



Embryo Donation

a guide to the donation process



ivf.com.au ♦ 1800 111 483

Life. Pass It On.

Introduction

The world's first successful pregnancy using frozen embryos occurred over two decades ago in Australia. The ability to successfully freeze then thaw embryos opened up a number of opportunities allowing couples to put embryos in storage for later use.

IVFAustralia's embryo donor program facilitates treatment with known or de-identified embryo donors. This booklet explains the embryo treatment program. IVFAustralia has a carefully organised system, including a waiting pool, to ensure fair and non-discriminatory access to treatment with de-identified embryos.

For many people who have completed their families through IVF, the presence of remaining embryos can create a real dilemma. At IVFAustralia, we give couples a number of options. These include: ending the storage of the embryos; donating them for research; or donating them to other couples that cannot produce their own embryos.

When a couple has embryos stored that are excess to their needs, it is possible to donate them to other people. The couple with the excess embryos are the '**Donors**' who are able to help others, the '**Recipients**', in their attempt to become parents.

Embryo donation is a relatively simple medical treatment but can be a very difficult process emotionally. It is critical that, before embarking on this approach careful consideration is given to the long-term implications for the family and, in particular, how the couple will feel in the long term about donating their embryos to another family.

Using donor embryos may not be the right option for everyone. We do not offer treatment with embryo donation to women beyond the age of natural menopause (52nd birthday) or to anyone whose health could be compromised by a pregnancy. Likewise we do not accept embryos for donation that were created when a woman was over 40 years of age. There are occasions when IVFAustralia may consider on medical grounds that donation of embryos is inappropriate and we will not necessarily accept all the embryos that are offered for donation.

Donor arrangements can be either "Known" where the donors and recipients know each other or "De-identified" where, initially at least, the identity of the donors is not known to the recipients. However, in both known and de-identified donation, the donors must give explicit written consent to provide identifying information to any offspring from this donation once they reach 18 years of age. They must also give written informed consent to their name being included on the NSW State Donor Registry.

How can I become an embryo donor?

If you have embryos in storage and they are excess to your needs, it is possible to donate them to other people. The first step in this process is to either nominate the option on the 'Declaration of Excess Embryos Form', call our information line on 1800 111 483 or register on the Embryo Donation website donation.ivf.com.au. We will then arrange for you to receive an information package.

Informed consent

To minimise the likelihood of long term social, emotional or psychological problems developing, professional implications counselling of all parties is required before the final decision is made to proceed with embryo donation. This is one of the most important aspects of preparation for embryo donation. We want to ensure that everyone involved makes the right decisions for themselves and their family; decisions that they will still be comfortable with many years from now.

All of this is discussed in detail in the later section, "*Thinking it over*"

Can I be paid to be an embryo donor?

No. It is illegal in Australia to receive or make any type of payment for human tissue, including donated embryos. The recipient(s) in a known donation should meet all expenses directly incurred in making the donation (e.g. travel, parking) but cannot provide remuneration beyond directly incurred expenses.

Becoming an embryo donor

Who can donate embryos?

All embryo donors at IVFAustralia are required to:

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- ◆ be older than 21 years of age; and
 - ◆ be shown by blood tests, before and after three months of quarantining of the embryos, to be free of any serious infections or genetic conditions;
- and
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- ◆ have no past or current history of mental health problems; and
 - ◆ have no medical conditions or illnesses, in either the donors' themselves or in their family that may be passed on to future children

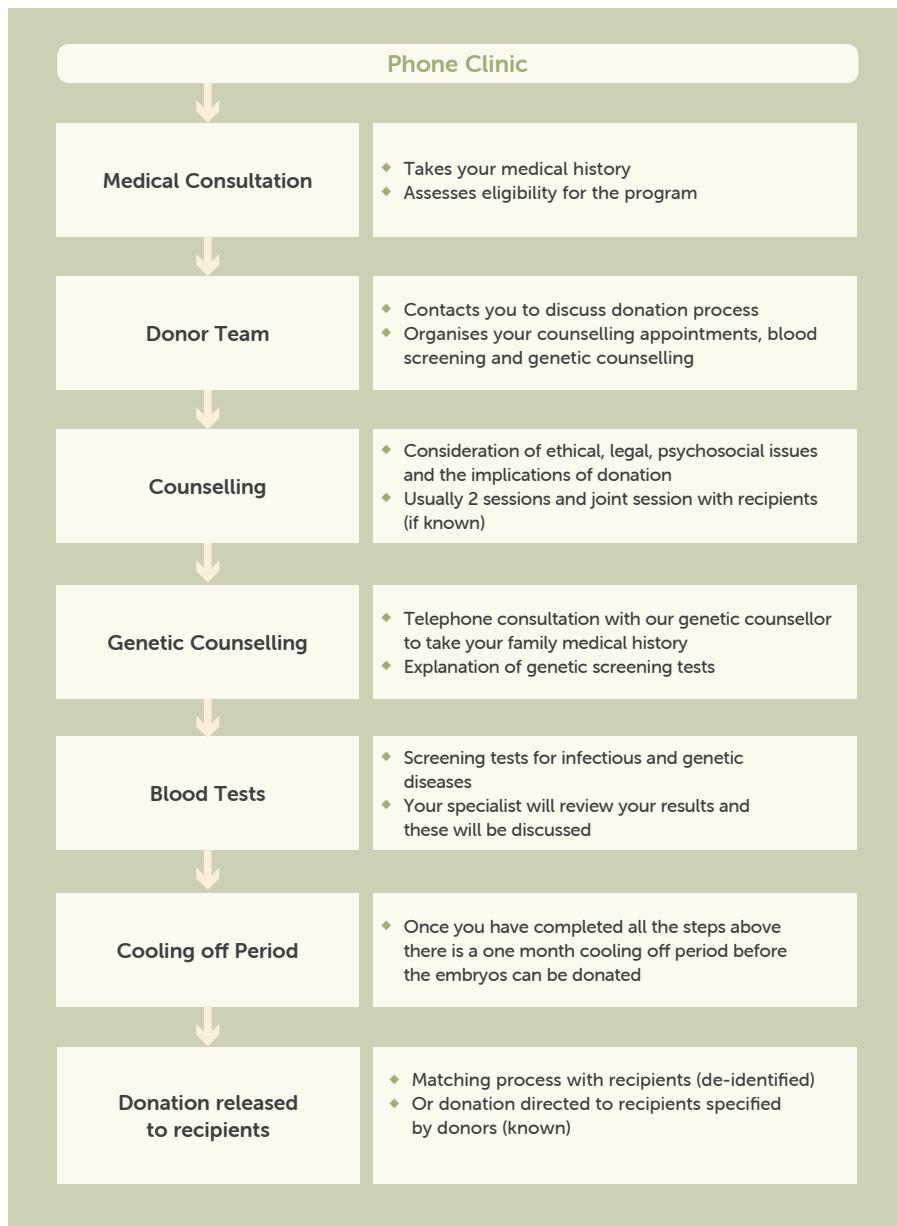
Conditions on embryos

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- ◆ embryos must not have been formed from donated eggs or sperm;
- and
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- ◆ embryos must have been stored for less than 10 years; and
 - ◆ excess embryos from one donated set cannot be further donated to other couples, they can only be returned back to the donors.

Patients may often have strong and very sound reasons for receiving embryos from particular known donors who fall outside these guidelines. In this instance, we will discuss the implications (health or otherwise) of using a specific donor with both the donors and recipients.

With all donors, it may become apparent during the assessment process that embryo donation is not a suitable option or that the donors are not suitable donors. When a problem of this sort arises, the first conversation we have will be with the embryo donors. We will never pass health or any other confidential information about the donors onto the recipient(s) without the written consent of the donors. However, if any health information about the donors arises, that could have serious implications for either the health of the recipient(s) or any children that could be conceived, we need the donor to give his/her consent to release of this information. We cannot proceed with the donation without this.

Figure 1 Embryo donor preparation



Preparation for embryo donation

Any couple that is interested in donating their embryos to others can indicate on the 'Declaration of Excess Embryos Form' that they wish to consider the option of donating their embryos or register their interest at donation.ivf.com.au.

The clinic counsellor will then contact the donors to give information on how the embryo donation process works and discuss some of the issues involved in embryo donation. If the donor decides to proceed, they will be booked in for a detailed implications counselling session with one of our Fertility Counsellors (available at all of our clinics) where social, emotional and legal issues are discussed, as described in detail in the section "*Thinking it over*"

The donor team will arrange an appointment with an IVFAustralia affiliated fertility specialist who will take a detailed medical history to ensure potential donors are suitable. The specialist will also arrange for blood tests to exclude infectious diseases (including HIV/AIDS) and to exclude some major genetic diseases such as the carrier status for cystic fibrosis.

Note that all information collected by us in the course of the medical assessment, the testing and the counselling is strictly confidential and that information will not be passed on to a recipient without the written permission of the donor.

Finally, all test results and their findings will be discussed with the donor. If anything arises during the assessment process that could have serious implications for the health of either the donor, the recipient or any child conceived, the doctor will discuss with the donor whether they are prepared to consent to the release of that information to the recipient. In some circumstances, if the information is serious and the donor decides not to release that information, we cannot proceed with the embryo donation.

Genetic counselling and testing

Careful thought should be given to the implications for both donors and recipients, of the Genetic counselling and testing process and the long-term consequences of potential inheritable conditions. Sometimes information may arise that could have important consequences for the donor and their own family.

What is Genetic counselling?

Genetic counselling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease.

Why is Genetic counselling important in a donation process?

Genetic counselling will carefully document the genetic background of the embryo donors so that if a child has health problems in the future, they have access to a full account of their genetic background. There is also the opportunity to provide expert advice and support in considering the long-term implications of any genetic information that emerges.

Do I need to prepare for the Genetic counselling session?

Yes. Prior to the genetic counselling session, both potential embryo donors will be asked to gather information about their family medical history. This sort of information is of a very personal and sensitive nature and is often difficult to gather. However, whatever information is discovered will be valuable to the genetic counselling process and enable the genetic counsellor to make the best use of the session.

To assist and guide the family medical history gathering we will provide you with an information sheet titled 'Documenting Your Family Medical History'.

What happens during the Genetic counselling session?

During the session, the genetic counsellor will go through the family medical histories gathered. This will help to understand the inheritance patterns of any potential disorders and assess the chances of a child born as a result of your donation being affected with those disorders. The genetic counsellor will distinguish between risks that every pregnancy faces and risks that are specific to pregnancies that may result from this particular donation.

The genetic counsellor will also discuss the specific tests that are planned, including the karyotype (chromosome analysis) and the Cystic Fibrosis and Thalassaemia genetic testing performed as a part of the donor assessment process.

Karyotype: The karyotype is able to identify any chromosomal anomalies that may increase the risks of a pregnancy being affected with a severe chromosomal abnormality.

Cystic Fibrosis: Cystic Fibrosis is a genetic condition that affects many organs in the body, especially the lungs, pancreas and sweat glands. About 1 in 25 people of European Caucasian ancestry are genetic carriers of Cystic Fibrosis and are at increased risk of having a child born with Cystic Fibrosis.

Thalassaemia: Thalassaemia is a genetic condition that can lead to serious diseases in the red blood cells. A person who carries only a single thalassaemia gene may have mild anaemia, but usually has good health. At least 1 in 20 adults carry a single gene for this condition, however the chances are higher in certain population groups such as those from Asia, Africa and Southern Europe.

Fragile X (only female donors tested): Fragile X is a genetic condition characterised by varying degrees of behavioural, emotional and learning difficulties. It affects about 1 in 4,000 males and between 1 in 5,000 and 8,000 females. The gene that causes Fragile X is found on the X chromosome and therefore men, who only carry one X chromosome, are at most risk of being affected. As women carry two X chromosomes, if one chromosome is affected they will be a carrier for the condition. The sons of a female carrier have a 50% chance of receiving the faulty X chromosome and being affected with the condition.

Daughters also have a 50% chance of inheriting the faulty chromosome and being a genetic carrier for the condition. Female carriers have an increased risk of premature ovarian failure.

Further genetic tests may be needed in some ethnic groups (e.g. Ashkenazi Jews) and, if these are necessary, the genetic counsellor will explain this to you.

Cooling off period

Once you have completed the counselling sessions and consented to donate, there is a one-month cooling-off period. This gives you the chance to fully consider your decision before your embryos are used by a recipient.

The NSW Donor Registry

Under current NSW law, a child born from a donated embryo is deemed to be the child of the recipient couple and, as such, the recipients put their name on the birth certificate. As parents, the recipients have the same rights and obligations as other parents. These rights and responsibilities to the children continue even if the couple separate or divorce. Embryo donation is a specialised area of the law. If you have any concerns in this regard, you should seek your own legal advice. IVFAustralia is not qualified to provide legal advice.

The NSW Assisted Reproductive Technology Act

The NSW Government has implemented the NSW Assisted Reproductive Technology Act, effective from the 1st January 2010.

The NSW legislation has a number of important implications for patients who are considering whether to donate or receive, donated eggs/sperm or embryos.

The main points of the Act are:

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- ◆ Donated embryos from a single set of embryo donors can only be donated to one family. (If the embryos are not used, the embryos are returned to the donating couple). A group of embryos from one family will not normally be split amongst multiple recipients.
 - ◆ When a child is born following treatment with donated embryos, identifying information about the donors of the embryos will be placed on The NSW Health Central ART register
 - ◆ Once the child is 18 years of age, he or she will have access to this information.
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At IVFAustralia, all donors are required to consent to this exchange of information. If the donor is unable or unwilling to give this consent, it will not be possible for their embryos to be used in the medical treatment of another couple.

The NSW Health Central ART Register is held by NSW Health in the strictest confidentiality. In the future, where a person aged 18 or above approaches NSW Health and can demonstrate that he/she is a person who has been conceived from donated embryos, they will be able to obtain access to identifying information about the donor from whose embryos they have been created. No other person will be granted access to this information.

Arrangements for exchange of information

Embryo donors are only entitled to non-identifying information about the recipient families and any offspring born. However, there is little doubt that the voluntary information exchange of a known donor relationship helps the children in the future. In a known donor relationship, the recipient family may often give the donors information about the child although the recipients are not obliged to do this. On request to the clinic, embryo donors are entitled to be told about the number, gender, and the year of birth of children born to each family using their donation but will not be given any further information without the consent of the recipients of the donation.

What information about the embryo donors is given to offspring or recipient(s)?

Any information about the donors given to the offspring and recipients is dependent on the consent of the donor. Most of the time, in a known donor relationship, there is direct exchange of information between donor and recipient. The amount of information exchanged will generally depend on mutual trust, level of comfort and shared plans regarding the donation and the length of the relationship.

Normally, we will provide recipients with:

- ◆ All relevant details of the medical and family health history of both donors
- ◆ The year of birth and gender of all children previously conceived by either of the donors.
- ◆ A detailed questionnaire completed by each donor describing themselves
- ◆ Details of the embryos themselves, including the quality, the date of formation and the age of embryo donors at egg collection

Once the conceived children reach 18 years of age, they receive identifying information about their donors. This information includes the donor's full name, date of birth and the last known address. This information is also provided to and stored with the NSW Donor Registry at the NSW Department of Health.

Donor/Recipient matching

Many embryo donation arrangements are made by people who know each other. On the other hand, embryo donors and would-be recipients will often approach us separately. Through our Embryo Donors website, we can assist donors and recipients in finding a match that all participants are comfortable with.

Once the participants have completed counselling and had a consultation with a specialist, they will be able to register on our Embryo Donors website to seek a match.

Both the donors and the recipients complete a short consent form and an online profile describing themselves. When filling this out, both the donors and the recipients decide, which information they wish to include and which information they do not wish to include. The donors are under no obligation to answer any question that they do not wish to. However, any medical information that is relevant to the future health of the recipients or their potential children may not be disclosed at this stage but will be made clear to potential recipients before any donation is accepted.

The Donors will then browse the recipients profiles and make an offer directly to a couple or individual either through the private messaging function or will make a silent offer via our donor team. All information exchanged is non-identifying unless the participants choose otherwise.

If the recipients decide to accept the gift of the embryos, they can contact our donor team to complete the process. The donors will then have their blood screens and genetic counselling if these have not already been completed, and the recipients will complete their counselling.

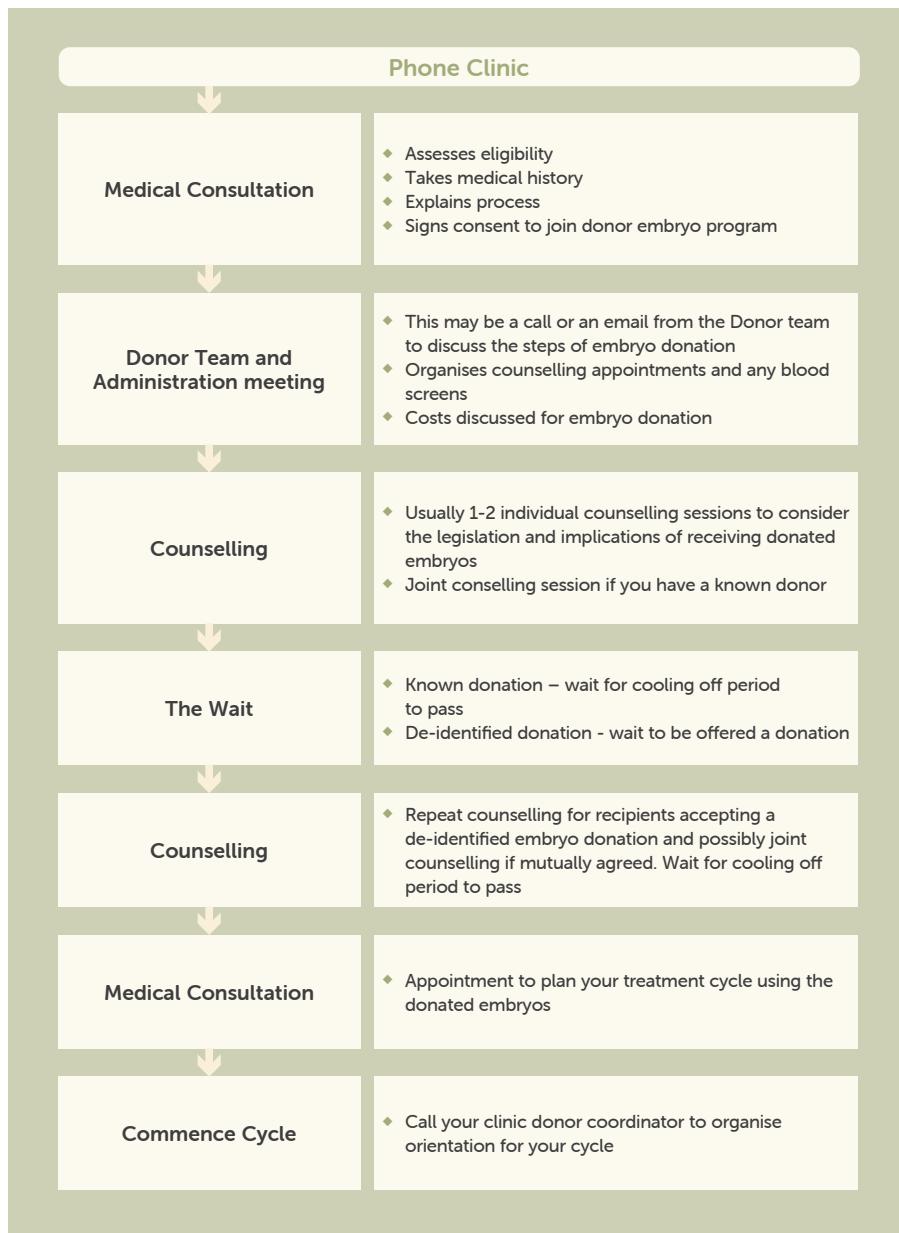
A treatment cycle will be arranged for the recipients where the embryos will be thawed and transferred, normally one at a time.

Once a recipient accepts a donation of embryos, all the embryos available from that donor will be made available for that recipient's use. Should the recipient be successful in achieving a child from those embryos and wish to have another child but have no embryos remaining from that donor, then the recipient can rejoin the website, and wait for an offer from another donor. If, the initial donation of embryos does not result in a child, the recipient can go back on the website to be considered for another match.

Unfortunately, due to the shortage of de-identified embryo donors, and the differences in donor's preferences, registering your profile on the website does NOT guarantee that you will receive treatment using donated embryos.

If, after accepting a donation, the recipients decide that they no longer wish to use all the embryos to have a child, the responsibility for decision-making about the embryos reverts to the original donor. The recipient of an embryo donation cannot make a decision to either dispose or on-donate the donated embryos.

Figure 2 Donated embryo recipient preparation



Use of donated embryos

Who would normally use donated embryos?

The embryo donation program is available to all IVFAustralia patients who have received medical advice that this will be the best approach for them and who wish to access this treatment. There is no Medicare rebate for fertility treatment unless there is a medical cause for the infertility.

For health reasons, treatment with donor embryos is not provided to women past the age of the natural menopause (the 52nd birthday).

The preparation process for the recipients (See Figure 2)

1. An appointment with an IVFAustralia specialist (GP referral required) who will take a comprehensive medical history. The ART information booklet and the necessary consent forms will be provided along with a preliminary discussion regarding the implications.
2. Detailed implications counselling, usually two individual appointments for the recipient(s) (including de-facto), are held with one of our fertility counsellor as described in detail below, "Thinking it Over". The fertility counsellor will also go through the consent forms with the recipients.
3. Standard blood tests for recipients are conducted to screen for heritable genetic conditions.
4. Where the recipient has a known donor the preparation of the donor proceeds in parallel with the recipient.
5. If the recipient does not have a known donor, the recipient then joins the Donor Embryo website as described previously.
6. Once embryos are offered for donation, the recipient will be notified and given time to consider the profile of a potential embryo donor couple. If the recipient is happy to receive this couple's embryos, the donation process continues. If the recipient does not wish to accept this couple's embryos, the recipient can remain on the website to wait for another offer of donation.
7. Second implications counselling for embryo donation. Once the recipient has accepted embryos for donation, further implications counselling takes place.
8. Follow up medical appointment with an IVFAustralia specialist to plan the treatment cycle and discuss any other issues that have arisen.

How are donated embryos used to achieve a pregnancy?

The frozen embryos are thawed and then transferred to the uterus at the right stage of the month, in a procedure that is similar to having a Pap smear performed.

Depending on the normal hormone levels and menstrual cycle of the woman receiving the embryos, the embryos will either be transferred on the right day of a natural cycle or hormone treatments will be used. If a natural cycle is used, the recipient undergoes blood tests to determine the day of ovulation and the embryo is transferred after that, depending on the exact stage of development of the embryo.

If hormone treatment is used, the recipient will receive oestrogen treatment for two weeks. An ultrasound scan will be performed to check that the lining of the uterus is thick enough then progesterone pessaries will be given for the second half of the cycle. The embryo is transferred after the start of progesterone pessaries, with the exact day depending on the stage of development of the embryo.

What are the chances of success?

The likelihood of success for each cycle using donated embryos varies enormously and really depends on the type of embryos to be used. Our experience at IVFAustralia from donated embryos (where normally babies have already been conceived from that batch of embryos) is that the overall success rate is approximately 65% per transfer.

What does embryo donation treatment cost?

The recipient is required to pay for all the costs of the potential donors' assessment and treatment. There are several separate components to the costs of treatment with donor embryos.

Donor preparation expenses

To comply with relevant Australian legislation that prohibits trading in human sperm and eggs, these expenses are calculated at cost recovery rates only. This includes the expenses involved in counselling, genetic counselling and medical testing both embryo donors.

This is covered by a single charge that is payable at the time of the initial medical consultation of the donor. There is a specific consent form for these charges that outlines the individual expenses involved. This charge is non-refundable.

Once the donation is complete (i.e. after the 1 month 'Cooling Off' period), the recipient will also be liable for ongoing storage fees for any remaining donated embryos in storage.

Costs for the cycle

The costs for the actual donor embryo treatment cycle are complex. The Unit Administration Manager will normally go through these in detail with the recipient.

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- ◆ The recipient may be able to reclaim some of the costs of a Frozen Embryo Transfer cycle under the Medicare safety net.

Thinking it over

Implications counselling for potential donors and recipients

When deciding to become an embryo donor or recipient there are many psychological, legal and ethical factors to consider. Your IVFAustralia counsellor will help take you through many of these implications to assist you in coming to a fully informed decision. Many people will have already researched and discussed the implications of embryo donation before beginning the formal process with IVFAustralia. It can be helpful to discuss these issues with your partner and the other participants before the initial medical consultations.

Issues raised in this session include:

- ◆ Exploring the reason/s why the donors wish to donate and any overt or covert coercion or pressure there might be to proceed with the donation
- ◆ How the donation will affect the donor's current life situation
- ◆ Whether both partners agree with the idea of the donation and whether there are any serious reservations or concerns for any party
- ◆ The donor's and the recipient's personal background and family history. This includes: mental health issues, alcohol/drug use, hobbies and interests and occupation
- ◆ How all the parties will feel about children born with the assistance of the donation
- ◆ The potential for feelings of grief and loss, should the donation not succeed
- ◆ Values, beliefs and wishes regarding termination of an abnormal pregnancy and around the use of embryos that are surplus to the needs of the recipient
- ◆ All parties understanding of the process and risks of treatment
- ◆ Readiness of all parties to undertake embryo donation, particularly both donors' and recipients' level of acceptance and understanding of the significance of the decision
- ◆ Recipient's feelings about the fact that neither parent will be genetically related to the child.
- ◆ The effect of the donation on the donor's and the recipient's families including existing children, partners and immediate family

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- ◆ 'What if' scenarios and their consequences are explored for a range of areas of family life related to embryo donation and family dynamics
 - ◆ Expectations are shared regarding contact between the donor and recipients and any potential child born from this process
 - ◆ Telling the children and other family members about the donation: who, what, how, why and when
 - ◆ Legal framework - IVFAustralia counsellors are not qualified to give legal advice and recommend qualified legal counsel for donors who have any legal concerns
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It is important to note that while the IVFAustralia counsellors are all registered psychologists or social workers, no formal psychometric assessment of the mental health of the donors, nor their ability to cope with donating, is made. If the counsellors note anything of concern in the session they will make a recommendation to the treating fertility specialist. Information shared in every counselling session at IVFAustralia is confidential. However, because IVFAustralia is a medical clinic, information affecting a patient's medical treatment may be recorded on the medical file.

Telling children about their conception

The welfare of the child is important and this includes any current children of the recipients or donors. Current research and the experiences of offspring conceived through donation suggest that children should be told of their biological origins and that secrecy can have adverse effects on family relationships. Parents may feel anxious about how and when to do this, and how their children will react. There is no one right way to go about this. Advice on how and when to tell children about their genetic origins is available from your counsellor, who will be able to provide you with extensive resources on this topic.

Exchange of Information and plans for contact between donors and recipients

Information can be exchanged either through the IVFAustralia clinic or directly between donors and recipients, provided all parties agree. It is recommended that both donors and recipients provide documentation of their preferences for the future exchange of information and contact during the counselling process.

Donors can nominate their preferences on their online profile and ask to have this documented in the counselling notes. Recipients can describe their preferences in their profile and ask to have their preferences documented in the file notes. It is important that all parties continue to update their contact details with IVFAustralia so that we can facilitate requests for future exchange of information.

Preferences for exchange of information that are nominated during preparation for donation will not be binding in the future. Rather, they will be used to guide IVFAustralia clinic staff as to whether an approach for exchange of information or contact will be welcome. All future approaches for exchange of information and contact can be considered and either declined or consented at that future point in time.

Letters, photographs or other information may be placed on file for future exchange, providing there is mutual consent to that exchange of information. If one party only gives consent, the information will be held on that party's file and a file note made in the other party's file indicating that information has been received by the clinic.

Relationship between known embryo donors and recipients

Where the donors are either relatives or close friends, there are important considerations. In particular, potential pressures that could surround the decision to donate, potential emotional reactions that may emerge and exist in the relationships between all parties and ways people may manage the feelings and reactions of other friends and family. Some of these feelings may include: gratitude, a need for space, jealousy, joy, anxiety and uncertainty. Professional counselling is available to support all parties before, during and after the embryo donation process.

Further Information

Weblinks

IVFAustralia

ivf.com.au

ACCESS Infertility Support

access.org.au

NSW Health

health.nsw.gov.au/aboutus/legal/art information about the NSW Donor Registry

Donor Conception Network

(United Kingdom) donor-conception-network.org

There are a series of booklets titled 'Talking and Telling' available for free download which consider many aspects of telling children and others about donor conception.

Infertility Treatment Authority

ita.org.au

This is the statutory body established by the Victorian Parliament to administer the regulation of infertility treatment within the State of Victoria, Australia. It has been established under the provisions of the Infertility Treatment Act 1995. It has very useful information to assist people with decisions about telling about donor conception. These resources are available free of charge and are in pdf format.

Books

Bourne, Kate. (2002). *Sometimes it takes three to make a Baby: Explaining Egg Donor Conception to Young Children*. Melbourne: Melbourne IVF. ISBN: 0958190305. (Children's Book)

Ehrensaft, Diane. (2005). *Mommies, Daddies, Donors, Surrogates: Answering Tough Questions and Building Strong Families*. New York: The Guilford Press. ISBN1-59385-133-2.

Other Resources

Telling & Talking free downloadable booklets from www.dcnetwork.org

Let the Offspring Speak from the Donor Conception Support Group

My Story dcnetwork.org

X, Y and Me Books xyandme.com.au



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