

Mitochondrial donation: consent to donating your eggs

About this form

This form is produced by the Human Fertilisation and Embryology Authority (HFEA), the UK's independent regulator of fertility treatment and human embryo research. For more information about the HFEA, visit www.hfea.gov.uk.

Who should fill in this form?

Fill in this form if you are donating eggs or embryos for use in another person's mitochondrial donation treatment so that they can avoid passing on inheritable mitochondrial diseases to their children, or for training purposes (to allow designated healthcare professionals to learn about, and practice, the techniques involved in fertility treatment).

If you are unable to complete this form because of physical illness, injury or disability you may ask someone else to complete and sign it for you in your presence and at your direction.

What does mitochondrial donation involve?

You will be donating eggs (containing your mitochondria) to women who have mitochondria containing gene abnormalities, for use in IVF-based treatment so that they can avoid passing on an inheritable mitochondrial disease to their child. The IVF-based techniques used to achieve this are called maternal spindle transfer (MST) and pronuclear transfer (PNT).

On this form you can consent to MST, PNT or both.

What are MST and PNT?

In MST, the nuclear genetic material (the genes which make us who we are) will be removed from your eggs and replaced with nuclear genetic material from the intended parent's egg. The nuclear genetic material removed from your eggs will be discarded.

Following MST, the eggs containing your mitochondria will be fertilised with the intended parent's (or a donor's) sperm to create embryos which will be used in the intended mother's treatment. **This means that the intended mother, not you, will be the genetic parent of any child that is born.**

In PNT, your eggs will be fertilised with the intended father's (or a donor's) sperm to create embryos. The nuclear genetic material within these embryos will then be removed and discarded. It will be replaced with the nuclear genetic material removed from embryos created using the intended mother's eggs and father's (or donor's) sperm. **This means that they, not you, will be the genetic parents of the child.**

If you're unsure of anything, please ask your clinic for more information.

Why do I have to fill in this form?

By law (the Human Fertilisation and Embryology Act 1990 (as amended)), you need to give your written consent if you want your eggs or embryos to be donated to another person for their treatment (for example, for in vitro fertilisation (IVF) treatment) or your eggs or embryos used for training purposes.

You also need to give your written consent to allow your eggs or embryos to be stored. You must state in writing how long you consent to them remaining in storage.

You can make changes to or withdraw your consent at any point up until your nuclear genetic material is removed from your eggs, or in PNT, the embryos created with your eggs.

After this point you will no longer have any rights over the eggs or embryos and cannot withdraw consent to their use in treatment, storage or training.

If your circumstances change after you have completed this form or if you wish to withdraw your consent, you will need to contact your clinic as soon as possible to complete further forms.

What do I need to know before filling in this form?

Before you fill in this form, you should have completed the **'Mitochondrial Donor Registration Form'**.

You should also be certain that your clinic has given you all the relevant information you need to make fully informed decisions. This includes:

- ▶ information about:
 - the different options set out in this form,
 - the implications of giving your consent,
 - the consequences of withdrawing this consent, and
 - how you can make changes to, or withdraw your consent.
- ▶ A suitable opportunity to have proper counselling about the implications of donation and storage

If you are unsure, or think that you have not been given all of this information, please speak to your clinic. There is a declaration at the end of this form which you must sign to confirm you have received this information. **If you do not receive this information before filling in this form, your consent may be invalid.**

For clinic use only (optional)

HFEA centre reference

Donor number

What uses (other than for someone else's treatment) are there for my eggs or embryos?

You can give your consent to your unused eggs or embryos being used or stored for training purposes. This means that eggs or embryos which are not used, or not suitable for use, can be either used immediately for training, or stored for potential future use in training, to allow designated healthcare professionals to learn about, and practice, the techniques involved in fertility treatment. **You can do this at section 4.**

If you also want to donate your eggs for use in fertility treatment which **does not** involve PNT or MST, you must complete a separate form '**Your consent to donating your eggs**' (WD form).

If you have entered into an egg sharing agreement, you must complete the '**Your consent to your eggs and embryos being used in treatment and/or stored form (IVF and ICSI)**' (WT form) or '**Your consent to providing eggs or embryos created with your eggs for your partner's treatment**' (WPT form).

You can give your consent to your eggs or embryos being used for research purposes, with the aim of helping to increase knowledge about diseases and serious illnesses and potentially develop new treatments. Research projects take place at HFEA licenced research facilities. Your clinic can give you more information about this.

What happens to my eggs or embryos if I die?

By consenting to donate your eggs or embryos you are also agreeing to them being used and stored if you were to die or lose the ability to decide for yourself (become mentally incapacitated).

If you do **not** want your eggs or embryos to be used and stored for the purposes set out in this form if you were to die or become mentally incapacitated, you can state this as a restriction (at section **2.3** of this form).

You may also state at **2.3** that you only want your eggs or embryos to be donated for someone else's treatment in the event of your death.

Please note that the clinic can only act on these wishes if they are informed about your death or mental incapacity. If you're unsure of anything in relation to this, please ask your clinic.

When filling in this form, make sure you sign the declaration on every page to confirm that you have read the page and fully agree with the information provided and the consent that you are giving. When you have completed the form, you may request a copy of it from your clinic.

For clinic use only (optional)

HFEA centre reference

Donor number

1 About you

1.1 Your first name(s)

Place sticker here

1.2 Your surname

1.3 Your date of birth

1.4 Your NHS/CHI/HCN/passport number (please select)

2 About your mitochondrial donation

2.1 Do you consent to your eggs undergoing MST and for embryos created from eggs following MST being used for the treatment of others?

This process will involve:

- ▶ your eggs undergoing the MST process (this means that your nuclear genetic material will be removed from your eggs and replaced with the intended mother's nuclear genetic material. Your nuclear genetic material will be discarded),
- ▶ the eggs, following MST (containing your mitochondria and the intended mother's nuclear genetic material) being used to create embryos outside of the body, and
- ▶ those embryos being used in the intended mother's treatment (embryo transfer).

Yes No

2.2 Do you consent to your eggs being used to create embryos outside of the body which will undergo PNT and be used in the treatment of others?

This process will involve:

- ▶ your eggs being used to create embryos outside of the body (those embryos will contain your and the sperm provider's nuclear genetic material),
- ▶ the embryos undergoing the PNT process (this means that your nuclear genetic material will be removed from the embryo, discarded, and replaced with the intended mother's and sperm provider's nuclear genetic material), and
- ▶ those embryos (containing your mitochondria and the intended mother's and sperm provider's nuclear genetic material) being used in the intended mother's treatment (embryo transfer).

Yes No

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Page declaration

Your signature

Date

For clinic use only (optional)

Donor number

2 About your mitochondrial donation continued

2.3 Would you like to apply any restrictions to your answers to 2.1 and 2.2 above?

You may want to put restrictions on who uses your eggs or, in PNT, embryos, e.g. a specified named recipient.

Please use this section to confirm if you do not wish your eggs or embryos to be used for someone else's treatment after your death or if you become mentally incapacitated.

Please also use this section to confirm if you only want your eggs or embryos to be used for someone else's treatment in the event of your death.

Please note that you can only place restrictions on embryos that still contain your nuclear genetic material (ie, before they have undergone the MST or PNT process).

Yes, specify your restrictions below No

3 Storing eggs and embryos

If your eggs or embryos are going to be stored before MST or PNT (e.g before your nuclear genetic material is removed), you must consent to this and state in writing how long you consent to them remaining in storage. The law permits the storage of eggs or embryos for use in someone else's treatment for any period up to 55 years from the date(s) that the eggs or embryos are first placed in storage.

You may want to think about how far in the future you want your stored eggs or embryos to be available for someone else's treatment. This has significant implications for you and any person born as a result of your donation, and your clinic should have given you information and an opportunity to discuss these implications with a counsellor before you complete this form.

You should be aware that embryos can only be stored if both the egg and sperm provider have given consent.

Please note that eggs donated for someone else's treatment may need to be stored before they are used.

Once your nuclear genetic material has been removed from your eggs or embryos, the intended mother and sperm provider (together with the clinic) will determine how long the eggs or embryos will be stored for.

3.1 Do you consent to your eggs (which still contain your nuclear genetic material) being stored for someone else's treatment?

Yes No

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Page declaration

Your signature

Date

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For clinic use only (optional)

Donor number

3 Storing eggs and embryos continued

3.2 For how long do you consent to eggs (which still contain your nuclear genetic material) being stored for someone else's treatment?

Only complete this section if you answered yes to 3.1.

A specific period (up to a maximum of 55 years). Please specify the number of years:

55 years

PNT Only

3.3 Do you consent to embryos (already created outside the body and which still contain your nuclear genetic material) being stored?

Only complete this section if you answered yes to 2.2. You should be aware that embryos can only be stored if both the egg and sperm provider have given consent

Yes No

3.4 For how long do you consent to embryos (already created outside the body and which still contain your nuclear genetic material) being stored?

Only complete this section if you answered yes to 3.3.

A specific period (up to a maximum of 55 years). Please specify the number of years:

55 years

If your circumstances change after you have completed this form or if you wish to withdraw or change your consent, you will need to contact your clinic to complete further forms.

4 Use and storage of eggs and embryos for training purposes

You can give your consent to your eggs or embryos being used and stored for training purposes. This means that eggs or embryos which are not used, or not suitable for use, can be either used immediately for training, or stored for potential future use in training, to allow designated healthcare professionals to learn about, and practice, the techniques involved in fertility treatment.

Eggs

4.1 Do you consent to your unused eggs (which still contain your nuclear genetic material) being used for training purposes?

Yes No

If you give your consent to storing your sperm for training purposes, your clinic may store your eggs for these purposes for up to **55 years** from the date that your sperm is first placed in storage.

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Page declaration

Your signature

Date

For clinic use only (optional)

Donor number

4 Use and storage of eggs and embryos for training purposes continued

4.2 If you consent to your eggs (which still contain your nuclear genetic material) being used for training purposes, how long do you consent to storage?

For a shorter period - specify the number of years (not exceeding 55 years):

For 55 years

PNT only - embryos

4.3 Do you consent to your unused embryos (already created outside the body and which still contain your nuclear genetic material) being used and stored for training purposes?

Yes No

If you give your consent to storing embryos for training purposes, your clinic may store embryos for these purposes for maximum of **10 years** from the date that you give consent on this form. This period cannot be extended.

4.4 If you consent to your embryos (already created outside the body and which still contain your nuclear genetic material) being used for training purposes, how long do you consent to storage?

For a shorter period - specify the number of years (not exceeding 10 years):

For 10 years

If your circumstances change after you have completed this form or if you wish to withdraw or change your consent, you will need to contact your clinic as soon as possible to complete further forms.

Page declaration

Your signature

Date

For clinic use only (optional)

Donor number

Please sign and date the declaration

Your declaration

- ▶ I declare that I am the person named in section one of this form.
- ▶ I declare that:
 - before I completed this form, I was given information about the different options set out in this form, and I was given an opportunity to have counselling.
 - the implications of giving my consent, and the consequences of withdrawing this consent, have been fully explained to me.
 - I understand that I can make changes to, or withdraw, my consent to use or storage for treatment or training at any point until the nuclear genetic material has been removed from my eggs, or in the case of PNT, the point at which nuclear genetic material has been removed from embryos created outside the body with my eggs.
 - I understand that by signing this form, I have consented to the use of my eggs or embryos (already created outside the body and which still contain my nuclear genetic material) after my death or loss of mental capacity in accordance with the uses specified above, unless I have given a specific instruction to the contrary at **section 2.3**.
- ▶ I understand that I must notify my clinic if my contact details change. I understand it is my responsibility to keep contact details up to date.
- ▶ I declare that the information I have given on this form is correct and complete.
- ▶ I consent to the clinic (or any subsequent HFEA-licensed clinic that may become involved in my treatment, donation or storage, or a data controller in line with the Data Protection Act 2018 and UK General Data Protection Regulation) using the information on this form in the process of providing licensed activities (in accordance with the provisions of the Human Fertilisation and Embryology Act 1990, (as amended)), or for record storage and archiving purposes.

Your signature

Date

If signing at the direction of the person consenting

If you have completed this form at the direction of the person consenting (because they are unable to sign for themselves due to physical illness, injury or disability), you must sign and date below. There must also be a witness confirming that the person consenting is present when you sign the form.

Representative's declaration

I declare that the person named in section one of this form is present at the time of signing this form and I am signing it in accordance with their direction.

Representative's name

Representative's signature

Relationship to the person consenting

Date

D	D	M	M	Y	Y
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Witness's name

Witness's signature

Date

D	D	M	M	Y	Y
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