NHS
Royal Papworth Hospital
NHS Foundation Trust

Donor choices in heart transplantation

Patient's guide and consent form

Heart transplantation is an excellent option for carefully selected patients with advanced heart failure. However, there is a critical shortage of organ donors in the United Kingdom. At three years after being placed on the routine waiting list, only 17% of patients have been matched to a suitable donor and admitted from home to undergo heart transplantation. Unfortunately, almost 30% of patients who are listed for a heart transplant die, or need to be removed from the waiting list, before they have the opportunity of receiving a heart transplant.

We are trying to increase the pool of potential donors for heart transplantation. It is important to understand that every potential donor undergoes thorough assessment by an experienced team and every heart has to satisfy stringent criteria before it is accepted for transplantation. Despite this, the function of hearts after they have been transplanted is not completely predictable and there is always a risk of serious complications that may be life-changing or fatal.

We would like to highlight four types of potential organ donor. We believe that you may benefit from receiving a heart transplant from any of these types of donor. However, it is your choice whether you would want to receive a heart transplant from these types of donor. We need to record your choices in advance, so that we can act in accordance with your choices when donor organs become available.

1. Heart from a donor with a current or previous cancer which has a low risk of transmission

We may be offered hearts from a donor with a localised brain, thyroid or skin cancer where the risk of transmission is believed to be less than 2%. We may be offered hearts from a donor who has received successful curative treatment for a curable cancer many years ago. We consider these hearts to be acceptable for transplantation. The small risk of inadvertent cancer transmission associated with accepting such organs should be balanced against the greater risk that you might die whilst waiting for a heart transplant or become too sick for a heart transplant.[1]

2. Heart from a donor who is over 60 years of age

We are sometimes offered organs from donors who are over the age of 60. Research has not yet established an upper limit for a safe 'older donor age' although it has been identified as a risk factor for death from any cause and from early failure of the transplanted heart. These donors will be assessed thoroughly for their suitability for organ donation and only used if survival benefit of heart transplantation for a recipient exceeds those risks associated with an older donor.[2]

3. Heart from a donor who has no detectable active infection but has a very small chance of carrying a transmittable infection (often due to lifestyle)

All organ donors are screened for viral infections like HIV and Hepatitis B. If these screening tests are positive, then organs would not be used. There is a small risk that screening tests may miss recent infection. This could happen if the donor has taken intravenous drugs or participated in high-risk sexual behaviour in the last few days or weeks of their life. In practice, the risk of infection from such donors is very small, between 1 in 5,000 and 1 in 10,000. Good treatments are now available for these viruses in the event that transmission did occur. We consider these hearts to be acceptable for transplantation.[3]

For a carefully selected group of patients, we may decide to use organs from donors with specific treatable infections such as Hepatitis C.[4] The transplant team will discuss this with you separately if we think you would be suitable.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

Consent 016
Donor choices in heart transplantation

This form should be completed before going on the list for heart transplantation and reviewed on a regular basis, particularly after any change in your condition.

Before filling in this form, please read the accompanying information. It is important to remember that refusing to accept organs from certain categories of donor will reduce your chance of receiving a heart transplant. Your decision can be changed at any time without affecting your care in any way. We would recommend telling your family or next of kin.

Please choose from the following options:

- ☐ I have read and understand the information given to me in PI 106 Donor choices in heart transplantation.
- ☐ I understand that limiting my selection of donor organs may reduce my opportunity of receiving a heart transplant.
- ☐ I understand that I can change my decision at any time.

- ☐ I would accept any heart from a donor that the transplant team considers acceptable for use.

Alternatively, please indicate below the categories of donor from whom you would **NOT** be willing to accept a heart:

- ☐ Heart from a donor with a current or previous cancer which has a low risk of transmission
- ☐ Heart from a donor who is over 60 years of age
- ☐ Heart from a donor who has no detectable active infection but who has a very small chance of carrying a transmittable infection (often due to lifestyle)
- ☐ Heart from a donor following circulatory-determined death (DCD)

Patient

Patient signature: ……

Date: ……

Name (PRINT): ……

Statement of interpreter (where appropriate). I have interpreted the information above to the patient to the best of my ability and in a way which I believe he/she can understand.

Signed: ……

Date: ……

Name (PRINT): ……

A witness should sign below if the patient is unable to sign but has indicated his or her consent. Young people/children may also like a parent to sign here (see consent policy).

Signed: ……

Date: ……

Name (PRINT): ……

4. Heart from a donor following circulatory-determined death (DCD)

Organ donation may occur after brainstem-determined (DBD) or circulatory-determined (DCD) death. Potential DCD donors are individuals with a severe medical condition who are being kept alive by artificial means. If there is no chance of recovery, the medical team may decide that ongoing treatment is futile. This decision is made by the relatives, doctors and nurses caring for the patient. If there is consent to organ donation, the ventilator and other machines will be turned off with the family in attendance. Once treatment has been withdrawn, the patient's heart may stop. Five minutes after the heart has stopped, the doctor will pronounce the patient dead and organ donation can occur.

At this stage, the donor is transferred to an operating room. The heart is removed and placed into a machine which pumps oxygenated blood into the coronary arteries of the heart and allows it to be assessed. At present, we use the TransMedics Organ Care System (OCS) for machine perfusion but other systems may be used in future. Hearts that are suitable for transplantation will then be transported back to Royal Papworth Hospital with machine perfusion. In some cases, the heart is initially restarted within the donor (without allowing any blood to be pumped to their brain) so it can be assessed by the surgeon before it is removed from the donor. The technical name for this procedure is thoraco-abdominal normothermic regional perfusion. In these cases, the heart may be transported to Royal Papworth Hospital using machine perfusion or cold storage if the journey is short.

What are the advantages of DCD heart transplantation?

DCD heart transplantation has increased the number of heart transplants at Royal Papworth Hospital by 30-40% since 2015. This means that patients have had a greater chance of receiving a heart transplant and a shorter waiting time for a heart transplant. Survival is equivalent to DBD heart transplantation. Our results have been published in the Journal of Heart and Lung Transplantation.[5]

What are the disadvantages of DCD heart transplantation?

There is uncertainty with any new technique. We have been reassured by our experience so far; it does not seem that DCD hearts work any differently to DBD hearts after transplantation. However, we remain careful with DCD hearts and usually only consider donors aged less than 50 years, because we think younger hearts are likely to be more 'resistant' to periods without blood flow. Long-term outcomes remain uncertain but we become more confident with every passing year.

How do I record my preferences?

Each of these options needs to be considered carefully. It is important to remember that advanced heart failure is a life-threatening illness and is likely to be the greatest risk that you face. We believe that you may benefit from receiving a heart transplant from any of these categories of donor. Declining one of these donor groups will reduce the chances that you are matched to a donor organ. However, it is your choice and we will respect your decision. You may also change your mind about any of your decision at any time by letting us know.

If you feel uncomfortable with any of these options, then please discuss this with the transplant team.

References

1. Watson CJE *et al.* How safe is it to transplant organs from deceased donors with primary intracranial malignancy? An analysis of UK Registry data. *Am J Transplant* 2010;10:1437-44
2. Costanzo MR *et al.* The International Society of heart and lung transplantation guidelines for the care of heart transplant recipients. *J Heart Lung Transplant* 2010;29:914-56
3. Halpern SD *et al.* (2008). Informing candidates for solid organ transplantation about donor risk factors. *New Engl J Med* 2008;358:2832-7
4. Kilic A *et al.* Outcomes of Adult Heart Transplantation Using Hepatitis C-Positive Donors. *J Am Heart Assoc.* 2020;21:e014495
5. Messer S *et al.* A 5-year single-center early experience of heart transplantation from donation after circulatory-determined death donors. *J Heart Lung Transplant* 2020;39:1463-75

Royal Papworth Hospital NHS Foundation Trust
Papworth Road
Cambridge Biomedical Campus
Cambridge
CB2 0AY

Tel: 01223 638000

www.royalpapworth.nhs.uk

A member of Cambridge University Health Partners

Author ID: Consultant Transplant Cardiologist
Department: Transplant Unit
Reprinted: March 2021
Review due: March 2023
Version: 3.3
Leaflet number: PI 106

© Royal Papworth Hospital NHS Foundation Trust

Large print copies and alternative language versions of this leaflet can be made available on request.