

Centre for disorders of reproductive development and adolescent gynaecology

# Vaginal dilator therapy for MRKH

## Information for patients, relatives and carers

### Introduction

This leaflet talks about vaginal dilator therapy and what this treatment involves. Please feel free to ask our team any questions you have about the information below.

### What are vaginal dilators?

Vaginal dilators are specially designed plastic tubes which are used to create a vagina. They come in different sizes.

### Who needs vaginal dilator therapy?

Most women who are born without a vagina are taught how to use vaginal 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.

Women with Mayer Rokitansky Küster Hauser syndrome (MRKH), an abnormality of the female reproductive system, are born with a vaginal dimple (opening) and because the vagina has a great ability to stretch, the result is usually excellent. More than 95 per cent of the women at our centre are successful in creating a vagina using this technique.

However, this does not mean that the remaining women are unsuccessful. Some occasionally discontinue or postpone their dilator treatment. 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 woman to woman 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 if you are having sex regularly, so there is no need to continue using the dilators once you have completed your treatment. If you are not sexually active for a short time you may have to use the dilators briefly again.

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## 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 your vagina will 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 session with the clinical nurse specialist. She will examine you at the start of your treatment and assess how stretchy your vagina is and what size dilator to use. You will start with some relaxation techniques and a small dilator and gradually increase the size of the dilator before you are discharged home to continue your treatment.

To start with, you will need to use the dilators three times a day, for 10 to 15 minutes each time. You might wish to reduce your treatment to twice a day after four weeks of treatment. Please discuss this with your clinical nurse specialist or the consultant first, as this may slow down your progress.

We will review you regularly in our clinic and advise on when to progress on to the larger dilators until you have completed your treatment and your vagina is an average size (6cm or more) and sex is comfortable.

When your vagina is fully stretched, you can stop using the dilators as your treatment is complete. 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 close supervision and guidance on using the 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, 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 so it is important that we show you how to use the dilators correctly. Any bleeding usually settles after a few sessions.

Most women feel 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 (the tube that carries urine from the bladder to the outside of the body). 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.

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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. We will also show you the correct angle of insertion and the correct pressure to use, to stretch your vagina to its full potential.

While in hospital, if you would like to see our clinical psychologist this can 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 but he must understand that he will not be able to penetrate you fully at 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.

You may choose to wait until you have completed your treatment 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 six weeks after being discharged. We will assess your progress and you will be able to discuss any problems that you 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 size of the dilators, how often you need to use them and whether you need to continue to use them.

## 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 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 you may experience pain during sex after vaginal dilator treatment which may be due to dryness or the lack of lubrication. If this happens, use a lubricant to overcome the problem.

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## Will I need to have cervical smear tests?

No. As you do not have a cervix you will not need a smear test.

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

At this centre we have a support group which offers encouragement for you, your parents and your partner. The group meets twice a year, in the spring and autumn. 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 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 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 would like to be put in touch with other women with the same condition. The helpline number is 020 3313 5363 and the service is available from 09.00 to 17.00, 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 [enquiries.drd@nhs.net](mailto:enquiries.drd@nhs.net) or write to us at 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 visit?

If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at [imperial.pals@nhs.net](mailto:imperial.pals@nhs.net)

Alternatively, you may wish to complain by contacting our complaints department:  
Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street  
London W2 1NY  
Email: [ICHC-tr.Complaints@nhs.net](mailto:ICHC-tr.Complaints@nhs.net)  
Telephone: **020 3312 1337 / 1349**

## Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:  
[imperial.communications@nhs.net](mailto:imperial.communications@nhs.net)