

Centre for differences in reproductive development and adolescent gynaecology

Mayer Rokitansky Küster Hauser syndrome (MRKH)

Information for patients, relatives and carers

Introduction

This leaflet talks about Mayer Rokitansky Küster Hauser syndrome (MRKH). Please feel free to ask our team any questions you have about the information below.

What is MRKH?

MRKH is a condition that you are born with that is characterised by a shortened vagina, absent cervix and absent or undeveloped uterus (womb). The ovaries are present and function in the same way as any other woman's by producing eggs and female hormones that keep you healthy.

There are two classifications of MRKH; Type I or Type II.

Type I is as described above and Type II is characterised by having additional differences such as variations in urinary tract and kidney development, hearing difficulties or bone changes. Around 40% of women with MRKH will have Type II.

MRKH affects 1 in every 5,000 women.

How will I know if I have this condition?

Women usually discover that they have MRKH during puberty. Although they develop breasts and pubic hair, they do not start having periods. This is because the ovaries produce the female hormones that allow puberty to occur but the absence of the uterus means that there is no period.

What tests will I have?

Your GP will normally ask you some questions and may examine you. Some GPs feel that this examination is best carried out at a hospital by a gynaecologist and may refer you for this. The doctor may also refer you for further investigations, including:

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- a blood test to check your chromosomes and exclude any other genetic abnormalities
 - an ultrasound scan or MRI scan to confirm the absence of the uterus (womb) and cervix, a shortened vagina and the presence of ovaries

If MRKH Type II is suspected your doctor may arrange for some additional tests to be carried out. This may include a kidney ultrasound scan or x-ray.

Will I need to have cervical smear tests?

No. As you do not have a cervix you will not require a smear test. However, it is still beneficial to receive HPV1 vaccinations (the vaccine that is offered to prevent human papilloma virus - HPV), as this protects against cancers caused by HPV including mouth and throat cancers, and some anal and genital cancers.

Will I be able to have comfortable sex?

Yes. The majority of women with MRKH are able to create a longer vagina by stretching the small amount of vaginal tissue already present. This is usually done by using specially designed smooth cylinder-shaped objects created for this purpose called vaginal dilators. Creating extra length helps patients to have penetrative sex and can help some with their gender and sexual identity.

The first line of treatment and the preferred choice for stretching the vagina is dilator therapy. 95% of our patients have been shown to be successful with dilator therapy and surgery has risks, is painful and requires long-term dilator use.

Our clinical nurse specialist will teach you how to use your dilators and will support and supervise you throughout the process. If you are having any difficulties we would always encourage you to discuss them with someone in our team. Treatment is considered complete when the vagina has been stretched to a size that is appropriate for you. This can vary from person to person. Please refer to our patient leaflet "Vaginal dilators and MRKH" for more information.

Will I need to use protection when I have sex

Yes, it is always advisable to practice safe sex. If you have male partner they should use condoms because you are still at risk of sexually transmitted diseases and blood-borne diseases such as HIV or Hepatitis B.

Will I be able to have children?

As you were born without a uterus (womb) you will not be able to get pregnant or carry a baby. However, your eggs can be removed and fertilised by your partner's or a donor's sperm and then placed in another woman's (surrogate mother's) uterus. This is known as In vitro fertilisation (IVF) surrogacy. The baby will genetically be yours and your partner's/donors.

This service is commonly available privately in recognised centers or clinics. It is possible to apply for part-funding so that you can have your fertility and IVF treatment completed in an NHS Centre. We would advise that you discuss this with a fertility specialist in the first instance.

Some women wish to consider other options and many of our patients have been successful in

adopting children. For more information please feel free to discuss this with one of our team. We are here to help you navigate your options.

Is it normal to feel angry and upset?

Yes. Most women and their parents find this condition difficult to accept and can experience feelings of shock, anger, sadness, isolation and rejection. Many parents also feel very guilty. We have a clinical psychologist who is part of our team and is available to all our women with MRKH. Our psychologist will offer appropriate support, which we consider a vital aspect of your care. Please ask more about this service and see our "MRKH Psychology Service" Leaflet.

Who do I contact for further information or advice?

At our Centre we have a support group which can offer you the opportunity to find out more about MRKH and to meet others who also have MRKH. The group usually meets twice a year, in the spring and autumn. The meeting in the spring is usually informal and offers the opportunity to meet other people with the same condition. The autumn meeting tends to be more focused on providing information, with specialist speakers. Some of our own 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, which will let you know when the support group meetings will be held.

Please feel free to call us whenever you have any questions or if you wish to find out 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?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. 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 The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

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: ICHCTr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

Additional information

[Vaginal-Dilation-Top-Ten-Tips.pdf \(britspag.org\)](#)

<https://britspag.org/wp-content/uploads/2018/10/Leaflet-Rokitansky-Syndrome.pdf>

[PowerPoint Presentation \(britspag.org\)](#)

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