practitioners and to have menopause guidance and support in every work place. She went on to show 500 pages of comments posted on the Make Menopause Matter campaign of women needing menopause support.

**Diane Danzebrink** emphasised that the key for menopause support is education on menopause. She stated there is a definite need for GP education, as GPs currently do not have the expertise and confidence to prescribe HRT. She stated that, in a recent survey that her company conducted, 85% of women didn't feel that their GP was confident, 75% felt their GP didn't have any knowledge, and 48% of those they surveyed have been forced into seeking private care – which many of which cannot afford. She emphasised the lack of knowledge amongst GPs by giving the example of a women wrongly prescribed oestrogen-only HRT, which led to her developing womb cancer. She went on to describe what is needed to become a GP and spoke about RCGP training and their competency level.

**Diane Danzebrink** highlighted that women going through a surgical menopause need expert health advice and pointed out that there are many areas of the country which are completely devoid with any specialist menopause NHS care. She gave the example of Cornwall and Devon, who do not have a single NHS menopause clinic. She ended by stating if basic education was given to current and student GPs and if the government funded a public health campaign it would save NHS time and money, would save GP time, would save onward referrals, and would save needless suffering for women. She pointed out that the greatest risk for suicide amongst women currently in the UK is between ages of 45-49 and stated that most women are perimenopausal at 45, with average length of symptoms of 4-8 years, therefore pointing out that this is not a coincidence and that in fact it is instead a hidden cost of menopause. She urged that something must be done to stop this.

**Carolyn Harris MP** thanked **Diane Danzebrink** and invited **Nina Kuypers** to speak.

**Nina Kuypers** stated that menopause is out of sight and mind. She spoke about her journey and personal experience **as a black woman going through menopause**. She stated that, from doing initial research, it became apparent that the images and experiences portrayed did not resonate with her on a personal level. She spoke about the range of symptoms she experienced on and off which she presented to the GP – she stated some included increase urination, body odour, to night sweats, to coarse thinning hair, to allergies and more. She stated that GPs attributed these symptoms to Type 2 diabetes and overlooked menopause. Nina pointed out the reasoning for this misdiagnosis could have been down to age, being too young, or due to her ethnicity. She said that, at age 43, she was told she was perimenopausal.

**Nina Kuypers** said that everything she knows about menopause was self-taught. She stated that black people are being diagnosed with menopause related illnesses such as depression, anxiety and diabetes whilst menopause is not considered. She explained that because of this, menopausal black women are often diagnosed with certain chronic health conditions. She pointed out that most studies have not included marginalized populations such as black people. She went on to give the example of the last study in the UK, which took place in 2007. This consisted on women aged 45-61 – a sample she stated she wouldn't have been a part of as she became perimenopausal at the age of 43. She drew on the assumption that many people believe menopause is the same for all those who go through it and pointed out that people need to recognise that black people face considerable discrimination which bleeds into and informs their experiences of health care. Nina stated this is what makes people less likely to seek or attend health care appointments.

**Nina Kuypers** stated it was evident to her that health care professionals are not trained in menopause in the cultural element, making the whole process even more challenging. She explained that she wished she had known more when going through perimenopause as to why she set up a safe supportive environment as well as providing educational events for black people to share their experiences and to learn from professionals about menopause and how to cope with the associated physical differences from a black professional. She emphasised the need to acknowledge that there are ingrained biases in menopause care, and that the lack of awareness around this leaves people unsupported during the menopause. She said that not having culturally competent health care professionals is what has left women feeling like they are not being taken seriously and as a result leads to long term consequences on health.

**Nina Kuypers** stated the need for her to set up the group and events on zoom. She explained that it provides an opportunity for black women to come together and know they are not alone. She read aloud some positive feedback from her events. She went on to say that menopause is indiscriminative and that there is a significant amount of work needed to be done to ensure menopause is inclusive and representative and that education supports and reflects all those directly and indirectly affected by menopause. She added that this is why black women in menopause is part of the menopause inclusive collective group. Nina ended by saying there is a need to collectively dismantle the existing menopause stigma and taboos. She pointed out the need to provide education and awareness on the cultural aspects affecting women as each community has its own cultural differences that affect women's menopausal experiences. She stated this would help encourage culturally competent conversations between people, different platforms and health care professionals in order to identify, bridge gaps and find practical solutions for women.

**Carolyn Harris MP** thanked **Nina Kuypers** for her spoken contribution. She thanked the attendees and the inspirational women who spoke. She stated that the Private Members Bill will make HRT free to women in England but continued to say that the Bill will help to give parliamentary credibility to pursue a larger vision for the UK Parliament to help to raise awareness and further focus on menopause.

**Carolyn Harris MP** opened the floor for any parliamentarians to speak.

**William Wragg MP** spoke and asked from a male perspective what is it that men need to be doing to help women going through perimenopause and menopause.

**Davina McCall** also responded saying she was touched with the number of couples who sat down to watch her documentary together and following the release of her documentary she spoke about the number of couples which approached her with the men thanking her for giving them a clearer understanding and insight in what women go through. She ended by asking 'how can we get more men to be a part of this movement'.

**Elizabeth Carr – Ellis** stated that men are a lot more involved than we think.

**Peter Dowd MP** said that, in being raised around women he said he has been enlightened on many issues.

**Rosie Duffield MP** asked the speakers what would their number one ask/request from MPs would be.

**Elizabeth Carr – Ellis** stated she would want to get GPs trained to allow for greater help available, have better awareness in GP offices and get a menopause nurse in every doctors surgery.

**Nina Kuypers** said there needs to be a balance and asked for education for everyone as well as health care professionals.

**Kate Evans** addressed the need for greater support for women in the workforce. She stated that something has to be done to help perimenopausal and menopausal women who are finding it difficult to hold down their job in the way they used to.

**Diane Danzebrink** highlighted the need for further education. She said that there has to be better education for all health care professionals as menopause affects so much of the body. She stated the desperate need to have a better educated public to ensure that all are aware of both menopause and perimenopause, what they are, the symptoms, effects and treatments.

**Carolyn Harris MP** thanked all the attendees and speakers.

The meeting concluded at 15:40pm.