

# Social, psychological and emotional wellbeing



## Key facts:

- It is important to be well prepared as early as possible given that there is no way of knowing exactly when you will be called in for your transplant. Every small piece of planning helps.
- If you are not already a Princess Alexandra Hospital (PAH) patient, the PAH could be a place you do not know very well.
- If you are from a regional area, being away from home could be a stressful time.
- Counselling and support services are available to all patients and their families, any time before or after a transplant. Telephone or in-person appointments can be made to suit your schedule.
- It is quite normal to experience a range of emotions before and after your transplant.
- Transplantation aims to bring a new sense of physical and emotional well being, and can greatly improve quality of life. Kidney transplants do not come with a guarantee, and life which had become routine on dialysis may seem less predictable in the first instance, after a transplant. Sometimes the new kidney takes a while to start working, and dialysis is required after the transplant. The treating team will keep you well informed and be available for ongoing support.
- Patients are sometimes anxious that their transplant might be rejected or that they might feel worse. There could be fears about returning to dialysis. Sometimes, patients report that they feel emotional, even quite teary, especially in the first few days after a transplant. These feelings can be one of several side effects of the new medication. Some patients worry that the new kidney feels strange, even alien to their body. Being away from home can be distressing for some patients. It is not uncommon to be dealing with many different feelings, often it seems all at once.



- Deceased donor transplant recipients and their families, sometimes report being anxious or sad for their unknown and grieving donor family who lost a loved one. In turn they might feel guilty that they are celebrating the “new” kidney and “being off dialysis”, during a time of the donor family’s loss and mourning. It can be distressing knowing that receipt of the transplant kidney, has come about because of somebody else’s sudden death. Patients often wonder about where their kidney came from, and what life their donor lived. Working through these mixed feelings can be challenging.
- It is important to remember however, that the death has happened, and that many donor families report that the opportunity to donate the organs and tissue of their loved one was a positive benefit to arise from their family member’s unexpected death. Many donor families have reported comfort from the knowledge that the donation honours the memory of their deceased loved one.
- Recipients are strongly encouraged to consider writing a Thankyou Letter or Card to their donor family. Not only does it acknowledge the gift of life provided by the donor, but it can help process your feelings about donation and transplantation and can help you move forward. Donor families generally treasure thank you cards and letters from transplant recipients, and sometimes they reply back. There is more information available from the outpatient staff and social workers in transplant outpatient areas. Please also visit the DonateLife website: [www.donatelife.gov.au](http://www.donatelife.gov.au)
- Transplantation can be an excellent long-term treatment. If, however the transplant is unsuccessful, as it is in a small number of cases each year, you will return to dialysis. This can be very disappointing and result in feelings of grief and sadness. The doctors will discuss the situation in detail with you and your family to help ensure that you fully understand the situation and have opportunity for as much support as you feel you need. Each patient situation is different. The doctors will discuss your future treatment options with you. Support for you and your family is available at any time. Let the team know if you wish to speak with a social worker.
- Moving from dialysis to having a transplant can bring about anxiety for some transplant recipients. Being discharged from hospital after the transplant is something most patients look forward to, but it can also cause patients to feel a bit anxious. You will be well supported by staff and will find the transplant clinics excellent. Monitoring of the transplanted kidney by hospital staff at the clinics provides reassurance and security for patients. However, these frequent visits to the hospital may also be frustrating for recipients at a time when so much time is spent at the hospital. The weeks do pass. Patients are encouraged to live their lives as normally as possible with the new kidney, while following all medical recommendations.

## What to do:

From the time you are placed on the waiting list for a kidney transplant through to after you receive a transplant, continue planning for the social, emotional and practical aspects relevant to your situation.

- **Talk to professionals:** Talk about transplants with your kidney specialists, dialysis nurses and other staff who look after you. They can give you an idea about what to expect and of details relevant to your situation.
- **Read, watch and listen:** Read any books or articles about transplants to get an overview about what to expect, and to learn about other peoples' experiences. The Queensland Kidney Transplant Service website provides a lot of information and support to help plan for a transplant.  
[www.qld.gov.au/health/services/specialists/kidney-transplant](http://www.qld.gov.au/health/services/specialists/kidney-transplant)
- **Kidney Transplant seminar:** Attend a Kidney Transplant Seminar, presented 3 times each year at the PAH or ask your dialysis unit to participate in the seminar video link. The seminars are featured on the Queensland Kidney Transplant Service website.
- **Talk to transplant patients:** Recent transplant recipients can be a helpful source of information and advice. Most people are happy to share their experience with you. It is important to remember and respect that everyone's experience is personal to them, and that no two transplant experiences are exactly the same. However, there are likely to be features common to all transplant recipients and their families.
- **Make lists and plans:** Patients need to be aware of what arrangements will have to be attended to when they come into hospital for the transplant and post-transplant period. This is especially important for patients who are on the deceased donor waiting list. After being called and told that there is the possibility of a kidney transplant, the patient needs to be at the PAH within a matter of hours. Your operation is unscheduled, unlike those receiving a planned live donor transplant. Matters to consider include childcare, pet care, cancellation of newspaper delivery, mail collection or holding services, notifying an employer, notifying relatives, closing the house for a while. Make a list now of all the things you would need to attend to, should you be having your transplant today. Know in advance who is most likely going to assist or be available to help sort out at the time, or shortly afterwards. Be prepared.
- **Seek counselling and support from the transplant unit:** The Social Worker is available by appointment to provide any further information or counselling which you or your family might need at any stage of the transplant journey. Some patients are a long way from their homes during the time of their transplant, and might be on their own if a family member or friend is not able to stay long. Sometimes patients experience complications or disappointments associated with their transplants or have been worried about family or personal issues, unrelated to the transplant. A transplant is a big change. If there are any matters with which you would like support, or you wish to discuss, please make an appointment with one of the social workers. It does not matter how long before or after the transplant this occurs. Referrals can also be arranged to other mental health practitioners such as a psychologist or psychiatrist. Never feel ashamed to seek help.

- **Writing a letter to the donor family:** After their transplant, patients will receive a brochure from Donate Life about writing to the donor family. Copies are also available from the outpatient clinics. Write and send the letter when you are ready, but perhaps don't leave it too long.  
Website: [www.donatelife.gov.au](http://www.donatelife.gov.au)
- **Consider the future:** One of the issues that patients find helpful to consider is how they are going to spend their time and live their best life. Returning to work or retraining can usually happen 3 months or so after transplant. With the time constraints of dialysis gone, work may be easier to maintain. There are many resources within the community, regardless of where you live, to assist with long term job seeking, training programs and courses that can be undertaken for either enjoyment or for general learning. Centrelink have fully trained disability support officers, who can assess the patient's specific needs. Many patients have gone on to learn new activities, commence university, TAFE or volunteer work. Much of the groundwork and planning can occur whilst on the waiting list for a transplant.
- **And remember -** Make the best choices you can. You are in charge of choosing how to respond to your situation and how best to live your life. There are many ways to move forward and the team of doctors, nurses and allied health staff can all assist you identify which way is best for you.

## Resources

### Queensland Kidney Transplant Service

website: [www.qld.gov.au/health/services/specialists/kidney-transplant](http://www.qld.gov.au/health/services/specialists/kidney-transplant)



### Kidney Health Australia (KHA)

website: [www.kidney.org.au](http://www.kidney.org.au)

### Transplant Australia

website: [www.transplant.org.au](http://www.transplant.org.au)

### Kidney Support Network

website: [www.ksn.org.au](http://www.ksn.org.au)

### The Transplant Network

website: [www.thetransplantnetwork.com.au](http://www.thetransplantnetwork.com.au)

## Further information contact



### PA Hospital Social Work Department

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