Understanding Trans, Gender Diverse and Intersex Experiences of Menopause Symptoms

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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.

About A Gender Agenda

A Gender Agenda (AGA) works with the intersex, trans and gender diverse community. This includes intersex people, transgender people, gender diverse and non-binary people and other gender non-conforming people. AGA acknowledge the important role that partners, family members and allies play and these people are all also welcomed as part of our community.

AGA is a unique community organisation actively engaged in increasing public awareness and understanding of intersex, trans and gender diversity issues through:

- training and education
- providing advocacy and support services
- providing information and resources
- engaging in human rights and law reform.

AGA is a vibrant community of sex and gender diverse individuals, their families, friends and allies. They hold regular community gatherings with some events being open to the broader public.

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Acknowledgements

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Glossary

Cisgender

A term used to describe people whose gender aligns with what their gender was assumed to be at birth. For example, a person who was assigned female at birth (and identifies as a girl/woman) or male at birth (and identifies as a boy/man). Sometimes this term is shortened to ‘cis’. It is used to refer to people who are not transgender.

Gender Binary

The gender binary is the false, Western idea that there are only two opposing genders – feminine (girls/women) and masculine (boys/men). It is a social construct that often appears when sex and gender are conflated (e.g. on forms, toilets, titles). This does not reflect social, cultural or historic realities.

Gender Diverse

This umbrella term refers to people whose gender identity or experience falls outside of the gender binary. It includes non-binary people, traditional, indigenous and cultural gender identities, and people who do not conform to typical gender categorisations, irrespective of whether a person considers themself transgender or not.

Gender Dysphoria

Some trans people experience gender dysphoria. This is described as negative feelings such as distress, discomfort or dissatisfaction with your body, voice, appearance or mannerisms. [1] Each person's experience with dysphoria is unique and it can happen at any time, or not at all.[2] Why it happens and what alleviates it will be different for everyone. Actions that may help to alleviate gender dysphoria are often termed "gender affirmation" and can range from using a different name or pronouns, changing your appearance, or seeking out hormonal or surgical interventions. Other actions can involve social or legal affirmation such as formally changing documentation, joining a gender affirming group or club, exercising or engaging in gendered spaces and activities.

Non-binary

This term is used to describe genders that sit outside of the gender binary. People might identify as non-binary or they may also use non-binary as an umbrella term to describe other genders. For example, genderqueer, agender, bigender and genderfluid.

Endosex

A term used to describe a person with innate sex characteristics (e.g., chromosomes, reproductive organs, genitals and hormone levels) that match the medical norms for a typical ‘male’ or ‘female’ body. It is the term used for people who are not intersex.

Intersex

A term used to describe variations in innate sex characteristics (e.g, chromosomes, reproductive organs, genitals and hormone levels) that do not fit the medical norms for typical ‘male’ or ‘female’ bodies.[3] There are over 40 known intersex variations that each affect a person’s sex characteristics differently. Intersex people are about as common as twins (about 1.7% of the population). Intersex people have diverse sexualities and gender identities just like the general population. Most intersex people are cisgender. Because Intersex bodies are seen as different, intersex people face discrimination, stigma and harmful practices.[4]

HRT

Hormone replacement therapy (HRT) is a term used to describe people taking hormonal medications to address imbalances or hormone production concerns. These hormones are prescription medicines that come in different forms such as pills, gels, pessaries, injections, implants or transdermal (skin) patches. Each person using HRT will have a different type and dose prescribed by their GP/specialist to meet their individual needs. Because this term is used for trans and gender diverse people for gender affirmation, intersex people as a form of medical intervention either desired or otherwise, as well as cisgender endosex women treating menopause symptoms – there are now 2 separate, additional terms for HRT (see below). The term HRT will be retained in this report to refer to the hormonal management of intersex variations unrelated to gender affirmation or menopause.

GAHT

Gender Affirming Hormone Therapy (GAHT) involves estrogen, testosterone, or hormone blockers. People use GAHT to increase or supress masculine or feminine traits.

MHT

Menopausal Hormone Therapy (MHT)) is a treatment to manage menopausal symptoms. The medicines contain estrogen (and often a combination of estrogen and progestogen).

Transgender

Often shortened to ‘trans’, this is a general term for a person whose gender is different to their assigned gender (as assumed from their sex assigned at birth). A trans person may or may not choose to take steps to affirm their gender, with or without medical treatment. This term is used to describe people who are not cisgender.

Executive Summary

HCCA, with the assistance of A Gender Agenda (AGA) sought out people who were Trans, Gender diverse or Intersex with experience of menopause symptoms. There were several reasons for grouping trans, gender diverse and intersex people together for this research.

These interviews highlighted significant gaps in menopause information and access to care. Participants described having to "collage" information from multiple sources to gain information relevant to their circumstances. This included mainstream resources designed for cisgender endosex women, community forums, and costly specialist advice. All participants raised needing high levels of health literacy, time, and financial resources.

The findings showed some consistent and connected barriers for trans, gender diverse and intersex people including:

- Menopause being predominantly or exclusively framed as a women's health issue tied to aging
- Health professionals lacking knowledge to provide affirming, holistic care.
- Health professionals who lack understanding about trans, gender diverse and intersex people, force these communities into energy-intensive self-advocacy and research roles to understand how to treat their own menopause symptoms whilst considering their gender identity, intersex variations, and/or other health conditions.
- MHT side effects, and these effects not being discussed before MHT was prescribed. For example, bleeding and chest swelling that can trigger significant gender dysphoria.
- The cost of specialist appointments
- The need for multiple referrals

Several enablers or suggestions were also raised by participants including:

- Promote open conversations about treatment options, side effects, costs, and potential drug interactions before prescribing.
- Remove the assumption that consumers seeking treatment for menopause symptoms will be cisgender, endosex women.
- Avoid gendered language, de-gender language when discussing menopause or offer tailored versions that do this.
- Consult with trans, gender diverse and intersex communities to create tailored, evidence-based resources that meet the needs of these populations.
- Encourage the use of pharmacists as a trusted and accessible source of information.
- Health professionals should:
    - Acknowledge the diversity of bodies and identities experiencing menopause symptoms. This could happen through more education on

providing affirming menopause care for people with diverse gender identities and intersex variations.
  - Ask patient's gender identity , intersex variations or other chronic conditions (rather than make assumptions).
  - Provide information and support that affirms people's gender and experiences.

About this report

Despite having a varied range of gender identities and sex characteristics, people belonging to these communities have shared experiences of healthcare that differ from the typical audience of existing menopause resources (i.e. cisgender, endosex women).

Trans, gender diverse and intersex people experience stigma, discrimination, misunderstandings and misconceptions within the health system. The range of experiences within trans, gender diverse and intersex communities are underrepresented in health services and information, especially in spaces often framed exclusively around 'women's' health.

Menopause is often framed as an experience linked to both womanhood and aging.[5] This resonates for many people experiencing menopause symptoms; however, menopause also affects people beyond these experiences. Menopause affects people who are born with ovaries, which can include some, but not all, women, trans men, gender diverse and nonbinary people of any age after puberty.[6]. Additionally, some people who are impacted by menopause have intersex variations, which have been historically overlooked or excluded from understandings of menopause-related healthcare. A narrow framing of menopause can exclude people who do not identify as women, have bodies that do not meet the typical expectations of female bodies, or who experience menopause symptoms before the average age of 51 years (because of either surgery or medications). [7]

Approach to the interviews

Initially, expressions of interest were collected for either an in-person focus group, based in the ACT or an online interview. However, since most interested participants were based outside of the ACT, all participants joined individual, unrecorded, online meetings instead.

The interviews were facilitated by two Quality Use of Medicines Project Officers from HCCA. This approach (i.e. online, individual, no recording, tailored recruitment through AGA and facilitation by HCCA) meant that participants felt comfortable and free to express their thoughts and share their experiences on this highly personal topic. Allowing each participant one hour to discuss their experiences, provided clear and varied insights into how trans, gender diverse and intersex people understand and seek treatment for menopause symptoms.

Data collection and analysis

A qualitative data collection approach was used for this project. The online interviews explored participants experiences, perspectives and preferences around menopause and menopause care through a discussion guide with open-ended questions. Interviews were facilitated by two HCCA staff members, who were also note-takers throughout. AGA provided support to ensure questions were suitable for participants. An inductive approach was used to analyse the data.

A total of four participants took part in interviews listing their genders as genderqueer, man, woman, and non-binary, respectively. All had female sex recorded at birth, with two participants also having an intersex variation. Participants ranged in age from 30 to 60. One had medically induced menopause, while the remaining participants had age-related perimenopause/menopause. During interviews, three participants identified as living with other chronic health conditions. Three participants self-identified as health literate and having an education/profession related to health or mental health. The symptoms participants experienced included night sweats, hot flushes, brain fog, dizziness, genital dryness, thin and dry skin, sleeplessness, mood changes, heavy/irregular cycles and hair thinning.

Key Findings

Finding information

Overall, participants highlighted finding menopause information relevant to their specific medical needs very difficult.

Participants highlighted that their biggest challenge is the lack of mainstream menopause information that reflects their experiences or needs, resulting in significant knowledge gaps. All participants noted that guidance is written for an audience of cisgender, endosex women, meaning they often need to “collage” information from different sources to fit their own circumstances.

> *“While I teach nurses to be looking at evidence based and peer reviewed resources, sometimes this doesn't exist. You have no choice but to look at anecdotal evidence with a grain of salt, then try and make an informed decision”*

Three participants also noted that seeing menopause

> *‘…presented as a women's problem is confronting’.*

Consequently, as a starting point for seeking information, participants predominantly rely on online forums, peer support groups and community networks to find anecdotal information. All participants mentioned these forums as a common source of information that helps fill in knowledge gaps and enables them to hear from others with similar experiences of managing menopause symptoms. They find these lived experience sources useful because the information feels relatable, especially compared to resources created for cisgender, endosex women.

“I prefer to use people and places that understand my experience"

One participant noted that their friendship group is younger, making it difficult for them to talk about and exchange information in person about age-related menopause symptoms they’re experiencing and get support from people who understand what they’re going through.

In addition to online resources, participants used a range of other information sources, including:

- pamphlets from health professionals
- emailing their health professionals (follow up post appointment)
- online medical journal articles
- sexual health clinic websites
- community organisation websites
- conversations with pharmacists (two participants noted their pharmacist as a particularly helpful source of information).

Even with multiple sources, participants felt that the onus was on them to piece information together, due to the limited availability of tailored information.

Knowing what information to trust

Participants noted that they trust reputable sources such as information from sexual health clinics (e.g. Sexual Health and Family Planning ACT), government websites and other clinics or services they are already familiar with.

“I know it has been edited, reviewed or recommended by a clinician”

Most participants highlighted that online medical journals (e.g. PubMed) are reliable sources of information and that they often compare articles to see whether the advice is consistent. Two participants explained that they also check who wrote the information, where it was published and what resources are listed to ensure information is trustworthy.

One participant explained feeling wary about other sources for health information:

“I don’t trust any AI tools or social media”

All participants described a very specific process to navigate the information and knowledge gaps. They talked about needing to “collage” information from multiple sources. This involves a combination of mainstream resources (for cisgender, endosex women), anecdotal experiences, trans or intersex specific resources and advice from different health professionals. Participants then try to piece it all together to guide decisions around which treatments best suit them.

> *"Effectively you are collaging information – mainstream, trans resources and the lived experience of people with the same variation I have"*

> *"I need to marry together advice from the endocrinologist [who will provide gender affirming care] and my gynaecologist [who may not address gender]"*

One participant explained that information they found on cancer treatment induced menopause, became useful once they compared the information within their own context.

> *"A lot is adapted from cancer treatment induced menopause, for that off brand use. There is a benefit to being on HRT (if intersex or trans) as your hormone levels will be monitored with a health professional keeping an eye on your levels"*

Although participants recognised they can access a range of trustworthy information, a lot of confusion comes from the amount of online information that contradicts what they have been prescribed. This makes information seeking frustrating. It also often means they must cross-check information multiple times and seek further information from their health professionals. This process is not only costly, but the health professionals also may not always have answers to the questions they have.

Experiences of menopause symptoms

Understanding menopause symptoms

The participants often described feeling confused about their menopause symptoms. For two participants, this confusion stemmed from not knowing if the symptoms they were experiencing were because of menopause or from the other chronic medical conditions they lived with.

> *"…until sweats kicked in, I wasn't even sure if they were related to menopause."*

Participants also described feeling confused about how to manage their menopause symptoms, along with their other health conditions. As one participant explained, finding the best way to manage their other chronic conditions took a long time and a lot of trial and error and they did not want to add new medications or treatments to the mix and potentially disrupt the balance they had built.

> *"Despite all this [health literacy skills and time to research] it's still frustrating. There is a lot of crossover with other poorly understood*

chronic conditions that can have unexplained symptoms. There is a lot of trial and error with a GP and it's about that person-centred care"

For other participants, the challenges lay within the availability and supply of menopause treatments in Australia. As one participant explained, they felt their oestrogen levels were best managed with oestrogen patches, however, due to the supply issues around the patches, this was an unreliable option.

"What I'm on is working, I don't want to stop and start"

Managing menopause symptoms

Prescription medications

Participants reported using a range of hormonal and non-hormonal medicines to manage their menopause symptoms, including:

- Testosterone
- Progesterone
- Femoston 2/10
- Ovestin
- Oral contraceptive pill
- Vagisil™
- Replens
- Black cohosh (CAM)

All participants emphasised the importance of evidence in guiding their decisions about which medicine to use. They reported accessing evidence-based information through peer support groups, medical journal articles and trusted sexual health clinics or community organisations websites.

Prescription medicines and gender dysphoria

Most participants described having to be strategic about which health professionals would understand their gender or intersex variation when discussing menopause symptom management medicine.

"People are trying to navigate the information/experience of menopause while their gender is not aligning"

Two participants spoke in detail about how MHT affected their trans journey and gender identity. They described having to compromise between managing symptoms and coping with the ways MHT could trigger gender dysphoria.

"Because I have menopause, I remember that I've been assigned female at birth"

Side effects of MHT could also trigger dysphoria, such as the return of bleeding or chest swelling. One participant described feeling like their gender identity journey had to go on pause to alleviate menopause symptoms. They described having to push through dysphoria caused by chest swelling from oestrogen and when they raised this with their health professional, they felt dismissed with the response that, this is a side effect that "most women would enjoy". Two participants described their menopause symptoms as unmanageable and requiring treatment even if it triggered gender dysphoria. One participant described taking MHT as a compromise between:

> *"…deciding to be gender affirming or give in"*

Three participants raised similar points about how gender dysphoria can appear when looking for information on MHT options. They found consumer information usually written for cisgender endosex women and used gendered language, framing menopause as a women's health issue. This makes it difficult to find inclusive, appropriate information to make informed decisions about treatment.

Participants also reflected on how the names and packaging of medicines can feel confronting when being prescribed medicines and collecting them.

> *"For example, you might need something like femme-tab, which apart from the name is also literally in a hot pink box"*

One participant noted that this issue can also affect cisgender women, as certain product names like "Vagisil" needed for symptom management can feel embarrassing or confronting to have to go and collect.

Testosterone

Participants discussed a range of experiences relating to testosterone use for both GHAT and MHT.

One participant who was using testosterone for GAHT and as a result experienced medically induced menopause, discussed the challenge of navigating misinformation about testosterone use. They said:

> *"[There] used to be information that, after taking testosterone for 5 years it was best to have a hysterectomy because they [doctors] just didn't really understand and suggested to get rid of it all"*

Another participant considering testosterone for both GAHT and MHT shared that they had taken out a loan for an endocrinologist appointment to explore the option of low dose testosterone. They noted that it is already prescribed off label for many cisgender endosex women. While they acknowledged the limited evidence for testosterone therapy treating a wide range of menopause symptoms, they still thought this option was worth pursuing to try and minimise menopause symptoms without triggering gender dysphoria.

Two participants discussed the uncertainty around MHT prescription decisions for people whose needs fall outside conventional MHT pathways. Specifically, one participant highlighted that some non-binary people who don't take testosterone as GAHT are at risk of gender dysphoria when prescribed oestrogen or progesterone as MHT. This participant reflected that even on trans specific forums, most discussions will only focus on transmasculine people who take testosterone for GAHT that may have already supressed their menopause symptoms. They emphasised that for those who are not on GAHT, there is very little information to guide decisions around MHT options and dosage, even at the anecdotal level.

Non-pharmaceutical strategies + Complementary and alternative medicines (CAMs)

Non-pharmaceutical strategies to manage symptoms were not widely discussed in any interviews.

Only one participant mentioned an initial preference for CAMs, avoiding any hormonal medicines due to concerns about potential drug interactions with the medicines they already take to manage other chronic conditions. They used black cohosh and pharmaceutical supplements recommended by their naturopath, to manage night sweats and hot flushes, but as the weather warmed up, their symptoms became increasingly unmanageable and disruptive in the daytime. After reading advice from journal articles recommending combined progesterone and oestrogen treatment, they decided to pursue this option instead. Although this participant initially opted for CAMs they also acknowledged and were aware that CAMs were not always a popular option for symptom management:

> *"...but it is not typical to go for herbs in the trans community. Most need gender affirming care [and wouldn't opt for alternative medicines]."*

Other participants were more hesitant about CAMs. One participant described how the menopause support group they follow, focuses on sharing evidence-based resources (like from the Australasian Menopause Society website). Members of this group predominantly advocate for progesterone and oestrogen based MHT instead of CAMs because, *"there is the evidence to back it up".* They also found that use of CAMs can be expensive and found that the ones they've tried didn't make a difference.

It was clear for all participants that evidence to support the efficacy of medicine was important to them when making decisions about their treatment.

> *"Things that are not body safe can pop up when people aren't aware of interactions with other medication. There are lots of balms and oils and lots of claims."*

> *“I would use CAMs if approved by GP but usually aren't covered by PBS and know it's probably serving more of a placebo effect for me. But I have used one, for example to counteract Replens side effects”*

One participant said they avoid CAMs altogether since they already take several supplements for other reasons and only use them when there is strong evidence behind their use. They noted that they need good evidence to change or add anything into their routine and wouldn’t use any CAMs without checking with a specialist like an endocrinologist first.

When talking about other non-pharmaceutical strategies, only one participant mentioned exercise for general health and mental wellbeing. Overall, all participants considered MHT as the most reliable option for managing menopause symptoms, despite sharing concerns related to gender dysphoria and managing medicines for other conditions.

Cost of menopause care

Participants highlighted that accessing care for menopause was expensive and they were often not informed of the costs associated with menopause care at the beginning.

The first cost barrier participants raised was multiple referrals needed for different specialists. They highlighted that they needed to see more than one specialist to identify the cause and the most appropriate treatment of symptoms. As one participant noted,

> *"I find that they are experimenting. It's costly. You need a consultation each time. Really you might be throwing away prescriptions [if they don't work] and that's a fair bit of money you're talking about"*

One participant explained having to take out a loan to be able to afford an appointment with an endocrinologist who specialised in gender affirming treatment. For this participant seeing a gender affirming specialist meant that they would then be able to better understand a how to manage menopause and other chronic conditions without having to ignore or compartmentalise their gender.

Accessing support for managing menopause symptoms

All the participants described seeking support from health professionals to help manage their menopause symptoms. However, for trans, gender diverse or intersex people, accessing appropriate menopause care comes with additional challenges.

Safe and inclusive care

Participants expressed significant challenges when accessing care if their health professionals did not have enough knowledge or expertise to provide affirming care for people who are trans, gender diverse or intersex. For two participants, finding a specialist who had adequate knowledge about their unique combination of care needs was challenging.

“Endocrinologists and GPs might not be aware of symptoms that could be a result of hormonal fluctuations”

Participants reported that their health professionals failed to recognise perimenopause or menopause-like symptoms. These symptoms could occur in people with long term use of testosterone or intersex people who have undergone particular medical interventions. For one participant this led to unnecessary and invasive tests, as their health professional did not initially recognise their symptoms as being related to menopause.

“If symptoms can cause bleeding or tears from dry skin, this can lead to unnecessary invasive tests like cervical screening and STI tests if health professionals don't connect symptoms with menopause”

Participants noted that they were not told what to expect using testosterone as GAHT longer term. As one participant explained, it is common to experience menopause-like symptoms when first starting to use testosterone, but it is not clearly explained that these symptoms can also pop up when stopping or starting testosterone treatment, or after longer term use.

“...there could be guys that started [taking testosterone] as young as 15 or 16, so when you turn 24 or 25, you're not thinking about menopause management for unexplained symptoms. Because I was closer to 30, it was more expected. When you are young maybe you are told about the hot flushes and brain fog and expecting it, but vaginal atrophy and dryness can happen after a few years – closer to that 10-year mark”

None of the participants felt their health professionals clearly explained potential side effects of the MHT when it was prescribed. They highlighted the importance of health professionals talking with them about potential side effects and contraindications, how to manage side effects and the potential costs of medications before prescribing them.

For participants, not knowing about potential side effects led to feeling distress when they experienced side effects of treatments like irregular or heavy cycles and chest swelling. One participant described feeling distressing gender dysphoria because of chest swelling.

“She didn't tell me I'd be getting a period"

"I wasn't told I could get bad dreams, and it could affect my sleep in a bad way”

“When I stopped and started [testosterone], I just got all the same side effects again and I wasn't expecting that to happen”

Participants explained that they often feel uncomfortable asking questions or getting more information from their health professionals. One participant reported being told ‘most women would like that’ when they asked their healthcare professional about the possibilities of chest swelling when taking MHTs, despite not identifying as a woman. Another participant said,

> *"Half the time they are just pushing you through the system. They're watching the clock and you feel uncomfortable going deep [with the questions you have]."*

Participants also described difficulties with accessing safe and inclusive care. They emphasised that health professionals need to apply the basic principles of inclusive care to menopause care. For the trans and gender diverse participants this meant that their health professionals needed to have asked, and not assumed their gender identity, anatomy or the pronouns of the person they were caring for or of their care partners. For the participants this is a key component of person-centred care and understanding the individual needs of each person.

> *“One experience is not all”*

These participants also reported challenges accessing care for menopause symptoms, as they may be misgendered or be dismissed when they did not fit the assumptions held by some health professionals. As a result, they described feeling hesitant or apprehensive about seeking care. One participant explained that they did not go to the local sexual health to seek treatment for heavy bleeding as they did not know if “it was too women-centred".

Another participant described that being non-binary is often seen as a “young person thing” and felt that health professionals were not as good at recognising and acknowledging older non-binary people. They described being in the “women’s health” space as a strange and uncomfortable experience. It was one where you may be dismissed as a woman, or where your non-binary identity is misunderstood.

> *“Overall, your appearance can really affect your interaction with services (depending on how [masculine or feminine] you look)”*

Two participants discussed their experiences of accessing menopause care as an intersex person. They noted that feelings of resentment towards having menopause-like symptoms is common amongst Intersex people. This arose from the impacts of having been through medical interventions as a child/teenager that impacted their anatomy, hormones and fertility without being able to choose or have say in what happened to them.

All participants also spoke about how trans, gender diverse and intersex people often need to compartmentalise their care needs with their health professionals, if they do not have the knowledge to holistically address their care needs.

> *"...the GP only does my simple stuff because it's too out of their range in terms of knowledge. The gynaecologist deals with any infections and the endocrinologist addresses hormones"*

For one participant, the access to safe and inclusive care was further limited because they lived in a rural area. There was only one GP available in town and no access to after-hours or weekend care.

> *"Only GPs available in the area are two older male GPs in their 60s, who have limited and outdated knowledge about menopause. You would have to travel a long way to find a female GP, which is not feasible for a lot of people."*

Self-advocacy

All participants mentioned the crucial role of self-advocacy to get necessary information for their treatment. Participants talked about gathering or trying to gather knowledge to navigate the system and get information about:

- their symptoms
- possible medications
- options for alternative medicines
- side effects of different medications

> *"...you have to become your own expert and advocate, particularly if it's not age related"*

The participants described needing to have enough health literacy skills to be able to do the research and advocate for their care needs. The participants described needing to advocate for themselves and their care with their health professionals by:

- Pushing for more information on the MHT medications they were prescribed.
- Seeking a costly second and third opinion on their symptoms and care after being dismissed by their GP/specialist initially.

> *"I actually emailed the specialist again to ask for more information. I want to know more, especially if I am paying 200-300 per appointment"*

Participants also reported feeling like they were only provided with information by their GPs or specialists when they pushed for more information and asked for it. One participant found their GP to be 'very dismissive and nonchalant' and did not discuss any of the potential benefits or side effects of the medication they prescribed. They also reported not being given or directed to any additional information about menopause or the prescribed medications.

> *"If I hadn't done so much research myself, it would have been really alarming... I had to ask if a follow up appointment was needed"*

For the participants, the need to self-advocate was further magnified by what they felt was limited or lack of health professional knowledge and understanding of menopause and its impact on the health and mental health of trans and non-binary people. They also noted a general lack of knowledge amongst health professionals about intersex variations. One participant identified that menopause training for health professionals is inadequate when it comes to caring for trans people and often only includes a single paragraph.

> *"It's important that doctors are educated about intersex people, even endocrinologists usually aren't specialised in this"*

Managing menopause and other health conditions

Participants discussed the challenges of accessing menopause care while also managing other health conditions. Three of the participants described how the intersection between their gender identities and neurodivergence complicated access to appropriate neuro-affirming care and information. The noted a lack of awareness about the needs of people from these communities, which made it difficult to find holistic care that affirmed both aspects of their identities. Additionally, having neurodivergent ways of thinking introduces further complexities to accessing care. As a result, these participants often had to separate and manage their gender-related care needs from their neuro-affirming care needs, even though these are interconnected, to ensure they were still able access the care they needed.

> *"...need to do a lot of mental gymnastics in preparing for appointments as [the doctor] may not talk about gender/deal with this well"*

For participants, having to mask and manage their identities and/or other care needs is emotionally draining and creates additional challenges to accessing care. Participants identified as being in

> *"...emotional limbo about how out I am in different situations"*

Overall, participants reported needing to rely on themselves to advocate for their care, to be taken seriously and to find appropriate solutions. One participant described the process of accessing menopause care as feeling like being in an experiment. They expressed feeling uncertain about using MHT medications because they were unsure about how it might disrupt other treatment regimens or interact with their existing medications and were reluctant to disrupt other treatments. As a result, participants avoided using CAMs and instead opted for specialist appointments, despite the higher cost to receive tailored and specialised care.

Gaps and suggested improvements for the future

Information on menopause

Lack of mainstream information

While some participants strongly advocated for access to information that is tailored to trans, gender diverse and intersex people, all participants highlighted that even when trying to build knowledge on menopause symptoms and treatment for cisgender endosex women, the information wasn't necessarily widely available or easy to understand.

> *"I don't feel like there is even much mainstream information"*

Participants highlighted confusion between the word menopause and perimenopause. One noted that in workplace menopause training, they learned that the word "menopause" technically refers to just one day. The confusion reflects a bigger issues around limited clear, mainstream information to begin with.

> *"...even when expressing interest in this interview. I wasn't sure if it was me"*

Participants highlighted that mainstream conversations frame menopause as something that only happens to cisgender endosex women in their midlife. They felt this leaves out younger people, trans, gender diverse and intersex people, and anyone whose experience doesn't fit the mainstream.

> *"[It's] not just a 'women in their 50s' thing. People in their 40s need to know about it and not be dismissed young. Information needs to be out there that you can get it younger than 40"*

One participant linked the lack of information to wider misogyny, saying menopause is dismissed or minimised because it's associated with women and aging.

> *"...it's a medical misogyny issue"*

Participants also described coming across a lot of contradiction and misinformation, making it hard to know what sources to trust.

> *"There is misinformation out there. Like hormone panels that don't actually show anything. GPs aren't aligned. Symptoms need to be taken seriously and not just default to anti-anxiety meds"*

One participant identified not knowing where to find support for changes to medication dosages as their GP and pharmacist gave them conflicting information. After having a conversation with their pharmacist about lowering their progesterone dose to reduce side effects like chest swelling, their GP said that, taking progesterone would be "pointless then".

No tailored information for community

All participants expressed that information about menopause that is appropriate, evidence-based, relevant to trans, gender diverse and intersex people is extremely difficult to find. When asked, no participants could think of any existing resources that fit the criteria listed above, despite most describing themselves as health literate and having spent extensive time searching for information online.

Participants noted that available menopause information is primarily written for cisgender, endosex women, while there is limited guidance for:

- Transmasculine and gender diverse people who are not using testosterone and therefore may experience feminising side effects of MHT such as chest swelling.
- Non-binary people who menstruate or experience menopause
- People looking for information that is gender affirming and non-triggering.

> *“I want to be on HRT to manage my menopause symptoms, but I find the information very triggering and discriminatory”*

Participants emphasised that they need clarity on how MHT and menopause symptom management differs in approach for trans, non-binary and intersex people, compared to cisgender, endosex women. They want tailored information that helps with thinking through concerns that may not be relevant for cisgender, endosex women. They felt having relevant resources would make it easier and help to understand their options and make informed decisions about managing their menopause symptoms.

Menopause Care

Role of pharmacists

When discussing accessing care for menopause, participants reflected on the instrumental role their pharmacists played in providing information, validating their concerns and providing advice.

Participants explained that their pharmacists were a key source of information and were able to address their questions and provide advice. As one participant explained,

> *“... [there is] only one in town and ‘doubles as a doctor’. They gave me lots of information, talked through symptoms and what to do if other my chronic conditions flare up, for example migraines, and how we might adjust the dose. When I spiralled about 10 days after [taking MHT] I called him. Even though he doesn’t understand my gender, he helped”*

For participants, the pharmacist is an essential part of accessing menopause care and a trusted source of care and advice for managing their menopause as well as their other care needs.

> *"Pharmacists do a lot of advocacy work for patients with doctors as well...I have tried to find a good pharmacist and stick with them. It's good to have someone who understands your health journey. Pharmacists know medicines. It's their whole job to know how medicines interact. People don't understand how useful they are."*

Medication options and alternatives

Participants identified that they wanted to know more about the different types of medicines available for managing menopause symptoms from their health professionals, before being prescribed something. Throughout the discussions, participants spoke about their concerns around taking menopause medications because they weren't sure of the potential side effects, or contraindications with other medications they were on.

Finding the correct management option for menopause, can be a lengthy and uncomfortable process while individuals trial treatments to assess their effectiveness and tolerance for it. However, being able to discuss the different options for treatment is essential in reducing some of the distress and anxiety associated with menopause treatment.

The discussions also highlighted the need to create information about potential drug interactions, particularly for people who have other chronic illnesses and health conditions. This information plays a crucial role in providing safe and holistic care for trans, gender diverse and intersex people. It is especially important in circumstances where health professionals may not have enough knowledge or experience in providing gender-affirming care. It also matters in situations where people may not feel safe or comfortable disclosing their other care needs to their health professionals.

Awareness of potential side-effects

During the discussions, participants reflected on their experiences of common side-effects of MHTs, particularly heavy bleeding and chest swelling. Participants feelings of gender dysphoria due to these symptoms, highlight the potential for unintended harm when potential side-effects are not properly explained and managed.

These discussions demonstrated the need for health professionals to provide inclusive and holistic care that considers the gender and sex characteristics of people when providing menopause care. It also reinforces the importance of creating information that is tailored for trans, gender diverse and intersex people. This is particularly important for people who are not taking testosterone as GAHT and want to avoid feeling feminine in their bodies.

Resource suggestions and considerations

When participants were asked how they would like to see menopause information presented, comments and suggestions varied. Overall participants' suggestions included an online hub of information, factsheets, videos and a podcast. Participants advised that details around anatomy and gender need to be presented thoughtfully and in consultation with community to try to avoid triggering readers unnecessarily.

Tailored advice

Participants also identified the need to separate information into sections tailored to different audiences so people can identify if advice is relevant for them. Intersex participants noted difficulty with developing universally relevant menopause resources for intersex people. The experience of menopause symptoms for intersex people is complicated by many being subjected to harmful medical procedures before reaching the age of consent, which can lead to early menopause symptoms or no menopause at all. They suggested that endocrinologists or other health professionals with expertise in intersex health should co-develop tailored information in collaboration with intersex community members, but it is unlikely that general content could adequately support a group with complex hormone profiles, experiences and care needs.

Web hub

Three participants suggested a website 'hub' with further links to additional resources that are trans, gender diverse and intersex inclusive. Content suggestions and considerations for this hub included a summary of the hormonal changes associated with menopause.

> *“Printable resources are becoming few and far between. I would seek out information online first”*

> *“There definitely needs to be a digital format considering the self-research involved”*

Factsheets

Factsheets were the only common suggestion mentioned by all participants. Practical information about using MHT was identified as a major gap that could be addressed in factsheet format. Participants suggested a factsheet could contains clear and practical explanations of medication timing, risks, common and serious side effects, and potential drug interactions. One participant stressed the importance of printed resources as their top choice for sharing information about menopause.

> *“I don’t like the idea of a digital link to more information – a physical copy is better”*

Printed material

Three participants acknowledged that while printed material may not be their first preference, it is a format that is familiar to most consumers and can serve as a useful tool during appointments.

> *“If content is distressing it is good to be able to print and take to a doctor or specialist, and it's also good for a doctor to be able to print something for a patient too”*

Two participants also noted that printed resources may be more relevant or suitable for people experiencing age related menopause, who may belong to a generation that prefers printed materials. One participant also shared their frustration that ‘Consumer Medicine Information’ leaflets are not always included in medicine boxes, putting pressure on the consumer to go away and find important information themselves.

> *“You used to get information in the medicine box but that's not the case anymore”*

Podcast

A podcast featuring clinical experts who treat trans, gender diverse and intersex patients was another suggestion from a participant. They shared that while they had explored several different podcasts covering the topic of menopause, the episodes only focus on cis women’s experiences.

> *“An episode with a Menopause and Gender expert, discussing how they work together to manage menopause symptoms in their patients would be good”*

Videos

Videos were another resource suggestion mentioned by two participants. One emphasised that videos would have better uptake, if they were published by a trusted source within the community (such as ACON). They acknowledged that the time they spent reading and accessing up-to-date medical articles, was not feasible for many people seeking out menopause information.

> *“Most people aren’t going to read a boring medical paper or pay attention to who’s written the information which contributes to misinformation”*

However, another participant with a background in health communications suggested some caution around videos on social media. They explained that videos on social media can’t provide comprehensive information but could be used to introduce topics that are covered in depth somewhere else.

> *“Short form videos can't cover everything. They might be useful just to direct people towards more detailed information”*

Language choice

Participants could not recommend specific or standardised terminology they thought would be applicable across trans, gender diverse and intersex communities. Three participants explained it is a good starting point to use language that is both gender neutral and clinical. However, warning that anatomy or identity words that feel appropriate to some, may exclude or trigger others. Language that also aligns with health professionals understanding of gender or intersex variations is also difficult to define.

> *"It's really hard to get that right. Talking about lower genitalia is really hard. Replacing breast with chest is easier."*

> *"For me I have a vulva and vagina but I am non-binary not trans. 'People with a uterus' might be preferred but it's different for everyone"*

To avoid the issue of trying to find the 'right' terminology, participants emphasised the importance of forms and in inclusive personal interactions as a crucial space to establish suitable language.

> *"Health professionals having the ability to shift your approach depending on the client is really important. I'm happy to see pink as long as the person in front of me uses different language for me"*

Participants were able to provide a few guiding points on language. This includes:

- Try to avoid gendered labels (i.e. women/female, breast, period)
- Where possible, de-gender descriptions (i.e. people experiencing menopause, chest tissue, bleed cycle)
- Where there is unavoidable gendered or anatomy specific language - offer trigger warnings
- Consider that not all non-binary people identify as trans and vice versa
- Assigned/designated Female at Birth (often under the acronyms of AFAB and DFAB) can be triggering for some people as it still places you in a binary male/female category
- Remember just having symptoms, menstruating, having female anatomy can be dysphoric

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[1] TransHub 'What is dysphoria?' website: https://www.transhub.org.au/social/what-is-dysphoria/
[2] A Gender Agenda "Transgender for individuals' website: https://genderrights.org.au/information-hub/transgender-for-individuals/
[3] Interlink, 'Intersex is...' website: https://ilink.net.au/intersex-is/
[4] A Gender Agenda, 'What is Intersex' website: https://genderrights.org.au/information-hub/what-is-intersex/

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[5] Tozea, Michael and Westwood, Sue, Experiences of menopause among non-binary and trans people. International Journal of Transgender Health, 2026 (2), 447–448. https://doi.org/10.1080/26895269.2024.2389924

[6] Australian Government, ‘Everyone experiences perimenopause and menopause differently’ website: https://www.health.gov.au/perimenopause?language=en

[7] Drysdale K, Burton-Clark I, Moline K. Reimagining menopause by expanding assumptions shaping research: A scoping review of gender and sexuality diverse people's experiences and expectations. International Journal of Transgender Health. 2025 (1), 162-177. https://doi.org/10.1080/26895269.2024.2447785.
HealthDirect ’Menopause‘ website: https://www.healthdirect.gov.au/menopause