Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
community.affairs.sen@aph.gov.au

HCCA Submission:
Inquiry into Issues related to Menopause and Perimenopause

Thank you for the opportunity to provide a consumer perspective on the issues around menopause and perimenopause.
HCCA received substantial input from our community on this subject. This is reflective of how impactful the experience of the menopause transition is and has been for many women and people assigned female at birth.

This is a subject which has gone unexamined for too long and HCCA is pleased to see proactive steps being taken to understand and address the challenges people encounter in this phase of life.

SUBMISSION

Inquiry into Issues related to Menopause and Perimenopause
March 2024

About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-profits Commission.

HCCA's approach to this submission

HCCA is a member-based organisation and we draw on the views and experiences of our membership and networks to advocate for consumers. In preparing our response to this Inquiry we have drawn on the knowledge and experiences of our members and their feedback on the issues they encountered throughout their menopause and perimenopause.

Consumers who talked with us shared a wide variety of experiences related to their health, health care needs and impacts on their work, family and social lives. The common thread throughout their stories was the sense that the information, support and understanding (from clinicians and systems) they needed was not readily available.

This feedback has been collated and contextualised to address the Inquiry's Terms of Reference below. There was significant interest in this Inquiry from consumers and we are responding to all the Terms of Reference provided.

The consumers who shared their thoughts with us have provided their express permission for the use of deidentified quotations.

Terminology and inclusivity

Throughout this submission we refer to both 'women' and 'people experiencing menopause'. We recognise that not all people who experience menopause identify as women and intend for this submission to represent the needs and interests of all people transitioning through menopause – including trans men, people who identify as non-binary and everyone with female reproductive organs.

We know that LGBTQI+ people will be impacted differently by the stigma, ignorance and misunderstanding they encounter when accessing health services and appropriate support in their workplaces.

In many cases, the research we refer to in this submission has been focused on people experiencing menopause who identify as cis women. For the sake of accuracy, we refer to 'women' when discussing this evidence.

Specific Comments addressing the Inquiry's Terms of Reference

a. the economic consequences of menopause and perimenopause, including but not limited to, reduced workforce participation, productivity and retirement planning;

The economic impact of the challenges associated with menopause is significant. Menopause is estimated to cost Australian women $15.2 billion in lost income and superannuation every year[1].

The Association of Superannuation Funds research paper, Impact of Menopause on Retirement Outcomes, notes that in Australia around 160,000 women enter menopause each year and estimates that 'around 20,000 will at some point switch from full-time to part-time work; around 10,000 will leave the workforce (to return later); and around 4,000 will retire early'[2]. Over coming decades, this annual figure will grow as Australia's population demographics shift.

HCCA's spoke to women who reflected on their own experiences and the financial impost, telling us:

> *'The physical discomfort, stress and/or the loss of confidence can end up being so trying that I imagine some people decide to quit their job out of despair. This could threaten their own financial situation and is surely a loss to their employer.'*
>
> *'The lifespan costs of menstruation, perimenopause and menopause impact womens' finances and thus their plans for retirement, often meaning they feel forced to work longer years.'*
>
> *'This is also a time during their lifespan where women may become single with the economic costs of less superannuation for women who have taken time out of the workforce to parent. The costs of perimenopause and menopause add to womens' financial burden.'*
>
> *'Financial stress, any stress will impact how a woman experiences perimenopause and menopause and can worsen symptoms.'*

The financial penalty can be exacerbated by the expenses incurred seeking care for their debilitating symptoms of menopause. Women report attending multiple expensive visits to health services and specialists before obtaining an accurate diagnosis and the support they need.

Delayed diagnosis along with under diagnosis have the potential for flow on impacts on womens' economic and workforce participation as their significant symptoms remain misunderstood and untreated.

Some women have told us that they are aware of overservicing by clinicians who do not have a good understanding of menopause:

> *'If a GP does not feel informed/educated sufficiently to manage menopausal symptoms they frequently refer to a Gynaecologist who is not necessarily a specialist in the management of menopause and this may lead to not only expensive specialist fees but over diagnosis/treatment and the expense this incurs to both women and the health system. (e.g., admission to hospital for a dilatation and curettage) which are unlikely to help but are commonly performed, and carry risks of anaesthesia and other side effects; uterine, cervical damage, infection.'*

And also about feeling gaslit and having the sense that their, often debilitating, symptoms were not take seriously:

> *'I was told I was anxious'*
>
> *'I was diagnosed with depression. It wasn't depression.'*

These attitudes had the effect of delaying or preventing women accessing the support or treatment they needed exacerbating the economic impacts.

b. the physical health impacts, including menopausal and perimenopausal symptoms, associated medical conditions such as menorrhagia, and access to healthcare services;

It is difficult to separate the physical and mental health impact of menopause and perimenopause as they are inextricably intertwined. Both deeply impact the other. The challenges of the physical symptoms, lack of sleep, brain fog, heavy periods, hot flashes and other distressing physical manifestations of menopause and perimenopause and the lack of support to cope with these can naturally give rise to mental distress.

Women told us about their own experiences and feelings of distress or hopelessness resulting from both unresolved physical symptoms and a lack of expert assistance to manage those symptoms.

> *'…quality of sleep is impacted because of hot flushes, feeling of something crawling over ou skin disrupted sleep can give rise to exhaustion, and anxiety and being anxious makes it difficult to achieve getting into a state of restful sleep and continually waking up feeling anxious often unable to identify what has woken us or what we are anxious about becomes a vicious cycle.'*

They also talked about the symptoms which prevented them from comfortably participating in their own lives including:

- Irregular cycles: never knowing when a period may begin, the length of women's cycles often changes dramatically to shorter or longer making it difficult for women to know when they will bleed and making planning their lives more difficult.
- Migraines
- Hot flashes/sweats
- Memory problems and brain fog
- Pain due to clots passing through the cervical canal then embarrassment of bleeding everywhere so the need to be constantly prepared and armed with pads etc in the office drawer, locker, handbag, spare knickers and even trousers or other clothing!
- *Menorrhagia:* As above and the health impacts of heavy bleeding; initially tiredness and when women finally get a health professional to do blood tests and are diagnosed with a very low haemoglobin anaemia. One member noted that:

  > *'a Womens' Health Nurse has told me this is frequently 6-7 GP visits, before symptoms are recognised as perimenopause or menopausal related and anaemia is treated. If women are referred to a Gynaecologist and after a wait of months for a private or health service appointment may still not treated appropriately.'*

While treatments are available, some of these have been impacted by misinformation and a perceived misunderstanding among medical professionals about the impact and severity of menopausal symptoms.

Women shared their experiences accessing Hormone Replacement Therapy (HRT):

> *'My doctor is reluctant for me to remain on HRT for too long; our conversations at the moment suggest that 5 years is probably too long…His concern about the length of time I am on HRT is based in part on the study of 20 years ago which showed an increase in some cancers, notably breast cancer, could be caused from taking HRT for the long term. There are other potential side effects of the treatment, but the cost of living with hot flushes and all the other attendant miseries are high. For me, the balance tips in favour of the HRT at the moment, though I have started reducing the dose to see what effect it has.'*

> *‘My mother’s doctor - a man - did not think HRT was necessary so would not prescribe it to her. She suffered - and we did with her - for around 10 years in from the late 1970s. I don’t know why mum did not see other doctors to see if there were other opinions. Her doctor seemed to feel that hot flushes, poor sleep, etc were just minor inconveniences. Perhaps he lived alone, perhaps his female loved ones were not adversely affected by menopause, or perhaps he thought that the impacts were not worth worrying about. It was hard yards for mum.’*
>
> *‘There are global shortages of relevant medications. Speculation that these shortages are not taken as seriously as shortages of other medications due to prevailing view that menopausal symptoms are trivial (ie jokes about grumpy women) and not, potentially, debilitating and life altering.’*

These physical symptoms are worsened for women, and are more likely to lead to psychological distress, when they feel dismissed by clinicians and unsupported in their workplace to make the changes they need to manage their symptoms. We explore this further under Term of Reference C.

c. the mental and emotional well-being of individuals experiencing menopause and perimenopause, considering issues like mental health, self-esteem, and social support;

There is limited social or medical support for women dealing with significant menopausal symptoms. HCCA heard the stories of women unable to access the help they needed and whose symptoms substantially worsened as a result. Many of the women who shared with us, perceive that menopause has been neglected by the medical field and some reflected that this contributed to a feeling of hopelessness – that there is no help available for them.

One woman shared with us her own profoundly affecting experience:

> *‘I lost two years of my life to severe symptoms of perimenopause. I am sharing this experience in the great hope that the medical profession will learn how to deal with cases like mine and to save other women from losing literal years from their lives, even potentially from taking their own lives.*
>
> *I collapsed into near catatonic anxiety. I was afraid to get out of bed each day. The anxiety had moved into an altogether different state. This was not like people usually think of as anxiety, like a feeling of worry. This was crippling. I literally couldn’t function.*
>
> *I ended up being admitted to the mental health unit at the hospital. There I was treated with an anti-depressant and I appeared to make a good recovery, until the symptoms all re-emerged a few days ahead of my next period. This pattern repeated over the next month as well – feeling well and normal up until midcycle, then crashing into severe anxiety, recovering again and then crashing again with menstruation.*

> *I talked to the doctors (multiple), nurses and psychologists in the mental health facility about what I was experiencing. One of the nurses observed that they tended to see a lot of admissions among women my age, including women who might have till then been strangers to anxiety and depression.*
>
> *it was an all-pervasive feeling of impending doom, of darkness and despair, and it didn't let up.*
>
> *It was insufferable and I really, really wanted to be dead.'*

You can see in this HCCA member's story the devastating psychological impact unresolved physical symptoms can have.

While many womens' experiences are less extreme, they are nonetheless evidence of the need women have for understanding, support and effective treatments for physical symptoms. This also contributes to safeguarding their mental health.

We heard a range of stories from women reflecting on the effects menopausal symptoms have had on their psychological wellbeing including:

> *'It is hard to get good sleep. Waking 6 or 8 or 10 times a night boiling hot and sweating is bearable for a few nights, but not night after night for months, or years. My hands and feet ached, which made it hard to go to sleep in the first place. Poor sleep affects everything. You are exhausted, you can't focus as well and thought processes can be fuzzy, decisions can be challenging to make, taking exercise and eating well get put in the too-hard basket. I was inclined to be grumpy, irritable and hard to live with, so everyone else in the house got to share in the experience.'*
>
> *'The laughter (or eye rolling, there's a variety of responses) of others without any direct experience or any expectation of dealing with menopause is hard to deal with. That laughter turns you into a figure of fun, even if the laughter is intended to be friendly, and can make you feel like you are whingeing, complaining about something that when you say it out loud can sound minor. This can further break down work relations and make it even less likely for a person experiencing menopause to talk about what is happening to them. It can entrench a feeling of isolation and in turn means the subject is not discussed at work and so makes it all worse.'*
>
> *'Menopause is utterly normal, and it can make life difficult for those going through it. But if you are in it, you can feel isolated as it is not discussed, and so the vicious cycle continues.'*

Women shared that finding the right support and understanding made a big difference to their experience of menopause. They said:

> *'Laughing with other perimenopausal, menopausal or post-menopausal women about the process was and is a relief, as they understand.'*
>
> *'For me, the best thing in the end was to risk the laughter and any other opprobrium and talk about what was happening to me; not all the time, and not to everyone, but when it was relevant, and briefly.'*

It is the supportive power of sharing the menopause experience which led to the development of the ‘Menopause Café’ which is run monthly in Canberra (as well as elsewhere). The Menopause Café is an opportunity for people experiencing menopause to connect with each other over shared experiences[3]. It is these community based responses to the unmet needs of menopausal women that our members have most benefited from as they have navigated menopause and perimenopause.

While hormone treatments were helpful, the difficulty in accessing this care, advocating for yourself, finding someone to believe you and understand what you are experiencing, overshadowed the health benefits in many women’s recollections.

d. the impact of menopause and perimenopause on caregiving responsibilities, family dynamics, and relationships;

Having heard the stories of many of our female members over recent weeks, at HCCA we wonder if the experience of menopause isn’t just as impacted by women’s caregiving responsibilities, family dynamics, and relationships, as the other way around.

With demographic changes that mean women are tending to have children at an older age, many are managing the responsibilities of child rearing, work and providing support to ageing parents or grandparents while going through menopause and perimenopause. While these pressures are not exclusive to women, they statistically provide the majority of such care[4]. These obligations place substantial stress on women at a time when they are negotiating their own transition with concomitant health issues.

In these circumstances, we think it unsurprising that many women are reducing working hours or bringing forward retirement from the workforce to help them manage.

While most members who shared their experiences with HCCA reflected on the passing impact of their moods and other symptoms on their caring responsibilities and relationships, some struggled much more significantly. In some cases this had a catastrophic impact on their ability to participate in their family or social life.

As one women shared:

> *‘I started to experience profound perimenopause symptoms at the age of about 50. At this age, I was married and a mother of three teenage daughters and had a high achieving professional career in government. I had held mainly upper middle management positions, but prior to my sickness, also executive positions. I had always been an active person as well, exercising in some shape or form every day, with a particular passion for open water swimming. I had no chronic illnesses, other than I had been a periodic migraine sufferer since my teens. I was also an active community member serving on committees of my children’s sporting associations and their schools. I had a small circle of close friends and a reasonably wide circle of acquaintances.*

> *This context is important, because it was all taken away from me when bouts of true clinical anxiety and depression became deep and entrenched and I withdrew from work, society and family.*
>
> *I became severely agoraphobic. I had severe lethargy and could do little more than lie on my bed all day. I was not working, in fact I found it difficult even to read, because I did not have the mental energy to focus. I eventually ran out of paid leave and while my employer kept my job open, I now was not earning.'*

Without increased understanding of menopause and the issues it can trigger within medical professions, and enhanced formalised support for women experiencing debilitating symptoms – particularly in the workplace, women and their families will continue to be negatively impacted and their valuable contribution to both social and employment spheres risks being lost more permanently.

This has both a personal and wider social and economic cost. There is 'evidence that when employee's health is supported by affirming and timely healthcare encounters, it has a transformational and positive impact on their economic lives'[5].

Women make up the majority of the workforce in range of essential industries where chronic staff shortages are a growing issue – such as nursing, personal care and teaching. Losing menopausal women, who may otherwise have continued working, to early retirement (or to otherwise unnecessarily reduced working hours, recognising that this can often be a response to other life pressures) has a significant impact on skilled and experienced provision of essential services.

Supporting women to manage and improve disruptive menopausal symptoms is likely to have a flow on effect in supporting retention of a valuable, expert labour force.

e. the cultural and societal factors influencing perceptions and attitudes toward menopause and perimenopause, including specifically considering culturally and linguistically diverse communities and women's business in First Nations communities;

Menopause is not a disease, and struggling with symptoms is not a sign of weakness, nor is this rare. It can manifest very differently from person to person. However, the very word Menopause strikes fear into the hearts of many women.

As one of our members shared:

> *'In Western Culture every transition through women's lives has been medicalised; from menarche, childbearing, perimenopause and menopause, rendering womens' lived realities invisible. There seems to be an increasing invisibility that all of these rites of passage are 'not normal' and need to be 'treated, fixed or indeed obliterated. This general cultural negativity leads to women feeling invisible.'*

The feeling of invisibility and of being alone in what you are going through was a pervasive one among the women who shared their experiences with us.

As one woman noted:

> *'Menopause is normal, it should be possible to talk about it in the work place when relevant, in general terms at the very least. Even just seeing the word every now and again in public places would help…'*

Ironically, our members also reflected on menopause as a time of life when they felt like they were growing in confidence and capacity. They experienced renewed drive to make a difference in the world. They described feeling held back by:

- 'Societal attitudes to ageing',
- 'Lack of education and knowledge from older women and the devaluing of older women',
- 'Health professional ignorance',
- 'Devaluing of womens' wisdom and ways of knowing',
- 'The loss of the rituals around our 'rites of passage' in most western culture when formerly there were ceremonies and celebrations by women and for women',
- 'The 'sanitising' and invisibility of all things menstrual'', and
- 'Workforce imperatives and the lack opportunity for time out or reduced participation at a challenging time'.

To ensure that women can meet their potential and have positive experiences of all the phases of their lives, we need to promote a culture where managing the impacts of menstruation, perimenopause and menopause is everyone's responsibility. Workplace and health service policies and procedures need to reflect the flexibility required to respond adequately to the needs of women in all phases of reproductive life. There is a tendency of employers to focus on the 'worst case scenario' costs of formalising support for menopausal staff through specific policies, however research around health staff suggest that employees do not seek accommodations that radically change how their employer operates and they, in fact, demonstrate a keen awareness of the demands of their role and desire to serve those in their care to the highest possible degree[6].

Care needs to be taken that policies do not homogenise womens' experiences. There needs to be a societal shift to address the impacts of inaccurate and negative assumptions. The *Lancet 2024 Series on Menopause*[7] reflects on the cultural factors that impact our expectations and understanding of menopause and, as a result, the way we respond to the symptoms such as hot flushes and night sweats, sleep disturbances, vaginal dryness, and muscle and joint pain.

A review of the medical literature on menopause, conducted as part of the Lancet Series, found misguided or harmful attitudes towards menopause were often pervasive in high-income countries. There is a tendency to pathologise the natural period of transition to menopause which does not occur everywhere[8]. An overly medicalised perspective on menopause can be disempowering and can drive anxiety in menopausal aged women. It also introduces the risk of over-treatment and devaluing of potential positives[9].

The over medicalisation and over servicing of consumers going through menopause can include unnecessary testing such as monitoring hormone levels. The Lanet Series on Menopause suggests screening only be offered as indicated for primary and secondary prevention of chronic disease[10].

Statistically, most women will navigate menopause without needing medical treatment. Professor Martha Hickey of the University of Melbourne Department of Obstetrics and Gynaecology and the Royal Women's Hospital in Melbourne, asserts 'there is a need for an inclusive approach that extends beyond medical treatments to include empathetic clinical care, workplace adjustments, and incorporating high-quality information on symptoms and treatment options[11]'. This approach would avoid over servicing of people going through menopause and would play in to a bigger cultural shift towards normalisation of the experience rather than medicalisation.

Hickey also reminds us that 'Whilst it is important to hear about difficulties, persistent messaging around loss of youth, cognitive function, and sexuality does not reflect the reality for many. Older women are not just oestrogen-starved young women'. This message is important and ensures menopausal women are valued – by themselves and others - and approach menopause with greater positivity.

f. the level of awareness amongst medical professionals and patients of the symptoms of menopause and perimenopause and the treatments, including the affordability and availability of treatments;

The *Lancet 2024 Series on Menopause* suggests that diversity in research addressing priority areas for menopausal women is needed. The lack of information and specific education on menopause continues to lead to women feeling gaslit and ignored or dismissed by clinicians who are uninformed and being marginalised in the workplace[12]

Consumers who spoke to us about their encounters with health services recalled their own experiences of being gaslit, ignored or dismissed by health care professionals from whom they sought help.

Conflicting information about the risks of Hormone Replacement Therapy (HRT) has made navigating treatment more complex and difficult than it should be. While there are some risks associated with HRT, these have previously been overstated. Regardless, these risks should prompt honest conversations between consumers and clinicians and decisions taken in partnership. HRT, and the risks it carries will be the right treatment for many women.

From the experiences of the women we heard from, the 2002 Women's Health Initiative study on HRT has had a significant impact on how menopause is treated[13]. While subsequent studies have formed a more balanced view on HRT and a range of hormone related treatment options, the 2002 study continues to impact care women receive today.

As one woman told us:

> *‘I clearly remember that the media on this study led to many women I knew stopping HRT and opting to deal with the symptoms (again) because they feared breast cancer.*
>
> *Still, in 2024, my GP talks to me about my increased risk of developing breast cancer because I continue to take HRT. When I saw him in February to get a new prescription, he said he would prescribe HRT if I had a mammogram. I could report I had recently had a mammogram and no cancer was detected. He wrote the prescription.*
>
> *My experience makes me wonder how many women are suffering the symptoms of menopause because of prescriber attitudes.’*

For all the controversy surrounding its risks, HRT was very effective for many of those who have chosen to use it.

As one woman said:

> *‘HRT is a game changer. It turned life from miserable to excellent for me’.*

However many women commented on the costs they incurred accessing what was, for them, a very effective long-established treatment.

Women told us:

> *‘It is quite expensive (mine currently costs about $54.00 a month) and there does not seem to be a PBS option. This is not surprising, though is offensive, just like charging GST on tampons but not on shaving equipment. It feels like women’s health issues are something for individual women to deal with, no one else. Which is baffling...’*
>
> *‘My HRT costs me $165 for 3 months supply. It is not on the PBS. I can afford to pay for this medication but I am concerned that this financial cost would be prohibitive for many women’.*

There are other challenges people experiencing menopause face accessing HRT including a global shortage of certain hormone replacement drugs. For many of these drugs there is not an easy or accessible alternative leaving women suffering debilitating symptoms until they can access their prescribed medication again[14].

People experiencing menopause have to spend a lot of time procuring their medications – shopping around to locate stock in a global shortage or returning multiple times to access their full prescription.

As one woman shared:

> *"Three months of my HRT is dispensed at a time. When I go to the pharmacy they never have three boxes in stock. I always have to go back a day or two later to collect the third box. The pharmacist says it is to do with the ordering system as it defaults to two boxes.*

> *I have asked repeatedly for this to be updated in the system, and each time they assure me the change has been made, however when I go to fill my script the next time, the same thing happens. This is such a waste of time."*

Many people face gaslighting when their symptoms don't meet a textbook version of menopause – and even when they do. In some cases clinicians making assumptions about the genesis of a person's symptoms is very damaging. While it can delay commencement of treatment or leave an individual feeling invisible and devalued, it can also have a dire impact on their quality of life.

One women told us her story of seeking treatment and support while an inpatient in a mental health ward:

> *'…while the psychiatrists at the hospital acknowledged that hormones could play a part, they … wouldn't move from the view that my anxiety and depression were attributable to mental health disturbances.*
>
> *They treated me with various classes of anti-depressants and psychology. They also made it clear that anything gyneacological or hormonal was outside their sphere of interest and if I felt this was a factor, that it would be up to me to follow up have to seek help outside for anything to do with menopause.*
>
> *It was true that I had had some stressful experiences, but I had also dealt with plenty of stressful experiences in my past. I also knew what I was experiencing was definitely linked to my fluctuating hormonal cycle. I felt at this stage that the life stressors were convenient for the psychiatrists to pin the blame on. I had worked in the health sector in my public service career and I knew about multi-disciplinary teams, but there was no initiative shown by any of these treating clinicians to bring another specialty into the sphere'.*

This story shows the importance of integrated, multidisciplinary care for people dealing with menopausal symptoms. It also demonstrates the need for more information about what is happening in female bodies as they move through menopause and how to support them to make those processes less debilitating.

Even clinicians who specialise in women's health do not always have the information they need to care for people whose symptoms are extreme as this woman experienced:

> *'I saw a GP in Canberra who specialised in women's health… I was a little dismayed that she expressed scepticism that perimenopause would be causing such profound symptoms, but tried to help me nevertheless by putting me on low dose hormone therapy patches. I didn't discern a difference with these patches and ended up discontinuing them'.*
>
> *'I saw my regular GP who recommended that I add a second anti-depressant to the one prescribed by the hospital. I later learnt that this was poor care. It ended up with me experiencing severe agitation, panic attacks, akathisia and suicidal ideation, so severe that I ended up back in hospital a few months later'.*

Regardless, accessing specialist support is also not easy – with long waiting lists and limited capacity of services preventing people from accessing the care they know they need.

We were told:

> *‘It took months before I could see a psychiatrist through the public system. The psychiatrist recommended that I be readmitted to hospital, which never happened due to a chronic shortage of beds. One thing that this psychiatrist did do was finally to listen to my observations about the correlation with my menstrual cycle. She suggested that I see a gynaecologist to enquire about hormone therapy, as she was aware that it was my strong view that there was a hormonal pattern to my mood downturns’*.
>
> *‘The first gynaecologist that I saw put me on the standard hormone therapy of estrogen and progesterone. This had no impact on my symptoms. Twelve months on, I was still dysfunctional. I ended up returning to see Dr T. She referred me to an endocrinologist. I feel like endocrinology has unfortunately become dominated by diabetes and the specialist did not have much to offer me. She recommended the oral contraceptive pill, which I tried, again to no avail’.*

Women find they need to be highly health literate and have strong self-advocacy skills to find and access the care and treatment they need.

This includes women seeking to access HRT from reticent doctors who are concerned about the risks and make assumptions about the decisions of their patients (for whom the risks may be acceptable) and also doctors who are disbelieving of women’s knowledge of their own bodies and needs or who have limited knowledge of what women may be experiencing and how to treat uncommon symptoms.

One woman told us how hard she had to advocate and research for herself while experiencing life changingly debilitating symptoms:

> *‘All this time, I continued to do my own reading. Many doctors curse “Dr Google”, but Dr Google helped me to press for the answers I needed from the local medical profession. I had read that declining estrogen levels is mostly blamed for perimenopausal symptoms. The few doctors who were interested in my perimenopausal story were fixated on raising the level of my estrogen. That strategy had not worked.*
>
> *Through my own reading, I found out that the level of estrogen per se may not be the whole problem, that estrogen rises and falls during the menstrual cycle and each time it drops—from whatever level—it can precipitate mood disorder.*
>
> *I am not a clinician or medically literate, but in simple terms, I had read that estrogen is linked with serotonin and the drop in estrogen links to a drop in serotonin, and that can precipitate the anxiety and depression.*
>
> *I implored Dr T for more help. She finally referred me to a gynaecologist at Prince of Wales in Sydney, who was at the time President of the Australasian Menopause Society[15]. I wrote him a long letter describing my experience. When I*

> *finally saw him for my appointment, he concurred immediately that what I was experiencing was major mood disorder connected to perimenopause. He prescribed me nafarelan to suppress my estrogen production (a hormone commonly used for endometriosis), coupled with a baseline replacement estrogen and the necessary accompanying progesterone. The hormone combination effectively flatlined my estrogen levels, eliminating the fluctuations. He said my body would take about 3 months to respond.*
>
> *He was right. This was my turning point. Gradually over the 3 months, the clouds cleared. The bouts of anxiety stopped, I returned fully to work and the office. I resumed my social interests and, in short, I became myself again. It was now a full 2 years from when I was first hospitalised with crippling anxiety.*
>
> *In the end, the treatment I needed was all so straightforward and simple. Why did my journey to wellness take two years, multiple GPs and specialists, psychiatrists, gyneacologists, endocrinologists, not to mention psychiatric nurses, and psychologists before just one person had the answer? Why did I suffer so badly for two years, holding out literally from killing myself only because of the pain that I knew it would cause my family and because of the hope that I gave myself through my own reading and research that there were treatment options for what I was experiencing? Why did none, but one, of those professionals believe that my experience could have been linked so integrally to the perimenopause?*
>
> *I have since discontinued my hormone therapy and passed through the menopause gate. I never had any recurrence of the anxiety and depression that I experienced in those years'.*

This woman's story shows just how little understanding there is of the complexity of hormonal changes through menopause and the diversity of needs and experiences of women seeking help.

HCCA believes there is substantial need for clinician education, especially general practitioners but also gynaecologists and endocrinologists and other specialities, on perimenopause and menopause. General practitioners will be managing a growing case load of people of menopausal age as Australia's population ages and they should be prepared with the information needed to offer appropriate support.

Consumers have suggested that this could be provided through:

- GP education through the PHN;
- Update the *Guidelines for preventative activities in General* Practise to include perimenopause and menopause which are not currently included in 9th Edition updated in 2018 Guidelines-for-preventive-activities-in-general-practice.pdf;
- Packages for GPs, Nurse Practitioners and Practice Nurses supporting interprofessional education and understanding;
- Work with Local Health District Networks to provide education. LHDs are responsible for promoting, protecting and maintaining the health of our community;
- A Helpline for GPs to access evidence-based menopause information for their patients;
- Build the capacity of Women's Health and Practice Nurses to be frontline primary health care providers for women experiencing perimenopause and menopause; and
- Establish services in the community accessible to all women.

Women’s Health Nurses in the Hunter Region of NSW are running outreach groups for women from Refuge and CALD groups at their local TAFEs where the women are already undertaking English Language Classes[16]. This is a way to provide proactive support and information to women who may otherwise not access menopause related care – either due to cultural factors or lack of familiarity with the Australian health system – and is a model that could be used to engage with a range of cohorts including the LGBTIQ+ community, who may otherwise not feel comfortable accessing care.

We can see a role for more emphasis on interprofessional education. Women’s Health Nurses could be leveraged to provide education to GPs, Nurse Practitioners, General Practice Nurses and Aboriginal and Torres Strait Islander Health Workers. The latter are well placed to provide culturally safe perimenopause and menopause support and health services to their communities.

The Womens’ Health Nurses HCCA spoke with also emphasised the importance of getting services back into the community, providing service by women for women, and a recognition of the value of a wholistic approach to women’s health.

They also suggested that it is important to recognise reproductive health impacts how women experience perimenopause and menopause, and that research is needed into the impacts of assisted reproduction treatments on perimenopause and menopause.

g. the level of awareness amongst employers and workers of the symptoms of menopause and perimenopause, and the awareness, availability and usage of workplace supports;

Workplace supports for people going through menopause and perimenopause are, at best, ad hoc and the issues people face at this time of life are poorly understood by employers more generally.

People can be dealing with a range of symptoms which impact on their ability to work in the way they have up until that point.

For some these symptoms are extreme and disabling such as for this woman who needed a full break from her role while she sought treatment:

> *'I became severely agoraphobic. I had severe lethargy and could do little more than lie on my bed all day. I was not working, in fact I found it difficult even to read, because I did not have the mental energy to focus. I eventually ran out of paid leave and while my employer kept my job open, I now was not earning.'*

For others, the symptoms were more manageable but still impacted them negatively day to day. Women shared with us that the sleep disruption and brain fog made it difficult to engage in work the way they wanted to and the way their employer had grown to expect.

As one woman told us:

> *'Lack of sleep affects your work, and, like at home, can make decision-making difficult: it's hard to think clearly, and your confidence is shaken, and things spiral downward'.*

Women reflected that they often felt isolated in the workplace by their belief that colleagues did not understand what they were experiencing and the possibility that assumptions would be made about their competence if they sought 'special treatment'.

A woman shared her concerns:

> *'I was often the only menopausal person in teams and meetings, and I started off being silent about what I was dealing with (poor sleep, grumpiness, lack of confidence, hot flushes, aching joints). There were several reasons, which varied depending on the situation: I didn't know the other people well enough to trust them, I didn't want the laughter (or even pity, just acknowledgement), I didn't want any perception that I wasn't coping, and I didn't want me to be the topic, as it was hard enough to get people to do things without further distraction or excuses'.*

This sense of isolation and their sense of there being professional risk in asking for support from their workplace led many consumers to find ways to manage their challenges in the workplace for themselves.

The women who spoke with us shared a range of techniques the used, with varying ease and success, including:

> *'A personal fan can help a lot if you are suffering from hot flushes, but these impact other workers, draw (sometimes unwanted) attention to the person experiencing the flushes, and are not something you can carry around from meeting to meeting. In my case, I didn't have a space to put a fan, as I was in an open plan office with no provision for any sort of fan, be it a pedestal, floor or even small desk fan. I just had to bear it'.*
>
> *'I did start talking about it, as if people don't really know how miserable it is, they will probably keep trivialising it. That approach helped me, and perhaps it helped others'.*
>
> *'Office buildings frequently lack opening windows. The air conditioning is commonly set for the comfort of a non-existent person, and in any case buildings seem to have unavoidable cold and hot spots. Being able to go outside can help, but in some buildings that can take a long time, and will draw attention which may not always be welcome'.*

While these women did their best to deal with their symptoms independently, they felt that formal engagement from management to educate employees would have helped them feel more confident in doing so.

Ways women thought their workplace could have assisted them include:

> *'Perhaps an HR-organised session once or twice a year for managers (and not just women managers either) to better understand what people are going through and what might be supportive. After all, most people will live with someone going through it at some stage, and they might find it helpful to understand how to support their loved one, as well as work colleagues'.*
>
> *'Menstrual, perimenopause and menopause leave in addition to personal leave entitlements'.*
>
> *'Flexible working arrangements including work from home, in roles where it is possible'.*

The move to work from home for office/computer based work in recent years has proven an unexpected benefit to people dealing with disruptive symptoms. Research has shown that reproductive symptom management can be easier when working from home, and this demonstrated a concomitant increase in productivity[17] [18]. There are positive physical and economic impacts of hybrid/flexible work policies which have the potential to assist management of menopausal symptoms.

Research into what women want from employer and line manager support showed three key themes of:

- employer/manager awareness, particularly of the impacts of the physical work environment.
- employer/manager communication skills and behaviours, specifically those considered helpful and desired and those considered unhelpful and undesired.
- Direct employer actions such as staff training and supportive policies around absences and flexible working hours[19].

Sustainability Victoria recently topped the 2023 AFR Boss Best Places to Work List. This coincided with the launch of their *Menstruation and Menopause Policy*. The policy offers additional paid leave as well as other flexible work options which can be tailored to suit staff member need[20].

Sustainability Victoria is leading the way among Government employers and report a very positive response to the policy throughout its development and implementation. They hope to develop a suite of policies which support their staff through 'different life experiences, their diversity and backgrounds[21]'

This is the kind of proactive and accommodating response, as well as employer trust, that menopausal people need to continue to perform their work.

h. existing Commonwealth, state and territory government policies, programs, and healthcare initiatives addressing menopause and perimenopause;

At a population level, the impacts of menopause on work and career vary significantly, as do the impacts on women's retirement outcomes. Appropriate government policy responses must consider the complex diversity of circumstances and outcomes for Australians experiencing menopause. While Sustainability Victoria's *Menstruation and Menopause Policy* discussed in Term of Reference G has been well received and is having a positive impact on employees, it is an answer to a question we do not well understand.

There is a paucity of relevant local data which would be required in order to properly assess and estimate the impacts of menopause transition. This is essential to ensure we are designing appropriate interventions to mitigate the very real effects of menopause and are supporting people in ways that provide the help and understanding they need.

In 2022, the then Australian Institute of Supoerannuation Trustees (now Super Members Council of Australia) estimated that if only 10% of women retire early due to menopause it would equate to a loss of earnings and super of more than $17 billion[22]. But without prioritising development of a relevant and complete data set, we don't know how many women are affected and to what degree or how to best assist them[23]. The social and economic impacts are substantial and it is vital that we understand the problem to understand the solution.

Hopefully the growing number of policies like Sustainability Victoria's will assist people experiencing menopause to remain in the workforce however the life impacts go beyond employment and holistic support is needed.

This is a need that Canberra woman Felicity Brazil, is hoping to meet with establishment of the first Canberra 'menopause cafe'. The café was created to support women going through the transition to menopause[24]. This is a peer support model which can be an effective way of leveraging support for people traversing shared experiences that are personally challenging.

HCCA has heard positive feedback regarding the Monash University, *Practitioners Toolkit for Managing Menopause*[25] from Womens' Health Nurses we spoke to. The wider use of an agreed standard of care for menopausal women may benefit clinicians who are less experienced and knowledgeable on the subject to ensure all women seeking help have access to high quality care.

HCCA notes with interest the initiatives announced by the Australian Government on 6 September 2023 around improvements to womens' health. In particular, the assessment and decision-making tool that aims to ensure menopausal symptoms are not overlooked when women are seeking care[26]. With proper integration into GP software, this tool has the potential to improve access to key information for GPs.
As the Assistant Minister for Health and Aged Care Ged Kearney said in September 2022:

> *'Menopause can wreak havoc to women's daily lives, from significant pain, crippling anxiety and sleeplessness. That's why it's so important that we're making it easier for women to have quality, accessible menopausal care from their GP.'*

The concern HCCA has with this approach is that accessing a GP has only become more difficult since that time and, with fewer and fewer bulk billing, it could be argued this will not be effective in ensuring women's access to quality care. This is particularly the case in the ACT where we have the lowest bulkbilling rates in the nation at 53.4%. GP care can be costly, with consumers in the ACT paying an average of $45.47 out-of-pocket for a standard consultation[27] with many paying much more. It is common for consumers to spend $105 to see their GP. And consumers tell us it is unusual to be able to get an appointment within a week with your usual GP .We would like to see the development of alternative models of primary care for women transitioning through menopause that are less reliant on GP care. Some suggestions consumers had for enhancing access to quality care included the possibility of utilising the full scope of practice of nurses, particularly women'swomens' health nurses who are educationally prepared to support women in managing all aspects of their menopausal journey.

i. how other jurisdictions support individuals experiencing menopause and perimenopause from a health and workplace policy perspective; and any other related matter.

In the United Kingdom, the Equality and Human Rights Commission has stated that menopause symptoms could be deemed a disability if disruptive enough to interfere with everyday activities, and that employers could be legally obliged to make reasonable adjustments[28]. While HCCA would be hesitant to frame menopause as a disability, there is good argument for placing obligations on employers and others to support and accommodate people experiencing disruptive symptoms. The United Kingdom has shied away from declaring menopause to be a protected characteristic, as pregnancy is, under their 2010 Equality Act however such a status may be an appropriate mechanism to achieve a reasonable social response without playing in to negative stereotypes about older women, which are already damaging.

In *An Empowerment Model for Managing Menopause*, the authors argue for ‘an empowerment model that recognises factors modifying the experience, in which the patient is an expert in their own condition and the health-care worker supports the patient to become an equal and active partner in managing their own care’[29].

The model they propose reflects the approach that HCCA advocates for in all health care but which is missing in the experience of many women seeking care in the ACT. We would strongly support the development of an empowerment model of care which describes the standard of care and provides guidance on integration of care specialties that menopausal people access in the course of managing their own care.

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