

Experiences of menopause support in North Tyneside

Summary

Feedback indicates that women in North Tyneside are dissatisfied with the level of information and support available. Many felt poorly informed about what to expect during the menopause and struggled with symptoms for many years without realising the cause. They found GPs often lacked the expertise needed to make an accurate diagnosis and did not make the connection between individual symptoms and menopause. GPs generally focused on offering HRT without suggesting alternative ways to manage symptoms. People felt they had to rely on their own research to get the full picture of options, particularly when HRT was not medically suitable or not chosen. However, accessing information about menopause was described as a 'minefield'.

The benefits of peer support were highlighted. People found that sharing experiences with others in the same situation made them feel more informed and less isolated. In the absence of any local support groups, many had found Facebook communities very helpful, along with a small number of support groups in the workplace.

It was felt that increasing publicity and education about menopause would open up the topic for discussion and develop awareness generally. Women would like to feel better informed well in advance of their symptoms starting. They want to know how and where to get reliable and comprehensive information and support when they need it.

This exploratory research has uncovered gaps in information and support that leave women struggling alone, with significant impact on their health, work, relationships and quality of life. Improving menopause support would enable women to stay healthier for longer thus potentially reducing later demands on the health service.

Suggested actions

- Commission information about menopause and support for the Living Well North Tyneside Platform
- Consider additional training/briefing for GPs on wider support than HRT
- Consider establishing a peer support group locally
- Examine opportunity for training within workplaces

Background

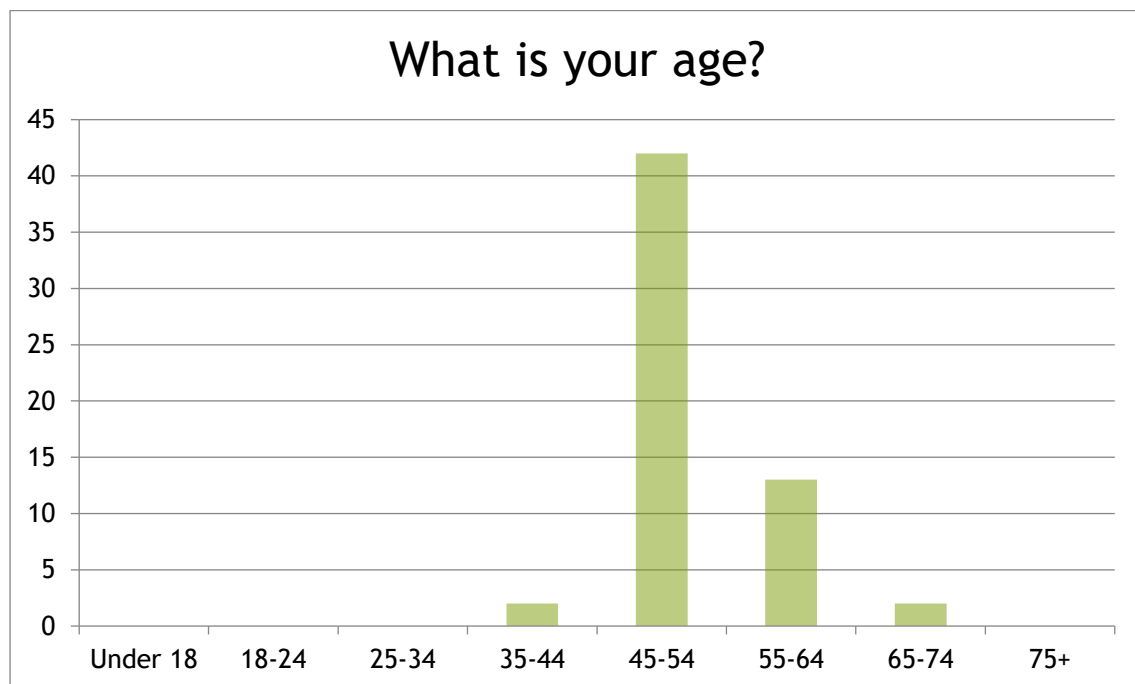
This exploratory project was prompted following a call to Healthwatch North Tyneside for signposting to menopause support groups. The call was from a GP surgery on behalf of a patient wanting face to face peer support. Preliminary research indicated a lack of support in North Tyneside which warranted further investigation into both availability and demand for support. We decided to run a short call for evidence to understand the issues and experiences better.

Method

An online survey was created to explore the experiences and needs of women in the local area. This was shared during March 2021 via our network of contacts and on social media.

Who we heard from

65 people responded via online survey.



I am in pre-menopause (peri-menopause)	22
I am in menopause	32
I am post-menopausal and no longer have symptoms	5
Other (please specify)	4

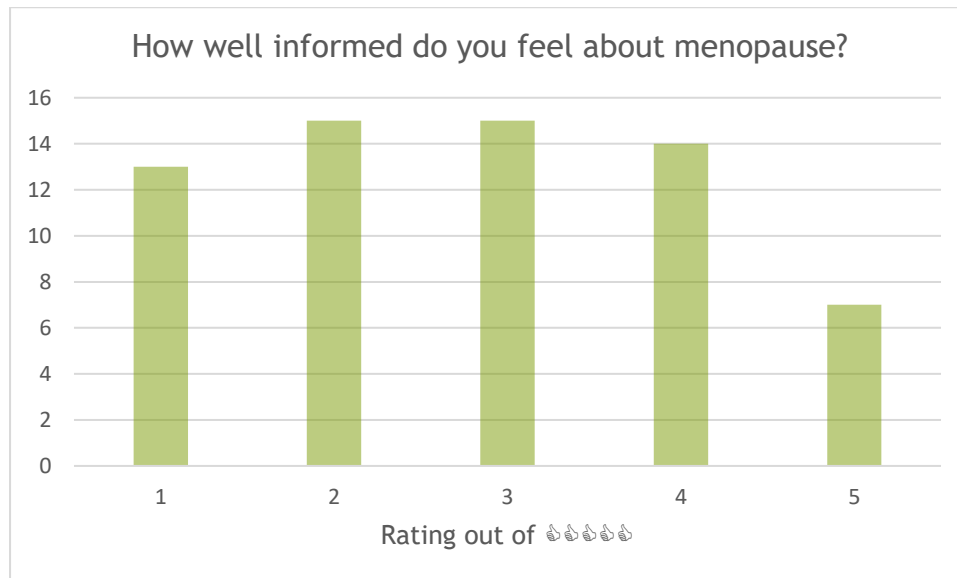
Other:

2 post menopause with symptoms

1 post menopause on HRT

1 peri menopause but needed confirmation from GP

What we heard



64 people gave a thumbs up rating for how well informed they feel about menopause. Ratings show a full range of experience of how well informed people feel, with many at the mid to lower end of the range.

Of 25 people who commented, 14 said they had relied on their own research to inform themselves. Sometimes this research resulted in information that was incomplete, confusing, conflicting or dated.

“I knew nothing about what was happening to me and have had to search for info and educate myself”

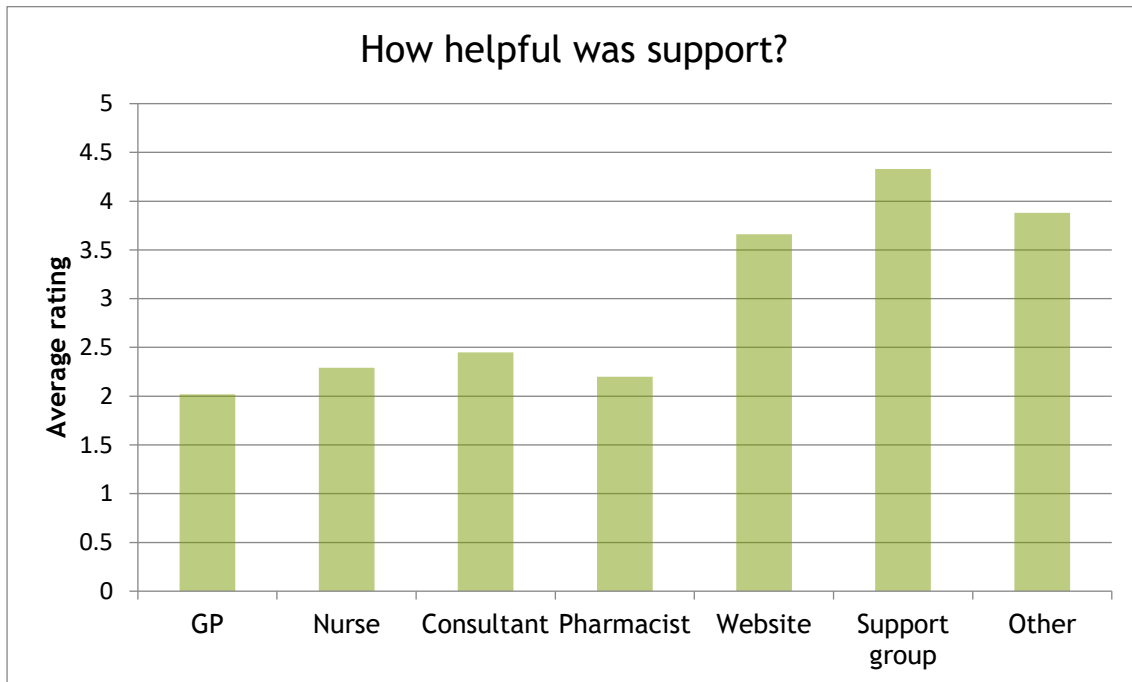
Three people told us about receiving information from their GP, although two of these commented that the advice was conflicting.

Four had learned about menopause at work via staff training sessions.

Two had learned through recent media coverage.

Two said they only found out about the menopause when it was too late.

“I wish I had known the range of symptoms when I was entering perimenopause as I was really struggling with mood changes and anxiety which had never bothered me before. I hadn't even heard of the term perimenopause until recently when I joined an online support group”



48 people commented on what worked well for them.

Many people said doing their own research worked well, particularly when support was not readily available or when people wanted to pursue nutritional and lifestyle changes or non-medical treatments rather than HRT. Once people had the information they needed they were less worried about what they were experiencing.

Sharing experiences with friends, family and peers was felt to be very helpful in “Realising that what you are going through is ‘normal’” and “Just hearing other women talking about it reassures you that you aren't alone”. Facebook groups were noted as being a good forum for sharing ideas and comparing advice with others in similar situations. One such group, Miss Menopause, was described as “A female-only closed group that provides a safe space to talk about serious matters in a light-hearted and often very funny way.” These groups have the benefit of being able to “dip in and out as required”.

Four people said that help, tests or treatment from their GP had worked well for them.

Impact of not having support and information when needed

46 people told us about the impact of not having information and support when they needed it and some talked of struggling for many years with increasing symptoms, feeling like they were expected to just get on with it. It was noted that menopause is particularly difficult when it occurs early or suddenly following a

hysterectomy or cancer treatment. With the latter, people were told to expect menopause but not how to deal with it.

Comments highlighted the dramatic effect on people's lives of the symptoms of menopause and of not realising what the symptoms were or knowing what to do about them. Many people talked about significant mental health issues including anxiety, depression, low mood and mood swings, along with the associated impact on their relationships and work. A number of people said they were convinced they had dementia due to issues with memory, confusion and word finding. They said the lack of information and support made them feel alone and isolated. They had not realised how awful it was going to be and felt very ignorant about this phase of their life. Some people felt unable to bear the prospect of coping with increasingly worse symptoms for years to come.

“I have no idea what is happening, or what to expect, or if there is anything I can do to help myself through it. This is having an impact on my mental health, self confidence and is affecting my personal relationships”

Some people told us they felt they were not listened to or taken seriously by medical staff and that it was put down to 'women's problems'. They felt GPs didn't always seem to know enough about menopause and were unable to connect inter-related issues that were menopausal, instead treating them as separate conditions. Some said they were offered anti-depressants but did not feel this was addressing the real issue. People felt they lacked enough information to know what questions to ask or who to see for help. Even when already using HRT, people did not feel they knew enough about menopause. People also struggled when their prescribed medication was temporarily unavailable and they had to go without or change to a potentially less effective option, with no support on how to manage the situation.

People highlighted the impact on their career of their menopause symptoms. These could result in significant time off work, loss of confidence in being able to do the job, and sometimes even leaving their job prematurely. Some have said they are afraid to bring up the subject with their employer.

What could be improved about the support available?

Feedback on how support could be improved was insightful and detailed, and covered a number of key areas, outlined below.

Testing, diagnosis and treatment

- Easier access to blood tests
- Blood tests to monitor oestrogen levels from age 45
- Ongoing conversation with GP about symptoms would remove stress of having to bring up the subject

- Consider menopause as a condition with a range of potential symptoms, rather than dealing with specific symptoms in isolation
- Consider impact on quality of life when symptoms have a long duration
- Make HRT a normal choice with clear information about options
- Address issues with availability of certain types of HRT

Expertise

- More/better training for doctors. Focus should be on best practice and broader than HRT alone
- More specialised GPs and nurses
- Knowing who to go to for support and advice
- Timely access to support
- A central point of contact for information and resources or dedicated menopause centre
- Menopause clinics
- Option to see a female doctor
- Option to go privately for advice/support
- Professional and empathetic staff. Good listening and non-judgmental advice
- One to one support in an informal and relaxed setting
- Advice/support that is relevant and practical
- Support in the workplace

Information

- Easily accessible
- Up to date
- About symptoms and how to cope with them
- About range of treatments/management strategies/lifestyle changes to enable informed decisions
- Leaflets
 - in GP surgeries and pharmacies
 - sent to individuals in targeted age band
 - handed out by GPs when menopause mentioned, even if consultation not specifically about this
 - handed out by nurses at smear test appointments
- Signposting information to local support
- National campaign to provide information rather than isolated pockets of provision

Education

- Menopause should be something that everyone knows about as it affects everyone either directly or indirectly
- Being able to talk about menopause openly, including both sexes
- More publicity on TV and in newspapers
- Being shown on TV shows as a normal part of life

Peer support

- Access to peer support, face to face and online
- More local peer support needed
- Online groups can work well, allowing people to access support as and when needed
- Publicising groups more
- Signposting