

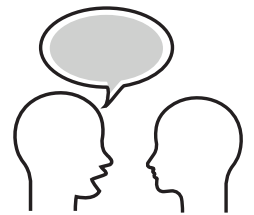
Life After Transplantation

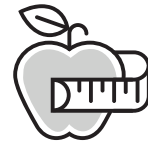
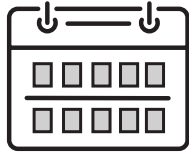
It can be helpful to think of life after transplant in stages. The first few weeks and months, the first year, and the years afterwards.

- Receiving a transplant, having not been sure if or when the surgery might go ahead, can bring relief and hopefulness yet concern for how the next few weeks and months will be.
- Each patient and family's experience of "life after transplant" is individual to them.
- There are many factors which influence recovery times and the sense of "getting back to normal".
- Support is available for all patients any time in the weeks, months and years afterwards, to move forward with life after transplantation. It is important that patients communicate with the treating team about their need for support, help, information, counselling or extra care.

After a transplant

- Until the transplant happens, no-one quite knows how it will be for each person.
- Every individual experience will be unique to that person. Some describe the early days as "a bit up and down". It can feel like a journey of a few steps forward, a few back, and then further forward again. For others it is quite manageable.
- For some, finding out they had complications and the need for a transplant came about very suddenly. Whilst for others it was something they had known for a long time might eventually happen. The pre-transplant experiences therefore can start very differently. In turn, this can have an impact on how things go afterwards.
- What most patients have in common, is that once transplanted, they want to get better and live the best life they can. They recognise how precious life is and feel grateful to the donor family and the treating team for the opportunity to move forwards.
- Information here provides a general overview of the questions and experiences most relevant to the three post- transplant stages.





The first 3 months

- On average, patients are inpatient in hospital for anywhere between 5 to 7 days for kidney and 6 to 14 days for liver.
- The first few weeks are like all post - operative situations: there is a lot of medical and nursing care provided to support pain management, bowel and bladder function, walking, eating, breathing and infection control.
- There is a team approach to ensure the best outcome for each patient. Some however experience complications, resulting in a longer hospital stay. This can be for extra weeks or even months. It is stressful for the patient and family when such complications occur, so support and communications from the treating team are maintained throughout. Extra inpatient rehabilitation might be needed. The aim remains to discharge the patient as soon and safely as possible.
- Patients who are discharged within the first few weeks of their transplant, attend the regular post-transplant clinics near the transplant unit for several weeks, and then at the ARTS Building and/or Burke Street clinic. These visits can be quite tiring. Plenty of rest, daily exercise, healthy food, correct medications at the right time and drinking lots of water all contribute to health and wellbeing. Give the body the best chance to start recovering and adapting.
- With time, patients often report feeling the best they have felt in years. Their energy is resuming, they are feeling fitter, they can breathe comfortably, their medications are generally working well. The side effects of the medications can be quite noticeable in this timeframe for some transplant recipients, so always best to discuss these with the treating team who can advise.
- Family members and others who have been providing early post-transplant care and support, generally need to provide less direct care and support by the third month or so. Patients are often quite independent and able to manage by this time.

The rest of the first year

The year can vary for patients depending on how they were before the transplant, the circumstances of their illness and hospitalisation. Including how well the early recovery has been, and depending on how aspects of their life are moving in general.

Several months after the transplant:

- Patients from the more distant geographic regions are usually discharged home. This can be a time of excitement, yet worry. Nervous to be away from the treating team and PAH, but pleased to be going home and starting afresh. To have the transplant behind, and health improving.
- Some patients are considering their return to work. Some are already back at work. Perhaps on a return to work program, part time work or work from home or flexibly. Carers who might have taken time out from their own work to provide care to the transplant recipient, are also on the way back to the workplace or to their usual activities.
- Some patients are starting studies. School, TAFE, university or distance education or online or direct attendance at school or college.
- For those who are retired. They are picking up with their previous or new interests, keeping in contact with their families and communities. Perhaps out and about, planning short trips or movies, walks, exercising regularly, or shopping.
- Everyone is making great efforts to eat well, exercise regularly and take medications as prescribed and attending regular specialist appointments.

After the first year

- By the end of the first year, most patients describe feeling fully recovered or close to that. It often does take a year to really feel on top of everything. By exercising and eating well, patients often report feeling stronger and healthier. The period in hospital is a more a distant memory. It is possible though that they have had re-admissions to hospital through the year. There might have been need for further biopsies, scans and tests.
- Many patients are back at work, re-training for new jobs or studying. Some become involved with volunteer activities within their communities. Patients and families report they are looking forward to attending their first Service of Remembrance, online or in-person to honour the donor families who so generously consented to organ and tissue donation enabling transplantation to occur. A letter expressing thanks and deepest appreciation has been sent to the donor.
www.donatelife.gov.au/all-about-donation/support-for-donor-families/contact-between-donor-families-and-recipients
- Some patients have sought or are in process of seeking counselling to support them reflect upon events, identify hopes and plans, and identify ways to move forward. In some instances, partners and family members have been involved with the counselling as well. For others, it is something they do individually.

- Some patients plan or embark upon their first post-transplant overseas trip after their first year post transplantation. The transplant coordinators are well placed in the first instance to provide information and advise about medications, follow up and what to do in case of a medical emergency. They can provide information about transplant supports overseas.
For current advice from the Australian Government regarding overseas travel:
www.smartraveller.gov.au
- Many patients are reconsidering their lives. Many are starting new and exciting activities. Learning musical instruments, singing, dancing, sports; exercising regularly, adapting eating patterns and taking healthier control of the kitchen and menus; volunteering – perhaps reading to children, the elderly or disabled, or through making regular or occasional financial donations to a humanitarian or animal support organisations. Some patients have their sights set on going to the National or International Transplant Games. If not that year, perhaps soon after.
- Values have been reassessed, priorities reconsidered. Life itself has a renewed value.

Summary

- Because transplantation is a treatment not a cure, there will be ongoing and lifelong medical reviews and management.
- Some patients keep excellent health for many years, whilst others do experience some problems along the way. Medical problems can recur. Patients might be referred for a second or further transplant in time to come. Re-transplantation can be highly successful, but not always.
- Living with uncertainty is always going to be a part of having a transplant.
- Ultimately, the advice patients provide to one another again and again, is to make the best of each day, set goals, work towards them, do not worry too much about small stuff and the setbacks, to keep going.
- Live for the moment, control what you can, release what you cannot. And seek support any time.