

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

Vaginal Dilator Therapy

For MRKH

Information for patients

**This leaflet has been provided to help answer some of the questions you
may have about Vaginal Dilator Therapy.**

What are vaginal dilators?

Vaginal dilators are specially designed plastic tubes, which are used to create a vagina. They come in different sizes and range from size 1 (smallest) to size 8 (largest), although most of you would only need sizes 6 or 7.

Who needs dilator therapy?

The majority of you with absent vaginas are treated with dilators to create a normal size vagina. This is the preferred method of creating a vagina and we use this as the first line of treatment at this centre. All of you will usually have a vaginal "dimple" (opening) and because the vagina has a great ability to stretch, the result is usually excellent.

85% of you are successful in creating a normal vagina using this technique.

Those of you who need surgery (amniotic vaginoplasty) will also need to use dilators afterwards to enhance the success of your operation. This is because the dilators will further stretch and keep the vagina open.

How long will I have to use dilators?

This varies from person to person but it usually takes between 6 – 12 weeks to create a normal vagina.

When should I start dilator therapy?

Most girls/women start treatment when they are in a relationship. This provides a good incentive to do something about your condition and has proven to be very successful because you feel the timing is right. Some of you need to feel that you are doing something for yourself to be able to have sex with your partner.

However, some of you feel that you need to start dilator therapy to have some confidence in yourselves before starting a relationship.

Whatever the reason, you should only start treatment when you want to. This is essential for the treatment to be successful. We will be very happy to discuss with you as to whether the timing is right.

What happens when I start my treatment?

You will be admitted to hospital for 2 – 3 days so that you can be shown and taught the use of dilators. We usually try to arrange a room for you so that you can have privacy when you are doing your treatment throughout your stay with us.

You will be examined at the start of your treatment so that we can assess how stretchy your vagina is and the appropriate size dilator to use. You will normally start with the size 1 dilator and gradually go up to sizes 4 or 5 before continuing your treatment at home.

You will need to use the dilators, 3 times a day, for 10-15 minutes each time to start with. When you are confident at using the dilators you will be discharged home. You should continue this for the next 2- 4 weeks until your vagina becomes stretched. We will advise you when it is appropriate for you to reduce your treatment to twice a day and when to progress on to the larger

size dilators. You will be reviewed regularly in our clinic until you have completed your treatment and your vagina is normal.

When your vagina is fully stretched (normal size), you may choose to stop using the dilators and instead have sex with your partner or husband. If you do not have a partner at the time, you should continue to use the dilator once a week to ensure that vagina remains normal.

Why do I have to stay in hospital?

Initially, you will need a close supervision and guidance on the use of dilators. A few of you may have slight vaginal bleeding at the start of your treatment and this can be quite frightening for you. As you do not have a uterus (womb), you will not know what it feels like to have a period and to use a sanitary pad or a tampon. This will be a new experience for you and it is important that we show you how to use the dilators correctly.

You will be shown how to examine yourself and how to insert the dilators so that you are stretching the right place. In order to stretch the vagina properly, the correct pressure must be used and the angle at which the dilator is inserted must be correct.

You may also have some discomfort or pain when you first use the dilators. This is normal as the vagina is being stretched.

By being in hospital for a few days, you will have the opportunity to air your feelings and ask questions. We will help you in any way that we are able. Occasionally, you may meet another girl with the same condition and who is also in hospital for the same treatment. This may be a great comfort for you to know that you are not the only person with this condition.

When can I have sex?

It is possible for some of you with supportive partners to try and have sex when you are using the medium sized dilators (sizes 4 or 5). This can usually help as your partners will be stretching your vagina as well but they must understand that they will not be able to fully penetrate you at this time. You should continue to use the dilators regularly and we will advise you when to progress on to sizes 6 and 7 until your vagina is the normal size.

Most of you prefer to wait until you have completed your treatment and are assured that you have a normal vagina.

How will I know when I have a normal vagina?

You will be reviewed in our clinic 2 weeks after your discharge from hospital. At this appointment, we will assess your progress and you will be able to discuss any problems that you might have had at home. Thereafter, you will be followed up 4 –8 weekly by the consultant and the clinical nurse specialist. They will advise you on when to increase the sizes of the dilators, the frequency of use and whether you need to continue using the dilators until you have a normal vagina.

What are the risks of having Dilator Therapy?

Most of you will experience some urinary symptoms of needing to pass urine urgently when you first start using the dilators. This is because you are stretching the vaginal space and may feel pressure on your bladder or your urethra (the channel from which your urine is passed). This sensation usually settles after a few days when the vagina becomes more stretched.

If you continue to have pain on passing urine, you must report this to your GP. If your GP thinks that you have a urine infection, he/she can then prescribe you the appropriate antibiotics.

Dyspareunia (pain with sexual intercourse) post treatment may be due to vaginal dryness or the lack of lubrication.

This occurs in 25% of girls/patients and it is common for girls with this problem to use a lubricant like KY jelly.

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 queries or concerns 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 – 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).

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. You will receive invitations to these meetings at the set times and you will automatically be put on our mailing list unless we are advised otherwise by you.

Alternatively, you can visit our website.

The address is www.mrkh.org.uk

