

Centre for differences in reproductive development and adolescent gynaecology

MRKH Psychology service Information for patients, relatives and carers

Introduction

This leaflets talks 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 that is characterised by a shortened vagina, absent cervix and absent or undeveloped uterus (womb). The ovaries are present and function in the same way as any other woman's by producing eggs and female hormones that keep you healthy.

MRKH affects 1 in every 5,000 women.

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 mood difficulties, for example feeling low, tearful or angry
- have low self-esteem and self-worth
- experience problems with gender and/or sexual identity
- experience difficulties in their relationships and sexual intercourse
- have concerns about the treatment
- have concerns about infertility, IVF and surrogacy

How can the psychologist help me?

The psychologist will 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?

The psychologist will initially meet with you for about an hour and identify 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 2 and 12 appointments, each lasting about 60 minutes. It is possible to meet weekly, fortnightly or monthly.

Attending the psychology service involves looking at difficulties in the 'here and now' and thinking about how to cope with these. 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 not need a psychologist.

This service is not appropriate for anyone who has concerns that are not related to their MRKH diagnosis or who have 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 in our service, you can contact the psychologist directly to request a referral by contacting 020 3313 5363 or by email: 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