The Shrewsbury and Telford Hospital NHS Trust

Patient Information

The Shropshire and Mid Wales Fertility Centre

Egg Donation

Information for Egg Sharers

Shropshire and Mid Wales Fertility Centre

Address: Severn Fields Health Village, Sundorne Road, Shrewsbury SY1 4RQ.
Tel: 01743 261202

Introduction

This leaflet has been designed to help those who are considering taking part in our egg sharing programme by sharing some of their eggs during treatment to help other women who are unable to produce or use their own eggs.

If you have any further questions about donating your eggs, please feel free to speak to a member of the nursing team at the Centre (Tel: 01743 261202).

What is egg sharing?

Egg sharing is a system whereby individuals can reduce the cost of their fertility treatment by agreeing to share (donate) a proportion of the eggs collected in the cycle with a couple who need donated eggs.

Egg sharing, therefore, is identical to egg donation except that the 'sharer' uses a proportion of the eggs collected for a cycle of IVF for themselves, with the remainder being donated. Because of this, potential egg sharers have to undergo all of the workup and screening that is normally expected of an egg donor.

Who is suitable for egg sharing?

In order to be considered for the egg sharing you must be no older than 35 years of age, must have provided a details medical and family history and undergone all of the screening procedures that are undertaken by potential egg donors (see below). Your response to any previous fertility treatment and the results of previous hormonal tests such as Anti-Müllerian Hormone (AMH) and antral follicle count at scan will be reviewed prior to deciding upon suitability.

Why is egg sharing needed?

There are many medical conditions that might make it necessary for a women to need eggs provided by a sharer. These include:-

- Premature menopause (usually classed as menopause before the age of 40)
- Poor response to ovarian stimulation at previous attempts at fertility treatment.
- Infertility caused by the removal of both ovaries or from chemo/radiotherapy treatment.
- Inherited disorders in the family of the female patient

Will I have to pay to share eggs?

Yes, there is a charge to cover the costs involved in your treatment, however this charge is smaller relative to that which would be made for a 'normal' cycle of IVF. The majority of the costs of the egg share cycle, including your medication, are covered by the egg recipients.

What are the arrangements for egg sharing?

The woman receiving a proportion of your eggs will remain anonymous and you will not be given any details about her or her treatment outcome. You will also remain anonymous to her.

If you have 8 eggs or more collected then you will share them equally with her (i.e. half the eggs each). If an odd number of eggs are collected then you will keep the extra egg. If you have less than 8 eggs collected, then we believe that there are too few eggs to share. In this case you will keep all the eggs at no extra cost and the potential recipient's treatment will be cancelled.

The eggs for your treatment are fertilised with your partner's sperm or donor sperm and the eggs for the recipient's treatment are fertilised with her partner's sperm or donor sperm.

You may withdraw your consent to share eggs at any time before the embryos have been transferred, however if you withdraw your consent to share your eggs then you become liable for the full cost of your

treatment.

You are required to receive counselling about the implications of the proposed treatment before agreeing to proceed. This is referred to Implication Counselling.

It is important to note that your treatment can only proceed if a matching patient who requires egg sharing is ready to start treatment. If you do not wish to wait, you can proceed with a standard IVF treatment without egg sharing at full cost.

Potential recipients and patients receiving donated eggs are given information on the characteristics of the donor such as eye colour, hair colour, height, build (body mass index), ethnic origin, blood group etc and non-identifiable information about yourself that you may provide. Some donors choose to leave a non-identifiable message about themselves and the reason for donating and recipients may ask to see this if they wish. This is referred to as the Pen Portrait.

It is possible that you want to specify extra conditions for the use of your eggs but please note we cannot accept donations from anyone wishing to place restrictions on the use of their eggs based on characteristics protected under the Equality Act 2010. These characteristics include:

age
disability
gender
marriage and civil partnership
race
religion or belief
sex
sexual orientation

Future financial considerations for egg sharing

Sharing your eggs reduces the cost of your treatment cycle significantly. However, please be aware that in doing so the number of embryos you may have available to freeze for future cycles is likely to be reduced compared to having a standard IVF cycle where you keep all the eggs for your own treatment. This means that if you want further treatment in the future you may need to have a more costly fresh cycle sooner than if you'd had additional frozen embryos to use. A fresh cycle (where no eggs are shared) costs around 3-4 times more than a frozen cycle.

How many egg sharing cycles can I have?

Whilst there is no theoretical limit to the number of egg collections a woman can have, in practice your chances of achieving a pregnancy do start to fall after the fourth cycle. In general most couples would not wish to have more than three or four cycles. In and egg share cycle you will only donate to one other person for that cycle. There is a legal limit of ten family units each achieving a pregnancy. You may stipulate how many family units you may wish to donate to if less than 10.

The ten family unit limit makes it absolutely essential that you inform the Centre if you have donated or stored eggs in the past at other fertility centres.

Sharer Counselling

All volunteers for egg sharing are carefully counselled by two separate members of the Fertility Centre team (nurse and doctor) and are also seen by the independent counsellor. The effects of the treatment cycle on the sharer, her family and children are discussed in detail. The Centre also ensures that if the sharer has a partner they participate fully and agree with the treatment.

If the sharer has children who are old enough to understand the implications, we encourage the counsellor to discuss it with them also.

We carefully counsel both the recipients and the donor/sharer to ensure that the rights of the unborn child conceived by egg sharing are carefully considered.

Egg sharing and the law

Any child born as a result of an egg donation during an egg sharing cycle will be the legal child of the recipient, not the sharer. The Human Fertilisation and Embryology Authority (HFEA) keeps a register of all egg and sperm donors as well as all treatments using donated eggs or sperm.

The law regarding sharer anonymity in the UK changed on the 1st April 2005 so that children born as a result of shared egg treatment will be able to find out the identity of the sharer

If you donate through egg sharing 'anonymously' only Centre staff and the Human Fertilisation & Embryology Authority will know your identity. Any child born as a result of egg sharing treatment will have the right to contact the HFEA at the age of 16 to ask for the following non-identifying information and details on the likelihood of being related to an individual if contemplating marriage or an intimate physical relationship.

- Physical description (height, weight, eye hair and skin colours)
- Year and Country of birth
- Ethnic group
- Whether the donor had any genetic children when they registered and the number and sex of those children
- The number, gender and year of birth of any half/full siblings they may have
- Other details you the donor may have chosen to supply (e.g. occupation, (religion) belief systems and interests)
- Ethnic group(s) of the donor's parents
- Whether the donor was adopted or donor conceived (if they are aware of this)
- Marital status (at the time of donation)
- Details of any screening tests and medical history
- Skills
- Reason for donating
- A goodwill message
- A description of themselves as a person (pen portrait)

At age 18 they will be entitled to receive *identifying* information (after appropriate counselling and notification of yourself) which will include:-

- Name of Sharer
- Address at date of donation
- Screening tests carried out
- Personal and family medical history
- Any additional information that the donor wished to provide

All of the above information is given by the donor prior to treatment and is held in clinic notes and on the HFEA register.

UK law allows a maximum of 10 family units to be created using the gametes of one individual donor. The HFEA do not regulate treatments outside the UK so it is possible that further families could be created this way.

The sharer will not have any obligations towards such children. The recipient couple being treated are the legal parents.

Donors are strongly encouraged to inform the fertility unit and HFEA of any change of contact details. This is so that you can be informed if anyone requests your disclosable information in future. We shall attempt to contact you should we become aware that a request for your identifiable information has been made. Counselling will be available on request.

Identifying information about donor-conceived siblings may be given from the age of 18 with mutual consent.

Are there other ways donors of shared eggs can be identified?

Yes. Although the fertility clinic and HFEA will continue to manage (and potentially disclose) the donor's information in line with the HFE Act donors and recipients need to be aware that it is possible for them to be identified through direct to consumer DNA testing matching services e.g. 23 and me and that this is outside of the control of both the clinic and the HFEA. It may be possible for those not registered with a consumer DNA matching company to be traced through genetic relatives that are registered.

Egg Sharer Screening and History

After a woman has been counselled and accepted as a potential egg sharer she must undergo a 'screening' programme. This is done to ensure that she has no infections or genetic conditions that might be passed on to the recipient or her child. We will take a medical, family and travel history. We will also ask for the sharer's permission to contact her GP for a more detailed medical history. A general examination is performed at the pelvic ultrasound scan by the doctors.

The sharer must provide blood samples to determine what her blood group is and to discover whether she has any infections such as Hepatitis B, Hepatitis C, Syphilis, Cytomegalovirus (CMV), HIV 1&2 and Human T-Lymphotrophic Virus (HTLV) 1 & 2. Screening is also undertaken for genetic disorders (karyotype) and Cystic Fibrosis. The sharer will provide a urine sample to test for Gonorrhea and Chlamydia.

Please consider the implication of the genetic and medical screening you will undertake and how this could affect you and any family you have if you receive any unexpected results. The implications of being tested for HIV are discussed with the patient prior to the test being taken. The results of the tests are confidential and are only made known to the sharer. Without her written permission her GP cannot even be informed. Patients from certain ethnic backgrounds require further screening.

Jews of eastern European descent should be screened for Tay-Sachs, people of Indian, Mediterranean and Middle-Eastern descent should be screened for β Thallassaemia and people of African descent should be screened for sickle cell.

Please be aware that the screening process is not a guarantee that any child born would be healthy and free from genetic disease or that the donor is free from all infectious disease.

All egg sharers are required to have a repeat screening three months after their egg donation and before a recipient goes on to have treatment using frozen embryos/blastocysts from that donation.

Will I be held responsible if a child born from my egg sharing is disabled in any way?

It is the responsibility of the sharer to inform us of any genetic (inheritable) diseases that are known in the family. It is essential that the Centre is informed of any such conditions as if it can be proven that the sharer has knowingly misled the Centre and the recipient then the parents of any child born as a result of treatment that is affected could sue the sharer for damages.

Should you become aware of any genetic or medical problems after you have donated you have a duty to inform the fertility clinic of this as it may have implications for the woman you have donated eggs to and any resulting children.

Matching the Sharer to the Recipient

As far as possible we try to match the general physical and clinical characteristics of the sharer to those of the recipient. The characteristics we try to match are:-

- Height
- Weight
- Build, BMI

- Hair colour
- Eye colour
- CMV status (the presence of Cytomegalovirus antibodies in the blood)
- Complexion
- Ethnic Background

We always attempt to match blood group. It is not always possible to get an exact match, but we try our best to get it as close as possible.

What treatment is involved for the sharer?

An egg sharer will basically receive the same treatment as a patient undergoing IVF/ICSI, with the main difference being that the sharer will only use half of their own eggs for IVF/ICSI.

You will view an information session and be seen by a nurse prior to starting your treatment. During this time, you will be taken through the medical and ethical issues involved in your treatment and you will be able to ask any questions that you may have.

You will be asked to sign consent forms following a full explanation of procedures and drug schedules. At this stage, the nurse will check that we have recent, satisfactory, sperm test results from the male partner or if donor sperm is being used, that samples are in the department.

Treatment involves medication to "switch off" the ovaries followed by other medication to stimulate them to produce more eggs. This requires a single "depot" injection and/or daily injections for 11-16 days. The doctor will decide which medication protocol best suits you. During this time we will need to perform 3-5 trans-vaginal ultrasound scans and blood tests to determine the growth of the follicles which will contain the eggs.

The egg collection is performed under conscious sedation and pain relief. After collection the eggs are divided as described above between egg sharer (donor) and recipient.

Some side effects to the drugs may be experienced. The depot injection can give symptoms similar to that of the menopause, for example, mood swings, hot flushes, headaches, vaginal dryness and breast tenderness. The stimulation drug can give rise to symptoms of ovarian hyperstimulation syndrome (OHSS), for example, abdominal discomfort, a feeling of being unwell, nausea, bloated abdomen, reduced urinary output and breathlessness.

On the day of the egg collection, the male partner of the sharer (your partner) will be asked to produce a semen sample to be mixed with the eggs that have been allocated for you. This sample is usually produced in the clinic after he has abstained from sexual activity for 3-5 days. If, for any reason it is likely that there will be difficulties in obtaining a semen sample, we may need to freeze some samples from your partner before the day of egg collection. If donor sperm are to be used, they will be prepared at this time.

If enough eggs have been collected for the recipients treatment these will be mixed with a semen sample from her partner or donor sperm following your egg collection.

In IVF/ICSI we normally expect about 50-70% of the eggs to fertilise, but this can vary from 0-100% as it is difficult to predict how well the sperm will fertilise the eggs. In about 10% of IVF/ICSI cases, there is no fertilisation. After the eggs have been inseminated, they are examined for signs of fertilisation. The resulting embryos are examined again the following day to see if they have developed and are then continuously monitored for a further 2 days to see if they are suitable for transfer into the womb.

Sometimes, the embryos have not developed, even though they fertilised normally. In this case, a transfer would not be performed.

The embryologist will telephone you on the day following egg collection to let you know if fertilisation has taken place and how your embryo's are progressing. If the eggs have not fertilised you will have a discussion with the Embryologist.. You will receive a phone call from the nursing staff to discuss what you do about your medication and to offer support. Your case will be reviewed at a clinical review meeting before you plan another treatment pathway.

The actual transfer of embryos is performed by a doctor 3, 5 or 6 days after the egg collection. The best

embryos are selected by the Embryologist, put into a fine catheter and gently transferred into the womb. After the transfer, the Embryologist checks that the embryos have left the catheter.

A maximum of 2 embryos can be transferred. Any remaining embryos that are of high enough quality can be frozen for future use, if you wish and have consented to this.

A pregnancy test is performed 14 days after embryo transfer and 12 days after blastocyst transfer. The risk of miscarriage after a positive pregnancy test alone is around 25- 30%. Once the pregnancy sac has been seen and fetal heart action identified, then the risk of miscarriage is significantly lower at about 5%. The risk of tubal or ectopic pregnancy is about 3-5%. It is possible, although very unlikely, to have a pregnancy in the womb and in the tube at the same time.

The risk of abnormalities in babies born after IVF is no higher than in natural conception. There is thought to be a slightly increased risk of some abnormalities in babies born as a result of the ICSI procedure, please refer to the HFEA website for more information on this. Babies born following embryo freezing after IVF have the same risks of abnormalities as those born following natural conception.

You may consider freezing any spare embryos. Your embryos need to be of good quality and the Embryologist will tell you if they are suitable for freezing. This will be done on the day of embryo transfer or a few days later. The replacement of any frozen embryos is performed in subsequent cycles with a different drug schedule and is simpler and less costly than another fresh cycle.

By law, the embryos can be frozen for a maximum of 55 years, but patients must remain in contact with the centre and are required to renew their consent in writing every 10 years. A donor/sharer may withdraw their consent to use at any time.

Confidentiality is maintained at all times, both for the sharer and the recipient. The Centre will not inform the sharer of the outcome of the donation. A year after the donation the egg sharer can request some non-identifying information (see section below called “can I find out about the outcome of my donation).

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The Risks to the Egg Sharer

There are some risks associated with donation but these are minimal and short term. There is a 1-2% risk of severe ovarian hyperstimulation (OHSS), (where too many eggs are produced) despite careful monitoring of injections. If this occurs the cycle may be abandoned.

There is a minimal risk of pelvic infection following an egg collection (less than 1%)

Can I find out about the outcome of my donation?

A year following the donation the donor may ask the centre for the following information if they wish:

- The number of children born as a result of the donation
- The gender of the children born as a result of the donation
- The year of birth of the children.

You may wish to ask again in future as often embryos are frozen for future use if the first treatment was not successful or the recipient wishes to try to have a sibling for the child.

Please consider how you may feel if your own treatment is unsuccessful but you find out the recipient’s treatment was successful. Counselling is available and encouraged.

The Importance of Telling Children About Their Donor-conceived Origins

Centres are now required by law to give patients undergoing treatment using donor gametes (eggs or sperm) or embryos information about the importance of telling any resulting child at an early age that they are donor-conceived. Centres are also obliged to inform patients about suitable methods for doing so.

Alternatives

Egg sharing is optional. You can decide to have standard treatment where you keep all your eggs but

you would be required to pay for this in full.

If you go ahead with egg sharing and there are not enough eggs to share (less than 8) you, as the sharer, will get to keep all the eggs for your own use at no additional cost to you, the fertility department will cover that cost. The potential recipient will go back to the top of the waiting list.

What Should I Do if I Wish to Participate in Egg Sharing?

You can contact the nursing staff at the Fertility centre (Tel: 01743 261202) to arrange an appointment or for an informal chat.

If you wish to know more about the drugs involved and the egg collection procedure itself please visit the unit website on www.shropshireivf.nhs.uk

What Happens if I Change My Mind?

You can withdraw your consent to the egg sharing up until the point where the eggs/embryos have been used. This could be when they are transferred to a woman, used for research or training (if you have agreed to this) or been allowed to perish. If you do withdraw consent at this stage your own treatment will no longer be subsidised by the intended recipient and you will become liable for the whole cost of the treatment.

Contacting the Centre

You can contact the centre at any time if you have any worries, concerns or questions about your treatment.

The staff are available on the following number 01743 261202 option 2 Monday—Friday from 9am—5pm.

Other Sources of Information

References
HFEA
www.hfea.gov.uk

Donor Conception Network
www.dcnetwork.org

The Seed Trust
www.seedtrust.org.uk

Contact details for more information

Useful telephone numbers
Fertility nursing team **01743 261202 option 2** or call the hospital switchboard on **01743 261000** and ask to be put through to the Fertility unit. Please note the department accepts calls from 9am to 5pm Monday to Friday.

Further information is available from;

Patient Advice and Liaison Service (PALS)
We act on your behalf when handling patient and family concerns, liaising with staff, managers and where appropriate, relevant organisations to negotiate immediate or prompt solutions. We can also help you get support from other local or national agencies.

Royal Shrewsbury Hospital, Tel: 0800 783 0057 or 01743 261691
Princess Royal Hospital, Tel: 01952 282888

Other Sources of Information

NHS 111

A fast and easy way to get the right help, whatever the time. NHS 111 is available 24 hours a day, 365 days of the year.
Telephone: 111 (free from a landline or mobile)
Website: www.nhs.uk

Patient UK

Provides leaflets on health and disease translated into 11 other languages as well as links to national support/self-help groups and a directory of UK health websites.
Website: www.patient.info

Information in other Formats

Please contact the Fertility Unit to discuss of you need this information in another format or different language.

Website: www.sath.nhs.uk

www.shropshireivf.nhs.uk

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