

13 November 2006

WHAT YOU NEED TO KNOW ABOUT DONATING SPERM, EGGS OR EMBRYOS

Introduction

The donation of sperm, eggs or embryos to help a couple have a child is one of the most generous gifts anyone can give. Many donors feel a sense of pride, knowing the joy they have brought to people who could not otherwise become parents. But the decision to donate can have far-reaching consequences for you, the people who receive your donation, any children that are born as a result, and for your own family if you have one.

This leaflet aims to:

- help prepare you for donating
- provide information about the law and how it affects you
- answer your questions about donating
- encourage you to think about the issues that you might face

What do I need to think about before donating?

The gift of sperm, eggs or embryos to people who long for a child is one like no other, but it can have a far-reaching impact on the people who receive your donation, the donor child, and you and your family.

In a legal and social sense, the people who receive your donation will be the parents of any child that is born. But the child will inherit your genes and therefore they, and any children of theirs, will be genetically related to you. You should consider how you feel about this now and try to imagine how you may feel in the future.

There are also legal issues to consider. As the law now stands, once they reach 18 anyone born as a result of your donation will be able to find out who you are, and may want to get in touch. You need to think about this carefully and discuss it with your partner (if you have one) and your wider family.

Why does the HFEA need to be involved?

The HFEA - Human Fertilisation and Embryology Authority - is the body that regulates fertility treatment in the UK. We keep a Register of all licensed fertility treatments, which includes information about whether the treatment involved the use of donated sperm, eggs or embryos. This is designed to protect everyone concerned, including people having treatment, their children and the donors.

What does the law say about donation?

Until recently, people who donated sperm, eggs or embryos could choose to remain anonymous. Donors had to give identifying details for our Register, but these stayed confidential. Under the Human Fertilisation and Embryology Act 1990, people could apply to find out if they were conceived using donated sperm, eggs or embryos. They could also check whether they were related to someone they wanted to marry. But they did not have the right to know who the donor was.

Over the past few years, attitudes towards donation and people's right to know about their genetic origins have changed. As a result, on 1 April 2005 a new law came into effect, which allows people conceived through donation to find out who the donor was, once they reach 18.

What does the change in law mean to me?

Because the new law gives donor-conceived people the right to know your identity once they reach 18, they could contact you. Not all donor-conceived people will want to do this. However you may want to think about how you would feel if they did. You should also consider how this could affect those close to you, such as your parents, your current or future partner and any children you have now or may have in the future.

What will children have been told about me?

This depends to a certain extent on you and to a certain extent on the child's parents. Parents can get the non-identifying information that you provided on your registration form. Many will have brought up their children from a young age knowing how they were conceived and have shared what they know about you so that they have a sense of the kind of person you are. This is why we urge you to put as much detail as you can on your registration form.

Do I have any say about how my sperm, eggs or embryos are used?

You can say who you want to receive your sperm, eggs or embryos. For example, you may have decided to donate to a friend or a relative. It is also possible to specify certain conditions if you are donating to people you do not know, although if you impose too many, the clinic may not accept you as a donor.

How many children could be born from my donation?

Your sperm, eggs or embryos can be used in the treatment of up to 10 families. There is no limit on the number of children each family may have. You may specify a lower number of families should you wish to. You may find it helpful to talk this through with your counsellor.

Why should I donate through a clinic rather than making a private arrangement?

All the fertility clinics the HFEA licenses must conform to strict medical, legal and ethical standards. This ensures that everyone involved in the donation is clear about their legal position and is protected by the law. Sperm, eggs and embryos donated through a clinic must also be screened for certain medical conditions that could be passed on and for sexually transmitted diseases. This helps to ensure that babies born from donated sperm, eggs or embryos are healthy, and that there are no risks to the woman who receives them. As these tests may reveal information about your own health or fertility, you should consider the implications of this before you go ahead. It is often helpful to discuss this with staff at the clinic or with your counsellor.

What if I change my mind?

By law, when you donate you must consent in writing to your sperm, eggs or embryos being used for treatment. You can change or withdraw your consent up to the point at which any sperm, eggs or embryos (or any embryos created from donated sperm or eggs) are transferred to the recipient. That means that you can change or withdraw your consent to frozen, stored sperm or eggs, or embryos created from them, being used after you have donated them. However, given that fertility treatment is costly, time-consuming and emotionally and physically stressful, it is important to be sure beforehand that you really want to donate. To find out more, see our leaflet *Consent to the use and storage of gametes and embryos*.

Do I have any responsibilities towards a child created from my eggs or sperm?

You have no legal obligations to any child created from your donation. The person who received your donation (and their partner if they have one) will be the child's legal and social parent(s). You will not be named on the birth certificate and have no rights over how the child is brought up, nor will you have to contribute financially. However, as you are genetically related to the child you may feel you have certain emotional and psychological responsibilities. Knowing about their genetic heritage helps people to make sense of who they are. This is why you are asked to give information about your family and medical history and to write something about yourself that a donor-conceived person can read when they reach 18, or the parents may ask for as the child grows up (see below).

Could I be sued for any reason?

A donor-conceived person born with an abnormality could sue you for damages if it could be proved that you had deliberately not told the clinic of relevant facts about your, or your family's, medical history that you knew when you donated. This is why it is important to tell the clinic if you know about any inherited disabilities or physical or mental illnesses affecting you or anyone in your family.

What details will I have to give about myself and why?

People conceived as a result of sperm, egg or embryo donation are often curious about their origins. They may want to know whether they look like you or have a similar personality.

They may also wonder why you decided to donate and whether you have children of your own. The form we send out to clinics aims to answer these and other questions. The details we ask for include:

- * Your name
- * The name you were born with if this is different to your current name
- * Your date and place of birth
- * Your NHS or passport number
- * Your address at the time of donation
- * Whether you have children of your own and, if so, how many and whether they are boys or girls
- * Your appearance – height and weight, and colour of eyes, hair and skin
- * Your ethnic group and your biological mother and father's ethnic group
- * Your medical history, any physical or mental health problems or disabilities you have
- * Whether there are any medical conditions that you know of in your own biological family that could potentially be passed on
- * Your job
- * Your religion
- * Your skills and interests
- * Your reasons for donating

Last but not least you will be invited to write a description of yourself and a goodwill message to any child or children. You will be encouraged to include information about your education, achievements, views, values and life experiences. This all-important information enables the child's parents to talk to them about their origins as they grow up and helps them build a mental picture of you.

Where will this information be stored and will it be safe?

All the details you give will be kept on our Register. The information is coded and is not available to the general public. Only those with a right to this information by law – in other words donor-conceived people aged 18 or over – will have access to it.

Can I get any information about a child created from my sperm, eggs or embryos?

The clinic where you made your donation should be your first port of call. They should be able to tell you whether a baby or babies were born as a result of your donation and, if so, how many births and how many children. They may also be able to tell you the sex of any such children and/or the year they were born. They will not, however, be able to tell you their names. If the clinic is unable to help you, you can contact the HFEA.

What if a child created from my sperm, eggs or embryos wants to get information about me?

If you registered to be a sperm, egg or embryo donor before 1 April 2005 (and did not re-register after the change in law), a child can obtain non-identifying information about you but will not have the right to know who you are.

If you registered (or re-registered) to be a sperm, egg or embryo donor after 1 April 2005, a child born from your donated eggs, sperm or embryos can apply to us for identifying information about you. We will contact you, if we have your up-to-date details, but we will not be able to tell you the name of the person or any of their identifying details. As a donor, you can choose to contact us to find out the sex and year of birth for your children born as a result of your donation.

What will happen if a child wants identifying information about me?

If you are a new donor the first time any donor-conceived children will be able to find out identifying details about you will be from 1 April 2023 onwards – in other words 18 years from the change in law.

If you donated sperm, eggs or embryos between 1991 and 2005 you can choose to be identifiable by re-registering yourself after 1 April 2005. In this case the earliest any donor-conceived children could get identifying information about you would be 2010 i.e. 18 years from 1991.

The process for providing information to donor conceived people follows:-

(a) Non-identifying information (step 1)

1. The donor-conceived person requests information about their donor.
2. An application pack is sent which includes a leaflet outlining the process and issues to consider, together with the contact details of relevant counsellors and a recommendation to seek counselling.
3. The applicant will return the form together with original proofs of ID to the HFEA, enabling a search of the Register.
4. Their original proofs of ID will be copied and returned immediately.
5. If information related to the applicant is found on the Register, they will be provided with the non-identifying details of their related donor together with a further suggestion that they might wish to seek counselling.

Where a donor conceived person (the applicant) is found to be related to an identifiable donor

(b) Identifying information (step 2)

1. The HFEA will attempt to contact the donor using their last known address to advise them that a request for identifying information has been made by a person born as a result of their donation. The donor will be provided with a leaflet explaining the process and the issues to consider together with the contact details of relevant counsellors.

2. A minimum of 14 days after the original request was received by the HFEA (to allow sufficient time to contact the donor), written confirmation of the donor's identity and contact details will be provided to the applicant. The HFEA will suggest that, if contact with the donor is intended, this is initially in writing and that mediation or counselling services may be particularly helpful at this stage.

What advice and support can I get?

Your decision to donate sperm, eggs or embryos is an important one, with life-long implications. There are many issues to consider and some of them are complicated. We strongly recommend that before coming to a final decision, you have some sessions with a clinic counsellor. He or she has a great deal of knowledge and expertise about donation. These sessions can be particularly helpful in exploring how the decision will affect you and any current or future partner, and any children you may have now or in the future. In this way, you will be much more confident that you are making an informed decision.

Find out more

HFEA publications:

The HFEA Guide to Infertility 2005

Embryo storage

Embryo research

Egg donation

Consent to the use of storage of gametes and embryos

The HFEA cannot be held responsible for any advice given or the content of web sites where links are shown. The organisations within this list are entirely independent of the HFEA and we do not endorse their content.

Organisations

Although mainly for parents these organisations may be able to help you if you have specific queries.

Donor Conception Network. A national support group for people who have conceived through donation and those considering it. Call 020 8245 4369 or visit www.dcnetwork.org

National Gamete Donation Trust. A national government-funded charity set up to raise awareness of and seek ways to alleviate the national shortage of sperm, egg and embryo donors. It provides useful publications for donors and recipients including information on donation and the law. Helpline call 0845 226 9193 or visit www.ngdt.co.uk

British Infertility Counselling Association (BICA). The professional association for infertility counsellors and counselling in the UK. Its website includes a list of counsellors providing services and a downloadable leaflet on choosing a counsellor. Call Tel 0114 263 1448 or visit www.bica.net

Infertility Network UK (INUK). The largest network in the UK offering information and advice by phone and face-to-face. It has groups throughout the country and also produces a range of publications on infertility. Tel: 08701 188088 or visit www.infertilitynetworkuk.com

Websites

These websites are intended for people with infertility. You may find it helpful to visit them to learn more about the experiences of those with fertility problems.

Fertility Friends. An active self-help community for people experiencing the pain of infertility. Useful site featuring message board and live chatroom. Visit www.fertilityfriends.co.uk

May-b-baby. UK infertility support website set up by Deanne Jenkyns, who herself is infertile. Helpful site with message boards, personal stories and information. Visit www.may-b-baby.co.uk

Fertility Stories. Another site set up by someone with personal experience of infertility, Research, articles and personal stories including information on egg and sperm donation. Visit www.fertilitystories.com: