



Rokitansky Syndrome

Information for patients

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What is Rokitansky syndrome?

Rokitansky syndrome is a condition in which the womb 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 Syndrome after the Doctors who discovered it or MRKH. 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 you that you have 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 tests for this include 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 a 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 uterus.

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 your doctor 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 partners 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.