

Centre for differences in reproductive development and adolescent gynaecology

Mayer Rokitansky Kuster Huser and the menopause

Information for patients, relatives and carers

Introduction

This leaflet talks about the menopause and its effect on people with Mayer Rokitansky Kuster Huser (MRKH). Feel free to ask our team any questions about the information below.

What is menopause?

The menopause means the stopping of periods. Meno means menstruation and pause means stop. It is a normal and natural event. The average age of the menopause is 50 to 52 years. But some women can go through the menopause under the age of 45 years.

The menopause can be harder to diagnose or identify in women with MRKH. This is because you do not have periods. As a result, you will not have the common sign where the periods have stopped. However, you can experience the same symptoms of the menopause such as hot flashes. They happen because of low oestrogen levels, and you do have ovaries.

Symptoms of the menopause vary. Some people have none. Others may find them quite severe. Hot flashes, night sweats and vaginal dryness are the most common. Night sweats may interrupt sleep. Tiredness and mood swings can also occur. Sometimes people notice low sex drive (libido). These symptoms last for different lengths of time for different people.

The ovaries do not suddenly fail. The amount of oestrogen they produce can drop gradually. This happens in the months or years before menopause. The phase before menopause is known as perimenopause. If that affects you, you may be sensitive to the lower levels of circulating hormones. You may start to notice the symptoms described above.

How can people best support themselves?

If symptoms are bad, we encourage you to talk to your GP about how to manage them. If symptoms are due to the menopause or perimenopause, you can discuss various treatment options. These include lifestyle changes, exercise, therapy, and the medication HRT, which stands for hormone replacement therapy.

Health and wellness

Medication is not the only thing that can help. We recommend taking some time to research. You can learn how exercise, diet, meditation and relaxation can support your overall well-being. All women should ensure they always eat a healthy, well-balanced diet, drink plenty of water and take regular exercise.

After the menopause, weight-bearing exercise and enough calcium in the diet help bone strength. You can take calcium supplements, especially if your diet is low in dairy products.

Cognitive behavioural therapies are helpful. Other non-hormonal treatments are also available. Having someone to talk things through with is beneficial. Coaching is one way to do this. It offers a private space, where someone truly listens and supports you around menopause. They also help you navigate life's changes and challenges. This support helps you remain in control.

Frequently asked questions

Will my menopause be different if I have MRKH?

The only difference is that there will not be any sign that the periods have stopped.

How will we know when we have actually stopped ovulating? Is it important to know for any medical reasons?

Some may be aware of menopausal symptoms – hot flashes, night sweats and so on. For example, if monthly pain makes you aware of ovulation, you might notice that it stops. Some will not be aware of the change, but this does not matter at all.

Is MRKH associated with early menopause?

No, there is no evidence to support this.

How will we know we are perimenopausal?

You may not know. If you are sensitive to lower oestrogen levels, you may be aware of symptoms such as hot flashes during this time.

Should we do anything once the symptoms start? For example, take herbal remedies, change our diet, visit the GP about possible HRT?

Everyone should ensure they always eat a healthy, well-balanced diet. They should drink plenty of water and take regular exercise. After the menopause, weight-bearing exercise and enough calcium in the diet help bone strength. Calcium supplements can be taken, especially if your diet is low in dairy products.

HRT is not routinely given. If considered, it needs careful discussion regarding the advantages and risks associated with treatment.

In the absence of a uterus, oestrogen-only therapy would be considered as progesterone is only needed to protect the lining of the uterus.

If you have a functional womb bud (anlage), then you will require progesterone as well as oestrogen as part of your HRT regime. You might have been diagnosed with a functional womb bud by your specialist team. This could have followed tests for cyclical abdominal pain or from previous MRI scans that have shown this.

If I have symptoms and decide to visit my GP, what information should I tell them about MRKH? Will they be confused given that with MRKH you don't have periods?

Your GP will be familiar with prescribing HRT after removal of the womb by surgery (a hysterectomy). So explaining that you do not have a uterus will be sufficient.

Remember you do not have to share any information you are not comfortable to share. If you encounter difficulties, you are always welcome to contact us for help or advice.

Vaginal dryness can be a symptom of menopause. How should this be treated? Would the treatment be different if I dilated or had surgery?

Vaginal dryness is a result of lack of oestrogen. If there is scarring after surgery, the skin may be more sensitive to the dryness. All the usual remedies apply. These include using lubricating gel during intercourse, local oestrogen treatment to the vagina or HRT.

Who can I contact for further information or advice?

Our Centre has a support group. It can offer you the opportunity to learn more about MRKH. You can meet others who also have MRKH.

The group usually meets twice a year, in the spring and autumn.

- the spring meeting is usually informal. It offers the opportunity to meet other people with the same condition
- the autumn meeting is more focused on giving information. It has specialist speakers.

Some of our patients who have undergone vaginal dilator therapy, IVF surrogacy and adoption may also attend to share their expertise and experience with everyone.

We also produce a twice-yearly newsletter. This will let you know when the support group meetings will be held.

Please feel free to call us with any questions. Or call if you want to learn more about MRKH or dilator therapy.

The helpline number is 020 3313 5363 and the service is available from 09.00 to 17.00, Monday to Friday.

Outside of these hours, you can leave a message on the voicemail for the clinical nurse specialist. You can also contact us at enquiries.drd@nhs.net or at the address below:

Gynaecology outpatient department

Queen Charlotte's & Chelsea Hospital Du Cane Road London W12 0HS

How do I make a comment about my visit?

If you have any suggestions or comments about your visit, please either speak to a member of staff or contact the patient advice and liaison service (PALS) on 020 3313 0088 (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or 020 3312 7777 (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net

Alternatively, you may wish to complain by contacting our complaints department: Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street London W2 1NY

Email: ICHC-tr.Complaints@nhs.net Telephone: 020 3312 1337 / 1349

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