

Information for families with a child needing kidney replacement therapy



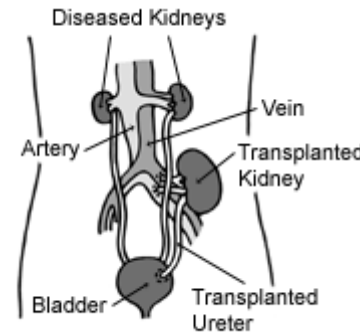
We've talked about your child's need for kidney replacement therapy and what the options are. This pamphlet puts into writing some of this information.

What are your child's options for kidney replacement therapy?

There are benefits and disadvantages to each treatment type. Talking with the team will help you to make the best treatment choice for your child and family. Sometimes different treatments are needed at different times during the life of someone with kidney failure.

- A. **Dialysis** is one treatment option, and can be done as **peritoneal dialysis** or **haemodialysis**. The renal team will discuss dialysis further with you, if they think it is the best option for your child at this time.
- B. **Transplant** means your child has an operation to put a donated kidney inside them. This kidney should perform normal kidney functions, but without medication the body will recognise the transplanted kidney as an invader and attack the kidney, a process known as rejection. Medications to stop kidney rejection (immune

system blockers or "immunosuppressants") have to be taken every day for as long as the transplanted kidney is working. Usually your child's own kidneys do not have to be removed, the transplant kidney goes in a different place inside the body.



Which is the best treatment and why?

For most children, kidney transplant is the best treatment for their health, growth, learning and lifestyle.

Going straight to transplant without time on dialysis is considered the best option if possible, however for many reasons it is often not possible (eg child is too small, some types of kidney disease, bladder issues needing to be fixed first and late diagnosis of kidney failure).

From New Zealand data, 94% of kidney transplants will still be working at 5 years, and 80% after 10 years.

Where do donated kidneys come from?

Kidneys can come from healthy living family members or friends (older than 18), or be donated by someone who has chosen to donate their organs after death. This is known as a deceased donor.

Living donor kidney transplants can be planned, have less complications early on and should last longer.

To receive a deceased donor kidney, your child goes on a waiting list. If a suitable healthy kidney is donated this will be given to the person who has been waiting the longest and/or is a good immune system match to the kidney (to be sure they are unlikely to reject the kidney). It is difficult to know how long your child will wait on this list before a kidney is available.

Risks of kidney transplantation

Kidney transplant, like any major surgery has risks. In the first few weeks these possible problems are mostly linked to the surgery itself and can sometimes mean your child will need a further operation. A rare but very serious risk is a major problem with blood flow to the kidney that cannot be fixed and the kidney needs to be removed. This is rare, and your child would

need to go onto dialysis until another transplant is an option.

Blood transfusion may occasionally be needed after transplant. Infections are fairly common early on and are monitored for carefully. If the kidney does not work well at the start dialysis may be needed until the new kidney starts working (this is more common for deceased donor transplants). Rejection occurs occasionally and if it does this is mostly in the first year post transplant or in teenagers. Depending on the severity of rejection, different treatments (more immunosuppression) are required.

Other problems that can happen early on include low levels of body salts like magnesium or phosphate, diabetes, weight gain and high blood pressure. These things are all monitored in regular blood tests and clinic visits.

Long term after kidney transplant , there is a higher risk of heart disease and cancer than in people without kidney failure. This risk however, is much less than being on dialysis long term.

Kidney transplants don't last forever. Over time, the kidney will slowly lose function due to scarring, rejection and medication side effects that can not be avoided. When this happens, dialysis is an option and further transplantation can be discussed.

Death in children after successful kidney transplant is very rare. If your child has other medical

problems in addition to kidney failure this can increase the risks in transplant and death. This will be discussed with you more by your Starship team. In general, the risk of death with a kidney transplant is much less than staying on dialysis long term.

Will my child's original kidney disease come back in the transplant?

Only a few types of kidney disease can come back in the new transplant kidney. Your Starship team will talk to you about this if it is a possibility for your child.

Preparing or "work-up" for transplant

To help get the safest and best outcome for your child's kidney transplant we need to do a number of tests and have check-ups by different teams.

These include:

- Blood and urine tests
- Dental check-up at your local dental service
- All necessary vaccinations done (children with transplants need extra vaccinations)
- Ultrasound of blood vessels in pelvis and possibly neck
- Heart ultrasound and seeing a cardiologist may be needed
- Education by Starship kidney doctor and nurse
- Transplant surgeon clinic
- Psychologist / social worker review

- Dietician input may be needed
- Bladder tests / seeing a urologist may be needed

Most of these things are done at Starship. Once the workup is complete, your child is discussed at the Auckland Regional Transplant Group meeting. When your child is accepted for transplant, once a living donor is also accepted, a date is set for the transplant. If there is no living donor at the time, your child will be considered for the deceased donor waiting list.

The testing/ workup for living **donors** is separate and confidential (private) from the Starship renal team. It often takes a bit longer and is best started as early as is possible. More information about living donation can be found at www.kidneys.co.nz/resources/file/thinking_about_being_a_donor.pdf

Contact information for the living donor coordinator for Auckland (ADHB) is as follows: Ann Rudolph 0212409103. She can also put you in touch with your local donor coordinator if you are from outside Auckland and don't know who to contact.

If you have any questions or worries please talk to the renal team so we can help further