

LIVING ORGAN DONATION

What You Need To Know

This information booklet was developed by:

TRANSPLANTATION UNIT
Medical Development Division
Ministry of Health Malaysia



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1. Introduction

The purpose of this booklet is to help you and your family understands what it means to be a living organ donor. It also provides specific information on unrelated living organ donation. In the event if you need any further information/clarification, please consult your doctor. Your doctor will discuss this with you personally, but we also want you to have something you can take with you to read. Please keep this booklet for your further reference.

2. What is organ transplant?

Organ transplantation is the replacement of diseased and damaged organs. It is an established treatment for end stage organ failure. Organs for transplantation can be obtained from living or deceased donors.

3. What is organ donation?

Organ donation is a surgical procedure for the removal of organs from donor for the purpose of transplantation. Organ donation saves lives and improves quality of life.

Organ donation in Malaysia is voluntary where expressed consent is required.

There are two types of organ donation;

- a. Deceased organ donation
- b. Living organ donation

Deceased Organ Donation

(from someone who has died)

- Malaysia practices an opting in system.
- In this case, an organ is removed from a person after his death.
- Retrieval of organ requires consent from family members.
- Someone who has died may donate both kidneys, liver, heart, lungs and also tissues like cornea (eye), skin, heart valves and bones.

Living Organ Donation

- A person (donor) chooses to donate one of their kidneys or part of their liver while the donor is still alive.
- The donor is usually a blood relative or spouse to the recipient.
- This type of transplant requires planning.
- Living donor remains an important source of organ due to shortage organ from deceased donors.

The major public transplant centres in this country are;

Hospital Kuala Lumpur	Kidney Transplantation
Hospital Selayang	Kidney Transplantation Liver Transplantation
University Malaya Medical Centre	Kidney Transplantation
National Heart Institute <small>(in collaboration with Respiratory Medicine Institute)</small>	Heart & Lungs Transplant

4. What are the advantages of living donor transplant?

a. Shorter waiting time

A patient with kidney failure usually waits for several years to receive deceased donor kidneys. However, with a suitable living donor such transplant can be done within weeks.

b. Living donation is an elective surgery

This means the transplant surgery can be done when both donor and recipient are in the best of health for surgery. Living donor transplant surgery can be electively scheduled to suit the donor and recipient.

c. Organs from living donors work better

Most of the time the kidney from living donor works immediately after surgery and continues to work better and longer than kidney from a deceased donor.

5. Who can be a living donor?

In Malaysia, the Ministry of Health allows living organ donation only to your close blood relative. This includes your identical twin, your first degree relative and your second degree relative. You may also donate to your legal spouse (husband/wife). If you wish to donate your organ to someone who is not genetically related to you or to a distant relative (a third degree relative and beyond), you will need to be evaluated by an Independent Committee appointed by the Ministry of Health. Following this evaluation, permission may or may not be granted.

Who are my first and second degree relatives?¹

FIRST DEGREE

Mother	Father
Daughter	Son
Full sister	Full brother

SECOND DEGREE

Grandmother	Grandfather
Granddaughter	Grandson
Aunt	Uncle
Niece	Nephew
Half sister	Half brother

6. Who cannot donate organs?²

In this country, children³ and mentally disordered persons⁴ are not allowed to donate organs while they are still alive. Prisoners are also not allowed to donate organs unless in life threatening circumstances involving close relatives. This is subject to approval by the Ministry of Health and other relevant authorities.

Of course, those with certain medical conditions are also not allowed to donate their organs (please refer to the next section). These medical conditions may be discovered during the evaluation process of living donors.

7. What is UTAC and what are the procedures?

UTAC stands for Unrelated Transplant Approval Committee (UTAC). UTAC is an independent committee set up by the Ministry of Health to evaluate every application for unrelated living organ donation. You cannot apply directly to UTAC, only the doctor responsible for you as the potential donor or a doctor responsible for the potential recipient can apply to UTAC. The doctor needs to do a preliminary assessment on you to determine your suitability to be a living donor. If the doctor is satisfied with your suitability, he/she will then apply to UTAC by filling in some official forms.

You will then have to undergo a series of interviews with independent donor advocates.

¹ National Genetic Education and Development Centre, National Health Service UK.

² The National Organ Tissue and Cell Transplantation Policy, Ministry of Health Malaysia, 2007.

³ According to Child Act 2001 [Act 611], a child is defined as someone who is less than 18 years old.

⁴ According to Mental Health Act 2001 [Act 615], a mentally disordered person means a person with any mental illness, arrested or incomplete development of mind, psychiatric disorder or any other disorder or disability of the mind however acquired.

8. Will I be paid for donating my organ?

The sale of organ and tissues is prohibited. A gift of life by someone who has donated his/her organ is priceless. The Ministry of Health will not pay you for your organ. Similarly someone who receives your organ should not pay you in return. Any other form of money worth rewards or non financial inducements are also not allowed. These include, among others, job promotion, house, cars, land and others.

However, reasonable reimbursement related to the donation process is permissible. In the Ministry of Health's hospitals, all charges pertaining to organ donation surgery including ward admission are waived¹. If you are a public service personnel, you are also entitled to unrecorded leave for not more than 42 days² during the recovery period.

The Ministry is committed, together with the World Health Organization³, in preventing trading of human organs.

As for the Muslims; while donating of organ is permissible ("harus"), trading of organ is prohibited ("haram")⁴.

9. Am I fit to become a living donor?

Living donors should be in good overall physical and mental health. Certain medical conditions like diabetes mellitus, cancer, HIV infection, hepatitis, and organ diseases will preclude you from becoming a donor. It is extremely important that you inform the donor evaluation team (doctors or nurses) about your physical and mental health.

You need to complete a full medical and psychosocial evaluation and also be fully informed of the risks involved. Your decision to be a donor should be completely voluntary and free of pressure or guilt.

If you decide to be a living donor, a "living donor advocate" may assist you. The living donor advocate will promote your best interests regarding living donation and assist you in obtaining and understanding information regarding the evaluation process, surgical procedure and follow-up. The donor advocate is not involved with the potential recipient evaluation and remains independent of the decision to transplant.

You can change your mind and decide not to donate your organ at any time during the evaluation process. Your reason not to donate shall be kept confidential.

10. What are the risks of living organ donation?

Most donors recover fully after the surgery and can do normal activities within a few weeks after the surgery. Recovery period for liver donation is slightly longer than kidney donation. Organ donation will not change your lifestyle in a big way. There's no evidence that it will change your life expectancy. Woman can still have children. As for kidney donation, it does not increase your risk of getting kidney disease in your other kidney. In fact, some people are born with only one kidney and live a completely normal life.

However, as with any major surgery, there are risks.

¹ Refer to circular "Kementerian Kesihatan Malaysia – Pengecualian Bayaran Bil Hospital bagi Pesakit Penderma Organ, ref: (95)dlm.KKM-203/19Jld.4, 29 December 2003".

² Refer to circulars "Surat Pekeliling Ketua Pengarah Kesihatan Bilangan 6 Tahun 2010, 24 February 2010" and "Pekeliling Perkhidmatan JPA Bilangan 3 Tahun 2010, 2 February 2010".

³ WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation, May 2010.

⁴ National Fatwa Council 1970.

Mortality risk for organ donation differs between kidney and liver donation:

Type of organ donation	Donor mortality risk
Kidney donation	3.1 deaths in 10,000 donation ¹
Liver donation	Right lobe liver: 1 death in 200 donation ² Left lobe liver: 1 death in 1000 donation

Other risks associated with the surgery include

- Pain or numbness around the incision area.
- Lung, urinary tract and wound infection. The chances of developing a lung infection can be reduced by breathing exercise.
- Bleeding is uncommon. However, you may require a blood transfusion if necessary. It is important you also understand the risks associated with blood transfusion.
- Blood clots may occur in your legs (called Deep Vein Thrombosis) which may travel to the lung. This can be life threatening. You will be advised to wear compression stockings and ambulate early after surgery to prevent this from happening.
- Anaesthetic complication including allergic reactions to anaesthetic drugs.
- Injury to surrounding tissue or other organs.
- Hernia. You should not do heavy lifting for four to six weeks after surgery to avoid this problem.

Negative psychological symptoms are possible during the healing process and even years after the donation. Your donated organ may not function in the recipient after it is transplanted. Scarring or other aspects of the donation process could possibly contribute to problems with body image. You may have feelings of regret, resentment or anger. You may develop anxiety and depression. Treatment of these conditions can be lengthy and you may experience side effects of the medications used.

Long-term risk

Based upon available information, overall risks are considered to be low. Risks can differ among donors. Risks can also differ according to the type of organ you donate.

Your doctor will explain to you more about the risks during the evaluation process.

11. What do I need to know about living donor evaluation process?

You will be meeting the transplant team for consultations and have several tests performed before donating an organ. Most of the tests are done on an outpatient basis. These are done to ensure your fitness and suitability to undergo the surgery.

During the first consultation with the donor, comprehensive medical history will be obtained.

¹ "Perioperative Mortality and Long Term Survival Following Live Kidney Donation" in Journal of the American Medical Association, Vol. 303, No. 10, March 10, 2010.

² "Live Donor Liver Transplantation" in Journal of Liver Transplantation, Vol. 12, 2006.

Your blood and the recipient blood will be taken for compatibility test. The initial tests are:

- Blood type: O,A,B or AB
- HLA cross match
- HLA typing

Compatibility test will help to determine the risk of organ rejection. This will guide the transplant team on the level of anti-rejection drugs or immunosuppression to be used in the recipient.

ADDITIONAL BLOOD TEST	<ul style="list-style-type: none"> • This is to screen for transmissible diseases like HIV, Hepatitis B and others. • This is also to assess your medical status such as presence of diabetes, heart disease and others.
URINE TEST	<ul style="list-style-type: none"> • In particular for kidney donation, 24 hours urine sample will be taken to assess your kidney function or presence of kidney stones. Usually three samples are taken.
CHEST X-RAY	<ul style="list-style-type: none"> • This is to assess your lungs and your heart.
ELECTROCARDIOGRAM (ECG)	<ul style="list-style-type: none"> • This is to screen for heart disease. Based on the ECG finding and other clinical reasons, further test may be required for evaluation of the heart such as stress test.
ULTRASOUND AND OTHER IMAGING LIKE CT SCAN	<ul style="list-style-type: none"> • This is assess your liver and/or you kidney.
CANCER SCREENING	<ul style="list-style-type: none"> • Types of test will be determined by your transplant team.
PSYCHOSOCIAL AND PSYCHOLOGICAL EVALUATION	<ul style="list-style-type: none"> • This is to assess your mental health, you ability to understand all information given and make an informed decision. The team will also assess your daily life circumstances.
CONSULTATION	<ul style="list-style-type: none"> • The transplant team including surgeon will give you further consultation and perform physical examination. Surgeon will explain about the nature of the surgery and risks.
OTHERS	<ul style="list-style-type: none"> • Some doctors may do liver biopsy for liver donation.

Once the initial tissue typing has been completed and a compatible potential donor is identified, the medical evaluation of that potential donor can continue. This evaluation can take place at the transplant centers, or if the donor lives far away, many of these tests can be performed at the nearby hospital. The additional tests include:

12. What do I need to know about the surgical procedures?

Kidney donation

There are two types of surgery for kidney donation; laparoscopic and open flank approach surgery.

Open flank surgery is a traditional approach which involves flank incision about 15-20 cm on either your right or left side. Both the skin and muscle need to be cut in order to reach your kidney.

Laparoscopic surgery involves the use of tube-like instruments. The use of laparoscopic instruments allows the kidney to be removed through a smaller incision. The major benefits of this type of surgery are faster recovery time and less discomfort for the donor.

The surgical team will suggest to you types of surgery depending on level of expertise and suitability of the donor and/or kidney.

Liver donation

The surgeon will make an incision on your abdomen approximately 2 fingers width below the rib cage. The length will depend on your body size. Either left or right lobe of your liver will be taken depending on the size of the recipient (usually right lobe is for adult recipient and left lobe is for the paediatric recipient). The incision will be closed with stitches or staples.

You surgeon and anaesthetist will explain to you further on what you should do before and after the surgery.

13. Where can I get more information?

If you want more information about living organ donation, you may contact:

NATIONAL TRANSPLANT RESOURCE CENTRE

Hospital Kuala Lumpur
Jalan Pahang, 50586 Kuala Lumpur

Email : ntrc@hkl.moh.gov.my
Tel. (office) : (603) 26942704/2705
Tel. (fax) : (603) 26156269
Tel (toll free) : 1-800-88-9080
Website: www.agiftolife.gov.my

You may also consult any kidney or liver specialist nearest to you.

This leaflet was designed to provide basic information to the public and prospective living organ donors about living organ donation. It is part of requirements in the Ministry of Health's guidelines "Unrelated Living Organ Donation: Policy and Procedures" that the doctor responsible for the prospective donor should provide the donor with this leaflet for further reading. This should not undermine the importance of verbal communication and consultations pertaining to risks and benefits of living organ donation. If necessary, assistance from an independent interpreter shall be obtained to translate information in this leaflet. The prospective living donor shall be provided with other relevant information to enable him/her to make an informed consent.

This information leaflet was developed by the Medical Development Division, Ministry of Health Malaysia. For any feedback please email to transplantation_unit@moh.gov.my, or write and address to Transplantation Unit, Level 5, Block E1, Complex E, Federal Government Administrative Centre, 62590 Putrajaya Malaysia.

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