



ORGAN.DONATION
have the conversation

Organ donation in Jersey

From 1 July 2019, the way people in Jersey choose to donate their organs is changing.

The intention is to make it easier for deceased Islanders to donate their organs and potentially save more lives.

However, there is also a recognition that not everyone wants to donate their organs and they must have the opportunity to opt out if they wish.

We want to raise awareness of organ donation and encourage people to have the conversation with their families about donating while still fit and well, rather than leaving families to make that choice in the emotive aftermath of a serious accident or illness.

Under the new arrangements:

- You can expressly consent to organ donation via the organ donation register
- You can do nothing and it will be assumed that you have no objection to donating
- You can expressly 'opt out' of donation via the organ donation register.

What is changing?

There will be an assumption (in law) that adults consent to donating their organs after death ('deemed consent') unless they expressly say otherwise before their death ('opting out'). There are some groups within the population for whom deemed consent does not apply (see the section 'Who cannot give deemed consent?').

Adults can continue to expressly consent to be an organ donor, as is the case currently. If you do not expressly consent to organ donation or do not opt out of the deemed consent system, you will be deemed to have consented to organ donation. As with express consent, the views of your family and close friends will play a role in any deemed consent decision around organ donation (see the section 'Does the family still have a role in organ donation?' below).

Until the change in the Law, express consent for donation has to be given by the person before death. This consent takes the form of registering the decision to be an organ donor on the Organ Donor Register. If you are not on the Register, then should the possibility of organ donation arise, your family would be approached and asked for permission to donate your organs.

How will the new deemed consent work in practice?

As a first step, formal checks will be undertaken of the Organ Donation Register to see whether you have opted out from the deemed consent arrangements. It will be unlawful for your organs to be taken when you have expressly opted out.

If you have expressly consented to be an organ donor (ie by registering that decision on the Organ Donation Register), the deemed consent arrangements do not apply to you and your express consent to donation will be taken into account on your death. Current registrations on the Organ Donation Register will remain valid when the law is changed; you do not need to take any further action. In a situation where organ donation is a possibility, your family will be informed and with their co-operation the process of examining the feasibility of donation would begin.

2

If you have not expressly consented to be an organ donor or if you have not registered a decision to opt-out from the deemed consent arrangements you will be deemed to have consented to donation.

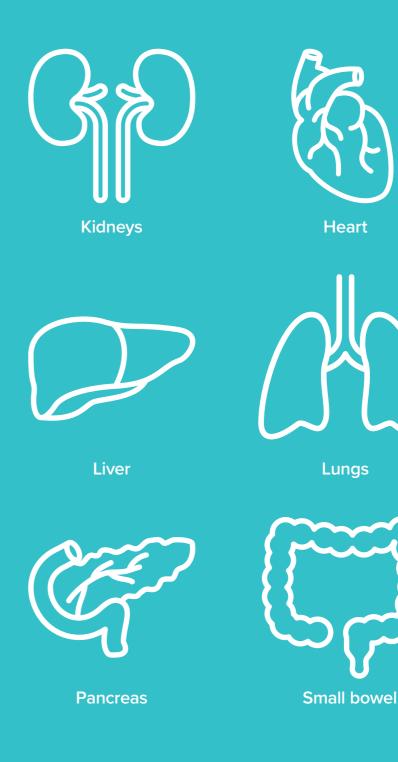
At that point, if you are considered to be a candidate for donation, your family or friends would be approached and asked if you had expressed any objections to organ donation.

If you were not known to have expressed any objections then the assumption would be that donation could proceed.

Where no family or close friend is contactable during the required time frame then donation is unlikely to proceed as awareness of your possible objection to organ donation, and important information about your lifestyle and medical history cannot be obtained.

Deemed consent only applies to a specified range of organs, such as

- kidneys
- heart
- liver
- lungspancreas
- small bowel
- corneas





Corneas

You do not have to wait until 1 st July to opt in or out. You can do it now.

You can register online at:

www.organdonation.nhs.uk

or call:

0300 123 2323

You can specify which organs you do or do not want to donate. You can change your mind on these matters at any time, and amend the details of your registration accordingly.

If you are already on the NHS organ donor register then you do not need to make contact again.

You do not have to wait until 1 July 2019 to opt in or out. You can do it now.

How do I opt out?

If you wish to opt out of the deemed consent arrangements, you need to contact NHS Blood and Transplant (see contact details on page 6, opposite) which maintains the single organ donation register for the UK and Crown Dependencies (Jersey, Guernsey and the Isle of Man).

It is the database that medical staff consult in the first instance to see if someone has registered their decision to be, or not to be, a donor during their lifetime.

Who cannot give deemed consent?

There are a number of groups to whom the deemed consent arrangements will not apply:

- Persons under 18 years of age
- Those who lacked capacity to understand the notion of deemed consent before their death
- Adults who have not been ordinarily resident in Jersey for 12 months immediately before their death.

Who gives consent for children?

The deemed consent arrangements do not apply to persons under 18 years of age. Express consent must be provided for donation to occur, with that consent being provided either by the young person himself or herself, if he or she is competent to deal with the matter, or by the young person's parent or guardian. Children under the age of 16 cannot give consent to organ donation.

People lacking capacity

The deemed consent arrangements do not apply to those people who, for a significant period before dying, lack the mental capacity to understand the notion of the deemed consent arrangements, and therefore are not able to make a decision as to opting out of those arrangements.

A person who has in their lifetime expressly consented to organ donation, but lost capacity before death, would have their views respected. Somebody would have to make a decision on their behalf.

Equally, if a person has appointed another person to make a decision on their behalf as to organ donation after their death (an 'appointed person'), and lost capacity before death, the decision of the appointed person would be respected.

Where there is no appointed person, the consent of family or close friends (ie a person in a 'qualifying relationship') is required for organ donation to take place.

People not resident in Jersey for the previous 12 months

If you have only been on the island for a short time, you may not be aware of the new arrangements which apply in Jersey (as compared to the arrangements in other countries, like England, where deemed consent does not yet apply) and the opportunity to opt out.

Therefore you are not covered by the deemed consent arrangements.

Can I appoint someone to make the decision for me?

Yes you can. You can make this appointment orally or in writing and record their name on the Organ Donation Register.

If you do not do this then a person in a qualifying relationship will be contacted to provide lifestyle and medical information to facilitate a donation – this could be a spouse, civil partner or cohabiting partner, parent or child.

If I have opted out, can this be overturned by my family?

If you have opted out then your decision will be respected. Your family or close friends cannot opt you in for organ donation should the situation arise. Once you opt out, you will remain out.

Does my family still have a role in organ donation?

Yes – families/close friends still have an important role to play in the organ donation process. If you have not opted out and where donation is a possibility, there will be engagement with your family or close friends on the subject of organ donation.

This is why it is important to make your family in particular aware of your decision.

Engagement with family members and close friends is required to obtain medical information about you as the potential donor, and your views as to donation if you have not made an express decision about donation or opting out.

Engagement with your family and close friends will also enable health authorities to determine if organ donation would, despite your consent or deemed consent to donation, cause undue distress or upset to your family or close friends.

These matters are all taken into account by health authorities in determining viability for donation.

8

Can the family object?

Where you register a decision to donate your organs, there will be a presumption in favour of donation rather than against it. Equally, where deemed consent arrangements apply, health authorities will presume consent to donation exists unless there is good reason for that presumption not to apply.

Donation would not proceed where your family expressed the view that you did not want to be a donor, for example because you had expressed views to the contrary prior to death, therefore overturning the presumption of consent.

The aim is to secure a balance between respecting the rights of family members while respecting the autonomy of the deceased. The onus will be on accepting the patient's wishes and not focusing on the family members' own wishes/values/beliefs.

However, if it became clear that proceeding would cause distress to your family and they potentially refused to provide the important background 'lifestyle' information required to enable the transplant surgeons to decide whether their organs or tissue are likely to be safe for transplantation, then donation would not proceed.

Clinicians will be able to exercise discretion in the face of extreme objection by families, even though families do not have a legal veto. It is unlikely that medical staff would proceed where doing so would clearly cause the family severe distress or lead to conflict.

However, the intention is that this situation would be much less likely to arise under the new arrangements. Families would be more likely to be supportive if their loved one was known to have wanted to be a donor and therefore such a choice was not a surprise. Therefore it is important that when you make a donation decision – to opt-in or to opt-out – you let your family know.

Should choices ever have to be made, specialist nurses in organ donation are specially trained in approaching families in a sensitive way regarding their loved one's organ donation decision and supporting them through the process at a difficult time.

What happens if I am a Jersey resident who dies in the UK?

If you live in Jersey, but die in another country, for example, while on holiday, you cannot be deemed to have given your consent to donate.

In such circumstances, medical staff there would check the organ donor register to see whether you had opted in or out, and if you had opted in would approach your next of kin about your suitability as a donor.

10

