

DECIDING TO BE A LIVE KIDNEY DONOR

A kidney transplant can help to improve the lives of people with kidney failure and offers them better health outcomes. They can have a more active life, free from dialysis and dietary restrictions.

Perhaps you have a relative or friend who has kidney failure and therefore are thinking about becoming a live donor. Some people find the decision to donate a kidney easy. For others, making the decision is very difficult and they may feel obligated or pressured by the expectations of family and friends.

Whatever you choose - the decision is yours alone. The information below may help you to think through this decision.

It is recommended that you also read the *'Live Kidney Donation'* fact sheet, which explains the live kidney donation process in more detail.

DO YOU HAVE ENOUGH INFORMATION?

Some people want lots of information and others feel overwhelmed by it. You need to feel satisfied that you have enough information to make an informed choice.

You may want to research these questions before making a decision:

- Are you aware of the positive effects that a transplant can have on a recipient's life?
- What is the transplant's chance of success for the intended recipient?
- Do you understand the steps involved in live donation including the testing, the operation and the recovery period?
- Have you found out about the risks involved in being a live donor, both physical and emotional?
- Do you plan to have a family in the future?

Information about live donation is available from a range of sources. The transplant team can provide a lot of answers and you can also do your own research. You may want to talk to someone who has been through it, attend an education session, or read up about it.

Kidney Health Australia has trained Peer Support volunteers that you can speak to - some have been live donors and others have received a kidney from a friend or relative.

You can also get information from our fact sheets – *'Live Kidney Donation'*, *'Life With A Single Kidney'*, *'Using The Internet To Research Health Information'*, and *'Making The Most Of Your Visit To The Doctor'*.



ARE YOU EMOTIONALLY READY?

You may be excited about becoming a live donor or worried about being asked to donate a kidney. Either way, these are some questions to think about:

- Why do you want/not want to donate a kidney?
- How do you feel about organ donation in general?
- What impact (if any) could donation have on your relationship with the intended recipient? Your family? Friends?
- Do you expect some sort of compensation or emotional 'pay-back' for donating?
- How will you respond if the recipient wants to express their gratitude in a way that you are not expecting?
- How do you think you will react if the recipient doesn't 'look after' the transplanted kidney in the way you expect, e.g. they smoke, don't take their medication properly or drink too much alcohol?
- Do you have a 'support network' - family and friends - to help you through the donation experience or are you going it alone?
- Are there other people who could be donors? If so, how will the donor be selected?
- How will you feel if the tests show you are not able to donate? Are you healthy enough to donate?
- Will your current job/home situation allow you to have time off for testing, surgery and recovery?
- How would you feel if the kidney transplant was not successful?
- Do you feel able to make an informed choice about being a live donor? Do you need more time or information?
- Would you like to speak with someone who has been a donor? Call Kidney Health Australia to talk to someone who has been a live donor.

You can change your mind about being a live donor right up to the moment of the operation. There's no reason to feel guilty, particularly if you've had time to educate yourself and think through the issues. However, it is important to think through the issues carefully before offering to be a live donor as changing your mind at a later stage may cause you anxiety. How do you think you would feel if this happened?

It is important to remember that quality of life on dialysis can be excellent, particularly for those who are otherwise in good health. People on dialysis can enjoy full lives - working, studying, caring for families, playing sport and socialising.



ARE YOU PHYSICALLY READY?

Not everyone has time to make sure they are in great physical shape before an operation. If there is time, live donors can strengthen their cardiovascular (heart) system, boost their immune system and reduce their recovery time by following some simple guidelines:



- Eat a balanced, healthy diet with plenty of vegetables and fruit and a low intake of salt, saturated fat and sugar
- Keep fit by doing at least 30 minutes of physical activity each day
- Maintain a healthy weight
- Drink plenty of water
- Be a non-smoker
- Drink alcohol only in moderation

ARE YOU SPIRITUALLY PREPARED?

Most religions do not oppose organ donation and believe that it is a personal decision. However, you may wish to consult with your spiritual adviser before making a decision.

ARE YOU COMFORTABLE WITH YOUR DECISION?

Some potential donors will have better tissue matches with the intended recipient and others may be unable to donate for medical reasons. This usually produces a small group of preferred donors but there may be only one.

Being the only medically suitable donor can create a lot of pressure, particularly if the need for an organ is urgent. Sometimes, even when there is more than one suitable donor from a medical point of view, pressure is put on one person to donate. Understanding where the pressure is coming from can help you to reach a decision.

It is very important that your donation decision is the right decision for you. It can be helpful to talk with someone outside of the family or friendship circle, such as a counselor or social worker from the transplant unit.

WHAT ARE YOUR RIGHTS AS A LIVE DONOR?

In summary, the potential donor has a number of rights, including:

- The right to medical information about the donation procedure and its short term risks as well as information about the possible long term risks
- The right to information about the recipient's medical prospects following transplantation
- The right to independent medical advice
- The right to counseling to discuss the potential psychological (mental) and social consequences of the decision to donate and adequate time to consider this information
- The right to decide not to donate

WHERE CAN I GET MORE INFORMATION?

Kidney Health Australia has trained Peer Support volunteers that you can speak to - some have been live donors and others have received a kidney from a friend or relative. Please contact the Kidney Health Australia Health Info Line (freecall) on 1800 454 363.

Other helpful resources include:

- '*Kidney Donation by Live Donors*' published by NSW Health, available to download at http://www.renalresource.com/pdf/live_kidney_donation.pdf
- '*Making a Decision about Living Organ and Tissue Donation*' published by the National Health and Medical Research Council, available to download at: http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/e70.pdf

NEW DEVELOPMENTS

In April 2013, the Federal Minister for Health, together with Kidney Health Australia, announced a two-year pilot of a Supporting Leave for Living Organ Donors Programme. The two-year pilot programme provided up to six weeks of paid leave at national minimum wage to employers, who passed it on to those eligible employees who became live organ donors.

In May 2015, the Government announced that the programme will continue for another two years, and employers will be reimbursed for up to nine weeks of the employee's leave. To register for further information from the Australian Government about the new scheme, please email livingorgandonation@health.gov.au or visit <http://www.health.gov.au/internet/main/publishing.nsf/Content/Leave-for-living-organ-donors>.

For more information about Kidney or Urinary health, please contact our free call Kidney Health Information Service (KHIS) on 1800 454 363. Alternatively, you may wish to email KHIS@kidney.org.au or visit our website www.kidney.org.au to access free health literature.

This is intended as a general introduction to this topic and is not meant to substitute for your doctor's or Health Professional's advice. All care is taken to ensure that the information is relevant to the reader and applicable to each state in Australia. It should be noted that Kidney Health Australia recognises that each person's experience is individual and that variations do occur in treatment and management due to personal circumstances, the health professional and the state one lives in. Should you require further information always consult your doctor or health professional.

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If you have a hearing or speech impairment, contact the National Relay Service on 1800 555 677 or www.relayservice.com.au. For all types of services ask for 1800 454 363.