

Centre for differences in reproductive development and adolescent gynaecology

# Vaginal dilators and MRKH Information for patients, relatives and carers

This leaflet is about vaginal dilators (also known as pelvic floor trainers) and how to use them. Please feel free to ask our team any questions you have about the information below.

## What are vaginal dilators?

Vaginal dilators are plastic or silicone rods/cylinders that have a rounded end. The dilators are available in different sizes and are used to help stretch the vaginal tissue.

## Why are dilators recommended?

The first line of treatment and the preferred choice for stretching the vagina is dilator therapy. Our results have shown that 95% of our patients have had success with dilator therapy. Surgical options are available; however, they are not without risks and can be painful. For those women who choose to have surgery, use of vaginal dilators is still required afterwards to prevent scaring and keep the vagina open. Without dilators the vagina is likely to shorten or close up after surgery.

The aim of creating extra vaginal length is to enable penetrative sex. It can also help some individuals with their gender and sexual identity.

The time you start your dilator therapy is very important. It is important to feel both physically and emotionally ready. Our team will ask you when you think the best timing would be, and agree this together with you, to ensure the best possible outcome.

## What happens when I start my treatment?

Treatment can vary according to an individual's needs; this can be done either as an inpatient (where you stay overnight in hospital) or an outpatient (where you come into hospital for the appointment but go home afterwards). This will depend on a number of factors including the clinical situation and treatment needed, where you live (as some of our patients are travelling long distances so prefer to stay in as inpatients), and what you'd prefer. This will be agreed between you and the team. You will be involved in the planning of your care from the beginning, and we will work together to decide what suits you best. Your privacy will be maintained at all times.

If you have inpatient dilator treatment (where you stay overnight), we will arrange a single room for you. The length of time you spend with us will depend on how the dilation treatment works for you. There will be plenty of time and support before and during your stay so that you can ask questions.

During your stay you will have one-to-one supervised sessions with our clinical nurse specialist. We start by talking about your anatomy and introduce you to some relaxation techniques that you might find helpful during the treatment. You will be examined at the start of your treatment to assess how stretchy your vagina is. It is beneficial if we can teach you how to examine yourself so you can assess your progress. We will also show you the correct angle of insertion and right amount of pressure to use, to stretch your vagina fully.

We take it slowly and start with a small dilator, gradually increasing the size of the dilator until we find the one that is right for you to take home to continue your treatment. We will discuss which lubrication is best for you to use with your dilators.

When at home you will continue your treatment and will need to use the dilators three times a day, for 10 to 15 minutes each time. After four weeks, you might wish to reduce your treatment to twice a day for 10 to 15 minutes each time. Please discuss this first so you do not slow down your progress.

We will review how the treatment is going regularly in our clinic and will support and advise you when to progress on to the larger dilators until you have completed your treatment and can enjoy comfortable sex with or without a partner.

## How long does dilator treatment take?

It usually takes around four to six months to elongate the vagina. This can vary from person to person. If someone is sexually active the vagina will remain fully stretched so there is no need to continue using the dilators. It may be useful to use dilators again if you have not had sex for a while or need to increase the length of your vagina.

Some prefer to use natural dilation through sexual intercourse and others may use a combination of natural dilatation and sexual intercourse to stretch their vagina. Our team are available to discuss these options with you.

## When is the best time to start using dilators?

This is an individual decision. Every person is different and will make the decision when they feel ready, depending on their circumstances. This may be influenced by a person's readiness to have penetrative sex, how they feel about their diagnosis, and/or to help with fertility treatment. Some people decide not to do dilator treatment at all.

# What challenges might I expect?

We supervise your dilator treatment to make sure you are comfortable. 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.it should settle.

Using dilators can be emotionally challenging. Many of our patients would like support with the process, please just mention this to us and we can arrange for you to see our clinical psychologist.

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. The bleeding also usually settles after a few sessions. Occasionally this may happen at home, and you may see some bleeding

either on the dilator or as light staining of your underwear. This is usually due to a slight tearing of the vaginal skin and is not serious but please mention this at your next appointment.

Most people feel the need to pass urine urgently when they first start using the dilators. This is because the vagina and urethra are guite close to each other. When the vaginal space is stretched you may feel some pressure near the bladder or the urethra (the tube that carries urine from the bladder to the outside the body). This sensation usually settles after a few days when the vagina becomes more stretched. It is helpful to let us know if you have a history of urinary symptoms, any problems, or urine infections. Whilst at home if you have any pain when passing urine, it is important to contact your GP, as you may have an infection and need antibiotics.

Sometimes you may experience pain during sex after vaginal dilator treatment which may be due to dryness or the lack of lubrication. Using extra lubricant may be helpful.

Whatever you are concerned about, you can always contact us to discuss things further and put your mind at ease.

#### How long will it take for penetrative sex to be possible?

It may be possible for you to try and have penetrative sex when you have started using the medium size dilators. Having penetrative sex also helps stretch the vagina, however, it may take a little time for the vagina to reach its required length. In the meantime, you should continue to use the dilators regularly and we will advise you when to progress on to a larger 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 practice safe sex because you are still at risk of sexually transmitted diseases and blood-borne diseases such as HIV or Hepatitis B.

#### Will I need to have cervical smear tests?

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

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

At our Centre we have a support group which can offer you the opportunity to find out more about MRKH and to meet others who also have MRKH. The group usually meets twice a year, in the spring and autumn. The meeting in the spring is usually informal and offers the opportunity to meet other people with the same condition. The autumn meeting tends to be more focused on providing information, with specialist speakers. Some of our own patients who have undergone vaginal dilator therapy, IVF surrogacy and adoption may also attend to share their expertise and experience with everyone. We also produce a twice-yearly newsletter which will let you know when the support group meetings will be held. Please let us know if you'd like to sign up to the newsletter by emailing us on enquiries.drd@nhs.net.

Please feel free to call us whenever you have any questions or if you wish to find out more about MRKH or dilator therapy. 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. You can also contact us at enquiries.drd@nhs.net or 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 <a href="mailto:imperial.pals@nhs.net">imperial.pals@nhs.net</a>

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 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: <a href="mailto:imperial.communications@nhs.net">imperial.communications@nhs.net</a>

#### Additional information

<u>Vaginal-Dilation-Top-Ten-Tips.pdf (britspag.org)</u> <u>https://britspag.org/wp-content/uploads/2018/10/Leaflet-Rokitansky-Syndrome.pdf</u> <u>PowerPoint Presentation (britspag.org)</u>

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