COLLAS CRILL

# The gift of life: To opt in or opt out of organ donation?

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Although many of us agree with the idea of organ donation, often, its importance only hits home when personal circumstances expose us to it. It is not surprising therefore that the majority of us have never formally 'opted in' to the process.

Less than one percent of people die in circumstances where it is possible for organs to be donated. With around 7,000 people currently estimated to be on the transplant waiting list, and approximately 600,000 deaths in the UK in 2022, organs suitable for transplant are in short supply.

The Human Tissue and Transplantation (Bailiwick of Guernsey) Law, 2020 (the "**Law**") came into force on 1 January 2023. This new law has introduced an "opt-out" donation system to the Bailiwick of Guernsey, meaning that members of the public are deemed to have ***consented to organ donation*** **by default** (this idea is referred to as, "**deemed consent**").

## Deemed consent will apply to all individuals unless:

1. they have specifically opted out of the system;
2. they are below the age of 18 (as express consent is required for anyone under the age of 18, namely from the parent or guardian if the child is under 16, or from the young person themselves if they are 16 or over and have sufficient understanding to make an informed decision);
3. they lack mental capacity to make the relevant decision;
4. they have appointed someone to make a decision on their behalf after their death;
5. they have not been resident in Guernsey for at least 12 months prior to their death; or
6. there are no other excluding factors (such as the type of material to be donated, medical conditions etc).

The underlying principle of the Law is that the decision to consent to organ donation rests primarily with the potential donor, who can record their decision about organ donation - ideally on the NHS Organ Donation Register (which operates throughout the UK and Channel Islands) (the "**Register**") - or alternatively in writing or by telling family or friends. Recording your decision is the best way to ensure that your wishes are known and respected following your death.

In cases of deemed consent or "**express consent**" (where an individual specifically confirms their agreement to donation during life or consent is provided by an authorised person), organs such as the kidneys, liver, lungs and heart can be donated, as can some tissue. Body parts such as the brain, spinal cord, arms and legs

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however, are considered excluded material and can only be donated if specific and express consent has been given.

When someone dies, the Register will be checked to establish if the deceased made a specific decision about donation. The Register allows you to consent to donate all organs and tissues, some specified organs and tissues, or not to consent at all.

## No donation

If the deceased has specifically chosen to opt out of the scheme (i.e. to not consent to donation), and at no point has altered that decision, then their decision cannot be overridden following their death and donation must not take place.

## Donation

The donation scheme is a 'soft' opt-out scheme, meaning that it will be necessary for registered medical practitioners to discuss the possibility of organ donation with a person in a qualifying relationship with the deceased immediately before their death (such as a spouse, civil partner, parent, child, sibling, grandparent, grandchild, aunt or uncle, niece or nephew, step-parent, longstanding friend or a guardian) ("**qualifying relationship**") (and in descending order of ranking), and take into consideration their views before donation takes place.

Having an illness or medical condition does not necessarily prevent a person from being an organ donor. The decision about whether some or all organs are suitable for transplant is made by medical practitioners at the time of donation, taking into account whether the death was expected, and the individual's medical, travel and social history.

## Specific opt-in

If the deceased has specifically chosen to opt in to the scheme (i.e. confirmed their express consent to donation), and again at no point has altered that decision, then the deceased's decision will be discussed with those with a qualifying relationship, who will be asked to provide a detailed medical and social history of the deceased before the donation takes place. If no individual can provide this additional information, a clinical judgment and risk assessment as to whether to proceed with donation will be taken by the relevant medical team.

## No decision

If the deceased has not recorded a decision themselves about donation they may have appointed an individual to make that decision on their behalf. The Law allows an individual to be appointed to do this provided that certain formalities are met. You should, however, ask the individual you wish to nominate prior to any

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appointment as the appointed individual will be asked to make the decision as to donation following death (and may refuse to do so). Those with a qualifying relationship will still be asked to provide the deceased's detailed medical and social history. If the appointed person cannot be reached or is unable to make a decision then express consent may be given by an individual with a qualifying relationship - again with family members, or other individuals with qualifying relationships providing information about the deceased's medical and social history.

If the deceased did not record their decision, nor appoint an individual to make this decision on their behalf, then there will be deemed consent and the donation will be discussed with those with qualifying relationships. If there are no family members or those within qualifying relationships to establish the deceased's last known decision then donation should not proceed.

Ideally, those with a qualifying relationship who may be asked to give express consent to donation should be given the time to reach an agreement as to the decision. However, if that is not possible, a decision will be obtained from the person whose relationship to the potential donor has the highest rank. If there is a disagreement between individuals of the same rank then a clinical decision will be taken to resolve the matter.

It is a core principle that every effort should be made to establish the decision of a potential donor during his or her lifetime, and to support that individual's decision. If an individual has specifically chosen to opt in to the scheme, or considered to have given deemed consent, then the assumption will be that a donation can proceed. It is important to note that no-one in a qualifying relationship can revoke a legal valid decision to give or withhold consent.

Where an individual has not given express consent to donation and it is apparent that the donation may cause severe distress or conflict for the deceased's family, or it is not possible to obtain relevant information about the deceased person's lifestyle and medical history, a decision may still be made not to proceed with the donation.

## Incapacity

In cases where an individual lacks mental capacity, and has not previously provided express consent, or cannot be deemed to have consented to donation, express consent will be sought from a person in a qualifying relationship.

It is important to note that, unlike other qualifying relationships, a guardian does not have the authority to give express consent on behalf of an individual due to a Guardianship Order being granted in their favour. A guardian would only be able to give express consent if they have been given this power separately by way of a valid appointment (as outlined above).

Should you wish to decide who will be able to provide consent to the donation of your organs in the event that you lose the mental capacity to make this decision yourself then you can appoint one or more people to do so by way of:

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1. a Health and Welfare Lasting Power of Attorney (a document appointing individuals to make decisions on your behalf when you have lost capacity);
2. in your Will or;
3. by way of a written appointment, provided that certain formalities are met.

## Final steps

Valid consent is sufficient for donation to be lawful but it does not mandate that it must proceed.

Following an individual's death, the clinical team will first seek to establish whether the deceased made a decision themselves about donation through checking the Register and then discussing matters with those in qualifying relationships to see if the deceased had authorised any individuals to make the decision on their behalf, or recorded their decision elsewhere. They will try to establish the deceased's most recent known decision and involve family members as appropriate.

If satisfied that donation can proceed:

1. two registered practitioners must examine the deceased and issue a certificate to the effect that they each have satisfied themselves that life is extinct (i.e. the deceased is no longer alive); and
2. an authorised person must issue a certificate demonstrating that they are of the opinion that there is express, or deemed consent for the removal of the deceased's organs.

Once the organ donation process has been completed (which will take place in Guernsey) the deceased's body will be released back to the family to make suitable funeral arrangements.

The decision to donate organs can be an exceptionally difficult and emotional one. It is important that discussions take place with family members and those closest with you to ensure that your wishes or preferences, and those of your loved ones, are known.

Whether you are someone who sees the benefit of organ donation as a gift, or feel strongly that organ donation is not right for you, you should make a formal registration of your preference on the NHS Organ Donation Register, which operates throughout the UK and Channel Islands.

If you would like further information or advice in respect of the Law or related areas of wills, estate administration, lasting powers of attorney or guardianship, please feel free to contact our International Private Client and Trusts team for further information.

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