

Heart transplantation

A patient's guide

Heart transplantation

Heart transplantation has the potential to significantly improve the length and quality of life for patients with severe heart failure.

Most patients return to a near normal life, including exercise, work, education and travel. Before agreeing to being placed on the list for heart transplantation, it is important to understand the complexities and complications of the whole transplant process: choosing the donor heart, the transplant operation, the problems encountered immediately after the operation and in the subsequent weeks, months and years.

As with all forms of medical intervention, there are risks and benefits of transplantation and these have to be compared with the risks of no intervention. Transplantation is associated with an increased risk of death in the short-term but a significantly increased chance of survival in the longer term.

Waiting list

If accepted onto the heart transplant waiting list, potential recipients need ongoing review approximately every three to six months to ensure suitability for transplantation. This may include blood tests, echocardiography, X-rays and right heart catheterisation.

Once on the list, patients wait for periods that may vary from a few months to several years for a suitable heart. Factors affecting waiting times include patients specific blood group and their size. Patients may be removed from the waiting list if their condition changes or deteriorates such that the risk of transplantation would be too high.

Some patients may be suitable to consider either listing urgently for transplantation as an inpatient or surgical placement of a heart pump known as a ventricular assist device (VAD) to help support the heart in case of deterioration. Despite these options, some patients die whilst on the waiting list for a heart transplant.

Donor organs

Accepting a donor organ for a recipient is complex and the decision is based on many factors including the donor, the organ and the recipient.

Before accepting a donor heart for transplantation, extensive information is obtained about the potential donor. This includes their general health including; alcohol and smoking history; specific diseases (eg diabetes, cancer); and previous or significant risk of infection (eg hepatitis, HIV, CJD) in order to prevent transmission to the recipient. Despite these precautions, there is still the possibility of transmitting unknown chronic infection (usually viral) at the time of transplant surgery.

Specific details are generally only passed to the recipient when this would increase the risk or complicate the outcome of the transplant.

This could include whether the donor poses a greater risk of transmission of infection or malignancy or whether the donor organ has a particular risk of poor function. No organ

is free of risk but the recipient has the right to decline offered organs where there is evidence of significant increased risk (which may be difficult to quantify) or there are factors they find unacceptable. This may occur either when going onto a transplant waiting list or at the time of offer.

The recipient must understand that declining an organ may put them at increased risk of dying before an 'acceptable' one becomes available.

At the time of transplant or afterwards, the recipient may feel they would like to know more about the donor but due to confidentiality this information may be limited to: age range (by decade), gender and how the donor died.

Transplant operation

The transplant procedure itself carries a significant risk (approximately 10% risk of dying in the first month following the operation). The main contributors to this are the function of the donor heart, other organs failing and infection.

Some evidence of reduced function of the heart or kidney in the early post-operative period is common, but usually resolves with appropriate support including temporary kidney dialysis. Patients may have to return to theatre if problems such as bleeding occur.

Occasionally a heart may appear to function well when studied in the donor but very poorly after transplantation. Despite support including mechanical pumps and treatment some hearts will not recover leading to death. Most patients are not in a suitable condition for a second transplant to be considered.

Long-term care

Transplant patients are cared for life-long by the transplant team. Patients and their carers may contact the team at any time for advice.

Internationally and nationally, overall survival after heart transplantation is approximately 80% at one year, 70% at five years, and 50% at 10 years. The one

year survival at Papworth Hospital during 2008 to 2011 was approximately 90% but individual centre results may vary over time.

Frequent follow-up at the transplant centre is important during the first year, but this may be no more than every six months after the second year. Readmission to hospital, other than for planned investigations is infrequent.

Drugs and side-effects

Transplant recipients need to take immunosuppressant drugs to suppress the immune system and prevent rejection from the time that have the operation for the rest of their lives.

We will monitor you regularly after surgery to look for evidence of acute rejection (damage to the heart by the immune system) and side effects of therapy including infection.

Rejection is looked for by taking small samples of heart muscle under local anaesthetic and is known as a biopsy of the heart. Biopsies are performed

routinely during the first 12 months after a transplant with decreasing frequency.

Rejection is usually successfully treated by increasing your immunosuppression. Patients normally take three immunosuppressive drugs each of which has specific side effects. The number of drugs and the dose usually decrease significantly between three and 12 months after transplantation. The specific side effects will be discussed following the transplant, dependant on which drugs are used.

There are a number of long-term side effects common to all of the drugs which include:

1. An increased incidence of cancer in patients on long-term immunosuppression. Approximately 30% of patients over 10 years will develop a cancer; over half of these are skin cancers which are rarely fatal. Lymph gland cancers (lymphoma) are also related to immunosuppression and can occur at any time after the transplant and may require chemotherapy. Many of these are curable with appropriate treatment. Cancers successfully treated before transplant may also recur.
2. Reduced kidney function is seen in most patients who receive the commonly used immunosuppressive drugs. Approximately 15% have severe kidney failure after 10 years and a minority (5% over 10 years) require dialysis.
3. Infection including bacterial and viral infections. Cytomegalovirus (CMV) is commonly transmitted from the donor. Preventative drugs against infection are routinely given during the first three to 12 months but CMV disease can occur later after the transplant.
4. Very common, but less serious side effects include high blood pressure, raised cholesterol, diabetes, weight gain, gout and osteoporosis.

Chronic rejection

The other major long-term problem associated with a heart transplant is chronic rejection which is damage to the hearts blood vessels by the immune system that occurs despite immunosuppression. This results in a form of coronary artery disease and is seen in approximately 50% of patients after 10 years.

You will have angiograms to look for this condition at varying intervals. The disease tends to be diffuse, affecting small and large vessels in the heart. Conventional methods of dealing with coronary artery disease (angioplasty and bypass surgery) are rarely feasible because of the diffuse nature of the disease.

Coronary artery disease rarely causes problems in the first five years after the transplant but is the single biggest problem after ten years and may lead to heart failure. Unfortunately re-transplantation is the only option and for most patients this is not possible for a number of reasons.

It is important to remember that despite these potential problems most patients have an excellent quality of life after a heart transplant.

The best outcomes after transplantation are in patients who have a healthy lifestyle; including maintaining a healthy diet and weight; not smoking or taking illegal drugs; drinking alcohol in moderation; exercising; taking all medication as suggested by the transplant centre; and attending outpatient visits and tests as necessary to monitor the success of the transplant.

Please feel free to ask a member of the transplant team if you have further questions or concerns about the procedure.

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