

**The National Centre for Adolescent & Adult Females with Congenital
Abnormalities of the Genital Tract**

**MRKH
The Absent Vagina**

Information for patients

This leaflet has been provided to answer some of the questions you may have about having a congenital absence of the vagina. It is known as Mayer Rokitansky Kuster Hauser Syndrome (MRKH) or simply Rokitansky Syndrome.

MRKH is a congenital abnormality which, means that you are born with this. The incidence rate is 1:5,000 female births.

Being born without a vagina is very distressing. This is usually associated with an absence of the uterus (womb). The ovaries are normally present and function in the same way as any other woman's by producing eggs and female hormones that keep you healthy. You are of course, entirely female.

How will I know if I have this condition?

You usually discover that you have no vagina during puberty. Although you develop breasts and pubic hair, you do not start having periods. This is because the ovaries will produce the female hormones that make normal development occur but the absence of the uterus and vagina means that there is no period. Most of you report this when you are 15 or 16 years old. However, some of you may have difficulties with having sex as your first problem.

What tests will I have?

Your GP will normally ask some questions and then examine you. Sometimes GPs feel that this examination is best done at a hospital by a gynaecologist and may refer you for this. During the examination, the doctor will discover that you have been born without a vagina.

Further investigations include:

- A blood test to check your chromosomes in order to exclude any other genetic abnormalities
- an ultrasound scan to confirm the absence of a womb but the presence of ovaries

As girls with this condition also have a 40% chance of having renal (kidney) problems or abnormalities, and 15% have a single kidney, a scan or X-ray of this area may also be recommended.

Will I be able to have sex?

Yes. After you have help from a specialist to develop your vagina, you will be able to have sex. The majority of you are able to create a vagina by stretching the short vagina that you already have. This is usually done with the help of plastic tubes known as vaginal dilators. We will teach you how to use these if it is appropriate for you. This is the preferred method for the majority of girls and 85% of our girls are successful in creating a normal sized vagina using this technique alone. The remainder of you who do not succeed may need an operation to create a vagina (known as amnion vaginoplasty).

If you had previous vaginal surgery, your vagina will not be as stretchy or it may have closed up due to scarring (vaginal stenosis). You need to consult a specialist consultant who will be able to tell you whether or not further surgery is possible or appropriate. Following surgery, it is very important that you use dilators to further stretch your vagina and to keep it open.

Will I have normal sex life afterwards?

Having sex with a partner is a personal and intimate affair. There is no reason why your sex life should be any different to anyone else's within a loving relationship. Once your vagina has been created, there is no reason why you cannot enjoy sex normally. However, men's penises are all different sizes and a man who has a large penis may cause you some discomfort as he would any woman. For this reason, you may need to stretch you vagina further. We will be happy to advise you on this.

What happens if I need to have an operation?

Those of you who need to have a vaginoplasty tend to find the procedure rather prolonged and arduous. Your stay in hospital is about 3weeks. It is normal to have some bleeding and vaginal discharge after your operation for up to 3-4weeks whilst the vagina is healing. If you have excessive bleeding or an offensive discharge, this may mean that you have an infection and you will need to have antibiotics. Your personal hygiene is very important and you will need to have daily showers and regular washes in the bidets.

It can be quite a painful procedure so it is advisable for you to take regular painkillers during your stay in hospital. This will also enable you to mobilise to prevent any risk of a chest infection and deep vein thrombosis (DVT).

The operation takes about an hour and involves lining your new vagina with an amnion graft and a vaginal mould in the shape of your new vagina being sewn into the vaginal space. You will also have a catheter (tube) inserted into the bladder to drain away your urine after the operation and this is usually kept in for 2 weeks.

You will return to theatre the following week for your vagina to be assessed and the amnion graft to be changed. The vaginal mould and catheter will be kept in for another week and then removed on the ward, in the 3rd week. You will need to spend this time in hospital. You will have a vaginal examination to ensure that the vagina is healing. For those of you who have had previous surgeries, it is very important that we check that there is no passage between the bladder into the vagina (urethral-vaginal fistula) or passage between the rectum into the vagina (recto-vaginal fistula), as your skin is more scarred and less stretchy.

Once the vaginal mould has been removed, we will teach you how to use vaginal dilators to ensure that your vagina remains a normal size and does not shorten or close. You will be discharged home when you are confident at using your dilators correctly. It is essential that you use the dilators as taught until your vagina is fully healed. You will need to have regular sex or continue

to use the dilator if you are not in a relationship, to ensure that the result remains satisfactory. **Failure to do so will result in the closure of your vagina.**

What are the risks of having a Vaginoplasty?

As with any operation, there is a risk associated with having a general anaesthetic - 1: 10,000
Urinary Infection - 10%
Vaginal Infection - 5%
Haemorrhage (excessive bleeding) - 1%
DVT - >1%
Urethral-vaginal Fistula - <1%
Recto-vaginal Fistula - 1%
Vaginal Stenosis - 10%

Will I need to visit the hospital again?

You will need to be reviewed in the clinic 2 weeks following your discharge from hospital. This is to assess your progress and to ensure that you are using your dilators correctly. It will also enable you to discuss any problems that you may have had at home. Afterwards, you will be reviewed 4 – 8 weeks until your vagina is completely healed and we will advise you on when you could start to have sex.

Will I be able to have children?

You cannot get pregnant because you are born without a vagina and uterus. However, your eggs can be removed and fertilised by your partner's sperm. This can then be placed in another woman's uterus, a method known as IVF Surrogacy. The baby is born genetically yours and your partner's. Unfortunately, this service is not offered on the NHS currently and is only available privately in recognised centres or clinics. The alternative to this is Adoption and many couples have been successful in adopting babies.

Is it normal to feel angry and depressed?

Yes. Most girls and their parents find this condition very difficult to accept at first. Most of you express feelings of shock, anger, depression, isolation and rejection and many parents feel very guilty.

Counselling is very important at this stage to help you and your parents understand and cope with these mixed and difficult feelings.

At this Centre, we have a **Support Group**, which offers support and encouragement for you, your parents and your partners. The support group meets twice a year. The meeting in the spring is usually informal and offers the opportunity to meet other girls with the same condition. The autumn meeting tends to be more informative, with speakers from outside the hospital giving talks on subjects like IVF Surrogacy and Adoption.

Further information and advice

We also have a **Helpline** and a list of **Patient Contacts**, so please feel free to call us whenever you have any questions or if you wish to be put in touch with other girls. The Helpline number is **020 8383 5363**.

This service is available from 09.00 hours -17.00hours, Monday – Friday.
Outside of these hours, messages can be left on the answer-phone for the
Clinical Nurse Specialist (number is as above).

Alternatively, you can visit our MRKH support website. The address is
www.mrkh.org.uk