

Centre for differences in reproductive development and adolescent gynaecology

MRKH Psychology service

Information for patients, relatives and carers

This leaflet is about our psychology service for patients with Mayer Rokitansky Küster Hauser syndrome (MRKH) and how to access it. Please feel free to ask our team any questions you have about the information below.

What is MRKH?

MRKH is a condition that you are born with and affects 1 in every 5,000 women. It is when you have a shortened vagina, absent cervix and absent or undeveloped uterus (womb). You have ovaries that function by producing eggs and female hormones that keep you healthy.

What is the MRKH psychology service?

It is a service available to anyone attending the gynaecology outpatient clinic who has MRKH. This condition can be distressing and those attending the psychology service may:

- find it difficult to adjust to their diagnosis
- find it difficult to talk to others about MRKH
- experience feelings of loss
- have noticed changes in their mood, for example feeling low, tearful or angry
- feel low self-esteem and self-worth
- experience problems with gender and/or sexual identity
- have problems in their relationships and with sexual intercourse
- have concerns about the treatment
- have concerns about infertility, IVF and surrogacy

How can the psychologist help me?

The psychologist can use a range of approaches including cognitive behavioural therapy (CBT), acceptance and commitment therapy (ACT), narrative and/or systemic therapy to help you to:

- adjust to your diagnosis
- manage negative thoughts and feelings
- deal with losses in relation to fertility and sexuality
- develop effective coping strategies
- identify sources of support

What can I expect from the psychology service?

In your first appointment, the psychologist will meet with you for about an hour and talk to you about any needs or concerns you have. After this meeting, if you decide that you would like to meet again, they will offer you a number of sessions. You can have between two and 12 appointments, each lasting about 60 minutes. It is possible to meet weekly, fortnightly or monthly, depending on what feels right for you.

You do not have to talk about anything that you don't want to.

The psychologist can also work with interpreters.

Is there anyone who is not suitable for the psychology service?

Evidence suggests that psychological support can be beneficial for those with MRKH. However, some people may find it more helpful to speak to partners, family and friends about their current difficulties and may prefer not to have a psychologist's help.

This service is not appropriate for people whose concerns are not at all related to their MRKH diagnosis, or people with significant mental health difficulties and/or is suicidal or self-harming. In those instances, patients would be referred by their GP to an alternative service, such as a local counselling, psychology or mental health service.

If you live a long way from the hospital and find it difficult to attend regular appointments, the psychologist will discuss this with you and may ask your GP to refer you to counselling or psychology services in your local area. Alternatively, you can ask for your sessions to be done virtually.

How can I be referred to the psychology service?

Your consultant or the clinical nurse specialist can refer you to the service when you attend your clinic appointment. Alternatively, if you are currently being seen by our service, you can contact the psychologist directly to request a referral by calling 020 3313 5363 or by emailing 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?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. 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 The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

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:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk