

HWW Menopause Survey Findings

January 2024



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Introduction - What is menopause?

- Menopause is reached 12 months after a person stops having periods, which usually happens naturally between the ages of 45 and 55 but could be earlier or later.
- For some time before this, a few months or for several years, periods may become irregular, and symptoms of menopause begin. This is known as the perimenopause. The most common symptoms are hot flushes or night sweats, experienced by 70-80% of people. Other symptoms include insomnia, low energy, low mood, anxiety, low libido, brain fog, joint aches, headaches, palpitations, vaginal dryness and urinary symptoms, which can all impact on life, including relationships and work. A quarter of people experiencing the menopause will find the symptoms severe and debilitating. More than a third of people will continue to experience symptoms after menopause is reached (British Menopause Society, 2022).
- For some people, menopause is induced due to medical treatment or surgery which can cause sudden severe symptoms.(British Menopause Society, 2021).

Introduction - National background

Recent publicity and research has identified gaps in menopause knowledge and support, impacting on people's lives.

- 1 in 10 respondents to a national call for evidence said they did not have enough information on the menopause. When asked about their experience of healthcare, women describe being dismissed and not taken seriously by health services, needing to persistently advocate for themselves, and having limited opportunity to discuss treatment options or to have their preferences considered. (Department of Health and Social Care, 2021).
- In 2022 The Fawcett society surveyed over 4000 women between 45-55 and found:
 - Over three quarters of respondents reported experiencing very difficult symptoms.
 - 1 in 10 left their job due to menopause; this was more likely for people with disabilities.
 - Almost half of the respondents had not approached their GP to ask for support.
 - Only 4 out of 10 women were offered HRT in a timely fashion, despite it being shown as effective in alleviating menopause symptoms.

Introduction - Local background

Healthwatch Warwickshire heard feedback about care during the menopause from 22 people in the first half of 2023. Over two thirds described a lack of support or knowledge from a GP when seeking help with the menopause.

We heard from people needing repeated appointments, or being misdiagnosed, before being supported during the menopause. People shared the wider impact on their lives, as a lack of support led to poor mental health, thoughts of suicide, increased challenges of caring for others whilst struggling with their own symptoms, and concerns about job loss.

Local menopause support group, <u>Action Menopause Warwickshire</u> held a small focus group in 2022 which highlighted:

- A lack of specialist menopause services locally.
- A need for better education about hormone replacement therapy.
- Symptoms impacting greatly on people's lives.

Warwickshire

Action Menopause

Challenges to accessing menopause help and support are leading to people using private clinics. This can result in inequality because of the cost of private services.

Introduction - Our survey

Following the national research and local feedback, we conducted a survey to find out people's current experience of menopause care in Warwickshire. Questions were developed with input from two local menopause support groups and covered:

- Which healthcare professionals are contacted for menopause support? Are people happy with the care and treatment they received?
- What barriers may stop someone contacting a healthcare professional to speak about the menopause?
- Do personal circumstances impact on the experience of menopause care?
- Does each primary care team have a named individual offering menopause support?
- What are people's feelings towards hormone replacement therapy (HRT)? Can people access HRT?
- What about the impact of menopause on people's lives?
- What suggestions do people have for improving their care?

Introduction - Collecting survey responses

The survey was shared widely online, via social media, and paper copies taken to our in-person engagement activities, between September and December 2023. Partner organisations were keen to share with their colleagues and clients, and to support individuals to fill in their responses as a way of opening-up conversations.

"That's music to my ears!
I'll definitely share this."

"I can ask Comms to share it as we know this is a key topic of interest to our staff given the demographic."

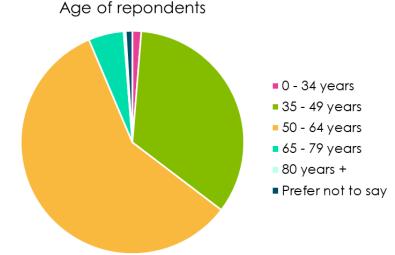


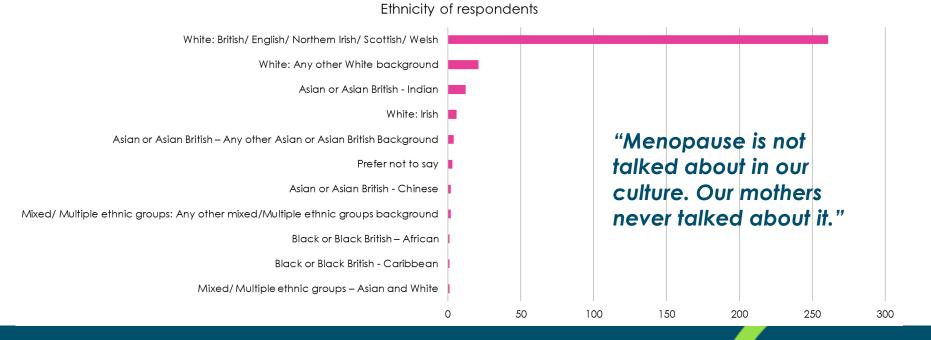
"Thank you for sharing this with me. I will definitely be sharing with groups as a few issues have been raised regarding this topic."

We received 314 responses from individuals.

Who did we hear from?

- 90% of people who completed the survey were between 35 and 64 years of age.
- The average age for the menopause in the UK is
 51 years of age.
- 83% were White: British/ English/ Northern Irish/
 Scottish/ Welsh





Who did we hear from?

We asked people to share if they have a disability, a long-term condition or if they are a carer.15 people preferred not to share this information.

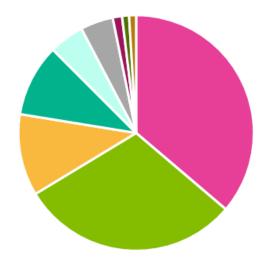
Out of 299 respondents:

- Almost 10% told us they have a disability.
- Over a quarter told us they have a long-term condition.
- Over 10% described themselves as a carer.

We asked this question to find out if people's circumstances impacted on the care they could access or their satisfaction with care received.

Who did we hear from?

Areas respondents live



- Warwick District
- Stratford District
- Nuneaton/Bedworth Rugby Borough
- North Warwickshire
- Coventry

Solihull

Worcestershire

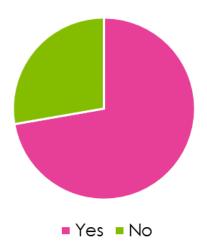
Unknown

- The higher response rate from South Warwickshire residents reflect the active menopause support groups and meetings we visited between September and December 2023. We searched but could not find equivalent groups in other areas of the County.
- The survey was shared at the Action Menopause Warwickshire meeting, Brunswick Hub menopause support group, Lifeways menopause morning, Bishopston menopause cafe and St Wulfstan Surgery, Southam menopause meeting, all based in South Warwickshire

Have people contacted a healthcare professional about menopause symptoms or experience of menopause in the last year?

312 people answered with almost three quarters of respondents having contacted a healthcare professional in the last year.

Respondents who contacted a healthcare professional in the last year



"No clue where to start, feel like my symptoms could be other things, nervous about medications. Sometimes not sure who/where to go"

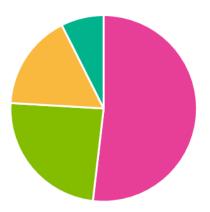
"I contacted my female GP who has been very supportive and prescribed HRT."

- Over 80% of respondents had experienced menopause symptoms.
- 5% of people told us they experienced menopause due to medical treatment.
- 4% of people told us they had experienced an early menopause.

What barriers may stop someone contacting a healthcare professional to speak about the menopause?

Space was provided to enable people to explain why they had or had not contacted a healthcare professional.

Themed responses for why people have not made an appointment



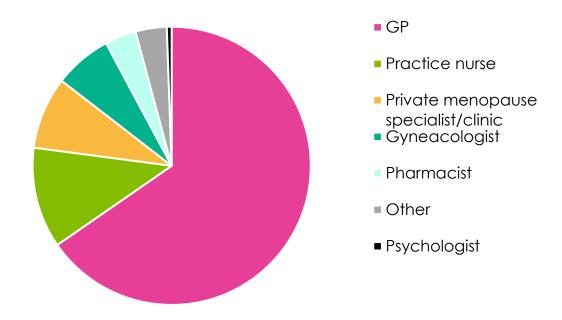
- No need for appointment
- Lack of trust in GP support
- Difficult to get an appointment/don't want to bother the GP
- Don't know what to do/ who to contact

- 237 people explained their answer, with over two thirds telling us they had made an appointment to discuss menopause symptoms, HRT, or have a medication review.
- Shown on the chart (left), 54
 people shared with us their reasons
 for **not** making an appointment.
 For the majority they felt an
 appointment was not needed, but
 we did hear about barriers to
 accessing services, lack of trust in
 the GP and people not knowing
 who to contact.

Which healthcare professionals are contacted for menopause support?

Almost three quarters of respondents had contacted their GP and 27% had been in contact with more than one healthcare professional to discuss the menopause. 72 respondents had not contacted anyone in the last year.

Healthcare professionals contacted in the last 12 months



"I have not started the menopause, but I wouldn't think to go to a GP about the menopause"

Were people satisfied with the care and treatment they received?

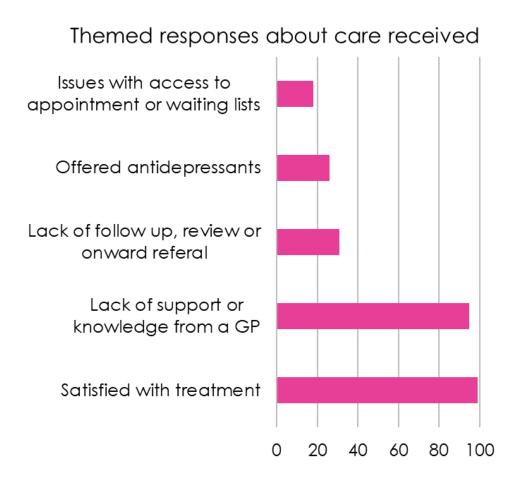
222 people responded to this question with a yes or a no.

- 56% of respondents were satisfied
- 44% of respondents were not satisfied

"First contact was a telephone appointment and comprehensive consultation (then sent info on patches so I could discuss with my husband). Next was a visit to see the GP face to face, which included a further chat and physical checks. The GP was very thorough and issued a prescription for patches after being satisfied I had considered all risks and benefits etc."

"I didn't feel 'heard' you know when you explain all symptoms and you're told "Oh next your periods will stop altogether!" Yet I'd stated in my symptoms that I'd not had a full period for over12 months and that I had suddenly started bleeding - very heavily, was struggling with brain fog, sweats, feeling insecure and weepy. I left feeling I'd wasted GP time and mine and battled through!"

Were people satisfied with the care and treatment they received?



We invited people to tell us more about the care they received.

- Positive comments praised healthcare professionals and their care.
- Negative comments described being dismissed or not listened to by a GP, highlighted a lack of follow up appointments for HRT reviews or referrals for further investigations. We heard from people who were given antidepressant medication and who had experienced issues with access to appointments or were on a waiting list for a service.

What we heard

"My GP and practice nurse listened really well and were very empathetic to my needs. They helped to educate me and offer advice about the options I had for my menopausal symptoms."

"HRT suggested by GP when consulted regarding anxiety. Am very grateful for that, as many women given anti-depressants when actually they need oestrogen. As a result, I have experienced few symptoms like myself again." but am going to stay on HRT to prevent

"Dr was open to trying HRT and blood tests etc. Easy to deal with and no pressure."

those symptoms and to benefit from the unseen protection for heart and bones."

"I was only able to receive the care I needed after going private. However, very grateful to my GP for taking the advice of the consultant I saw. Also, very grateful to the NHS Warwickshire Gynae Service which is run by GPs with a 'can do' attitude so rarely seen these days!!"

"I felt listened to and heard. I got good advice and was prescribed the medication I needed to make me feel

"Excellent care but there was an excessive wait to seek medical guidance with the NHS."





"Although all the staff at my surgery are really helpful, I think I need to see a specialist menopause specialist, I cannot afford to do this privately so have not been able to get this help."

"My GP said she would like to prescribe me HRT but that they were in short supply so she couldn't. No other help was offered."

"I haven't received any support for my symptoms, every time I discuss it with a GP, they offer to take bloods to check levels of things but nothing particular shows up so nothing gets done." "I'm confused, I had cancer, and I am high risk for breast cancer so can't take HRT. I was given the vaginal cream though, so I am confused. When I looked at it, it was out of date so I went to the pharmacist who said they can't do a repeat prescription as it is so old. I went to the practise nurse who said I couldn't have oestrogen cream without a progesterone cream which I don't want so I'm not sure."

"Told could not help until I was 12 months passed my last period."

"I was given the wrong information due to the GP not knowing enough about the Menopause."

"I was well read up on menopause and treatments and asked for treatment over the phone which was granted. Follow up consultation has not been offered so altering my own medication"



Do personal circumstances impact on the experience of menopause care?

We considered people's personal circumstances when looking at their answer to two questions in particular:

In the last year have you contacted a healthcare professional about your symptoms or experience of menopause?

Our data showed there was little difference in the percentage of people who had contacted a healthcare professional based on ethnicity, having a long-term condition or being a carer.

Respondents over 65 were less likely (29%) to contact a healthcare professional, as were those who identified themselves as having a disability (62%). Compared to 72% for all respondents.

Were you satisfied with the care you received?

Our data showed there was little difference in the percentage of people who were satisfied with the care received based on ethnicity or having a long-term condition.

Respondents over 65 were less likely (43%) to be satisfied with care received as were those who identified themselves as having a disability (44%) or being a carer (33%). Compared to 56% for all respondents



"I am a carer so haven't time for me."

"Due to being diagnosed with ADHD only last year and still awaiting medication my surgery has refused me any menopause treatment until I am on ADHD meds. I had a DVT in 2009 obviously also making things more complicated. I have been waiting over a year for ADHD meds and do NOT feel supported by the NHS in this or the menopause. I feel invisible and ignored."

"Often the GP doesn't have any knowledge/sympathy of symptoms. I can't get a review appointment after being prescribed HRT - it was left too long. I was on an incorrect HRT dose - I feel that no other medical conditions would allow this. menopause/ over 50s are an unseen populations."

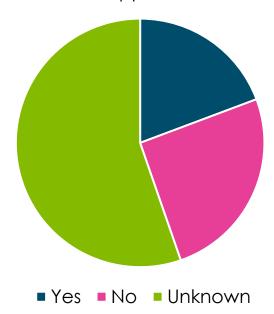
"I have a long-term health condition as well as the menopause, and to be honest, I find it hard to fit my health in with all other family commitments. I already have appointments regarding my long-term health condition that take up time."

"It took too many appointments; I was offered anti-depressants these do NOT help if your anxiety is hormone related. Doctors need more training and understanding."



Does each primary care team have a specified member of staff offering menopause support?

Does your GP surgery have a specified member of staff to provide menopause support?



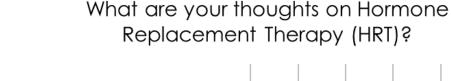
We heard from patients registered at 80 different GP practices in and around Warwickshire.

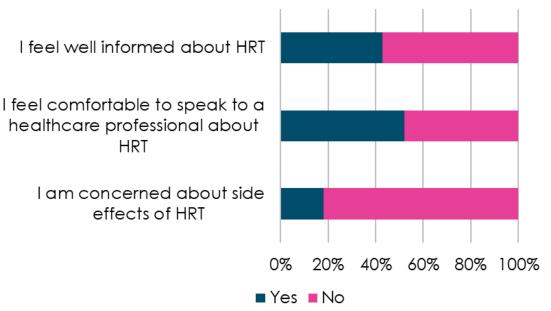
Out of 15 people who responded to this question at the same GP practice, which does have a named individual for menopause support, 3 people indicated yes, whilst 12 indicated unknown. This shows that not all patients are aware of this additional service covering menopause.

For those that did not have, or did not know about, a named member of staff providing menopause support, only 51% of people were satisfied with the care they received. This rose to 73% for people who told us that their GP surgery did have someone providing menopause support.

People were more likely to be satisfied with their care if they knew of a specified member of staff providing menopause care.

What are people's thoughts towards hormone replacement therapy?





- 43% of respondents told us they feel well informed about HRT.
- 52% are comfortable speaking to a healthcare professional about HRT.
- 18% are concerned about the side effects of HRT.

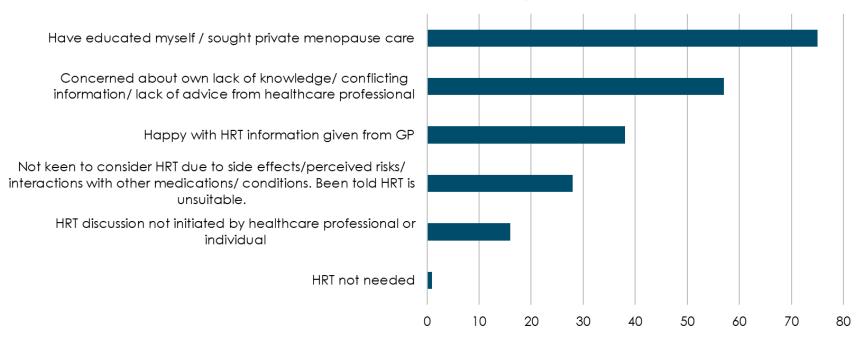
63% of respondents told us they have been prescribed HRT.

The number of people who have been prescribed HRT is greater than the number who feel well informed or are comfortable to discuss it.

What are people's feelings towards hormone replacement therapy?

We invited people to tell us more about the care they received.

Themed responses to people's feelings about HRT



75 people told us they have educated themselves about their potential or experienced symptoms, and possible treatments, or that they have sought out private menopause care. A further 57 people told us of concerns about their own lack of knowledge, and conflicting information or lack of advice from healthcare professionals.



"I had reduced symptoms when I was on the tablets previously. I'm keen to try another form, on advice, due to migraines. I am disappointed that women have to fight to get HRT, particularly testosterone."

"I've heard of HRT but am unsure when I'm supposed to start it. My mother was on it but has more recently developed dementia" "I have been on HRT for over 12 months now after about 2 years of conflict with my GP about symptoms. Being told that at 41 I was too young to have perimenopause symptoms, having blood tests that aren't reliable and being told to take antidepressants because it won't hurt to try them. Wasn't listened to, was labelled as depressed/anxious, no help whatsoever. Unprepared to consider perimenopause despite discussing NICE guidance"

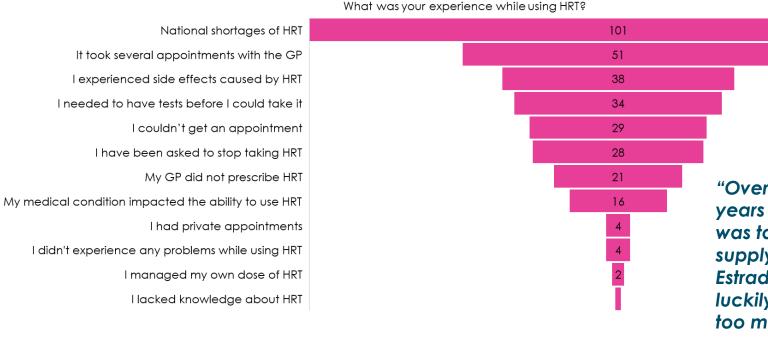
"I feel there is no discussion about pros or cons or alternatives – it's left to me to Google."

"From research, and advice from GP, I am satisfied that HRT is the right option for me."

"I feel confused and anxious about side effects following my GP consultation, hence my decision to book a private consultation. I am delaying starting prescribed HRT until after the private consultation."



What are people's experiences of using HRT?

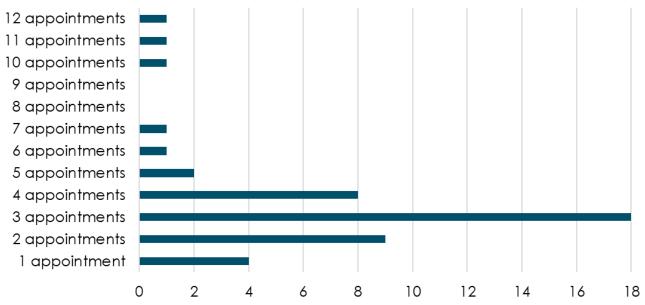


"Initially I had to pay privately to access HRT as I didn't feel my GP was hearing me when I was talking about all my symptoms. I was being referred here, there and everywhere to rule out other things. My private practitioner wrote to the GP so I could have repeat prescriptions. I was then asked to stop HRT by the GP due to fibroids and a thickened womb lining. The gynaecology community service has arranged for me to restart HRT."

"Over the past few years tablets which I was taking were in short supply & more recently Estradiol last year which luckily didn't affect me too much, but I did lower the dose for a few weeks until the supply went back to normal."

Can people access HRT?

How many appointments did you have with a GP before HRT was prescribed?



- who responded to this question) told us that they had 3 appointments before HRT was prescribed. This was the most common answer to this question.
- Four people told us they had 'several' appointments and two people told us they had appointments spanning several years.
- Three people told us they had between 10 and 12 appointments. Four people told us their appointments are still ongoing and three people told us they opted for private medical care.



"During my 11 virtual appointments my symptoms were dismissed as period/women problems. Once, when I was too ill to function, my GP practice put it down to an allergic reaction. Afterwards they investigated me for lupus. I went private and was prescribed medication that treated the symptoms successfully straight away and my GP practice was advised to prescribe me HRT as I was perimenopausal."

"I feel I have had to fight hard to get the treatment I needed & was only taken seriously when the private clinic had been prescribing me HRT for a year. I have suffered for years with excessive bleeding, bleeding after sex and exercise, and night sweats until it was treated."

"Not having HRT was horrible and I felt my daily life was impacted greatly."

"I felt like I lived under a horrible black cloud for years due to not being prescribed HRT at the time of my cancer treatment which led to an early menopause. No one cared. I wasn't heard. I felt like I lost years of my life but was expected to be grateful for getting through my cancer treatment despite the devastating effects this treatment had on my health in a wider sense."



What else did we hear about the impact of menopause on people's lives?

- 33 people felt the healthcare staff they spoke were reluctant, either to consider their symptoms as peri-menopause/ menopause related, or to prescribe appropriate medication.
- 31 people told us about their positive experiences.
- 28 people feel that women should be prepared from a younger age about what the menopause is and have more knowledge about the impacts.
- 27 people told us about how their symptoms have negatively affected their working lives.
- 23 people felt that their symptoms had led to negative consequences, with a further 12 specifically mentioning poor mental health. 15 more told us that the duration of their symptoms was a problem for them.
- 10 people felt that a delay to diagnosis, or a delay to being prescribed medication, had worsened their situation, and 3 people specifically mentioned feeling like they had to battle to receive appropriate health care.
- 10 people spoke about the increased visibility of menopause information as being positive.

What we heard

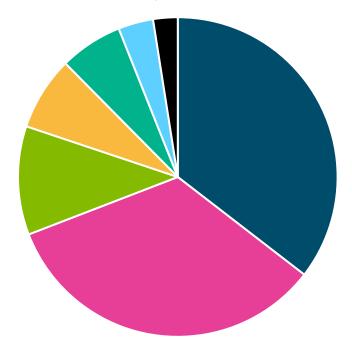
"In the past two years the symptoms of the perimenopause have certainly affected me both physically and mentally. I tried to 'soldier on' for the first two years afraid to actually admit this was happening. I was probably 40-42 when symptoms first hit. But it is a relief now to have the HRT, hopefully soon get the right dosage."

"I nearly lost my job because of the severe symptoms. I was going through a hideous divorce with domestic violence & my doctor was trying to prescribe antidepressants & not looking at the holistic bigger picture & would not give me a blood test. I had to fight through & find my own way out doing my own research & changed my GP surgery to one who trains their doctors in menopause."

"Surgical menopause is a separate area of menopause care that is completely neglected- I became suicidal, I couldn't work, my relationship nearly broke down, I lost years of my baby sons' life where I just wasn't functioning. All the while I was taking the wrong dose of HRT, prescribed antidepressants instead of changing HRT... there was no after care, no support, no information... I found out that the memory loss, panic attacks, suicidal thoughts and joint pain were due to menopause through Instagram- not from my doctor. I thought I would feel like that forever. Then I eventually saw a doctor who actually knew what she was talking about, and it changed everything."

What suggestions do people have for improving their care?

What would make menopause services better for you?



- More easily accessible support
- More informed staff
- Increased accessibilty to medication Preparation in advance

Regular updates/ reviews

- More holistic approach
- I've had positive experiences

35% of the comments we received suggested that making all types of support, including through primary care, community staff and venues, more easily accessible would be beneficial to all patients.

34% of comments spoke about either having greater numbers of staff available or staff being trained to be better-informed about menopause care.



"If ALL doctors and practice staff were trained in the needs of women going through the menopause. It is something that EVERY woman will go through in their lives so surely, we should be entitled to and provided with the right support and medication to live well through this period."

"Having a regular menopause clinic where I can attend and ask questions from a professional and get support from peers."

"If I had been asked to attend an appointment to do some basic health-checks in my mid 40s, I could have been made aware of symptoms and ways to manage them. I would have been prepared for the massive changes I went through before they happened and been prepared. I could have prepared my family for the changes I went through."

"An all-round specialist that is genuinely interested in the subject matter and keeps up to date with the private sector in their research and progress with making life more bearable when in this process. After all the retirement age is now 67 for women."

"We need to have more services to support all women. Not everyone can afford private. I am lucky - I don't know what I would do without it."



Conclusions

"HRT: I have heard of it but did not know what it is or that it is helpful for menopause. I wouldn't have thought to ask for it."

Throughout our survey people told us about a lack of knowledge around the menopause, the treatment, care and support available.

- Individuals were unsure who to contact, what to ask for, and told us about their knowledge gaps and the need to educate and advocate for themselves.
- We heard from those who had visited their GP and were dissatisfied with their care, that this was frequently due to a lack of knowledge or support.
- We heard about repeated appointments, delays to diagnosis, treatment and onward referrals.
- Whilst there are some GP practices with a named member of staff to provide menopause care, this was not widely known about.

"As a healthcare professional, I understand HRT indications and use. However, my initial consultation with a GP (by phone) about HRT was dreadful. I got a lecture about diet and exercise (irrelevant to my situation) and a huge reluctance to prescribe HRT despite it being the appropriate treatment for me. "

Recommendations

"The menopause affects every aspect of my life at work and family life."

• Use online training to increase knowledge, encourage conversation and raise awareness in your organisation. For example:

Catalogue (learninghub.nhs.uk)

BMS PPMC Resources Toolkit - British Menopause Society (thebms.org.uk)

Menopause: diagnosis and management (nice.org.uk)

• Signpost to support for individuals.

<u>Action Menopause Warwickshire</u>

Menopause and Perimenopause | Healthwatch Warwickshire

Women's Health Concern | Confidential Advice, Reassurance and Education (womens-health-concern.org)

 Promote the role of a named member of staff in primary care for support throughout the menopause, to improve access and increase patient satisfaction with care.

Next Steps

"The menopause affects every aspect of my life at work and family life."

This report will be:

- -Published on the Healthwatch Warwickshire website and social media channels.
- -Shared with the WCC Adult Social Care and Health Overview and Scrutiny Committee (HOSC), and the Menopause Task and Finish Group.
- -Shared with WCC Health and Wellbeing Board.
- -Shared with the Coventry and Warwickshire Integrated Care Board.

Comments from Action Menopause Warwickshire

"An excellent report from Healthwatch Warwickshire. The findings regarding the inconsistency of women's experiences going to their GP practices and the lack of specialist menopause services, echo what we hear from women who attend our regular peer support group meetings.

We hope that these findings will help Public Health leads and local healthcare commissioners to redress the obvious gaps in adequate and equitable NHS menopause support within primary care to enable all women to live their lives as well as possible through the menopause. As a local menopause charity, we would be happy to collaborate with them and support this work."

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