

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

## Vaginal dilator therapy for MRKH

Information for patients, relatives and carers

### What are vaginal dilators?

Vaginal dilators are specially designed smooth cylinder-shaped plastic objects which come in different sizes, to create a vagina.

### Who needs vaginal dilator therapy?

The majority of women with absent vaginas are treated with dilators to create a vagina. This is the preferred method of creating a vagina and we use it as the first line of treatment at our centre.

Most women usually have a vaginal dimple (opening) and because the vagina has a great ability to stretch, the result is usually excellent. More than 95 percent of the women at our centre are successful in creating a vagina using this technique. However, this does not mean that the remainder of women are unsuccessful. Some occasionally discontinue or postpone their dilator treatment until a later stage in the future. Therefore, the time you start your dilator therapy is very important – we will

---

discuss and agree when this is appropriate for you, to ensure the best possible outcome.

## How long will I have to use dilators?

This varies from person to person, but it usually takes around four to six months to create a vagina. When your vagina is fully stretched, it will remain a normal size, so there is no need for you to continue using the dilators once you have completed your treatment. However, sometimes if you are not sexually active for some time you may have to use the dilators briefly again.

## Are there any alternatives to this treatment?

Surgery is only offered after dilator therapy has proven to be unsuccessful – which is rare. However, we must stress that you will still need to use dilators after surgery. This is because the dilators will further stretch and keep the vagina open. If you do not use the dilators after the surgery it will cause your vagina to shorten or close up.

## What happens when I start my treatment?

We will admit you to hospital for approximately three days so that we can teach you how to use the dilators. We will arrange a single room for you so that you can carry out your treatment in privacy during your stay with us.

You will have a one-to-one supervision of dilator therapy with the clinical nurse specialist. She will examine you at the start of your treatment so that she can assess how stretchy your vagina is and the appropriate size dilator to use. You will start with a small dilator and gradually increase the size, before you are discharged home, to continue your treatment.

To start with, you will need to use the dilators three times a day, for ten to 15 minutes each time. You might wish to reduce your treatment to twice a day after four weeks of treatment. However, you should discuss this with your clinical nurse specialist or the consultant first, as this may slow down the progress of your treatment.

You will be reviewed regularly in our clinic and advised on when to progress on to the larger sized dilators until you have completed your treatment and your vagina is an average size (6cm or more).

When your vagina is fully stretched, you may stop using the dilators, as you would have completed your treatment. If you have a partner, you will be able to enjoy comfortable sex.

## Why do I have to stay in hospital?

Initially, you will need to receive close supervision and guidance on the use of dilators. Although we use a lubricating gel, you may have some discomfort in the first three days of using the dilators. This is normal as the vaginal skin is being stretched. After this initial period, the soreness usually settles as the vagina begins to stretch.

---

You may have a small amount of vaginal bleeding at the start of your treatment, therefore it is important that we show you how to use the dilators correctly. Any bleeding usually settles after a few sessions of treatment.

Most women experience the need to pass urine urgently when they first start using the dilators. This is because your vagina and urethra are quite close to each other and when you stretch the vaginal space, you may feel some pressure on your bladder or your urethra ('water pipe'). This sensation usually settles after a few days when the vagina becomes more stretched. However, if you have other urinary symptoms or problems, please let us know as you may have a urine infection and need antibiotics.

It is important for us to show you how to examine yourself and where to insert the dilators so that you are stretching the right place. You will also need to be shown the correct angle of insertion and the correct pressure to use, to enable your vagina to stretch to its full potential.

Whilst being in hospital for a few days, should you wish to have the opportunity to see our clinical psychologist this can also be arranged.

## **When can I have sex?**

It may be possible for you to try to have sex when you are using the medium-sized dilators. Having sex can help, as your partner will be stretching your vagina, however he must understand that he will not be able to penetrate you fully at this time. During this time, you should continue to use the dilators regularly and we will advise you when to progress on to larger sizes until your vagina is an average size.

However, you may choose to wait until you have completed your treatment and be assured that you have a normal size vagina before you have sex. We will be happy to advise and discuss this with you too.

## **Will I need to use protection when I have sex?**

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

## **How will I know when I have a normal size vagina?**

We will ask you to come back to clinic two weeks after your discharge home 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.

After this, the consultant and the clinical nurse specialist will see you every four to eight weeks. They will advise you on when to increase the sizes of the dilators, how often you need to use them and whether you need to continue to use the dilators.

---

## Is there anything I need to watch out for at home?

You may notice your bladder is slightly irritable which can be due to pressure on your bladder from the dilators. If you have any pain when passing urine, you must contact your GP, as you may have an infection and need antibiotics.

Occasionally you may see some bleeding either on the dilator or staining your pants, this is usually due to a slight tearing of the vaginal skin and is not serious, but do mention this at your next appointment.

Sometimes pain may be experienced with sexual intercourse after vaginal dilator treatment; this may be due to vaginal dryness or the lack of lubrication. If this happens, it is advisable to use a lubricant such as KY Jelly to overcome the problem.

## Will I need to have cervical smear tests?

No. As you do not have a vagina, cervix or uterus you will not need to have any cervical smear tests or HPV1 vaccinations (the vaccine that may be offered to prevent human papillomavirus).

## Who can I contact for further information or advice?

At our centre, we have a support group, which offers support and encouragement for you, your parents and your partner. The group meets twice a year, in spring and in autumn. The meeting in the spring is usually informal and offers you the opportunity to meet and talk with other women with the same condition. The autumn meeting tends to be more formal and informative, with specialist speakers and some of our own patients who have undergone IVF surrogacy and adoption, coming to share their expertise and experience with everyone.

As well as the support group, we have a helpline and a list of patient contacts, so please feel free to call us whenever you have any questions or if you would like to be put in touch with other girls.

The helpline number is **020 3313 5363** and the service is available from 9.00am until 5.00pm, Monday to Friday. Outside of these hours, you can leave a message on the voicemail for the clinical nurse specialist.

Alternatively, you can visit our MRKH support website at [www.mrkh.org.uk](http://www.mrkh.org.uk). For details of how to register online, please telephone **020 3313 5363**, email [nuala.dixon@imperial.nhs.uk](mailto:nuala.dixon@imperial.nhs.uk) or write to us using 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 treatment?

We aim to provide the best possible service and staff will be happy to answer any questions you may have. However, if your experience of our services does not meet your expectations and you would like to speak to someone other than staff caring for you, please contact the **patient advice and liaison service (PALS)** on **020 3313 3322** or **020 3312 7777** (St Mary's Hospital). You can also email PALS at **pals@imperial.nhs.uk**.

The PALS team will listen to your concerns, suggestions or queries and is often able to help sort out problems on behalf of patients.

Alternatively, you may wish to express your concerns in writing to:

The chief executive  
Imperial College Healthcare NHS Trust  
Trust Headquarters  
The Bays, South Wharf Road  
London, W2 1NY

## Alternative formats

This information can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on **020 3312 5592**.