

Consent and donor choice in lung and heart-lung transplantation

A patient's guide

Lung transplantation is a good option for carefully selected patients with end stage lung disease but sadly there is a critical shortage of organ donors which results in many patients listed for lung transplantation (20-30%) dying of their disease before donor organs become available.

There are many ways in which we are trying to increase the pool of potential donors and this information leaflet has been developed to help explain some of the choices that you might be asked to consider when you are on the waiting list for a lung transplant and indeed you might have already stated your preferences or have had a phone call to discuss some of the issues.

We would like to record your preferences in advance so that we do not have to confront these issues at the time when donor organs becoming available.

It is important that you understand that all organ transplants are associated with a risk of complications or

death. Organs only become available because sadly someone has passed away and whilst every potential donor undergoes a vigorous and thorough assessment by a team of experienced surgeons the function of these organs is unpredictable.

Organs from a donor who is a current smoker or recent ex-smoker

Half of the potential donors we are offered have a smoking history. Finding out the extent of this history can sometimes be difficult, however we are very careful to ensure that the lungs are functioning well, undergoing vigorous examination and assessment by the donor retrieval surgeon prior to the transplant proceeding. Looking at our results, the short-term (under three months) outcomes are not as good for a smoking donor but the longer-term outcomes (greater than three years) are the same.

For these reasons we will consider carefully donors with a smoking history and we would ask that you do the

same. Declining such lungs may limit your chance of survival, the transmission of a smoking related lung cancer being small.^{1, 2, 3}

Organs from a donor with a brain tumor

Occasionally we are offered organs from patients with either known or possible tumors. Usually these are isolated brain tumors with a very low-risk of spread and as a result would be considered a low-risk for transplantation. Even in patients with a brain tumor classified as high-grade there is less than 3% risk of transmission of cancer, a risk which needs to be balanced against the likely mortality for potential recipients who remain on the transplant waiting list.⁴

Organs from an older donor (greater than 60 years of age)

We are often offered organs from donors who are over the age of 60. In older donors, age alone should not be a strict criterion to reject older lungs as their appearance often suggests better quality in never-smokers compared

with smokers of a younger age. These donors will be assessed thoroughly for their suitability for organ donation recognising that there is a slight but progressive increase in risk of death for patients who receive organs from older donors with a lower ten year survival related to older donor age.⁵

Organs from a donor who may have taken intravenous drugs or had high risk sexual behavior

All organs donors are screened at time of donation for infective viruses like HIV and those which cause hepatitis. When the donor may have taken intravenous drugs or had high-risk sexual behavior there is a small risk of them being infected at a stage before the blood test will pick up the virus.

In practice, the risk of infection from such donors is very small, around 1 in 5-10,000. High-risk behavior is where either the donor has injected, been paid for sex or paid for sex, had unprotected vaginal, oral or anal sex with a high-risk partner in the last three months before death. A high-

risk partner includes someone who comes from a country with a prevalence of HIV or hepatitis, has injected drugs, is paid for sex or is a bisexual or gay man.⁶

Organs from a DCD donor

Organ donation after cardiac death (DCD), also known as donation after circulatory death, is the type of donation that was used in the early years of organ donation. Before brain death criteria was established, DCD donation was the only option. This type of donation occurs when a patient has an illness from which he or she cannot recover and the patient is being kept alive by artificial means, including ventilators and supportive drugs. The patient is not brain dead but has no hope of recovery.

Only once the family makes a decision to withdraw artificial support, is the possibility of organ donation discussed. In this way the decision to withdraw support is made independently of the decision to donate and if the donation falls through, the family has

still made the correct decision for their loved one.

If the family is interested in donation and has made the decision to withdraw support, the patient will be taken to the operating room for this process of withdrawal to occur. Once treatment has been withdrawn if the patient's heart stops within the designated time frame for donation the team then waits for several minutes to insure that the heart does not function. At this time, a physician from the hospital will pronounce the patient dead and the organ retrieval team can begin the assessment of the organs.

As a recipient of lungs from a DCD donor the arrangements will be the same. You will be admitted to the ward and prepared for theatre. The coordinator may ask you to shower and change into a gown perhaps a little earlier than with a brain stem dead donor and the time from finding out about the condition of the donor organs and the transplant proceeding may be less and you may find yourself

being transferred to the operating room within a few minutes of finding out that the organs are suitable. This is to minimise the time organs are without a blood flow. As not all the donors will reach suitable criteria after withdrawal of treatment the false alarm rate is higher than with a DCD donor than a brain stem dead donor.

Ex-Vivo Lung Perfusion (EVLP)

Many donor organs deteriorate in the donor prior to transplantation. However, techniques have been developed to try and improve their function. Lungs are placed on a machine and can then be assessed. Only if the function is then deemed acceptable are the lungs then used for transplantation. Studies have shown that EVLP has comparable outcomes to standard transplantation.

We believe that this method will improve the number of donor organs available for transplantation and we strongly recommend that you read carefully the information given to you at the time you

are listed about the DEVELOP Study and the Organ Care System.

Thank you for reading this information.

Each of these potential options needs to be considered carefully in the context of a severe life threatening illness. We believe that many people will benefit from these different approaches however, if you feel uncomfortable with any of these different options then please indicate this on the accompanying form.

Likewise if there is anything you are unsure about or wish for further clarification then please do call the Transplant Coordination team.

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