Centre for differences in reproductive development and adolescent gynaecology

Mayer Rokitansky Küster Hauser syndrome (MRKH) – considerations for parenthood A short guide for patients, relatives and carers

Introduction

Fertility and the desire to have a child is a concern for some people with MRKH. We hope this short guide will answer some of your questions. Please note: the information in this guide is current at the time of print. But things may change. If you need to, please feel free to contact us for further information.

What is MRKH?

MRKH describes a difference in development. It is set apart by a shortened vagina, absent cervix and absent uterus (womb). The ovaries are present and functioning. This means they produce eggs and hormones. These include oestrogen and progesterone. They have a role in fertility and health.

MRKH affects approximately 1 in every 5,000 female births.

Will I be able to have children?

Women with MRKH are not able to get pregnant or carry a baby as they were born without a uterus (womb). Many people live happy and fulfilled lives and do not have children; some choose to not become parents for many different reasons.

If you decide that you would like to consider the possibility of having a child and becoming a parent, there are several options available.

1. Assisted conception

Using your own eggs

The ovaries of most women with MRKH remain functional. So, it may be possible to use your eggs along with your partner's sperm or a donor's sperm to create an embryo. The embryo will

be genetically linked to you and your partner or donor. These embryos can be put into the surrogate. She will carry the pregnancy until birth.

Collecting eggs for IVF involves stimulating the ovaries with drugs. This makes them produce multiple eggs. The eggs are then collected under ultrasound guidance. This is done through the vagina or via the abdomen.

A longer vaginal length makes it easier to collect eggs through the vagina. So, women are advised to have practised vaginal dilatation treatment.

Egg collection may be done through the abdomen. This is for women whose ovaries are higher up. This will happen under abdominal ultrasound scan guidance.

Your fertility specialist will tell you about the best route for you. This will depend on the accessibility of the ovaries on ultrasound scan.



See the Human Fertilisation & Embryology Authority (HFEA) website to find reliable up-to-date information.

For more information about egg freezing please go to Egg freezing | HFEA

Freezing embryos

It is also possible to freeze embryos. Your eggs are fertilised with sperm before they are frozen. Your partner's sperm or a donor's sperm can be used to do this. But, if you and your partner decide to use their sperm, both of you will need to consent to the use of these embryos in the future.

For more information about embryo freezing please go to Embryo freezing | HFEA

Using donor eggs

You may choose to use donor eggs. This may be a personal preference. Or it may be because ovarian stimulation has not produced enough eggs. This is because your ovarian reserve is low. Your fertility clinic will tell you which treatment offers the best chance of success for you. They will provide further details of the process.

For more information about egg freezing please go to <u>Using donated eggs, sperm or embryos in treatment | HFEA</u>

Also see: Becoming the legal parents of your child | HFEA

Surrogacy

Surrogacy is when a woman carries and gives birth to a baby for another person or couple. The regulations that govern surrogacy differ across countries of the world. This includes whether it is allowed to take place at all.

The UK allows altruistic surrogacy. This means a woman:

- carries the child and gives birth
- does not receive financial compensation for anything other than medical expenses.

Please refer to the HFEA website for the most up-to-date information. Go to *Surrogacy | HFEA*

How do I start the surrogacy process?

Consider joining one of the main UK surrogacy organisations. Trying to do it on your own is not advisable because of the potential legal outcomes.

If you decide to go ahead without help, consider the information in this guidance very carefully. Always take legal advice.

Surrogacy organisations can support and advise you at each step of the journey.

Two Acts of Parliament relate to surrogacy:

- the Surrogacy Arrangements Act (1985)
- section 30 of the Human Fertilizations and Embryology Act (as amended 2008)

Both have key info about what is legal or illegal when having a child by surrogacy.

The HFEA website has further detailed information about surrogacy. We advise you to read this if you want to pursue this option.

You can also use the HFEA website to identify clinics offering surrogacy services in the UK. See Clinic search | HFEA

Helpful information

- Childlessness Overcome Through Surrogacy (COTS)
 – www.surrogacy.org.uk/
- www.brilliantbeginnings.co.uk/
- Surrogacy | HFEA
- Recommendations | Fertility problems: assessment and treatment | Guidance | NICE
- www.gov.uk/government/publications/having-a-child-through-surrogacy

Funding and sourcing funding

To proceed with funding, women must be registered with a GP and be eligible for NHS treatment. There are strict eligibility criteria to support NHS funding for specialist fertility treatment. Currently, fertility specialists make funding requests on behalf of individual patients.

Requests are made to local Clinical Commissioning Group. The success of funding applications varies across the UK.

Costs and funding | HFEA

2. Adoption

To be eligible to adopt a child:

- you need to be over 21 years of age
- you do not need to be married or in a civil partnership. However, it is preferable if you are in a relationship that is considered stable
- you do not have to be a British citizen, but you (or your partner, if you are a couple) must have a fixed and permanent home in the UK, Channel Islands or the Isle of Man
- or you (and your partner, if you are a couple) must have lived in the UK for at least one
 year before you begin the application process

Other considerations include:

- smoking status. It is preferred that potential adoptive parents are non-smokers, meaning that someone has stopped smoking completely within the last 6 months before starting the adoption process. This includes e-cigarettes
- criminal convictions or cautions in respect of offences against children
- homeowners or renters with a spare room to accommodate a child

Adopted children may have additional needs so as a potential adoptive parent it is also helpful to consider:

- work commitments
- finances and financial status
- criminal offences
- safety issues
- pets within the family
- support systems

To adopt a child, you can go through either:

- an adoption agency that is part of your local council
- a voluntary adoption agency

You may wish to consider adopting more than one child, siblings or a child with special needs. To be eligible to adopt a child you need to go through a process. This includes:

- making your initial enquiry by contacting an agency of your choice
- starting the application process
- a home visit
- training and checks, to include a police check and references
- a formal assessment, this may include a medical examination and a written social services report
- an independent adoption panel meeting and recommendation
- approval
- finding a family
- · matching with a child or children
- support to include ongoing support

We cannot advocate for different agencies or suggest which route you may take. It is useful to look at agencies that may be able to support you through the adoption process.

Helpful information

- Child adoption: Overview GOV.UK (www.gov.uk)
- Statistics: England | CoramBAAF
- London First4Adoption
- Contact us | Adopt London

Adoption Support Fund team

asf@mottmac.com

3. Fostering

The main difference between fostering and adoption is that fostering is usually temporary while adoption is typically a more permanent, long-term solution. The goal of fostering is not adoption. Foster parents can be registered with a local authority or an independent fostering agency.

As a foster parent, you are in the role of a parent but ultimately, the local authority and the child's birth parents have responsibility for the child, though you may share some decision-making capabilities. However, when you adopt a child, you have full parental responsibility – and the child is a permanent member of your family.

There are four types of fostering:

- short-term fostering
- long-term fostering
- emergency foster care
- therapeutic foster care

Foster parent approval

There are five requirements to be approved as a foster carer:

- you must have a spare bedroom for each foster child
- be at least 21 years old
- be considered in good health
- a recommendation to the foster panel by a social worker
- attend training sessions

Foster parents:

- always have a supervising social worker available to help with any problems or concerns
- receive an allowance that covers the cost of caring for the child
- can request additional funds from the fostering agency to meet the needs of a child who has special needs

Long-term fostering is also known as permanent fostering. Permanent care is rare because the hope is that problems with birth families are resolved and the young person or child returns home.

Only when things cannot be resolves will a court order be issued to find the child a permanent home. Rarely this may mean that the child is eligible for adoption. Approval as an adoptive parent differs from that of a foster parent.

Helpful information

Fostering Vs Adoption - What's the difference? | Capstone Foster Care

4. Uterine (womb) transplant (future)

Uterine (womb) transplant is not yet a routine option for fertility treatment. However, research is being done and there is potential for this to be possible in the future. This means you may be able to carry your own pregnancy after a uterine transplant. For further information, email the charity Womb Transplant UK on info@wombtransplantuk.org

Contact us for further information or advice

Please call us with 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 email us at enquiries.drd@nhs.net

Or write to: 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 3312 7777 (10.00 – 16.00, Monday to Friday). 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

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