

What is Rokitansky syndrome?

Rokitansky syndrome is a condition in which the womb (uterus) and vagina do not develop normally. It usually leads to the absence of the womb, neck of the womb and upper vagina. The other names for this condition are Mullerian agenesis, Mayer-Rokitansky-Kuster-Hauser ('MRKH') Syndrome after the Doctors who discovered it. It occurs in approximately 1 in 5000 female births. The cause is not known.

Are other female organs affected?

In Rokitansky syndrome, the ovaries are normal (as they develop from a different place), and the external female organs (vulva) are also normal. The breasts are normal and people with this condition have normal female chromosomes and produce normal amounts of female hormones. No one can tell (not even doctors) by looking at a woman that she has the condition.

Can other organs be affected?

Sometimes, because the kidneys and womb develop very close to each other, they can develop differently in location, but work just as well as normal kidneys. Also, sometimes the spine (backbone) can be affected, giving a curvature of the spine (scoliosis).

How is it found out?

The most common way for this condition to be diagnosed is when a teenager does not start her periods. Part of the testing for this includes an ultrasound scan, when it may be noticed that the womb is missing or very, very small.

The other way is when it is difficult for the woman to have sexual intercourse because the vagina is short.

Can it be treated?

At the moment, there is no treatment to grow or develop the womb.

There are several treatments available to lengthen the vagina to allow sexual intercourse. The simplest is by vaginal dilators which involves using plastic shapes to stretch the vagina over a period of time. There are also surgical procedures to increase the length of the vagina. These will be discussed with you as is appropriate in your individual case.

Will I be able to have children?

Women with Rokitansky syndrome do not have a womb and therefore cannot carry a pregnancy. They can, however, have a baby using their own eggs (as their ovaries work normally) and their partner's sperm.

The baby can be carried by a surrogate (another woman who has a womb). The baby therefore would have their genes. Another option many women prefer is adoption.

Support groups and websites:

MRKH support group (USA):
www.mrkh.org

Childlessness overcome through surrogacy group:
www.surrogacy.org.uk

British Agencies for adoption and Fostering: www.baaf.org.uk

If you require any further information, please contact:

Dr Gail Busby
Paediatric and Adolescent
Gynaecologist
Saint Mary's Hospital

(Secretary): 0161 276 6119
Monday to Friday, 9.00 am – 4.00 pm



Suggestions, Concerns and Complaints

If you would like to provide feedback you can:

- Ask to speak to the ward or department manager.
- Write to us: Patient Advice and Liaison Services, 1st Floor, Cobbett House, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL
- Log onto the NHS Choices website www.nhs.uk - click on 'Comments'.

If you would like to discuss a concern or make a complaint:

- Ask to speak to the ward or department manager – they may be able to help straight away.
- Contact our Patient Advice and Liaison Service (PALS) – Tel: 0161 276 8686 e-mail: pals@cmft.nhs.uk. Ask for our information leaflet.

We welcome your feedback so we can continue to improve our services.

**Paediatric and Adolescent
Gynaecology Service**
Saint Mary's Hospital
Oxford Road
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M13 9WL
www.cmft.nhs.uk

No Smoking Policy

The NHS has a responsibility for the nation's health.

Protect yourself, patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted within any of our hospital buildings or grounds.

The Manchester Stop Smoking Service can be contacted on

Tel: (0161) 205 5998
(www.stopsmokingmanchester.co.uk).

Translation and interpretation service

These translations say "If you require an interpreter, or translation, please ask a member of our staff to arrange it for you." The languages translated, in order, are: Arabic, Urdu, Bengali, Polish, Somali and simplified Chinese.

اذا كنت بحاجة الى مترجم، او ترجمة، من فضلك اطلب من احد موظفينا ترتيب ذلك لك
اگر آپ کو ایک مترجم، یا ترجمہ کی ضرورت ہے، تو برائے کرم ہمارے عملے کے کسی رکن سے کہیں کہ وہ آپ
کے لیے اس کا انتظام کرے۔

আপনার যদি একজন দোভাষী, অথবা অনুবাদের প্রয়োজন হয়, দয়া করে আমাদের একজন
কর্মীকে বলুন আপনার জন্য ইহা ব্যবস্থা করতে।

Jeśli Pan/Pani potrzebuje tłumacza lub tłumaczenie prosimy w tym celu zwrócić się do członka personelu.

Haddii aad u baahantahay tarjubaan, fadlan waydii qof ka mid ah shaqaalahayga si uu kuugu.

如果你需要翻译或翻译员, 请要求我们的员工为你安排



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Saint Mary's Hospital

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Information for parents/carers

