

# NHS Organ Donor Register

Information about the faith and beliefs declaration





### Information about the faith and beliefs declaration on the NHS Organ Donor Register

This booklet has been produced to provide information about the faith and beliefs declaration that is now part of the registration process for the NHS Organ Donor Register.

Individuals registering as organ donors on the NHS Organ Donor Register are now able to state on their registration whether or not they would like the NHS to speak to their family, and anyone else appropriate, about how organ donation can go ahead in line with their faith or belief system.

They can do this by answering an optional question during the online registration process at organdonation.nhs.uk or through our contact centre on 0300 123 23 23.

The declaration style question states:

Faith/beliefs I would like NHS staff to speak to my family and anyone else appropriate about how organ donation can go ahead in line with my faith or beliefs.	
No - this is not applicable to me	they approach them about organ donation.
Prefer not to say	

People can select '**yes**', '**no**', or '**prefer not to say**'. They can also ignore the question.

A response to this statement will be part of their NHS Organ Donor Register record. Specialist nurses in organ donation working for NHS Blood and Transplant have access to the NHS Organ Donor Register. If someone is identified as a potential donor, a specialist nurse will be able to check whether someone had recorded a donation decision on the NHS Organ Donor Register, view any existing record and see if a response has been recorded to this question.

While our specialist nurses routinely discuss faith and beliefs with an individual's family when discussing organ donation, this new feature will provide additional reassurance to those who may have further issues to consider that are important to them. This may include questions such as whether a family or religious figure will have time to say prayers, how washing or dressing requirements in line with someone's faith will be met, whether a swift burial will still be possible and how pastoral care needs can be supported.

Our specialist nurses will respect the decision recorded on the NHS Organ Donor Register and will discuss what this means to the individual's family as part of end-of-life care conversations.

### The questions and answers that follow provide more detail about this feature that we hope will be helpful.

### Are families always involved in organ donation discussions when someone dies who could donate their organs?

Yes. A specialist nurse in organ donation always discusses organ donation with someone's family before organ donation goes ahead. They recognise that this is a difficult time for a family who are coming to terms with the death of a loved one. And, family members provide important information about the person's history to help ensure the donor's organs can be transplanted safely.

### Don't specialist nurses already discuss faith and beliefs with families?

Yes, they do. We hope this declaration will provide additional reassurance. This is the first time someone can proactively record on the NHS Organ Donor Register whether or not they want the NHS to talk to their family and anyone else appropriate about how organ donation can go ahead in line with their faith and beliefs.

### Is the new faith and beliefs question mandatory?

No. Someone can answer yes if it's applicable to them, answer no, or answer that they prefer not to say. They can also ignore the question.

#### Why hasn't this feature been added before now?

Our specialist organ donation nurses have always explored an individual's faith and beliefs with families as a matter of routine. However, the Government's consultation on organ donation in England highlighted the role of faith and beliefs further and this is one of the ways the Government and NHS Blood and Transplant have addressed the issue.

### I have already registered and didn't have this question offered to me, how can I update it?

If you have already recorded a decision to donate on the NHS Organ Donor Register you can **amend** your registration online, or contact us on 0300 123 23 23 where we will be happy to update your record.

### If I say yes, that I want NHS staff to talk to my family and anyone else appropriate about my faith and beliefs, what else do I have to do?

We need everyone to share their organ donation decision with their family. This is important because your relatives will be approached before organ donation can proceed. Make sure you tell your family you want to be a donor, how it fits with your faith and beliefs and if you have any particular requests or requirements, such as any end of life care practices that you want to be respected. Also let them know if you want them to involve a faith leader or pastoral carer in any organ donation discussions.

### I have changed my mind about the answer I gave for the faith and beliefs declaration, how do I update it?

Just go to the amend your details form on www.organdonation.nhs.uk/ register-to-donate/amend-your-details-on-the-register and update your registration. Your record will be updated. Or you can call us on 0300 123 23 23.

## I don't know if my faith or belief system supports organ donation, how can I find out?

To clarify what your particular faith or belief system's views on organ donation are, you can take a look at the 'Organ donation and my beliefs' section of the organ donation website

www.organdonation.nhs.uk/about-donation/organ-donation-and-my-beliefs

You may also wish to speak to your adviser from your religion or belief group.

### What does it mean if I say yes, that I want the NHS to talk to my family and anyone else appropriate about my faith and beliefs when registering as an organ donor?

Specialist nurses for organ donation check to see if someone had recorded a decision on the NHS Organ Donor Register before approaching an individual's family to discuss organ donation.

If you register as an organ donor and say yes in response to the faith/ beliefs question, a specialist nurse will be able to see this when they access your record.

When speaking with your family, they will explain that you registered as an organ donor and will discuss your faith, beliefs and values. During the conversation, they will answer any questions and seek further guidance or support from additional family members and / or faith representatives if required and try their best to ensure any requirements are met.

### What does it mean if I say no, that it is not applicable to me for the NHS to talk to my family and anyone else appropriate about my faith and beliefs?

If you say no, our specialist nurses will respect that you have indicated that you do not want your faith or beliefs to discussed prior to organ donation proceeding. The specialist nurse will ask your family what is important to them in honouring your decision to be an organ donor.

### What is the difference between the faith and beliefs declaration and the religion question on the registration form?

The optional information we ask for under the 'religion' question is only used for statistical analysis by NHS Blood and Transplant and is not recorded against your registration. The faith and beliefs declaration is recorded against your registration and will be visible to our specialist nurses, to enable the conversation about your requirements to take place with your family.

### What if I register as a donor but my family disagrees about whether my desire to donate is supported by my faith or belief system?

The focus of our specialist nurses is to try and identify what you would want and how donation can go ahead in line with your beliefs. Our nurses will explore any issues raised by your family and work with them to allay any fears or concerns. While organ donation would never proceed without your family's support, our nurses would try and help your family respect your decision.

#### I want to show people my support for organ donation and that I feel it fits with my faith or beliefs. How can I do this?

The organ donor card that we send out to all new registrants is a very popular symbol of someone's decision to be an organ donor and we see thousands of people share pictures of their organ donor card each year. Many people also use its arrival in the post as a conversation starter with their family too.

Recognising that someone's faith or beliefs can play an important role in their decision to be an organ donor we have worked with faith leaders and other organisations (such as Humanists UK) to develop downloadable faith and belief-specific donor cards. You can download and share a card appropriate to you with your friends and family to show you want to be an organ donor. You can download a card from the relevant faith and belief system page on www.organdonation.nhs.uk

### Why are the faith and belief donor cards only available online?

As a person's faith and belief is very sensitive to them, we don't collect and store that information against your registration. Therefore, we are unable to send out a card that is specific to you. Instead we send the standard organ donor card to everyone who registers as an organ donor for the first time.

#### How do I check or update my details on the register?

You can update your details and/or change your donation decision:

- online at www.organdonation.nhs.uk
- by phone on **0300 123 23 23**
- in writing to: **FREEPOST RRZKSHUX-SBCK, NHSBT, Fox Den Road, Stoke Gifford, Bristol BS34 8RR**. (Please note, you will need to provide your full name, date of birth and address to make any changes, please also provide a contact number).

#### Can I change my mind?

Yes. You can change your decision, or withdraw (remove your name) from the register:

- online at www.organdonation.nhs.uk
- by phone on **0300 123 23 23**
- by writing to **FREEPOST RRZKSHUX-SBCK**, **NHSBT**, **Fox Den Road**, **Stoke Gifford**, **Bristol BS34 8RR**. (Please note, you will need to provide your full name, date of birth and address if making this request in writing, please also provide a contact number).

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#### **NHS Blood and Transplant**

NHS Blood and Transplant saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England. We are the organ donor organisation for the UK and are responsible for matching and allocating donated organs. We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells.

For more information Visit nhsbt.nhs.uk Email enquiries@nhsbt.nhs.uk Call 0300 123 23 23