

Common worries and concerns after receiving a diagnosis of Rokitansky Syndrome

Information for patients



This leaflet provides information to patients who have received a diagnosis of Rokitansky Syndrome, otherwise known as MRKH. This leaflet relates to how people may feel after this diagnosis, how people may cope differently and what psychological support is available if required.

What is Rokitansky Syndrome (also called MRKH)?

Rokitansky Syndrome is a rare congenital condition that affects the female reproductive system. The uterus (womb) may be small or absent and the vagina may be shortened.

Receiving a diagnosis

Being diagnosed with MRKH can be a difficult process. You may have had a lot of appointments over a period of months or years, and some of those appointments may have been uncomfortable, unhelpful or difficult, both physically and emotionally.

You may have worried about things like why you are not having periods for a long time.

- You may need time to come to terms with your diagnosis and it may take a while for things to sink in and your emotions to settle.
- Diagnosis can be received at different ages, but the average age of diagnosis is between 15 and 18 years old.

- Being diagnosed in your teens can make you think about aspects of your future (such as having a family) much sooner than you were expecting. However, understandably you may not be ready to think about these aspects of your future yet.
- You will have choices about treatment (e.g. the use of a plastic vaginal dilator in a size to fit your needs) - some people opt for treatment soon after diagnosis, some wait until they are older, and some choose to not have treatment at all.
- You may have other priorities or concerns such as school, exams, going to college/university, and are not ready to make decisions about treatment (e.g., dilation/surgery or fertility treatment) straight away.
- It is important you have the opportunity to ask questions about what this diagnosis means to you and your future at a time when you feel ready to take on this information.



Photo by Kyle Broad on Unsplash

What you may feel after a diagnosis

Please note this is a non-exhaustive list and not all of these reactions will be felt by all patients with MRKH; everyone's experience is unique. Whatever you are feeling is valid, whether listed here or not.

- Shock at the diagnosis.
- Ashamed that your female anatomy/body is different, and embarrassed or uncomfortable talking about such a private body part with others.
- Sadness or grief – about being unable to carry a pregnancy
- Isolated and different to your friends.
- Low self-esteem or self-worth – feeling negative about yourself, or question your identity as a person.
- Feeling jealous of or comparing yourself to others without MRKH.
- You may experience difficult thoughts relating to femininity or gender roles.
- Let down – sometimes a diagnosis can really change your outlook on life and may make you feel disappointed or let down, or as though your future is not as bright as you hoped.
- Anxiety or worry - these could relate to different areas of your life or medical treatments. For example, you may be concerned about how to talk to friends and partners about the condition, or whether you can have sex or if it will hurt, or you may have worries about the future (e.g., going through the process of fertility treatment/surrogacy).

- Frustration or anger - understandably, you may have thoughts like, “Why me?” or be angry that this has happened to you.
- A lack of control in relation to your hopes for the future and ability to have a family, which may leave you thinking, “What’s the point?”
- You may feel okay about the diagnosis.

How you can help yourself

- After getting a diagnosis you may feel that you don’t want to talk about it. It’s important that you don’t feel pressured to talk but bottling up difficult thoughts and feelings can also be unhelpful for some people.
- It may help to share your feelings with one or two people who you really trust.
- Letting your feelings show is not a sign of weakness, it’s usually important to share them to deal with them in more helpful ways – most people find that talking and learning about new strategies in therapy can really help.
- Understandably, you may find yourself thinking a lot about the impact of the condition on your future. If these worries are getting in the way of living your life, talking to someone (a friend, family member, or seeking talking therapy) could help.
- You might want to see different medical specialists to ask questions and voice concerns which may help you manage particular anxieties/worries. For example, your consultant, and nurses or counsellors in the fertility service can all provide support and information about the physical/practical aspects of the condition.

- Reading about the experiences of others with MRKH, finding MRKH advocates online/on social media may help to reduce feelings of isolation or 'being different'.

When you might need further support

Not everyone will want to speak to a psychologist but may prefer to speak to family, friends and partners about their feelings.

If you are interested in speaking to a psychologist, your consultant gynaecologist or nurse specialist can make this referral for you. Our psychologists are specialists into gynaecology and have experience in working with people who are affected by gynaecological conditions.

You may want to consider asking for a referral to a psychologist if you:

- Find that your diagnosis is getting you down and the future looks full of problems.
- Are thinking about it a lot of the time but seem to be going around in circles.
- Feel very alone, like you can't talk to anyone about it.
- Feel very critical of yourself and find yourself thinking that you are not 'normal' and are upset about that.
- Would like to talk to someone independent of your loved ones about how you're feeling.

How a psychologist can help

Offering a confidential space and using talking therapies, such as cognitive behavioural therapy, to help you to:

- Make sense of your feelings
- Adjust to the diagnosis
- Manage difficult thoughts and feelings
- Process feelings of loss in relation to fertility and sexuality
- Think about how you want to manage difficult situations/ conversations with friends
- Support you to find ways of other ways of coping

Sessions with a psychologist are about 50 minutes and you can meet fortnightly.

Useful resources

Some people prefer to connect with a support group of others going through the same thing. For support groups and further information:

The National Centre

- www.mrkh.org.uk

The National Centre is the largest MRKH Support Group in the UK with a membership of over 600. Meetings are held twice a year and the group is supported by a Consultant, a Clinical Nurse Specialist and a Psychologist. Any person with MRKH is welcome. All partners and parents are also welcome. For non-members, please contact:

Clinical Nurse Specialist on 020 3313 5363 for details.

MRKH Connect

- www.mrkhconnect.co.uk

MRKH Connect was established to relieve and promote the relief of those diagnosed with Mayer Rokitansky Kuster Hauser (MRKH) Syndrome and to provide support both to them and their families. They offer support and resources.

Beautiful You MRKH

- www.beautifulyoumrkh.org

Beautiful You MRKH Foundation is a supportive online space which welcomes members from all around the world. Their mission is 'to create a supportive community that partners with healthcare professionals to increase awareness and empower women of all ages with MRKH to feel beautiful, just as they are'.

Contact us

Fielding House Clinical Health Psychology

- Telephone: 0113 206 5897

This leaflet was developed in consultation with a service user.

What did you think of your care?

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Your views matter



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