



* M R Q Q Q B *

Use Plate, Label, or Print:

Name:

CH MRN#:

DOB:

Gender: M F

To the parent/guardian or surrogate decision-maker:

You have been given information concerning organ donation after cardiac death for this patient. If you agree to donate, you will be signing forms provided by the New England Organ Bank, a federally designated organ procurement organization that is separate from Children's Hospital Boston (CHB). There are certain additional points we want to make sure you understand. If you have any questions about these points, or anything else, please speak with the CHB physicians, nurses or other caregivers involved. Please make sure you understand the points below, and feel free to ask questions if you do not.

As parent, guardian or surrogate:

1. I understand that I do not have a legal obligation to donate organs. It is a free choice. CHB staff will not be upset or treat the patient less well if I decide not to donate organs. If I do not donate organs, CHB will provide end-of-life care as it otherwise would.
2. I understand that donation of organs after cardiac death will change the way end-of-life care is delivered compared to non-donation. For example, after withdrawal of life support, the patient will be rapidly moved to the operating room for organ donation, instead of staying for a period of time in the intensive care unit or other hospital unit where death would be anticipated to occur. That means that the time I will be able to spend with the patient, including time immediately after withdrawal of life support, may be much shorter than it otherwise could be. Also, there may be some variations in end-of-life care that are designed to help preserve organs, but without harming the patient, since the doctors will be trying to fulfill my wish that donation be effective. My doctor will explain, in as much detail as I want, how end-of-life care is likely to be different for the patient. Other changes, compared to ordinary end-of-life care, likely to be present in this case are:

3. I understand that the process of withdrawal of life support is different for every patient, and the precise course of end-of-life care varies. The doctors are trying to give their best professional judgment about this, but events could happen differently, including that the patient may survive for an unanticipated period of time after withdrawal of life support. For example, if the patient's heart does not stop within a certain time after life support is removed, the patient will likely be returned to the intensive care unit, without donation occurring.
4. I have received an explanation of tissue donation, and how it differs from organ donation. I understand that tissue donation can occur with or without organ donation. I have considered tissue donation as well as organ donation and my questions about it have been answered.
5. I understand that I can change my mind and cancel the donation any time up to the point the patient is taken to the operating room. I need to inform _____ if I want to change my mind.
6. While donation is often successful, sometimes it is not. This can happen, as in the example given above, where the patient's heart does not stop within a certain time after life support is removed, and the patient is returned to the intensive care unit. Or, it may be that even if donation occurs, not all organs are useable for transplantation; some deteriorate very fast during the process of donation after cardiac death.

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7. There is a national system for determining who receives organ transplants, and CHB does not decide who will receive donated organs. While the majority of organs donated from children will go to help another child, in some cases organs will go to an adult. This will depend on a number of factors including the size of the organs.
8. Once the organs are removed, they will not be returned to the body even if they are not suitable for transplantation or research (assuming consent for research is granted). This means that even if transplantation does not take place, removed organs will not be returned to the body for burial or other disposition of the body. In this case, CHB, the New England Organ Bank, or the recipient transplant center, will follow its usual procedure for respectful disposal of the tissue.
9. The clinical and other staff who have been working with me in the care of the patient, including end-of-life care, may be different from the staff who work with the patient and me in connection with donation. CHB will not require staff to participate in donation after cardiac death if it is something they object to on personal grounds or because of their feelings for the patient.
10. There are certain things CHB will not do, even if these things might possibly enhance the survival of organs. For example, Children's will not knowingly change end-of-life care in a way that it believes causes the patient suffering. Here are some other things, possibly relevant to this patient and this donation:

11. I understand that CHB staff are available to answer questions I may have, but that conversations about donation will also be had with the New England Organ Bank, which is separate from Children's, and that CHB staff may defer some conversations to representatives of the New England Organ Bank. I understand that CHB will release information related to this donation, in accordance with laws and regulations, to the New England Organ Bank, and to other entities as permitted or required by law, and I consent to this release.

Parent/Guardian/Surrogate

Date

Telephone Consent

Witness

Witness

Date