

## Menopause APPG Inquiry into the Impact of Menopause Session 2: Experiences and Perceptions of Menopause

Date: Tuesday 8<sup>th</sup> September 2021

Time: 10:00 am – 11:00 am

Location: Virtual, Zoom

Minutes taken by: Erza Llumnica, Interel UK

### Members Present:

- Carolyn Harris MP – Chair of the APPG
- Ruth Jones MP
- Paula Barker MP
- Liz Saville Roberts MP
- Jackie Doyle Price MP
- Nickie Aiken MP
- Alex Davies-Jones MP
- Baroness Jenkins
- Tonia Antoniazzi MP

### Guest Speakers:

- Justine Roberts CBE – Founder and Chief Executive, Mumsnet
- Katie Taylor – Founder and CEO, The Latte Lounge
- Gaynor Tucker – Founder, Perimenopause Support
- Rachel Weiss – Founder and Chairperson, Menopause Café
- Liz Prinz – Insight Manager, Women in Sport

### External Guests:

- Jo Lloyd - Office of Carolyn Harris MP
- Sarah Swinglehurst – Office of Carolyn Harris MP
- Angus Bugg-Millar – Office of Judith Cummins MP
- Elizabeth Carr-Ellis – 50 Sense
- Katherine Morgan – Interel UK
- Sarina Kiayani – Interel UK
- Erza Llumnica – Interel UK
- Holly Ramsey – Interel UK
- Victoria McNish – Interel UK
- Debbie Killingback – Hot Flush Club
- Lynda Connikie – Hot Flush Club
- Helen Loannou – Solicitor, Goodwins Family Law

Minutes of the meeting – 10:00am – 11:00am

**Carolyn Harris MP** welcomed everyone to the meeting and noted the launch of the Menopause Revolution. She mentioned that the Private Members Bill second reading will be taking place on the 29<sup>th</sup> October which will allow parliamentarians to speak on the day and share their own experiences as well as the experiences of other women that are suffering and have suffered from perimenopausal or menopausal symptoms. She went on to introduce the guest speakers, inviting them to speak.

**Justine Roberts** introduced herself as the founder and CEO of Mumsnet and began by briefly talking about the experiences of the women within Mumsnet. She stated that the pages relating directly to the menopause and perimenopause have attracted 3.5 million views in the last year alone. She mentioned that Mumsnet have been campaigning to help women have a better experience of menopause by making HRT readily available to women, providing more menopause training for GPs and aiming to ensure that anti-depressants aren't prescribed when HRT is more clinically appropriate. She said that users have repeatedly said that, when it comes to the menopause, they feel that they

are not being listened to, some saying their GPs were left confused when the term perimenopause was mentioned. She provided statistics from their surveys; they found that, in 2021, nearly four in 10 women seeking treatment for perimenopause symptoms were told to simply 'live with it' whilst 26% of users said to have visited their GPs more than 3 times until they were prescribed with appropriate medication or help. She highlighted the issue of misdiagnoses of GPs, with GPs wrongly prescribing anti-depressants for menopause symptoms.

**Justine Roberts** explained that Mumsnet is one of the few female-dominated communities where users can share knowledge and advise and discuss issues to see they are not alone. She mentioned they also host experts to give informed medical advice. She highlighted that the discussions on Mumsnet show that there are extensive gaps in the women's knowledge about menopause and perimenopause, gaps that aren't filled by GPs or medical sources. She read out some of the posts on Mumsnet of women praising and thanking Mumsnet for informing them and providing a platform in which they gain further insight and knowledge of perimenopause and menopause, experiences of others, the symptoms and the help and treatments women have taken. She mentioned that women have posted about the difficulties of hiding their menopause symptoms at work and said Mumsnet has become a form of a 'communal diary' in which users can document their feelings and symptoms, build online friendships and get support in their situation. She ended by saying that from Mumsnet it is evident that women going through perimenopause and menopause need more; they need more access to suitable medication and better conversations from health care professionals about what's available i.e. more information on alternative treatments such as plant-based alternatives or natural remedies.

**Carolyn Harris MP** thanked **Justine Roberts** for her contribution and invited **Katie Taylor** to speak.

**Katie Taylor** spoke about her personal experience with menopause, which brought her to set up The Latte Lounge. She said that, from the age of 43- 47, she suffered from low moods, low energy, had heart palpitations, anxiety, joint problems, , insomnia and poor memory. She explained that, in this four year period, she was sent back and forth from doctors, to a neurologist, to a psychiatrist as they diagnosed her with depression and offered anti-depressants all the way through. She added that although she didn't experience hot flushes, she was having heavy periods, sleeping all day and became severely anaemic. She said that these symptoms meant she had to leave her job as she couldn't cope, it led her to lose her self-confidence and described herself as becoming a shell of a woman. Her father advised her to see a gynaecologist and, in doing so, she was told she was going through perimenopause and was prescribed with HRT.

**Katie Taylor** explained that her frustration around her doctor's lack of knowledge to diagnose her as perimenopausal led her to start a Facebook group which attracted a 1000 members within one night. She found through this group that a lot of women had gone through a similar experience if not worse, many women saying they were suicidal and speaking about their inability to continue work. She stated that, following the volume of responses on the group, she put together a medical advisory team with doctors, menopause specialists and various bloggers to support, inform and signpost these women for the help they needed. She explained that this was set up five years ago and since there has not been much progression. She provided statistics from a survey they recently did with a fertility company which found that seven in 10 women have not spoken to their employers about their menopause, despite 42% of women considering leaving their jobs due to menopause. She highlighted that the main issue is that there is very little education for health care professionals at medical schools and urged that there needs to be more focus around this as too many women are being let down.

**Carolyn Harris MP** thanked **Katie Taylor** for her contribution. **Carolyn Harris** briefly explained that there is very little around the menopause that politicians can currently legislate from easily and highlights that the Private Members Bill is the catalyst for change. She explained that the Bill has given the opportunity to talk about HRT and that it is not free in England, although free in Wales and Scotland, and through this will follow further progression and change around menopause through negotiation.

**Carolyn Harris MP** invited **Gaynor Tucker** to speak.

**Gaynor Tucker** introduced that she set up the Perimenopause Support UK Facebook group in May following the Davina McCall programme. She explained that since the group has received nearly 2.2k

members (2.200), that women have shared their experiences and have said they are thankful they are not alone. She stated that, when she went to the doctor personally, before setting up the group, she was told that, because of her regular periods, she would not be tested for menopause and instead should continue on anti-depressants. She highlighted that through reading the experiences of other women on the group it is clear to see there is not a lot of support available, that women do not understand what's going on, that there is a variety of symptoms women can experience during peri-menopause and menopause and explained that there is a need to educate and provide further knowledge around this particularly that peri-menopause can happen at an early age as well.

**Carolyn Harris MP** thanked **Gaynor Tucker** for her contribution and invited **Rachel Weiss** to speak.

**Rachel Weiss** shared her slides and introduced Menopause Café. She explained that it started in 2017, is run entirely by volunteers and is open to everyone regardless of age or gender and she highlighted menopause is not a women's issue but it is a workplace issue and a general population issue. She mentioned Menopause Café have no agenda, no intention of leading people to any conclusion or course of action, are not for profit and not sponsored. Instead she said Menopause Café was introduced to create an accessible, respectful and confidential space where people can talk about the menopause. She stated that their popup events are held in cafes or in the workplace and are run by volunteers worldwide. She said anyone can set up these events, all that is required is a space where people can share their stories. She spoke through her slides and highlighted that holding Menopause Cafes at work can lead to policies, management training, education and support groups. She stated that they also hold a Menopause festival, Flush Fest, with comedy, storytelling and other activities, as they believe menopause needs to be celebrated and mentioned in the creative arts to further break the silence.

**Rachel Weiss** spoke through her slides and explained what people on their social media have said needed to be addressed. She stated that menopause needs to be recognised at any age, surgical and chemical menopause, she said there is a need for workplace recognition and support (not necessarily a menopause policy), the need for menopause in the school curriculum and further GP training and access to specialist menopause advice.

**Carolyn Harris MP** thanked **Rachel Weiss** for her contribution and welcomed **Liz Prinz** from Women in Sport to speak.

**Liz Prinz** shared her PowerPoint slides, introduced herself as the insight manager at Women in Sport and gave a brief description of the charity. She stated that sport and exercise have a whole range of benefits at midlife as it can help women stay healthy into later life; she said it can prevent health problems, can improve cardiovascular health, it can strengthen bones (which she said is a concern during menopause) and stated it can help with Alzheimer's and dementia. She highlighted that women are not getting the recommended level of exercise. She spoke about a research project they embarked on which found that menopause feels like a very isolating experience, that it is a taboo, with women saying they do not have anyone to talk to about it. She said many women said they turned to google for answers and explained that google can provide misleading information. She stated the need for women to have reliable places to turn to for information and mentioned that women felt invisible during midlife as well as feeling like the lynch pins in their families. She mentioned many of the barriers that women felt held them back from taking part in sport and physical activity.

**Liz Prinz** stated that menopause can be a time of reappraisal and a great time to reintroduce exercise, that sport and exercise can provide meaningful benefits both social and physical now and later. She provided the statistic that 90% of women stated they would consider exercise if recommended by a GP or health professional. She spoke through her slides and highlighted a few things that need to change. She explained that healthcare workers need to promote sport and exercise, the sport sector needs to improve opportunities for women in midlife/menopause, the media needs to reframe the conversation around women in midlife, menopause and exercise and finally said that employers need to support women to be active, they need to find alternatives to facilitate this in workplaces.

**Carolyn Harris MP** thanked **Liz Prinz** for her contribution and opened up the conversation to parliamentarians.

**Baroness Jenkins** spoke about the menopause charity she ran, which former MP Teresa Gorman set up. She said that, because she was on HRT, her life felt transformed. She spoke about the campaign and spoke on her personal experience on HRT, saying that she felt fitter and healthier now than she did 20 years ago. She said she was shocked and appalled that, 33 years later, discussions about and support for those experiencing menopausal symptoms has seen very little progress. She spoke about the debate on Women's Health which she led and spoke about the entire lifecycle of a woman as well as on the menopause. She stated that this gained a positive response. She added that she is appalled that it is still as hard today to get access to HRT as it was thirty years ago, and that she is ready and able to help.

**Liz Saville Roberts MP** said she started HRT in July 2021 and mentioned that it is free in Wales. She touched on her personal experience saying her GPs were fantastic but did advise her to get more information/advice from a new South Wales website. She mentioned the push for more research, the push for more accessible information and she drew on Liz Prinz's point for the push for positive images which are essential for society.

**Jackie Doyle Price MP** followed up on Baroness Jenkins point about women's health generally not being a priority for governments past and present and said she thinks that all women's health issues do not generally get sufficient attention within the health establishment. She said there remains a lack of understanding around HRT amongst the health establishment, let alone women going through menopause. She said that there is a need to collectively "make noise" to make the health establishment change in order to change behaviour.

**Debbie Killingback** from Hot Flush club stated they are a diverse forum she set up. She shed light on alternative treatments to menopause as she herself could not take HRT due to medical reasons, and instead she looked into vitamin supplements, exercise and yoga which she said has helped her a lot.

She highlighted that there are doctors who do not know how to treat menopausal women, explaining that she too was offered anti-depressants. She spoke about the dismissiveness of doctors to diagnose women with menopause and highlighted the need to have acceptance and understanding of the menopause by all genders. She mentioned that some women cannot afford HRT or private sections and stated the importance of their Hot Flush Club meetings and the need for more forums to help communities understand and learn about menopause as well as the alternative treatments that may be available.

**Carolyn Harris MP** said women should continue to engage in further conversation about menopause and the symptoms in order to dispel the long-held taboo and stop it being a sensitive topic. She stated that a lot of what needs to be changed around menopause does not need to be changed through legislation, for example curriculum content for GPs training at medical schools. She highlighted the importance of the Private Members Bill which will help to initiate change around menopause, around its treatment and will further discussion around it. She spoke about the dangers of women essentially self-diagnosing either through Google searching their symptoms or not telling their GPs and doctors everything they are experiencing which may lead to incorrect diagnosis. She mentioned the strong, passionate parliamentarians, both women and men, who are happy to say menopause is something that should be spoken about. She stated that this APPG is not merely political but is about putting women first for a change.

**Carolyn Harris MP** closed the session by thanking all attendees and speakers.

The meeting concluded at 11:00am.