Egg Donation

Information for recipients
Welcome

This booklet explains the process of receiving donated eggs at Leeds Fertility.

You can find further information at: www.leedsfertilityclinic.co.uk

How to contact us:
Please see page 50 for urgent and non-urgent contact details.
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What is egg donation and why is it needed?

There are several reasons why some couples need donated eggs in order to have the best chance, or any chance of having a family.

Some women may be born without ovaries or with ovaries but without eggs inside them. Women are born with all of the eggs they will ever have and there is no treatment to create or multiply them. The eggs are aging with the woman and their quality deteriorates with time. By the time of the menopause, when the menstrual cycle stops, all the eggs have been used up. Most of the eggs available in the ovary do not actually ovulate over a lifetime. They are lost with the day to day turnover of cells like hair and skin. For some women the ovaries age prematurely. This can be as early as the teenage years or in one’s 20’s, long before parenthood is seriously considered for many people. This is called premature ovarian insufficiency.

Some women and girls will lose their eggs or whole ovaries as a result of surgery or cancer treatments including chemotherapy and radiotherapy. Unfortunately, unlike hair which regrows, new eggs do not develop.

The most common situation where egg donation is considered is in women whose own ovaries are too weak to try IVF or who have had unsuccessful IVF largely because of the poor quality of their own eggs. This is more common in women over 40 years old and can result in repeatedly unsuccessful treatments or miscarriages.

There are some rare conditions that are inherited through the female line via the egg genes.
Some couples may choose to avoid the risk of having a child with a serious disability who may suffer handicap and a short life expectancy, by using an egg from a donor who does not carry the condition in her genes.

Who can be a donor?

Egg donation is a remarkable and special thing to consider. It is a voluntary act of kindness to help another woman or couple to achieve their dream of having a family. In the UK, donating eggs is a gift, like blood and organ (kidney, heart etc) donation. The HFEA permits limited financial compensation to the donor up to £750 (see www.hfea.gov.uk).

The basics:
Ideally, donors should be healthy women between 21 and 35 years with no known history of inheritable illnesses in the family. It is preferred (but not essential) if she has had a child of her own.

Anonymous volunteers:
Some women come forward voluntarily as a result of learning about the process through some form of publicity or knowing the story of someone in need.

Women recruited by the recipient couple in need of donor eggs:

Known donors
Some patients may choose to use the eggs from someone they know, for ethnic, cultural or religious reasons. Donation between relatives is not uncommon e.g. sisters.
Same-sex female partners may choose to donate eggs from one to the other. In these cases, the donor may be older (than 35 years) but the recipient will be made aware of the possibility of a reduced chance of success because of this.

**Cross-over anonymous donors**

A donor may be recruited by the couple in need but they may not feel comfortable about using her eggs themselves. In this situation the clinic can match the donor to another couple and vice versa with their donor to ease the psychological process for all parties.

**Infertility Patients:**
The process of ‘egg-sharing’ involves couples needing to have treatment to conceive themselves, who have been appropriately screened and counselled, donating some of their eggs to an anonymous couple in return for subsidised (cheaper) treatment.

**Where do I find a donor?**

Women who come forward to offer their eggs are rare and special. Leeds Fertility has a managed waiting list of potential recipients who are carefully matched up with donors as they successfully complete the screening program. The waiting time is not easy to predict as the matching process can be harder for some (e.g. ethnic minorities).

Some self-funding recipients may choose to explore treatment overseas to speed things up. Leeds Fertility can recommend a reputable clinic and assist with this if you wish to know more. Other countries have different laws relating to anonymity of and payment to the donors which means there are more donors available and treatment can take place more quickly.
What do I need to know about being an egg recipient?

Who can find out information about me and my treatment (and what can they access)?

Egg donation treatment in the UK is licensed and registered by the HFEA. Since 2005, children born from egg or sperm donation have had the right to access identifiable information about their donor once they reach 18 years of age.

Free counselling support is available through Leeds Fertility for help through this process and you are strongly recommended to make use of it.

Your child can access to the following non-identifiable information about their egg donor, from the age of 16 years.

• Physical description (height, weight, and eye, hair and skin colour).
• Year and country of birth.
• Ethnic group.
• Has their donor had any genetic children, and if so how many, when registering to be a donor and whether any other children have been born through their donation, and the number and sex of those children.
• Other details their donor may have chosen to supply (occupation, religion and interests).
• The ethnic group(s) of their donor’s parents.
• Whether their donor was adopted or donor conceived (if their donor was aware of this).
• Their donor’s marital status (at the time of donation).
• Details of any screening tests and medical history taken at the time of their donor’s donation.

• Skill, ability or talent that their donor has stated.

• Their donor’s reason for wanting to donate.

• Their donor may have also left a good-will message for you and may have provided a brief description of themselves as a person (pen portrait).

The last two points would only be available if their donor had chosen to provide them.

Your child can access their donor’s name, date of birth and last known address (identifiable information) from the age of 18 years.

HFEA has a legal obligation to contact the donor when your child makes a request for this identifiable information.

From the age of 18 years, your child can join the Donor Sibling Link to exchange their contact details with other adults who share the same donor, provided they’ve also joined the Donor Sibling Link or they join in the future.

If your child is below the age of 16 years and wish to know about their donor, you can apply to the HFEA on their behalf to obtain the following information about their donor:

• Physical description (height, weight, eye, hair and skin colour).

• Their year of birth.

• Their ethnicity.

• Whether they had any children at the time of donation.
• Any additional information they chose to supply such as their occupation, religion, interests and a brief self-description.

• Whether they have agreed to share their identity with people conceived from their donation when they turn 18 (if you were conceived before 1st April 2005).

• You can also find out the number, sex and year of birth of their donor-conceived siblings.

Legal parenthood: Who are the parents in the eyes of the Law if a child is born?

The recipient of the egg who gives birth to the baby is the legal mother. The donor has no rights over the child. Both donor and recipients (both partners in a couple who are married or in a civil partnership) will sign consent forms clearly stating that this has been understood. The parents do not have to tell the child they were conceived from a donated egg. Leeds Fertility will encourage you, the recipient couple, to tell the child and help you to manage the subject sensitively and appropriately.

For couples who are not married or in a civil partnership

The partner must give written consent that they will be the legal parent of the child before treatment starts. This applies to same sex partners even when one is donating eggs to the other.

Please ask for guidance if you and your partner are in this situation as it has implications such as for your child’s nationality and their inheritance rights, for your financial responsibilities and decision-making on behalf of your child (medical treatment, schooling, etc).
It is also important for your child to be clear who their legal parents are. The legal parent’s name will appear on the child’s birth certificate.

Consent can be withdrawn up until treatment takes place (insemination of donor sperm or transfer of embryo). You must inform Leeds Fertility immediately, and in writing, if you change your mind.

See HFEA leaflet “Becoming the legal parents of your child” available from Leeds Fertility or online: https://www.hfea.gov.uk/treatments/explore-all-treatments/becoming-the-legal-parents-of-your-child/

How does the clinic match donors and recipients in anonymous treatments?

The clinic aims to match basic physical characteristics such as ethnicity (skin colour / tone), hair and eye colour, and physical build.

The donor is invited to provide a short paragraph about themself, a ‘pen-portrait’ which they would be happy to be shared with the recipient couple and possibly the child.

It is not common for recipients to have a wide choice of donors but if there are options, this information may be helpful. It is not compulsory for the donor to share any further information about themselves if they do not wish to. Sometimes the child does not clearly look like either the egg donor or the provider of the sperm. This is no different to children who have been conceived naturally.
What support is available to help me decide whether to go ahead or not, and what if I change my mind?

All donors and recipients of eggs are counselled in detail regarding the implications of their decisions and actions. Leeds Fertility has a duty to ensure that the welfare of any child resulting from any of our interventions is assured, to the best of our ability. You will be supported in reaching the decision that is right for you.

There are many other resources available including the National Gamete Donation Trust, Donor Conception Network and local support groups of families with donor-conceived children (see page 47 for details).

We would hope and expect that all parties are comfortable and sure of their decisions before treatment starts. It would be very very unusual for a donor to withdraw her consent before the embryo (fertilised egg) is placed in the recipient. If any party has any doubts, treatment should NOT begin. Further counselling will be offered.

However, the egg donor has the right to withdraw her consent any stage, up to the time the embryos are transferred. This may include situations where the embryo created from egg donation is in storage: if the donor withdraws her consent at this stage, those embryos have to be removed from storage and allowed to perish.

**Does the donor get paid?**

Egg donation is a voluntary gift but there is compensation available up to £750 for the time and commitment required. This is managed by Leeds Fertility.
What does it cost me to receive donated eggs?

Accessing egg donation treatment is subject to the same criteria (e.g. age, body mass index, smoking status, stable couple) as other fertility treatments within the NHS. For some patients where the ovaries are very weak or not working from early on, egg donation treatment is likely to be available where NHS funding is offered. If you have already attempted IVF treatment with your own eggs and received an embryo (but not had a pregnancy / baby), you may not be funded by the NHS for further treatment. Please consult your GP or Leeds Fertility for the current local policy for your area. Leeds Fertility will provide up to date costs for those needing to self-fund. You will have to pay for the donor’s screening process and her IVF program (including medications) in addition to your own preparation and receipt of treatment.

Could I do it more than once?

It is possible to receive eggs more than once (from the same or different donors). It is more common for recipients to have multiple cycles of single embryos (fertilised eggs) created from the eggs of the one donor.

How do I / we access treatment with donated eggs?

Treatment with donated eggs may be funded by the NHS, particularly if you have not had any NHS-funded fertility treatment to date. Each Clinical Commissioning Group (funding body) has different criteria so you should check with Leeds Fertility whether you are entitled to funding or not. If you are not eligible, Leeds Fertility will be pleased to help through our private patients’ clinic within Leeds Fertility, provided it is medically safe to do so.
How does the process work

For the donor

The donor will go through this pathway in order to be accepted on the program.

Donor screening includes:

- Tests to make sure the donor has plenty of eggs in her ovaries.
  - Blood tests for hormones (FSH, AMH).
  - Internal pelvic ultrasound scan.
- Tests to make sure she is not at risk of transmitting any infection.
- Blood tests for antibodies to viruses (HIV, HTLV, Hepatitis B and C, Syphilis, CMV, rubella).
- Vaginal swab for chlamydia and gonorrhoea detection.
- Tests of general well-being.
  - Up to date cervical smear according to the National Screening Program.
  - Blood count, liver, kidney and thyroid function, blood group.
- Tests to minimise the risk of genetic conditions being passed on.
  - Chromosome screen (Karyotype).
  - Cystic fibrosis screening.
  - Screening for blood disorders (thalassaemia, sickle cell disease) and Tay Sach’s Disease in relevant ethnic groups.

The risk of having a baby with a congenital abnormality is no higher in a pregnancy achieved with a donated egg than would have occurred with your own egg (1-2%).

**For the recipients**

You and your partner will be seen by a Leeds Fertility Counsellor to ensure that you have fully considered all the implications of receiving treatment with donated eggs and that you are both comfortable with the process.
You will then undergo screening tests to enable a safe and appropriate match with your donor and to ensure your own safe passage through the treatment.

**The female partner will have the following tests:**
- Test to make sure your womb is healthy for pregnancy.
  - Internal pelvic ultrasound scan.
- Tests to make sure you are not at risk of transmitting any infection.
  - Blood tests for antibodies to viruses (HIV, Hepatitis B and C, Syphilis, CMV).
  - Confirmation of rubella immunity: Blood test or evidence of having received x 2 vaccinations e.g. MMR.
- Screening for current vaginal infections.
  - Vaginal swab for chlamydia and gonorrhoea detection.
- Tests of general well-being.
  - Up to date cervical smear according to the National Screening Program.
  - Blood count, liver, kidney and thyroid function, blood group.

**The male partner will have the following tests:**
- Semen analysis.
- Blood group.
- Screening for genital infections.
  - Urine screen for Chlamydia and gonorrhoea detection.
• Tests to minimise the risk of genetic conditions being passed on.
  - Chromosome screen (Karyotype).
  - Cystic fibrosis screening.
  - Screening for blood disorders (thalassaemia, sickle cell disease) and Tay Sach’s Disease in relevant ethnic groups.

• Tests to make sure he is not at risk of transmitting any infection.
  - Blood tests for antibodies to viruses (HIV, Hepatitis B and C, Syphilis, CMV).

The egg donation coordinator will then begin to find you a suitable match.

How do I prepare for healthy pregnancy and boost my chances of success?
• Stop smoking completely.
• Reduce alcohol intake to a minimum for both men and women. No safe limit has been identified for women so no alcohol consumption is advised. Men should ideally restrict alcohol intake to 3 to 4 units per week.
• Women should restrict their caffeine intake as this has been shown to lower IVF success rates.
• Women should have been vaccinated twice against German measles (rubella) or have confirmed immunity.
• Women should have an up to date, normal cervical smear test.
• Women should be taking folic acid (vitamin B) supplement at 400 micrograms daily before and during treatment, and for at least the first three months of pregnancy. Vitamin D 10 micrograms should be taken throughout. Over-the-counter multivitamins for pregnancy should contain the necessary ingredients.
• Both partners should aim for normal body weight for their height. Women in particular should aim for a body mass index ideally under 25kg/m$^2$, and absolutely under 30kg/m$^2$ to access NHS-funding. Treatment is less successful and more risky at heavier weights. Pregnancy is also less healthy with a higher risk of blood pressure problems and diabetes in heavier mothers.
• A healthy, varied diet and regular physical exercise are helpful for overall health, weight management and stress reduction. Please see the website for more information on preparing for pregnancy.
How is an egg recipient cycle done?

Nurse consultation

Once your donor has been identified and synchronised with your proposed treatment timeframe, your nurse consultation will be booked. This hour long appointment with a nurse specialist is the gateway into your treatment cycle. Both partners must attend.

Tasks:

1. Planning

You will be given a Treatment Diary explaining your individually tailored treatment program and the expected dates when key parts of the process should fall.

Please be aware that our bodies do not always ‘read the textbook’ and sometimes we have to reschedule for minor delays such as your period coming later than expected, or the donor taking longer to stimulate than predicted. This is quite normal and the service will stretch to fit you in.

Please bring your treatment diary to every visit after this.

2. Medication

The woman will be using medicines on a daily basis, some by injection. We will teach you both how to do this properly and safely.
Many patients find this worrying to start with, but get the hang of it very quickly. The medicines are dispensed by a home-delivery pharmacy who will bring them to the address of your choice.

The nurse will show you examples of what will arrive and advise you how to store them. More information is available on our website e.g. injection teaching video.

3. Consents
The consents are detailed legal documents and it is critical that they are completed correctly and truly express your wishes.

You will be guided through the consent forms by EngagedMD, a password-protected online program.

The nurse will ensure that the online paperwork is all in order. You may take a copy away for your own records.
4. Settlement of Invoice

If you are paying for your treatment, we respectfully ask that the bill is settled by the time of the nurse consultation appointment. This can be done by card over the telephone or in person on the day, with the Business Support Team (0113-206 3157).

The Treatment

Preparation of the womb

The principle of treatment with embryos created from donated eggs requires the development of the recipient’s womb lining (endometrium) and the control of natural ovulation to enable the precise coordination of the embryo transfer and developmental stage of the lining.

Down-regulation

Standard treatment begins with a Prostap injection (on day 1 or day 21 of the cycle) which switches off the natural cycle and prevents a new egg from developing or ovulating. A scan two weeks later will confirm ‘down-regulation’ or shut-down of the natural mechanism.

Stimulation

The womb lining will be thin and ready to be stimulated to thicken. This is achieved with oestrogen hormone taken either as tablets or patches (or both) for 10-12 days. A further scan will confirm adequate endometrial development a few days in advance of the donor’s expected egg collection procedure.

Progesterone hormone will be added to the oestrogen medication to precisely synchronise the womb lining for the stage of the embryo at the time of expected transfer.
Progesterone can be given as vaginal pessaries (tablets) or by injections. Both the oestrogen and progesterone supplements will need to be taken together until the pregnancy test and for the first three months of pregnancy if the test is positive.

**Laboratory phase**

**Fertilisation and embryo selection**

The male recipient partner will be required to attend on the day of the donor’s egg collection to produce a fresh semen sample. Donor sperm (if required, will be thawed on this day).

The eggs and sperm will be put together on the afternoon of the harvest. If ICSI (sperm injection) is required, this will be done at this time. The need for ICSI is almost always known beforehand and you will be aware if this is planned for your treatment. Very occasionally, a sperm sample may be poorer than expected on the day of treatment. The embryology scientists will discuss the possibility of injecting the eggs instead of the standard IVF insemination, with the consultant on duty and with you, the couple. The main reason for suggesting ICSI is to give the eggs the best chance to actually achieve fertilisation, which is the first step towards embryo development. Therefore it is worth all patients understanding some of the issues around this technique. *(See Treatment risks, page 29)*

Fertilisation happens during that night. Usually about 70% of the eggs accept the sperm. After this time, if they have not, they will not as the window of time will have passed. The unfertilised eggs will be discarded the next morning at the fertilisation check.
You will receive a telephone call from the embryologist informing you how many of your eggs have fertilised, and therefore how many embryos are now in the culture incubator.

The embryos will be supported in their further development for three to six days, until such time as the best quality one (or two) can be selected out for transfer into the womb. Embryos that reach the blastocyst stage of development (usually at day 5) have a higher chance of attaching (implanting) and producing a baby. However, if the number of embryos available to you is small (e.g. 2-3), it may be clear which is / are the best much earlier (day 3). In this case, we would call you in for embryo transfer at this stage rather than keep the embryos in an artificial environment that will offer no further advantage over the woman’s womb.

* Images courtesy of The Association of Clinical Embryologists
Leeds Fertility is pleased to be able to offer Embryoscope time-lapse imaging incubators. These machines allow the embryos to be cultured in a closed system because they have built-in cameras (microscopes) taking pictures of the embryos every ten minutes. This means that details of the individual embryo’s development can be monitored throughout the culture period without disturbing it, and pieced together in a short video clip. Embryoscope incubation is separately funded so please check with the Team as to your position. If you wish to use Embryoscope you must declare this at the time of Nurse Consultation. Please note that the maximum number of embryo slots available per couple is 12. Any additional embryos will be incubated in the standard machines. Good quality blastocysts that cannot be used in the first treatment will be frozen for potential future use. On-going storage charges will apply in this case. The latest data from our unit indicates that the use of EmbryoScope results in a 1.3-fold increase in live birth rate per fresh embryo transfer and that the risk of early preterm birth and very low birth weight are reduced.

**Embryo transfer**
The timing of the transfer will depend on the date of the donor’s egg collection and the number and quality of available embryos generated. It would be usual to have a single embryo transferred at the blastocyst (day 5) stage of development.

Please bring your treatment diary with you.

You will be called by the embryologist on the day of your transfer with news of your embryo development / quality and a recommendation of the proposed number of embryos to transfer. EmbryoGlue® is available at Leeds Fertility to enhance the potential for implantation. Please ask for separate information (at your Nurse Consultation) on the evidence and cost if you are interested in adding this to your treatment. You will be given a time to attend for your transfer (usually early afternoon) and advised to be filling your bladder in anticipation of the procedure. A full bladder helps the passage of the fine tube (catheter) containing the embryo that makes the procedure easier, quicker and safer.

The procedure itself does not require any pain relief or sedation. It is similar to having a smear test. We introduce the embryo through the vagina and cervix, guided by an ultrasound scan through the tummy. Partners are welcome to support the woman and watch from the side. After the transfer, you may empty your bladder immediately if necessary. There is no need to lie down or rest. You will be given information about your pregnancy test timing and technique.

Two week wait
You will continue the medications you have been taking after the transfer up until the pregnancy test.
The medication will continue for three full months if the pregnancy test is positive. After the transfer and before the pregnancy test is often described as the hardest time of an IVF treatment cycle. We will not usually need to see you during this time and generally recommend that you continue with your normal activities, in order to keep your mind off the uncertainty of the result. If you wish to exercise, we recommend low impact activity and not to swim.

**Pregnancy test**

We will advise when your urine pregnancy test is due, depending on the timing of your transfer. Instructions will be provided after your transfer procedure.

**Pregnancy scan / follow-up**

The first scan is done about five weeks after the transfer when the pregnancy sac, fetal pole (baby) and a heart beat should be visible.

If all is well at this stage, we will discharge you back to your GP to make arrangements with the midwife and antenatal clinic. We shall look forward to the news of your new arrival in due course, and will then complete the final information on your treatment in the HFEA register.
Timeline summary

Donor's egg collection; male partner sperm sample required. Fertilisation and embryo culture (usually 5 days)

Baseline Scan +/- Mock Embryo Transfer

1st day or 21st day of menstrual cycle

Stimulation scan

Start preparation of the womb lining

Antibiotic vaginal cream (for five days)

Day 11-12 scan. A further scan may be necessary

Coordinate with donor's stimulation. Commence Progesterone

Donor's egg collection; male partner sperm sample required. Fertilisation and embryo culture (usually 5 days)

Embryo transfer

Pregnancy Test (approx 2 weeks after embryo transfer)
Treatment risks

Risks of ICSI

Intracytoplasmic sperm injection, ICSI has been used worldwide for over 20 years in the assistance of male factor infertility.

The risks described in this section reflect the current state of our knowledge and the guidance provided by the Human Fertilisation and Embryology Authority.

ICSI is an unnatural, invasive technique and may also use sperm that would not otherwise be able to fertilise an egg. For these reasons, concerns about the potential risks to children born as a result of ICSI have been raised. The concerns mostly involve the risk of passing on a genetic problem that would not be transmitted under normal conception circumstances. The potential result is a fertility problem in the child, especially if it is a boy. The studies of ICSI children published so far have involved relatively small numbers of children and do not yet include effects that may be seen in older children or in the next generation. Work is on-going and we would encourage patients needing ICSI to participate in long-term follow-up studies.

There is no clear evidence that ICSI results in more birth defects than occur randomly with natural conception. There is also no clear evidence to give cause for concern regarding the on-going physical and intellectual development of ICSI children.
Multiple pregnancy and the One at a Time initiative

It is our joint wish to achieve a healthy pregnancy and live birth. This is more likely with a single baby at a time, rather than twins or more. IVF has had a poor reputation for producing multiple pregnancies and these can be complicated for both mother and babies, sometimes with tragic outcomes. It is not wise to take unnecessary risks by transferring more than one embryo at a time in couples with the highest chance of success. Therefore, it is our usual policy to transfer embryos singly in treatment where the egg has come from a woman under the age of 38 years, during the first or second cycle of treatment, where the embryo development has been good overall. This practice is consistent with the HFEA Code of Practice (www.hfea.gov.uk) and the One at a Time initiative (www.oneatatime.org.uk). Egg donors are almost exclusively under 35 years and therefore it is common to perform single embryo transfers in the early cycles of treatment.

The chance of a pregnancy is closely related to the age of the egg (and therefore its quality) and to the performance of the clinic as a whole. Our figures show clearly that if we have two good quality day 5 blastocyst embryos, and we transfer both together, there is a 50% chance that if pregnancy results, it will be a twin implantation. If we only transfer one, the chance of a pregnancy resulting at all is less than 1% lower than if two were transferred. So the price paid for avoiding twins is very small relative to the high risk of seeing a twin pregnancy through to two healthy live births.

The Law permits the transfer of a maximum of two embryos in women under 40 years of age. Over 40 years, the maximum number of embryos permitted is three at any one time.
We will be happy to discuss your embryo development and the context of your chances of pregnancy on the day of embryo transfer, if you have any concerns about the advice proposed.

**Miscarriage**
The risk of miscarriage after a positive pregnancy test is approximately 20-30%, whether the pregnancy has been assisted through IVF (fresh or frozen embryo) or occurred through natural means.

Once the pregnancy sac has been seen and the heart beat identified then the risk of miscarriage falls (<5%). The risk of birth defects in babies born after IVF is no greater than in naturally conceived pregnancies.

Your personal risk is more likely to relate to the age of your donor, your family history and whether or not you have a multiple pregnancy.

**Ectopic pregnancy**
Embryos do not implant immediately upon transfer. There is a small chance that an embryo may wander up and settle in the Fallopian tube.

This is an ectopic pregnancy which, if unidentified, may burst and cause serious internal bleeding. Women whose tubes have been identified to be less than perfect are at higher risk of ectopic pregnancy after natural or IVF conception.

We will perform your first pregnancy scan early (6+ weeks) if you are at risk. The standard first pregnancy scan is done at 7 weeks (3 weeks after your pregnancy test).
Please note:

It is important to perform a pregnancy test even if you have bled, and attend for the scan after a positive test. If a pregnancy sac is not seen on scan, a blood test is taken to measure the pregnancy hormone (hCG) level in your blood. You may be asked to attend for more tests after a few days’ interval. If this hormone level is steady or slowly rising, then we may need to perform further investigations that may include a laparoscopy (surgery).

Risk of premature birth and low birth weight

There appears to be a slightly increased risk of premature birth and low birth weight after IVF with donated eggs (10-15%) compared to IVF with one’s own eggs (9%). It is not yet clear why this happens, but it could be because of immune problems as the egg donor is genetically different from the birth mother.

Women who get pregnant with donated eggs tend to be older than women using their own eggs. Pregnancy in the older woman is more risky for lots of reasons so it is important to be as fit and healthy as possible.

Risk of equipment failure:

Leeds Fertility maintains service contracts for all our equipment. There are also many safety checks in the laboratory to give early warning of any possible problems. Despite all our efforts, and very uncommonly, equipment failure may sometimes lead to loss of eggs or embryos. This is a ‘Category A’ incident that will be immediately notified to our licensing body (HFEA), the Leeds Teaching Hospitals Trust and to you.
There would usually be a thorough investigation and steps taken to prevent a recurrence of similar problems. The HFEA also operates an Alert system which all clinics use to learn from incidents elsewhere and can then reduce risks locally.

**Treatment failure**

Sometimes we may not have an explanation for why a pregnancy fails to occur even when everything has apparently gone well. We suspect that in most of these cases, the embryos were, in fact, faulty in their genetic make-up and were never destined to produce a baby. Unfortunately, the time that the embryos spend under observation in the laboratory is short and we cannot identify everything about their (genetic) chances of continuing to develop normally, and as far as a baby. When IVF embryos do undergo genetic testing, they are found to carry the same rate of genetic faults as naturally conceived miscarriages. The faults arise in the eggs of women of all ages but they are less common in younger women, which is why we do not accept anonymous donors over the age of 35 years. Genetically abnormal eggs can be as high as 50% of the total, and they become more common in women over the age of 40 years. There are often no signs of these faults at the early stages of development that we are able to observe (such as in the Embryoscope). There is still much work to do to try to overcome what can often feel like a lottery. You may rest assured that we will not stop trying.

We welcome feedback on the various aspects of our service. We use it to ensure that we are maintaining a high standard of patient experience and to try to improve the service that we provide. We would be grateful if you would spend a few moments to complete our questionnaire once your cycle is over.
Counselling and patient-to-patient support

We recognise that struggling to conceive can be upsetting. We aim to provide supportive care for both partners through this process, regardless of the outcome. You will have met one of our team of counsellors during the preparatory phase of your treatment to discuss the implications of treatment with donor eggs. They also provide support in dealing with the social and emotional aspects of fertility problems and help to find ways to cope with the on-going situation.

Counselling is free and usually delivered on Leeds Fertility premises. Some counsellors offer evening appointments. Please call 0113 206 3124 to leave a message if you would like to make an appointment, or request a referral from the doctor or nurse attending to you.

Some patients choose to support each other through social media and there is a private FaceBook page for patients from Leeds Fertility (formerly LCRM). The Donor Conception Network and National Gamete Donation Trust may also be helpful (see Useful Resources on page 47 for details).

Infertility Network UK (www.infertilitynetworkuk.com) is the leading national charity for people having difficulty conceiving. They also offer emotional and practical support with a wealth of personal experience.
Consents

Fully informed consent to the different aspects of fertility treatment takes quite a long time but it is critical to ensuring you and we understand our respective responsibilities in all possible circumstances. Further relevant information will be provided through the process in written and spoken forms. Please do not sign until you are completely clear and satisfied with your stated position. Both partners must sign all of the consent forms before we can proceed with your treatment.

Please refer to page 11 for guidance on Legal Parenthood consent requirements for both partners when donor eggs are involved.

Your consent advises us of your informed choice but does not commit you to undergo any form of treatment. **You have the right to change your mind until, but not after the event.** It is vital that all the issues are thoroughly considered beforehand and that snap decisions are not regretted afterwards.

You will have the following issues to consider at the start of treatment in relation to the eggs once they have been donated to you, your sperm and the embryos created with both:

- Fresh IVF treatment.
- Freezing of eggs / sperm / embryos.
- Research on eggs / sperm / embryos.
- Long -term storage of eggs / sperm / embryos.
- Use of eggs / sperm / embryos after death.
Fresh IVF treatment
Both partners must consent to the use of their eggs / sperm and creation of embryos with them, for the treatment of their current partner.

Freezing of Eggs, Sperm and Embryos
Please note that you have to decide the fate of your spare eggs / sperm and /or embryos and that we act as per your written consents.

Frozen eggs:
Egg freezing is extremely unlikely in the context of donor egg treatment. Eggs are not commonly frozen but can be to preserve fertility in single women facing likely early menopause (usually due to chemotherapy for cancer treatment).

Frozen sperm:
Your sperm may be in storage if it has been banked before treatment. Not all the sperm stored may be used in one treatment cycle leaving some surplus to your immediate needs.

Frozen embryos:
The best quality embryo (s) is / are selected at the time of fresh transfer. Further good quality embryos may be stored. Poor grade embryos have a low chance of surviving the freeze-thaw process such that freezing is not a sensible option.

Approximately 90% of good quality embryos survive the process and have a good chance of resulting in a pregnancy if they are intact.
Embryo freezing can only be performed with your prior written consent. The legal storage limit for embryos is 10 years from the date of freezing. The period of storage can be extended under exceptional clinical circumstances, with the agreement of a fertility specialist doctor. You also have to decide the fate of the embryos in the event of death or mental incapacitation. We strongly advise you to updated us of any change in your contact details and recommend that you consider replacement of your frozen embryos at the earliest opportunity.

**Embryo donation**
You can consider donating your embryos to help another couple. Before we can accept them for this purpose, you would both be required to have counselling to ensure all the implications have been considered, and the necessary screening tests would need to be completed. You might opt to do this if / when you have completed your family, or decided not to pursue further treatment yourselves.

**Egg / Sperm / Embryo research**
All human embryo research requires specific permission (License) from the HFEA for the project in question. All research is experimental and embryos used or created during the project cannot be transferred for treatment after the project has finished.

They must be allowed to perish. You may be offered the option to donate embryos for research, only if there is an active project running during the remaining time period available for your embryos to be in storage. Once the legal storage period is up, the embryos will have to be discarded.
Embryos destined for research are anonymised which means that there will be no feedback to you of the outcome of the experiments.

Occasionally, embryos may be specifically used in genetic projects. If the results could have implications for your or your family’s future, you will receive more information and counselling before you agree to your embryos taking part.

Offering to take part in a research project is always voluntary and will never affect your own treatment. You can change your mind and pull out at any time before your embryos are used.

**Training of embryologist scientists**

Leeds Fertility is part of the Leeds Teaching Hospitals Trust and as such, is involved in the training of junior scientists. As part of training in techniques such as egg and embryo handling, freezing, thawing or injection, it is necessary to use real eggs, sperm and embryos.

These will only ever be those that are not required for your treatment and would be otherwise discarded (e.g. unfertilised eggs, surplus sperm or poorly developed embryos). Your consent will be requested for this, in order to train junior staff, improve our service and develop new techniques.

**Humane discarding of spare embryos**

Only *good quality* embryos can be successfully frozen, donated to another couple or used for research. If you do not wish prolonged culture with a view to freezing then you must instruct us to humanely discard your spare embryos.
Use of eggs / sperm / embryos after death

Men can opt to permit their female partner to use their sperm or embryos created with them after their death. There are ethical and legal concerns that you must consider very carefully before making this choice.

We recommend that you have a discussion with the counsellor to consider the implications to all parties fully, if you are considering this.

General legal information about how Leeds Fertility is regulated and conducts its work

The Human Fertilisation and Embryology (HFE) Act (1990, amended 2008) and the HFE Authority (HFEA) regulate all treatments involving human eggs, sperm and embryos.

The HFEA issues the Code of Practice that we work by and it inspects us regularly to ensure standards are maintained. All UK clinic results are reported to them and are publically available (www.hfea.gov.uk).

HFEA register

The Authority keeps a confidential register of identifying information on all patients, their treatments, donors, recipients and children born after HFEA licensed treatments.

Since 2008, adults may request information from the HFEA as to whether they were conceived with donor material and the HFEA may disclose such identifying information as was available at the time of the treatment.
Confidentiality of fertility treatment

All information regarding your FERTILITY treatment is strictly confidential under our HFEA License and is subject to both the HFE Act and the General Data Protection Regulation (GDPR).

We may only communicate with your general practitioner, referring consultant and other carers with your written consent.

Once we have disclosed treatment information to individuals who are not subject to the HFEA Licence (e.g. your GP) that information can no longer be controlled by us in its onward travel. It will still be regulated by the GDPR and General Law of Confidentiality, as for all private medical information. In general practice, information will be accessible to other GPs and staff working within the practice even if your consent specifically named only one of the several GPs in your practice. When changing GPs, your medical records will be transferred to your new GP practice without any regard for any specific named consent you gave us in the past. The General Law of Confidentiality will apply.

From time to time your notes may be inspected at Leeds Fertility for audit (standards checking) by other officials e.g. HFEA members, Care Quality Commission, Patient Safety Agency and National Care Standards Commission.

You have the right to decline consent to share your fertility information but we need to consider your reasons for declining consent in our assessments. Generally, it is advisable for us to keep your G.P. informed of the progress of your treatment in case you need them in an emergency.
Leeds Fertility patients should be aware that Leeds Teaching Hospitals uses a password-protected system for the requesting and reporting of medical investigations to which healthcare providers have access within the hospital and in Primary Care (General Practice). Professional conduct dictates that a healthcare provider should only access results for a patient under their specific care. Inappropriate access to results is a disciplinary offense and all usage of the system is audited.

**Welfare of future children**

The Law states that ‘a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child (other children in the household or the family) who may be affected by the birth’.

It is therefore our legal responsibility to have a written procedure for assessing the Welfare of the Future Child and that of any other existing child who may be affected by our treatment.

*Factors considered in assessment include:*  
1. The couple’s commitment to having and bringing up a child.  
2. The couple’s ability to provide a stable and supportive environment for the child/children.  
3. The couple’s medical history and that of their families, considering factors that may risk the child’s wellbeing.  
4. Both partner’s health (including their ages) and their ability to provide maternal and paternal nurturing to the child.
5. The couple’s ability to meet the needs of the children in the event of a multiple birth.

6. Any risk of harm e.g. that of inherited disorders, transmissible disease, neglect or abuse.

7. Any risk a new born may put on the welfare of the existing child within the family.

Our protocol has been approved by our local Ethics Committee. Under specific circumstances, we may also need to contact your general practitioner, other medical specialists, authorities and agencies e.g. social workers, police etc for information.

This is to enable the members of the team at Leeds Fertility or the Clinical Ethics Committee in The Leeds Teaching Hospitals Trust to formally consider the welfare of the future child when appropriate.
Glossary

• **Biochemical pregnancy:** This is a pregnancy where the embryo has tried to implant but has not continued to develop. Pregnancy hormone reaches the bloodstream and urine to make a pregnancy test positive but the level is invariably low / weak and falls to zero within days.

• **Blastocyst:** This is a particular stage of development of an embryo which should be reached by day 5-6 after egg collection. A blastocyst has 50-60 cells and they have begun to separate into those that will form the baby and those that will form the placenta (afterbirth). A small area of fluid separates the two types of cells. Shortly after this stage the embryo will hatch and should implant into the lining of the womb.

• **Cleavage:** Cleavage is the term used to describe the multiplication of the cells of the embryo.

• **Down-regulation:** This is the first phase of treatment in a recipient cycle where the natural cycle is switched off.

• **Ectopic pregnancy:** This is when the pregnancy implants somewhere other than the heart of the womb where it should be. The commonest location is in one of the fallopian tubes but ectopics can also occur in the cervix and the top corners of the womb where the tube comes into the main cavity (cornual ectopic).

• **Eggs:** A woman’s lifetime supply of eggs is present in the ovary at birth. They reduce in number and quality with time. They pass on the woman’s half of the genetic instructions to the embryo / baby.

• **Embryo:** Once the fertilised egg begins to cleave (multiply its cells) it is called an embryo.
• **Fertilisation:** Fertilisation is when the genetic material from the egg and sperm combine to create a new and unique cell which may go on to develop into an embryo and then a baby.

• **Follicles:** These are the sacs in the ovary that contain the egg. One follicle develops in every natural monthly cycle. The IVF process should cause several to develop at the same time which makes the ovaries larger for a short time (several weeks).

• **FSH:** follicle stimulating hormone causes the eggs to mature in the ovary.

• **GnRH Agonist:** A hormonal drug that first stimulates and then inactivates the pituitary gland e.g. Prostap, Buserelin, Naferelin. These can be used to block ovulation during long IVF cycles and cause ovulation in short IVF cycles such as those used for donor stimulation.

• **GnRH Antagonist:** A hormonal drug that inactivates the pituitary gland e.g. Orgalutran, Cetrotide, Fyremadel, only used to prevent ovulation in short IVF cycles, especially in donor cycles.

• **Gonadotrophins:** Hormones produced naturally by the pituitary gland to stimulate the ovary to produce and release eggs e.g. FSH, LH. These drugs are produced as medicines to over-stimulate the ovary of the donor during IVF to get lots of eggs ready at once e.g. Merional, Menopur, Gonal F, Puregon, Meriofert.

• **HCG:** Human chorionic gonadotrophin is also a gonadotrophin but it is not produced in the pituitary. Normally, it is only produced by the placenta (afterbirth) during pregnancy. It is able to act like LH, but is stronger. We often use it in injection form to begin the ovulation process (trigger) before the egg collection. It can also help to prepare the womb lining for implantation.
• **ICSI**: Intracytoplasmic sperm injection: a technique where an individual sperm is injected inside an egg. It is used to improve the chance of fertilisation when the sperm quality is not ideal.

• **LH**: luteinising hormone causes the release of the egg at ovulation and prepares it for fertilisation by the sperm.

• **Luteal phase**: This is the phase after egg collection, including the embryo transfer, up until the pregnancy test, when the recipient is taking progesterone.

• **Miscarriage**: any positive pregnancy test which does not reach 24 weeks of pregnancy and the potential for a live-born child is a miscarriage. Miscarriage is as common after IVF as it is after natural conception. Bleeding in early pregnancy is not always bad news, especially if there is no cramping pain. Unfortunately some pregnancies miscarry without any outward signs (bleeding) and are not identified until a scan is done.

• **Oestrogen**: This hormone is naturally produced by the follicle in the ovary as the egg is growing. Its main job is to thicken the lining of the womb for the pregnancy to implant. It can also be given in tablet or skin patch form e.g. progynova, Elleste.

• **OHSS**: ovarian hyperstimulation syndrome is a risk of IVF treatment which can be serious if not recognised and treated. It happens when the ovaries are over-sensitive to the stimulation (FSH) injections and produce too many follicles. It can cause pain, abdominal bloating, sickness, diarrhoea, dehydration and rarely, serious blood clots. Your donor will be warned if she are at risk, for the symptoms and signs to look out for and report to us for further advice.
• **Ovary:** Stores all the woman’s eggs for her whole life and produces hormones.

• **Pituitary gland:** In the head, behind the nose, produces many hormones including those that control the ovary and testis.

• **Progesterone:** This hormone is naturally produced by the follicle after ovulation and is also responsible for preparing the lining of the womb for implantation. It can also be given as a vaginal pessary e.g. Cyclogest or as an injection e.g. Gestone, Prontogest, Lubion.

• **Sperm:** The sperm develop in the man’s testis and continue to do so throughout adult life. They do not suffer the same deterioration with age as the woman’s eggs, as they are constantly being replaced. They pass on the man’s half of the genetic instructions to the embryo / baby.

• **Stimulation:** This is the phase where the daily injections stimulate the ovaries to produce multiple eggs for the donor, and when the recipient starts her oestrogen tablets.

• There are 2 types of gonadotrophins produced by the pituitary gland: FSH and LH.

• **Trigger shot:** This is usually hCG (5000-10,000 units) but can also be buserelin (0.5-0.75ml). This injection begins the release of the egg 35h before the egg collection. The timing is specific to your donor and she should follow her personalised instruction.
Useful resources

Donor Conception Network
- www.dcnetwork.org
  A UK-based support network for families with donor-conceived children, those considering donor conception and donor-conceived individuals.

National Gamete Donation Trust
- www.ngdt.co.uk
  An excellent resource for donors and recipients covering the process in detail and from all aspects.

Human Fertilisation and Embryology Authority, HFEA
- www.hfea.gov.uk
  The regulatory body website has lots of information for patients.

Infertility Network UK
- www.infertilitynetworkuk.com
  The UK’s leading infertility support network offering extensive information and support through treatment. They provide advice regarding funding and a variety of factsheets.
British Fertility Society
• www.britishfertilitysociety.org.uk
  The UK professional society promoting high quality practice and research.

British Infertility Counselling Association
• www.bica.net
  The professional association of infertility counsellors in the UK.

The Daisy Network
• www.daisynetwork.org.uk
  This charity provides support and information for women who are facing premature ovarian insufficiency (premature menopause) and its consequences.

Multiple birth matters
• www.oneatatime.org.uk
  This site provides information behind the drive to reduce multiple pregnancies during assisted conception treatments.
• www.multiplebirths.org.uk
• www.tamba.org.uk
  These two sites offer a wealth of information on twins and multiple births / pregnancies.
Health information for before and during pregnancy
• www.nhs.uk/conditions/pregnancy-and.../pregnancy-and-baby-care.aspx
  This is a comprehensive NHS resource on preparing for and achieving a healthy pregnancy.

The Miscarriage Association
• www.miscarriageassociation.org.uk
  If you have been affected by miscarriage, ectopic pregnancy or molar pregnancy you will find information and support here.
Contact us

By post

• Leeds Fertility, Leeds Teaching Hospitals NHS Trust, Seacroft Hospital, York Road, Leeds, LS14 6UH

By Email

Egg donation coordinator (Nurse Specialist)

• leedsth-tr.Eggdonors@nhs.net

Online

• Web: www.leedsfertilityclinic.co.uk

By telephone

Mon-Fri 08.00-17.00

• For all NHS appointments: 0113 206 3100
• For clinical queries: 0113 206 3102

Sat-Sun 08.00-12.00

• Clinical queries only: 0113 206 3102

In an Emergency

During working hours

• Please call appointments or clinical queries as needed on the above numbers.

Outside working hours

• Please call Leeds Teaching Hospitals Switchboard on 0113 243 3144 and request to be put through to the Duty Nurse / Dr for Leeds Fertility. If necessary, attend your local Accident & Emergency department.