



# **Post-transplant** kidney care

Discovery Health Kidney Care member guide





# Contents



# Welcome to your renal care handbook

Congratulations on receiving your organ transplant.

Having a kidney transplant is a life-changing opportunity.

You, and your family and your healthcare team would have invested a lot in your journey so far. Together we will work to keep you as healthy as possible for as long as possible.

Kidney transplant is considered the best treatment option for people facing kidney failure because it can increase your chances of living a longer, healthier life.

Kidney transplant surgery techniques and anti-rejection medicines have advanced significantly since the first operation was performed in 1954. Kidney transplantation is now considered routine and safe, with very good long-term survival rates.

Whether you had dialysis for years before your transplant, or received a kidney as a result of a sudden event; and whether your donor was anonymous and deceased, or a loved, living family member, there's a lot of information to take in after your transplant. The purpose of this book is to offer you answers to some of the questions you might have, to provide information, inspiration and direction along with resources to support you as you adjust to this exciting new chapter.

Your medical team is available to answer any further questions you have.

Remember, you are not alone, there's a whole team of supporters behind you, championing your success. We're here to help.

A handwritten signature in black ink that reads "Errol Gottlich". The signature is stylized, with the first name "Errol" written in a cursive-like font and the last name "Gottlich" written in a more formal, slightly cursive font.

Prof Errol Gottlich  
Clinical specialist



# A brief history of transplantation

”

*‘I owe it all to my kidney donor’s mom’*

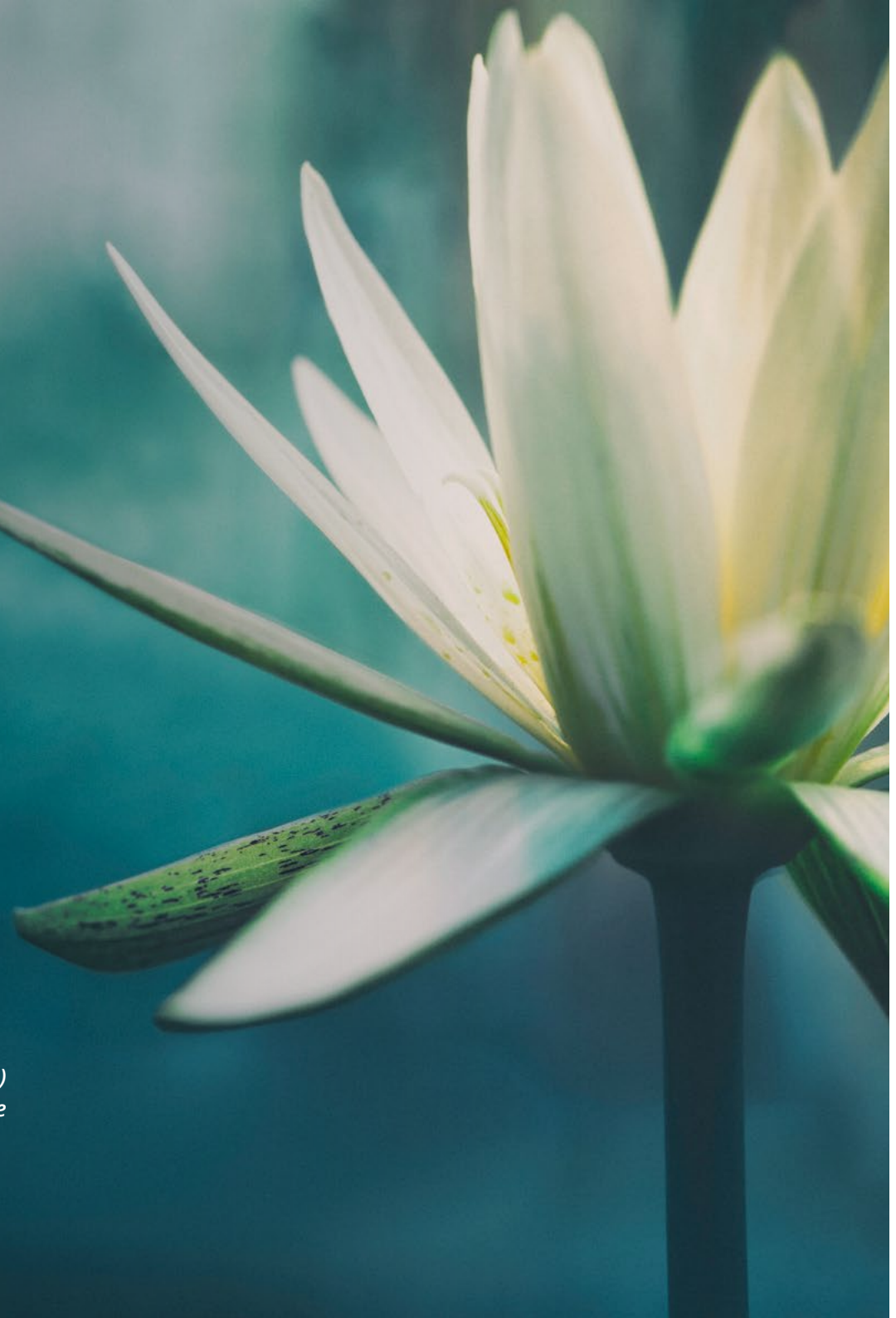
*Martinique du Preez’s kidneys failed when he was 13. After a failed transplant from his mom, he received a donor organ when he was 18. The surgery was a great success, and three months later he started training to regain his fitness.*

*‘Five months after my transplant I took part in the National Transplant Games in Stellenbosch. I broke the 200m South African record. I got three gold medals – in 100m, 200m and shot put,’ he says.*

*In 2017, Martinique represented South Africa at the World Transplant Games in Málaga, Spain, and returned with a gold in the ball-throw, silvers in long-jump and javelin, and bronze in the 100m.*

*‘I owe it all to my kidney donor’s mom,’ he says.*

*~ Martinique du Preez (21)  
World Transplant Games athlete*



# A brief history of transplantation



→ 1954

## The first successful organ transplant in the world

An American man donated a kidney to his identical twin brother. (The lead surgeon, Joseph Murray, won The Nobel Prize in Medicine in 1990 for his pioneering work.)

Today, more than 69% of all solid transplantations worldwide are kidney transplants.<sup>1</sup>



→ 1966

## The first organ to be transplanted in South Africa

A kidney transplant was performed in Johannesburg.



→ 1967

## The first successful liver transplant

Thomas Starzl performed a liver transplant on a 19-month-old patient in Denver, USA.



→ 1983

## Immunosuppressant approved for use

The discovery of the immunosuppressive effects of Cyclosporine, derived from a microscopic fungus, greatly reduced the risks of organ rejection and dramatically improved long-term outcomes.



→ 1988

## The Organ Donor Foundation of South Africa (ODF) was established

The organisation works to address the critical shortage of organ and tissue donors in South Africa through awareness and education campaigns. Around 250 kidney transplants are performed in South Africa per year. (In 2016, 47% of donations were from live donors, and 53% from deceased donors.)



→ 2013

## South Africa hosts the World Transplant Games

Durban hosted athletes from 70 nations, participating in events such as athletics, tennis and lawn bowling, swimming, racquet sports, golf, volleyball, and cycling. Team SA placed third overall after Great Britain and Northern Ireland, and the USA.



→ 1958

## The beginning of tissue matching

French immunologist, Jean-Baptiste-Gabriel-Joachim Dausset, developed a histocompatibility system for matching tissue.



→ 1967

## The world's first heart transplant

The world's first successful heart transplant was performed at Groote Schuur Hospital in Cape Town by Christiaan Barnard and his team.



→ 1978

## First World Transplant Games

The first competitive sporting event for transplant recipients took place in Portsmouth, England with around 99 competitors from the UK, France, Germany, Greece and the USA. The aim was to demonstrate the benefits of successful organ transplantation and increase awareness of organ transplantation.



→ 2019

## World Transplant Games were held in Newcastle, UK

Summer Games are held every two years. 2019 saw athletes compete in the UK. The International Olympic Committee has committed to helping to create awareness within the Olympic Movement and amongst athletes for organ donation and transplant.



→ 1996

## First split-liver transplant

American surgeons performed a split-liver transplant, using a portion of the organ in transplant.

<sup>1</sup> Source: World Health Organisation <http://www.who.int/transplantation/gkt/statistics/en/>





# Adjusting to life after surgery

Getting the call to say there is a matched donor for you is a major event, no matter how long you wait to receive it. Having a transplant may feel like a second chance or a new start.

You may want to take a moment to reflect on the gift you've received.

The five-year mortality rate for patients on dialysis is 40 – 60% compared to 95% for cadaveric recipients after one year and 86% at five years. For those who receive their organs from living donors, the survival rates are 98% after one year and 93% at five years.<sup>2</sup>

Coming off dialysis improves your (and your family's) quality of life significantly. That's something to celebrate!

#### **YOU CAN LOOK FORWARD TO:**

- Increased energy
- Returning to work and being able to fully commit your time
- More freedom in socialising and planning your daily life
- More time with family and friends
- Easier travel and transport
- Possibly a renewed sense of purpose and excitement for life.

Your focus now shifts from managing regular dialysis to keeping yourself and your kidney healthy. Along with a healthy lifestyle, the most important part of this is your taking your medicine and having regular follow-ups with your doctor.

There is plenty you can do to take care of yourself and your new kidney and reduce the chances and frequency of complications.

<sup>2</sup>Source: Transplant Research and Risk Management, 15 December 2017 Volume 2017:9 Pages 49 – 56. Siavash Rezapour, Aliasghar Yarmohammadi, Mahmoud Tavakkoli. <https://www.dovepress.com/one-year-survival-rate-of-renal-transplant-factors-influencing-the-out-peer-reviewed-fulltext-article-TRRM>

# Here are some guidelines to help you adapt to life with your new kidney

## DIRECTLY AFTER SURGERY

- For managing pain, you will probably be tapered to oral meds within 24 – 48 hours after your operation.
- Early mobility is key to pain control. We suggest moving a little as soon as possible after your surgery.
- You might find you have some initial weight gain in hospital from fluids given during and after surgery, this is quite normal.
- Exercise is essential to managing weight gain and associated complications.

## ARRIVING HOME AFTER SURGERY

- Avoid driving for at least two weeks after your surgery.
- Shower rather than bath for the first four weeks.
- Avoid being around people who have colds, flu, or generally feel unwell.
- Avoid crowds and queues and busy public places to reduce the risk of infection.
- Avoid handling pet waste.
- Keep your hands clean. Antibacterial soaps and wipes when you're out and about may be useful.
- Take care to wash fresh fruits and veg, to avoid fungus and mould.
- Keep an eye on minor wounds, cuts and scrapes. Let your doctor know if these don't heal.
- Let your GP and dentist know about your transplant so they can take care of infection control.
- Take it easy in the first 12 weeks. Avoid lifting, and don't do any cardiovascular activity just yet.
- Avoid smoking and being around smokers.
- A healthy diet, exercise and rest will boost your immune system.



## MAKING MEDICINE PART OF YOUR LIFE

A medicine regime, including immuno-suppressants, will be part of your life from now on.

The main purpose of immunosuppressant medicines is to prevent rejection of the new organ. Our bodies are built to recognise 'non-self' entities and attack them, so anti-rejection or immunosuppressant medicines work to help your body accept the new organ.

A typical post-transplant medicine schedule usually consists of intravenous drugs at the time of surgery, and several oral medicines daily.

Strict adherence to your prescribed medications is crucial for maintaining the health of the transplanted kidney. Your life depends of it.

Read more about rejection, medicines, and potential side effects on pages 00 and 00.

## REACHING OUT FOR EMOTIONAL SUPPORT

Your emotional and mental health is just as important as your physical health. If you have any existing mental health conditions you might find your new medicine has an effect on these. If this is the case, don't hesitate to reach out to let your doctor know.

*Keeping in touch with your team is essential to maintaining good mental health.*

You might also find support groups or sharing your feelings through artistic endeavour helpful.

Some people who receive kidney transplants also find they go through a range of emotions, including guilt. It's perfectly normal to feel guilt associated with both living and deceased organ donations, and some sense of responsibility. Caring for a transplanted organ requires effort, which may feel like a burden at times. All of your feelings are perfectly acceptable, you have been through an intense physical and emotional experience.

- Go easy on yourself: adjusting to new routines and new feelings takes time. Be realistic, manage your own and others' expectations, and allow yourself some time to come to terms with all the changes you'll be making.
- Reach out for support as much and as often as you need. You might prefer a one-on-one conversation with a professional, a support group with people with similar experiences and challenges, or to have a regular phone catch-up with a counsellor.
- Involve your family and friends in the process. Be specific about how you'd like them to help you.

## DEALING WITH COMPLICATIONS

Complications after kidney transplant are fairly common. Complications most often relate to infection and happen early after surgery. Most of the time these issues are resolved routinely.

Complications are likely to happen at some point. Don't take it personally, or feel you have done something wrong. This is part of the new territory you're navigating. Stay close to your transplant team, and keep them in the loop with anything you're concerned about. It's better to resolve any issues earlier than later.

## SEXUALITY AND FERTILITY AFTER A TRANSPLANT

Sexual activity will not harm your transplanted kidney. It will also not increase your risk of infection. It is recommended that you wait about four weeks after your transplant before having sex.

As your health improves after your kidney transplant your fertility may increase. This is true for both men and women.

If you are a woman and would like to have a baby it's best to discuss your plans with your doctor. He/she may suggest you wait at least a year after your transplant before trying to get pregnant. This gives your body time to become stable on your anti-rejection medicine.

If you become pregnant some of your medications may need to be changed and you will be carefully monitored to make pregnancy as safe as possible for you and your baby.

What does  
rejection mean?





Rejection is the most common and significant complication that people with kidney transplants face. Since the kidney is new to your body, and made up of tissues that are not identical to your own, even though they match yours, it will identify the tissue as 'foreign' and will try to protect you by 'attacking' it. Rejection is a normal response of your body after any transplant surgery.

## THERE ARE TWO TYPES OF REJECTION THAT CAN HAPPEN AFTER A TRANSPLANT:

**01 | Acute rejection** will usually happen within the first three to six months after your kidney transplant. Many kidney transplant patients have some acute rejection episodes to begin with, which means their body shows signs that it is fighting the new kidney. The good news is that fewer than one in 20 transplant patients have an acute rejection episode that leads to complete failure of their new kidney.<sup>3</sup>

**02 | Chronic rejection** happens more often and occurs slowly over the years following your kidney transplant. Over time, your new kidney may stop working because your immune system will constantly fight it. This is one of the reasons that regular follow-ups with your doctor are so important. Together you will monitor your kidney health and function and assess your medicine to ensure it's working as it should.

Remember a rejection response of some sort is normal. It **does not** mean your new kidney is not working or that it will be completely rejected. Adjusting the dose of your immunosuppressant medicine can usually treat this problem.

Kidney rejection can be hard to diagnose in its early stages. Never stop taking your medicine no matter how good you feel, or how well you think your transplanted kidney is working. The kidney is depending on you to keep it that way.

### Some of the signs and symptoms of kidney rejection include:

- Flu-like symptoms: for example, body aches, chills, headache
- Fever of 38°C or higher
- Urinating less than usual, or blood in your urine
- Very high blood pressure
- Sudden weight gain (within 48 hours)
- Ankle swelling
- Pain or tenderness of your new kidney
- Feeling very tired

If you suddenly start to feel unwell, please contact your doctor or transplant team right away.

<sup>3</sup> Source: American Kidney Fund

# Understanding your medicine, managing side effects



A lot of the time, living with a transplant is about keeping a balance between rejection and infection.

To prevent rejection, and help your body accept the new kidney, you need to lower your natural immune response. This makes you more prone to infections. You'll work with your doctor to find the right medicine regime to prevent rejection, and at the same time keep your risk of infection as low as possible.

The role of immunosuppressants, or anti-rejection medicines, is essential to the success of your transplant.

## **THERE ARE THREE GROUPS OF IMMUNOSUPPRESSANT MEDICINES:**

- Induction agents: powerful immuno-suppressant medicines used before the transplant in the operating room, or immediately after the transplant surgery.
- Maintenance agents: the immuno-suppressants you take every day.
- Rejection agents: medicines that treat rejection episodes.

When it comes to the everyday maintenance agents, you can give your kidney the best chance of a long and healthy life by being a hundred percent compliant. That means taking your medicines every day, exactly as prescribed.

If your immunity increases, even for a few hours, you may find your body starts 'fighting' the new organ. This can lead to rejection. If you ever miss taking your medicine, DO NOT double dose the next time, call your doctor right away.

### **Maintenance drugs**

There are four classes of maintenance drugs.

Your doctor will discuss the exact medicines and doses that are best for you.

Write down your medicine schedule on page 00 for reference. Note down any changes to your regime, in order to stay on top of your essential immunosuppressants.

- Calcineurin inhibitors: Tacrolimus or Cyclosporine (twice daily, 12 hours apart)
- Antiproliferative agents: Mycophenolate Mofetil, Mycophenolate Sodium or Azathioprine (twice daily, 12 hours apart)
- mTOR inhibitor: Sirolimus (once daily)
- Steroids: Prednisone (once daily, with food)



# Never miss a dose!

Use some of these simple strategies to stick to your medicine schedule.

Get creative and find ways that work for you. It's easy to forget, especially when you're feeling well, so it's wise to pick more than one reminder.

- Make taking your medicines easy and part of your daily routine. Always take them at the same time, in the same order, for example, just before you brush your teeth morning and night.
- Set your phone alarm to alert you when it's time to take your medicine. You might pick a special tone that's different to any others you use.
- Make sure you are set for home and away: set up your meds in a tidy and obvious place in your home, so they are easily visible. A dedicated space will help you prioritise them (and keep them out of reach of children and animals).
- Enlist the support of family and friends to remind you when you're out of your normal routine, such as on holiday. Make sure to take enough medicine when you go away.
- Make sure you have containers to take your medicines in if you're going to be out during the times you need to take them. Keep them handy all the time.

”

I keep my meds in a holder for each day of the week. I know by the end of the night it should be empty.

*~Julie, 6 years post-transplant*

- Make sure to keep an eye on your supply, and fill your scripts in plenty of time, so you're never in danger of running out.
- Think about what motivates you. Are you a list-maker? Would a chart or wall calendar where you tick off each dose help you adhere to your schedule? Do you need social interaction – would a 'buddy' keep you accountable? Or do you need rewards? A treat at the end of every month of perfect compliance might be your motivation.
- It helps to know all of your medicines by name and dose. Knowing the reason for taking each medicine might make the daily ritual more mindful and meaningful.

- There are apps that make taking medicine much easier: try out some of the top reviewed medicine adherence apps, such as: Patient Partner, Medisafe, Dosecast, Medhelper Pill Reminder, My Pillbox, MyMeds and MyMedSchedule.
- Let your team know how you feel on your medicine and if you have any concerns at each follow-up visit. If your doctor makes any changes to your medicines, dosages, or frequency, ask for written instructions. Then make sure you adapt your routine at home to match.
- If a doctor other than a member of your transplant team gives you a prescription, let your transplant team know before taking any additional medicines. Certain medicines can interfere with your anti-rejection medicines.
- Remember to continue to take your anti-rejection medicine no matter how great you feel. The effects of the medicines are part of the reason you're feeling so good.

Store your medicines in a cool, dry place out of direct sunlight, in the original containers with the caps closed. Don't keep them in the bathroom as damp and heat can make them less effective.

# Risks and side effects of immunosuppressant medicines

Like any medicines, immunosuppressants come with risks and side effects.

Around six months to a year after transplant, immunosuppression can sometimes be lowered, and the side effects should be reduced. In the meantime, discuss any concerns with your doctor. Most side effects should be manageable.

## Infection

One of the biggest side effects of immunosuppressants is infection. You are at higher risk for infections, such as from common viruses like flu, as well as bacterial or fungal infections, since your immune system is lowered. Infection is the most common problem soon after transplant or following treatment of a rejection because the dosage of your immunosuppressants is higher at these times.

### STAYING HEALTHY

Finding and treating infections early is the best way to keep you and your transplanted kidney healthy. Wash your hands often and try to avoid being around sick people, especially in cold and flu season, and people recently vaccinated with live vaccines. Avoid large crowds. Make sure you practice good food hygiene, for instance, washing fresh fruits and veg well, keeping meats separate from other foods, and disinfecting food preparation surfaces and utensils. Assign pet care duties to another family member – it's best not to handle pet waste.

### WHEN SHOULD I CALL MY DOCTOR?

Report any of these symptoms to your doctor as soon as possible:

- Sores, wounds, or injuries that don't heal
- Urinary tract infection symptoms such as frequent urge to urinate, pain or burning feeling when urinating, cloudy or reddish urine, or bad smelling urine
- Respiratory infection symptoms such as cough, nasal congestion, runny nose, sore or scratchy throat, or fever.

## UPSET STOMACH

Some people report having an upset stomach from their medicines. Talk to your doctor about the amount of the medicine you take, whether you can space out your doses differently (particularly the calcineurin inhibitors and antiproliferative agents), or find alternatives to reduce this side effect.

## SUN SENSITIVITY

Immunosuppressants can make you sensitive to sunburn. Always wear a sunscreen with protection of at least SPF 30 or higher and avoid being outside during the harshest hours of the day (10am – 3pm). A wide-brimmed hat and sunglasses with help protect your skin and eyes from sun damage.

## WEIGHT GAIN

Most people gain some weight after kidney transplant.

You will have fewer dietary restrictions than you did on dialysis, but it's just as important to eat healthily and exercise.

Gaining too much weight can lead to obesity, which increases your risk for heart disease and new-onset diabetes after transplant (NODAT). A renal dietitian can help create a healthy eating plan incorporating your preferences and tastes.

## HIGH BLOOD PRESSURE

If you had high blood pressure before receiving your new kidney, it may continue after your transplant. Some people develop high blood pressure as a side-effect of medicine, organ rejection or obesity (from weight gain after transplant).

Check your blood pressure regularly. Your target is to be under 130/80.

Along with hypertensive medicines, you can control your blood pressure through maintaining a healthy weight and a low-salt diet.

Some people also experience hair growth, acne, osteoporosis, tremors and other side effects initially. Discuss any concerns you have with your doctor.

### Did you know?

Many medicines, foods, and supplements can affect the levels of immunosuppressants in your blood. Some of the common ones are grapefruit juice, St. John's Wort, erythromycin, anti-TB medicines, anti-seizure medicines and common blood pressure medicines. Some studies also implicate papaya and pomegranate. Before taking anything that's not on a prescription from your transplant team, get the all-clear from your doctor.





# Sticking to your treatment plan

# 5 steps for success

There are several steps you can take to ensure your kidney is as healthy as possible. Your treatment plan will include a number of important components. If there's anything you're not sure about, don't hesitate to check in with your transplant team. Knowledge is power: the more you know about your condition and treatment, the more likely you are to make wise choices, and the better your quality of life.

01 

## TAKE YOUR MEDICINES

The importance of strict adherence to your medicine schedule cannot be overemphasised. Never stop or skip or substitute your medicines. Don't deviate from your prescribed plan under any circumstances. Before taking any over-the-counter medicines, herbal remedies or supplements, please check in with your transplant team.

Your kidney simply can't function without the support of these essential medicines.

02 

## CHECK YOUR BLOODS

Initially after transplant, you will need to have blood taken frequently (twice a week). This helps your team keep a close eye on how your new kidney is working.

Blood tests enable the team to monitor and identify any changes in your body. They will be able to react swiftly to any concerns.

As time passes and your immunosuppressant levels stabilise, you won't need blood tests so often.

03 

## ATTEND FOLLOW-UPS

Once you are discharged from hospital, you'll need to have weekly clinic check-ups for the first six weeks. These appointments are to assess your medicine response, and discuss any concerns and side effects you may have. Unless you have any complications, these sessions will also become less frequent over time.

04 

## MEASURE YOUR BLOOD PRESSURE, TEMPERATURE, WEIGHT, AND GLUCOSE DAILY

You'll need to do some measurements at home too. This information helps you monitor for signs and symptoms of infection and rejection. You'll discuss normal ranges with your doctor, and what to do when levels are too high or low. You'll be shown how to take and record your measurements. Bring these to your clinic appointments.

05 

## LIVE WELL!

Follow a healthy lifestyle including good quality food, plenty of exercise, rest, and stress management. A healthy body is the best home for your new kidney.

# The importance of medicine adherence

Adherence means  
'obeying a set of rules, or sticking to an agreement'.



Adopting a  
healthy lifestyle



and adhering to your  
medicine schedule



will give you and your kidney the **best chance of a healthy life.**

**22 – 30%**

of kidney transplant  
patients are non-adherent<sup>4</sup>



Patients who don't take their  
medicine as prescribed have a  
**60%** increased risk  
of kidney failure<sup>5</sup>

Non-adherence was the **third leading cause** of transplant failure<sup>6</sup>

On average, with **good care**,  
living kidney donor transplants last

**15 – 20 years**



while **deceased kidney**  
donor transplants last

**10 – 15 years**

Some of the reasons people don't take their medicines are:



they **forget**



they are **not supported**  
by their families



they **don't understand**  
why it's important<sup>7</sup>

Non-adherence could be responsible for

**20%**

of late acute rejections

and up to

**36%**

of graft losses<sup>8</sup>



**75%** of the people who are non-adherent  
can improve with **information** and **training**,  
and **simpler drug regimes**<sup>9</sup>

## Sources:

<sup>4</sup> Denhaerynck K, Dobbels F, Cleemput I, Desmyttere A, Schafer-Keller P, Schaub S, De Geest S. Prevalence, consequences, and determinants of nonadherence in adult renal transplant patients: a literature review. *Transpl Int.* 2005;18(10):1121–1133. doi: 10.1111/j.1432-2277.2005.00176.x. [PubMed][CrossRef]  
Butler JA, Roderick P, Mullee M, Mason JC, Peveler RC. Frequency and impact of nonadherence to immunosuppressants after renal transplantation: a systematic review. *Transplantation.* 2004;77(5):769–776. doi: 10.1097/01.TP.0000110408.83054.88. [PubMed] [CrossRef]

<sup>5</sup> The National Center for Biotechnology Information

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4724760/>

<sup>6</sup> Didlake RH, Dreyfus K, Kerman RH, Van Buren CT, Kahan BD. Patient noncompliance: A major cause of late graft failure in cyclosporine-treated renal transplants. *Transplant Proc.* 1988;20(3 Suppl 3):63–9.[PubMed]

<sup>7</sup> Iran J Nurs Midwifery Res. 2017 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5443003/>

<sup>8,9</sup> Nephrology Dialysis Transplantation, Volume 29, Issue 8, 1 August 2014, Pages 1597–1607, <https://doi.org/10.1093/ndt/gfu207>



# Linked conditions



While having a transplant and taking immunosuppressant medicine does raise your risk of certain associated conditions, many of these risks can be reduced and the effects managed with healthy living. It's more important than ever to eat well, make exercise part of your life, rest and manage stress, and ditch any bad habits.

## DECREASING DIABETES RISK

Sometimes, even if you didn't have diabetes before, you can develop diabetes after transplant. New-Onset Diabetes After Transplant (NODAT) can occur as a result of immunosuppressant medicines.

Your chances of having new-onset diabetes after transplant will be higher if you are obese or if others in your family have diabetes.

Developing diabetes is dangerous as high blood sugar levels can cause serious damage to your heart, blood vessels, eyes, feet, and nerves. This is one of the reasons that your medical team will check your blood glucose levels often after transplant.

Your healthcare team can develop a plan to help you keep your blood sugar under control, such as:

- Limiting carbohydrates
- Exercise, and
- Diabetes medicine.

## CONTROLLING CARDIAC EVENTS

People with kidney transplants are at greater risk for heart disease. There are many causes of heart disease including: smoking, diabetes, overweight, hypertension, high cholesterol and blood lipids, and number of years on dialysis.

You can lower your chances for getting heart disease in the future by:

- Controlling high blood pressure
- Managing cholesterol and blood lipids
- Stopping smoking
- Exercise
- Keeping to a healthy weight
- Managing diabetes well.

### Kick the habit

#### Why should I stop smoking?

Smoking significantly increases your risk for a number of chronic diseases, such as heart disease, cancer and lung disease. It can also cut the life of your new kidney: cigarette smoking is associated with increased chances of death and graft loss in kidney transplant recipients.<sup>10</sup>

**If you need help to quit**, ask your doctor about medicine or support programmes. Many Discovery Vitality members have had success with Smokeenders. See: **[www.smokeenders.co.za](http://www.smokeenders.co.za)**.

<sup>10</sup> Advances in Medicine. <https://www.hindawi.com/journals/amed/2017/6213814/>  
<https://pdfs.semanticscholar.org/33b2/abef1f7ea4921614287b463edc91fe0a7b89.pdf>

## HANDLING HIGH CHOLESTEROL

Many people may have higher cholesterol and blood lipid (fat) levels in the blood after transplant due to medicine side-effects, as well as weight gain, restricted diet, family history, or limited physical activity.

Kidney problems that cause protein in the urine (proteinuria) can also increase blood lipids.

High blood lipids can lead to clogged blood vessels – and an increased risk of heart disease and stroke. Your doctor will help you manage your cholesterol and blood lipids, usually through healthy eating, exercise, and medicine to lower lipid levels.

## CURBING CANCER RISK

Immunosuppressant medicines lower your immune function and may decrease the body's defence system against certain types of cancer.

Skin cancer is the most common type of cancer. If you have fair skin, are exposed to a lot of direct sunlight, or have a history of skin cancer, you may have a higher chance of getting skin and lip cancer. People with dark skins can also get skin cancer, although this is less common than for fair-skinned people.

Some immunosuppressants increase your risk of skin cancers more than others.

It's wise to use sunblock every day, and take steps to limit your exposure to the sun.

- Avoid direct sunlight
- Avoid sunbeds
- Wear UVA and UVB sunscreen protection, a minimum of SPF 50 outdoors
- Be aware of any changes in your skin. Do a regular skin self-exam, and let your doctor know if you notice any changes to your skin or moles
- Check in with a dermatologist annually for a full skin exam or mole map.

Women should also discuss their risks for cervical, breast and colon cancers with their doctors regularly and schedule routine Pap smears and mammograms.

For men, prostate and colon cancers are important to check for; your doctor will recommend regularly exams for these.

## BUILDING BONE STRENGTH

Bone disease (also known as chronic kidney disease-mineral and bone disorder or CKD-MBD) may continue even after your kidney transplant. Bone disease can cause weak and brittle bones and increase your chance of fractures.

The disorder can result from medicine side-effects, previous kidney disease, diabetes, smoking, lack of exercise, menopause, or number of years on dialysis.

To check your bone health your doctor will test your blood levels of calcium, phosphorus and if necessary parathyroid hormone (PTH) and vitamin D.

Weight bearing exercises such as walking, biking and using weights is a good way to increase bone and muscle strength. If your blood level of vitamin D is low your doctor may prescribe a vitamin D supplement.

## ADDRESSING ANAEMIA

Anaemia (low red blood cell count) is fairly common after transplant, due to the surgery, medicine side-effects, infection, abnormal breakdown of red blood cells, or organ rejection. Blood pressure medicine can also cause your body to make fewer red blood cells.

Mild anaemia can cause minor problems like fatigue and pale skin. If left untreated, anaemia can cause a lack of oxygen to organs and lead to more serious health problems such as heart failure.

If you have anaemia your doctor may discuss your diet and ways to include more iron, or prescribe an iron supplement.

## GETTING A GRIP ON GOUT

Gout is a condition that occurs when high blood uric acid levels cause crystals to build up in the joints, causing painful swelling.

Your body may have a hard time getting rid of uric acid (a normal waste product in blood) after your kidney transplant. This is often due to side-effects from medications, such as cyclosporine, leading to a high uric acid level in the blood.

Your doctor will help you manage the situation, usually through:

- Medicine (avoid non-steroidal anti-inflammatory drugs (NSAIDS) whenever possible)
- A diet that limits certain foods and beverages including red meat, seafood, sugary drinks and alcohol (especially beer)
- Keeping a healthy weight
- Controlling high blood pressure, high blood lipid levels and diabetes.



# Managing the emotional aspects of transplant



While having a kidney transplant has a major positive effect on your life, you can expect to feel a range of emotions after going through this intense physical and emotional experience.

Most people initially feel grateful, elated, hopeful and relieved to have received a transplant.

A variety of highs and lows may follow. Sometimes the joy is followed by sadness or guilt towards the grieving family, if your donor was deceased. Or towards friends who may still be on dialysis. You may have hoped or wished for an organ, and those feelings might feel a bit confusing when you do receive a kidney. One way to deal with these feelings is to focus on the gift you have been given, and the fact that the donor and their family had chosen to give the organ in order to find a sense of meaning in their loved one's passing.

You might also want to write a letter to the family expressing your gratitude and your feelings. Your transplant coordinator can pass the letter on to the family through the Organ Donor Foundation.

It can be hard to accept an organ from a relative or friend. Some people also describe a 'burden of responsibility' when it comes to caring for a donated organ. You might feel overwhelmed by the strict medicine regime, frequent blood tests and follow-ups.

You might be worried about taking care of your kidney, about rejection, about taking your medicine or be concerned your original condition might come back.

Complications often happen, and this can also be hard to manage. The kidneys can be slow to 'wake up' and you might have ups and downs with kidney function or have to have dialysis again for a short while. You might find your relationships change too, as your family and friends adjust to you being more active.

After the initial period of adjustment, which varies for everyone, and as you make positive lifestyle changes you are likely to feel better and more energised, you should be able to look forward to improved overall physical and emotional wellbeing.

Because living with any chronic condition can lead to feelings of frustration, depression and anxiety, it can be helpful to be aware of the potential difficulties you might face and take steps to feel supported. It's important to ask for help and reach out to others when you're in need. No one said you have to do this alone.

- Involve family and friends early on so they can be part of your progress, understand your situation and your needs.
- Be realistic about the stage you're at, and the fact that things may go wrong at times. Set some simple goals to work towards that can improve your quality of life.
- Stay in touch with your medical team. Keep them in the loop with how you are responding to medicine, how you are managing lifestyle aspects of your care such as returning to work or study and adjusting to life post-transplant. You might find your team can help you find solutions to any problems you encounter.
- Make time for fun, going out, and doing things you love.

- Make sure you're getting enough sleep, good food and exercise – these can immediately help you feel stronger and more in control. Good physical health is a good basis from which to improve mental health.
- Stay connected with your social circle and loved ones. It's important to have a network to draw strength and support from, and to lean on when you're having a hard time. Becoming isolated can lead to depression.
- Don't hesitate to get help: rather than wait until you feel overwhelmed to reach out for professional help, work with a counselor to develop coping strategies for any aspects of life you have trouble with. There are a number of ways to enlist this support – through phone counseling, meeting one-on-one with a therapist, or joining a support group run by a psychologist.

### Keeping depression away

Look out for these signs of depression and talk to your doctor right away if you think you are at risk. Depression and anxiety are not inevitable and can be successfully treated. Don't suffer in silence.

- Prolonged feelings of sadness, hopelessness
- Losing interest in activities you used to enjoy
- Changes to appetite (separate of the side effects of medicine)
- Changes to sleeping habits (excessive sleep, or insomnia; as your immunosuppressants can also affect your sleep and mood to a degree, discuss this with your doctor)
- Feeling agitated or irritable
- Lethargy or having low energy
- Difficulty concentrating
- Poor performance at work or school
- Becoming isolated from friends and family, not wanting to socialise

Most of the time, depression can be successfully treated. The sooner you address it, the better the outcome.





# Children who've had transplants



A kidney transplant is recommended for children who have serious kidney dysfunction and will not be able to live without dialysis or a transplant. Lifelong dialysis is not an option for children.

Some of the diseases that lead to transplants in children include: congenital renal obstructive disorders, congenital nephrotic syndrome, and diabetes.

Compared to the complicated medicine regimes, constant tests, hospitalisation, travel to dialysis centres and uncertainty which are often part of life with end-stage kidney failure, the medicine regime and follow-up schedule after a transplant are often not particularly challenging for families who have already been through so much.

Even so, aspects of having a chronic condition can be hard. Children may not understand why they have still have to stick to rules, and take medicines every day. It can be particularly difficult when children feel 'different' from their friends.

An age-appropriate, open approach can help your child understand and accept the changes in his/her life. Talk to your child about these changes and how you will work them into your routine. While you'll need to be diligent in helping them take their medicine, and sometimes they may not be able to do what other kids do (such as contact sports or going to crowded events), it's important to find ways to do fun things together with family and friends.

## MANAGING BIG FEELINGS

'Children sometimes fear the unknown, and the adjustment to life after transplant can feel overwhelming at times. The best approach is to answer direct questions honestly and openly and to discuss any concerns and worries they might have,' says Stacey Hanekom, Trust Manager at the KidneyBeanz Trust, an organisation supporting children with life-threatening kidney disease.

Your child's age and previous experiences may influence their feelings as they recover from transplant surgery. Here are some of the dominant worries per age group:

- Children under the age of six years primarily fear the operation.
- From six to 12 years children may also worry about their donor or family's wellbeing.
- Young people of 12 years to 18 years sometimes have fears linked to the success of the operation, concerns for the individual donating, pain, challenges related to change – such as medicine. The responsibility shifts to them as they mature, for managing their own medicine schedules.

### Healthy eating for young people after kidney transplant

Children and adolescents who have kidney transplants may have experienced weight loss or delayed weight gain and growth before the surgery.

After surgery, your goal is to provide enough nutrition, protein, and other essential nutrients to promote healing, weight gain, and growth. Avoid diet restrictions as much as possible and encourage your child to eat a wide variety of healthy foods. Your dietitian will work with you and your child to identify wholesome and tasty foods that are easily tolerated.

## HOW TO SUPPORT YOUR CHILD'S ADJUSTMENT

Your child may have lots of questions about what's happening and why. It is very important that the child feels involved in and part of the process rather a passive participant. Having some control over what's happening can help them accept any limitations and routines. Here are some of the ways you can support them through a period of adjustment.

### OPEN COMMUNICATION

Honest, age-appropriate conversations will help your child understand their situation, and what they need to do to go forward with their healing.

'How you answer can depend on their age and level of understanding. For example, a picture book or toys may help a younger child understand; while with older children a discussion can provide the information they are after,' says Dr Cathy Davies, Play Therapist and Social Worker in private practice.

If you are not able to answer some of your child's questions, don't worry, encourage your child to ask their doctor.



## What we learned through our experience...

- Let God to be part of your life.
- Develop a strong support group.
- Stay positive.
- Don't let your child feel neglected and out of place because of some restrictions.
- Be patient, it's easy as a parent to become exhausted and emotional.
- Listen to your doctor.
- Give attention to the rest of your family members.
- As a family see a psychologist pre and post-transplant.
- Attend regular follow-ups.
- Take care of your precious child.
- Don't isolate yourself or your family.

*~Agnes de Waldt, mom of Julian (12)*

### We need more organ donors

In South Africa, 12 children had kidney transplants in 2016. Only four kidneys were from live related donors. That means eight organs were donated by the families of people who died.

It's really important to encourage friends and family to become organ donors, so we can save more lives.

## INVEST IN UNDERSTANDING

'I would encourage parents to talk to their children about the risks and the reasons for any limitations placed on them,' says Cathy. This gives the child the opportunity to understand the purpose behind the instructions and why they are important. Without understanding the reasoning behind them, children may resent the limitations. The child then feels more empowered to make the choice to follow the instructions given.

## OFFER OPTIONS

Provide the child with alternatives rather than focusing on the limitations. Offering options also enables the child to make choices and feel empowered and exercise some control over their situation.

## SHARE THE KNOWLEDGE

Inform other adults/caregivers of any limitations so that the child is not placed in a potentially harmful environment due to lack of knowledge of others. This also saves the child having to explain numerous times.

## CREATIVE EXPRESSION

Encourage the child to express his/her feelings in as many ways as possible. This could be through talking, writing, playing, drawing and so on. Give the child different options and multiple opportunities to do this, without judging their creations, or fear of a negative response.

## PROFESSIONAL SUPPORT

If possible, children should continue to receive emotional support or therapy after the transplant process.

## LEAN ON YOUR SUPPORTERS

Let your extended family and friends help with emotional support and practical assistance. This also allows the child to rely on other adults and relieves a bit of stress off you and your partner.

You might also like to reach out to other families who have experienced a transplant as their understanding of your situation and the support they can offer may be invaluable.

”

The medicine schedule after transplant was a breeze! After two years of dialysis every two to three hours, medicines four-hourly, six-hourly, three times a day, twice a day, once a day, daily injections and three times a week, peg feeding, vomiting, continuous night feeding, scratching and itching during the night due to high urea levels, medicine post-transplant was a pleasure. Hanna feels 'special' because she is the only one in the house who has to take medication.

*~Danel Treurnicht, mom of Hanna (4)*

## 'Living life at 200%'

Born with congenital nephrotic syndrome, Hanna was not expected to survive her first year of life. After receiving a kidney from her mother, she's now enjoying life at full speed.

'For the first three months of Hanna's life, she didn't stop crying at all,' says her mother, Danel Treurnicht. When she eventually stopped crying, she started to accumulate fluid. Blood tests confirmed she had congenital nephrotic syndrome.

She was only three months old and already in failure. 'A month later she went into end-stage kidney failure and we started emergency dialysis,' says Danel. Little Hanna was on five cycles of peritoneal dialysis per day, starting at 5am until 8:30 at night with three-hour intervals.

'The chances of Hanna surviving until she was big enough for a transplant were minimal. It was hard to accept that she would most probably not make it. Somehow we managed two years of dialysis and with a lot of work, prayer and grace, she survived,' says Danel.

In May 2017 Hanna had a massive crash. 'She was resuscitated several times and stayed in ICU for a month until she was strong enough to be airlifted to Mediclinic Morningside in Gauteng, from Windhoek where we live.' By the age of two, Hanna had already spent 11 months in Morningside.

'We knew she would not survive another setback. If she was going to get a transplant – it was now or never,' says Danel.

The next day, Hanna's medical team started a fast-tracked matching process. Hanna's health allowed a small window period, and the team moved fast. Three weeks later, when Hanna was just two and a half years old, and weighed only 8,8kg (the minimum weight for transplant is usually 10kg), Danel and Hanna underwent surgeries. Danel's kidney was transplanted vertically into Hanna's abdominal area.

'It was a major success!' she says with obvious relief. 'The kidney started to produce urine immediately – the first urine in more than two years. Hanna had been peg fed from four months old, so when she ate pumpkin by herself, and loved it, it was a major highlight. It is the most awesome thing to see your child eat food by themselves, of their own free will, and not vomiting,' says Danel.

Hanna is now nearly four years old. She attends pre-primary school, where she loves playing in the sand and with her friends. She could not walk properly before transplant and now she is running around. The transformation is unbelievable, she's a different child.

'It's difficult to teach her that she must be careful and protect her kidney because she is living life at 200%.'



# 'The best day of our lives'

A rare genetic condition meant Julian spent much of his childhood in hospitals. A transplant has given him hope for the future.

Julian's journey started at six weeks of age when his face and feet started swelling. He was soon diagnosed with nephrotic syndrome. When he was six months old, a kidney biopsy at The Red Cross War Memorial Hospital in Cape Town revealed more. 'We discovered his kidney disease was caused by a rare genetic condition called Denys-Drash Syndrome, which also caused hypospadias (abnormal genitals),' says his mom Agnes. Although Julian was born without a urethra, a surgical repair was done when he was 18 months old.

Julian visited Life Vincent Pallotti Hospital every six months for six years for follow up and treatment. As his kidneys were leaking protein, causing high blood pressure, he started taking blood pressure medicine at the age of three. 'We already knew that in due time he would need a kidney transplant,' says Agnes.

When he was 11, Julian had a relapse and his blood pressure went through the roof. He was transferred to Johannesburg where he started dialysis three times per week for four hours. 'This changed our life as a family; between the dialysis centre and home we built our daily routine,' says Agnes. Julian was not doing well, and just before Christmas that year, he was admitted to Mediclinic Morningside in Johannesburg.

By January, he went into stage-four kidney failure and had a bilateral nephrectomy to save his life.

'A family member offered to donate a kidney to Julian, and this gave us hope for the future,' says Agnes. Testing began and six months later the transplant was approved. 'It was the best day of our lives,' she says. 'We received support from our families and from Julian's late father's side of the family. It was a turn-around for us as a family because we were so used to a high-adrenaline life and now it changed to a no-adrenaline life!'

'One of the highlights for Julian post-transplant was to be able to drink as much water as he wanted and to go on a holiday without restrictions,' says Agnes.

'As a mother my task is to make sure he takes his immunosuppressant medicine at the same time every day twice per day, and to teach him to take it by himself for the rest of his life. He is learning to eat well, avoid crowded places and be vigilant about infection.'

Julian is still adjusting to life after his transplant, but he is excited to be returning to school soon. The future is full of hope.



# Adolescents living with a transplant

Immunosuppressant therapy can be particularly challenging for young people since the medications can cause side effects, such as:

- acne or aggravate acne
- weight gain
- mood swings and anxiety
- trouble sleeping at night
- problems with increased blood sugars (or diabetes), sometimes requiring insulin
- high blood pressure
- increased risk of infection.

We know these side effects can feel unbearable at a time in your life when social connectedness is everything. But taking your medicine is saving your life, and your new kidney, so it's not negotiable.

It's really important that you don't change or stop any medicines without talking to your doctor.

However, there are some things you can do to lessen any negative effects you're experiencing. Sometimes, your doctor can change the medicine you're on to ease the side effects, or there may be other things you can do to reduce the things that are worrying you. Be open with your team about your concerns, and they will try to help.

## HERE ARE SOME OF THE WAYS YOU CAN GET SUPPORT FOR ANYTHING THAT'S ON YOUR MIND:



Speak to your mom or dad or a carer about your feelings; it can feel really good to share your thoughts, and let an adult help you carry the burden.



You might like to find other young people who have had similar experiences, either online or in person. Ask your transplant team to help you find a support group.

Bear in mind there is no filter on the internet, there are all sorts of opinions out there, so be selective and find a group that is positive and uplifting. When it comes to practical advice, make sure you check with your doctor before making any changes to your lifestyle. The best advice is scientifically sound, and evidence based.

- Relieve stress and connect with others through music, art, exercise classes or just catching up with a good friend.
- Keep your transplant team in the loop with how you are feeling.
- A healthy lifestyle can make the world of difference: eat a healthy, balanced diet, get plenty of rest, exercise and stay socially connected.
- Get creative: start a blog, make some art, or write a journal. Expressing your thoughts and feelings gives them a healthy outlet.
- Ask to meet with a therapist: there's no substitute for professional support. Find a counsellor you connect with, and work with them to find strategies and support for the things you find difficult.

**Famous transplant recipients include:**

Sarah Hyland (Haley in Modern Family) received a kidney from her father in 2012.

Selena Gomez, the American singer and actress received a kidney transplant in 2014.

NBA/Miami Heat basketball star Alonzo Mourning underwent a kidney transplant in 2003, after which he made his athletic comeback in 2006.

Former US vice president, Dick Cheney had a heart transplant in 2012, at the age of 71.

Apple boss Steve Jobs received a liver transplant in 2009.

American actor and comedian, Tracy Morgan received a kidney transplant in 2010.





# The role of diet

Your main dietary goals after a transplant are: to nourish your body with good quality nutrients, reach and maintain a healthy weight, boost energy and feel great.

A good diet will also help you control blood pressure, blood sugar and cholesterol levels, and in turn protect you from developing (or help you manage) obesity, diabetes and heart disease.

If you are overweight/obese, losing just five to 10 percent of your body weight will substantially reduce your risk of illness and improve your management of existing conditions.

## IN THE FIRST SIX WEEKS AFTER TRANSPLANT

Although you may need to continue some of your previous dietary restrictions in the weeks directly after your surgery, your sense of taste and appetite should improve.

You may sometimes have some side effects from your medicine such as diarrhoea, nausea and constipation, high glucose or high potassium levels. These side effects may affect what you eat. If you find your medicines make you nauseous, try smaller snacks throughout the day.

### Don't let nausea stop you from eating well

- Avoid skipping meals. An empty stomach can make nausea worse. Eat small amounts often, and eat slowly.
- Try several smaller meals during the day instead of three larger ones.
- Try cold foods (such as sandwiches, salads, or yoghurt), as these have milder tastes and smells than hot foods.
- Snack on dry biscuits, toast or crackers.
- Avoid spicy or fatty foods.
- Eat when you feel well.
- Hang in there, nausea won't last forever.

## PROTEIN

In the early weeks after transplant, your protein intake is important to help promote recovery, wound healing and prevent muscle loss associated with high-dose immunosuppressants.

If your kidney function isn't optimal, you may need to have less protein, but your doctor will discuss this with you.

## GLUCOSE

If your glucose levels are high, you can support your body in controlling blood sugars by:

- Having regularly spaced meals, don't skip meals.
- Choose high-fibre, low glycaemic index (GI) carbohydrates (for example, oats, sweet potato, wholegrains).
- Avoid taking in big hits of sugar, such as sugary soft drinks, fruit juice, cakes, chocolates and sweets.

## MINERALS

Your regular check-ups and blood tests will show the levels of minerals in your blood. Your doctor will measure your magnesium, potassium and phosphates.

If you need extra **magnesium**, good sources are green vegetables such as spinach, broccoli, leeks, peas, cabbage, and asparagus; wholegrain breads; beans and legumes, nuts and seeds; and seafood and fish.

You may need more or less potassium and phosphates.

**Phosphate** is found in protein-rich foods such as meat, dairy, nuts and seeds. Good sources of phosphate include: cheese, yoghurt, milk and soymilk, wholegrain breads/cereals, wholemeal pasta, beans and legumes, nuts and seeds, chicken, eggs and fish.

**Potassium** is found in fruit and vegetables and dairy products. Good sources of potassium include: dried fruit, fruit or vegetable juices, tomato-based pastes, sauces and purees and baked beans. When potassium is too high or too low, you can develop problems with muscle and heart function.

### High magnesium and phosphate snack ideas

- Muesli with milk or yoghurt
- Wholegrain toast with peanut butter
- Baked beans on wholemeal toast
- Cottage pie
- Tinned salmon on rice cakes with cheese
- Ham and cheese sandwich on wholegrain bread
- A glass of Milo made with milk
- A handful of raw or roasted nuts.

## FLUID: IT'S A WHOLE NEW WORLD!

Your new kidney needs water to clear waste and filter toxins. Drinking water each day will keep your creatinine low and help to increase the life of your transplanted kidney. Your transplant nurse will let you know how much you should drink each day, usually around six to eight glasses. Enjoy no more fluid restrictions!

## FOOD HYGIENE

Safe food preparation and handling is important as your immune system is lowered, making you more prone to foodborne illness. Always wash your hands, surfaces and utensils with hot water and soap, then dry thoroughly before and after making food. Rinse fruits and veg thoroughly and keep your fridge clean. Keep meat separate to other foods. Store foods in the fridge promptly and defrost frozen foods in the fridge rather than at room temperature. Cook all foods thoroughly, especially meat.

### Avoid high-risk foods such as:

- Raw and undercooked seafood and meat
- Cold cooked chicken
- Cold deli meats
- Foods containing raw eggs
- Pre-packaged fruit or veg
- Paté and meat spreads
- Soft and semi-soft cheeses
- Unpasteurised dairy (raw milk).

## FOR THE LONG TERM

You'll most likely enjoy greater freedom with your diet after transplant, if you have no complications, compared to while you were on dialysis. It's just as important to make wise choices. Setting healthy habits for life may mean making positive and permanent changes to your lifestyle. You need good quality, healthy food and exercise as the basis to live your best life.

Making activity and healthy food easy and enjoyable will help you make it sustainable. Don't forget to call on the support of a renal dietitian for information, ideas and inspiration.

Your dietitian will work with you to develop a nutritional plan that's just right for you. Your plan may be determined by your weight, blood test results, kidney function, and medicines. It will also take into account your nutritional needs, any deficiencies, and your personal or cultural tastes and preferences.

A balanced diet includes a variety of fresh fruits and vegetables, lean meats, reduced-fat dairy products, whole grains, and plenty of water. Limiting salt will support your new kidney and help it to function optimally.

**Protein** is important to support health, but it may not be emphasised as much as it was in the first six weeks after transplant. Unless you experience chronic rejection, you can eat as much as the general population (a modest 60g per day is recommended). The best sources are plant-based proteins like beans and legumes; add them to stews, salads and vegetable side dishes. Lean meats, with visible fat removed, are the best types of meat for general health.

**Carbohydrates**, found in breads and cereals, rice, pasta, fruits and fruit juice, potato, soft drinks, cordial, cakes and biscuits, are converted to glucose (sugar) which enters the bloodstream. Wholewheat options are the best choice; we can all benefit from limiting highly refined carbohydrate-rich foods.

If you have diabetes it is especially important to try and maintain good blood glucose levels.

Stable blood sugar levels are supported when we eat regular meals with small amounts of carbs, and avoid foods with large concentrated amounts of sugar like sweets, cakes and soft drinks.

### Use salt sparingly

Keeping salt to a minimum in your diet can help in lowering high blood pressure and maintaining a good fluid balance. There is usually enough salt in natural foods to meet our daily needs. Avoid adding salt to your cooking and at the table, and eating high-salt foods. Many foods have reduced-salt options.



## CALCIUM

Bone mineral density loss can be a problem for some people post-transplant. Including calcium-rich foods in your diet can help keep bones strong. Dairy products are the richest source of calcium; low-fat varieties have just as much calcium as full-fat products. Other sources include fortified soy products, fish with bones (such as salmon or sardines), vegetables (such as broccoli) and almonds.

## HIGH-RISK FOODS

There are only a few foods that are off limits after you've had a kidney transplant. Dietary restrictions may depend on how well your kidney is functioning, and these may change, so it's best to be in touch regularly with your renal dietitian.

Avoid foods that are more likely to contain bacteria as these can cause infections.

It's best to steer clear of raw or undercooked meat, poultry, fish, and shellfish. Avoid raw eggs (such as in fresh mayonnaise) and ensure dairy products such as yoghurt and cheese are made from pasteurised milk.

Always check with your renal dietitian or medical team if you're not sure about what you can eat, and don't take any supplements, over-the-counter medicines or herbal remedies as these can interfere with your immunosuppressants and put you at risk for rejection.

### A note about weight gain

Most people find they put on weight after transplant, due to restrictions falling away, an increased appetite from feeling well, and the effects of some immunosuppressant medicine.

The combination of eating healthy foods and exercise is proven to be the most effective strategy to reach and maintain a healthy weight. Small changes can lead to big results; for example, cutting out sugar-sweetened beverages (some contain up to 55g or 13 teaspoons of sugar per can!) can dramatically reduce your calorie intake and improve your overall health. People who have soft drinks daily are 26 percent more likely to develop diabetes. Fizzy drinks can also interfere with the uptake of calcium to the bones.

Some fruits and vegetables can affect your immunosuppressant levels, and how effectively your medications work. Avoid this hazardous handful:

- Grapefruit and grapefruit juice, pomegranate and pomegranate juice
- Unwashed fruit, veg and salads and damaged or overripe produce
- Unpasteurised juices
- Deli meats and salads
- Sprouts (alfalfa or bean sprouts).



# Exercise

Exercise and physical activity should be a regular part of your life after a kidney transplant to continue improving your overall physical and mental health.

*These are general guidelines only; always check with your doctor before beginning an exercise programme after a transplant.*

## Your path back to fitness



### After surgery

On the first day after surgery start by walking in your room and hallway. Start with 5 minutes.



### After two weeks

Gradually increase your time as you feel comfortable. By the time you leave the hospital, you may be walking for up to 30 minutes a day.



### After six weeks

In addition to walking, you could add cycling on a stationary bike to your routine.



### After three months

You can participate in most activities.

But care for your kidney! Avoid pulling or straining your abdominal muscles – avoid heavy lifting, sit-ups, and contact sports or any jarring sports.

”

Kidney transplant patients have a higher life expectancy if they exercise more.

*~Clinical Journal of the American Society of Nephrology*

## EXERCISE HAS THE FOLLOWING BENEFITS:

- Improves your circulation
- Boosts energy levels
- Strengthens your heart and cardiovascular system
- Increases endurance
- Lowers blood pressure
- Improves muscle tone and strength
- Improves balance and joint flexibility
- Strengthens bones
- Helps reduce body fat and reach a healthy weight
- Helps reduce stress, tension, anxiety and depression
- Boosts confidence
- Improves sleep.

## YOUR EXERCISE PLAN

The ideal exercise plan includes all three of the following elements. Once you have reached a level of activity that is comfortable, mix it up to keep it interesting. Find something you love, and try something new. Keep challenging yourself, whether you like the gym or prefer the great outdoors.

- 01 | Flexibility:** this exercise type is all about slow lengthening of the muscles. Stretching the arms and legs before and after exercising helps prepare the muscles for activity and prevent injury. Regular stretching, yoga and Pilates also increase your range of motion and flexibility.
- 02 | Cardiovascular:** steady physical activity using large muscle groups helps build endurance. Cardio strengthens the heart and lungs and improves the body's ability to use oxygen. Over time it can help decrease your heart rate and blood pressure and improve your breathing – since your heart won't have to work as hard during exercise. Examples are: walking, running, skipping with a rope, cycling (stationary or outdoor), and rowing.
- 03 | Strength training:** repeated muscle contractions until the muscle becomes tired, helps you build muscle and stay strong.

For maximum benefit, work towards exercising for at least 30 minutes, a minimum of three to four times a week. Exercising every other day will help you recover in between and keep a routine.

Aim to exercise for a minimum of 20 to 30 minutes, at least three to four times a week.



## EXERCISE GUIDELINES

- Start slowly and set realistic goals.
- Gradually increase your activity level, especially if you haven't been exercising regularly.
- Exercise at your own pace – don't push yourself.
- No activity is too small – take the stairs, park further from an entrance, walk the dog, or clean the house. It all adds up.
- Stay hydrated to help restore the fluids lost through exercise.
- Make it fun: choose an activity you enjoy – and try new things. You're more likely to stick with it if you enjoy it. Consider if you prefer group activities, or solo time? Indoor or outdoor? What time of day do you like to get active? Mix up your routine to keep it interesting and challenging.
- Leave an hour and a half after eating before exercising.
- Dress for the weather conditions and wear protective footwear.
- Factor in a 5-minute warm-up, before any cardiovascular activity and include a 5- to 10-minute cool down afterwards. Stretching while standing or sitting.
- Make exercise a priority, schedule your sessions on your calendar and try to stick to your plan.
- Exercise at a steady pace. Keep a pace that allows you talk during the activity.
- Enlist a partner: training with a friend will help you stay motivated, accountable, and make it more fun.
- Using a heart rate monitor can help you stay in the safe zone.

Kidney transplant patients are at high risk of developing cardiovascular disease: exercise can lower your risk.

## EXERCISE CAUTION

When to sit it out, or call for help:

- New medications can affect your response to activity, so check with your doctor if you've made any changes to your schedule.
- Avoid heavy lifting, pushing heavy objects, and chores such as raking, shovelling, mowing, and scrubbing. Exhale while lifting.
- If you become overly fatigued or short of breath while exercising, take a rest. It's best to sit, not lie down.
- Avoid exercising outdoors when it is too cold, hot, or humid. High humidity may cause you to become fatigued more quickly, and extreme temperatures can interfere with your circulation.
- Avoid extremely hot or cold showers after exercise.
- Do not exercise if you are not feeling well or have a fever. Wait a few days after all symptoms disappear before starting your exercise programme, unless your health care provider gives you other directions.
- You'll need to start small and gradually increase your exercise if you've taken a break. Ease back into it.
- If you develop a rapid or irregular heart beat or have heart palpitations, rest. Check your pulse after resting for 15 minutes. If your pulse is still above 120 to 150 beats per minute, call your doctor.
- Don't ignore pain. If you have chest pain or pain anywhere else in your body, stop the activity. If you continue to perform an activity while you are in pain, you may cause stress or damage on your joints.
- Stop exercising and rest if you:
  - Have chest pain
  - Feel weak, are dizzy or lightheaded
  - Have unexplained weight gain or swelling (call your doctor right away)
  - Have pressure or pain in your chest, neck, arm, jaw, or shoulder
  - Have other symptoms that cause concern.

Contact your health care team if any these symptoms persist.

Consult your doctor  
before beginning any  
exercise programme.

# Transplant patients share their exercise tips and successes

”

‘I use the elliptical trainer at the gym at my own pace. I also use the stationary bike; Today I did 14 kilometers.’

*~Martha, 11 weeks post-op*

”

‘After three months, I started walking and doing yoga. I do light jogging, while being careful to take care of my kidney area. I found some exercises on YouTube which I do at home.’

*~Sapna, three months’ post-op*

”

‘Staying physically active helps your entire body. I walk, swim, strength train and do a lot of gardening. There are two golden rules: 1. Stay hydrated and 2. Avoid any activity that may result in a blow to your new kidney.

Being physically active is also the best way to improve your mood and outlook on life. Transplant can be stressful, and just walking outside can be a good stress reducer!’

*~Rebecca, one year post-op*

”

‘Even though I don’t like gyming that much, I still go to keep in shape. The main thing is not to get dehydrated, and to start slow.’

*~Manish, eight months post-op*

”

‘By the end of my first year I started playing squash to get back in shape. I also did a few group classes at the gym, which was fun.’

*~Corne, three years’ post-op*

”

‘I enjoy cycling and hiking. I have tried doing weights in the gym, but I prefer outdoor activity. Recently I went on a trip to see the northern lights.’

*~Jeremy, two years’ post-op*



# Glossary of medical terms



## YOUR A TO Z OF KIDNEY TRANSPLANTS

### Acute tubular necrosis (ATN)

Reversible kidney damage resulting in delayed kidney function. Can be caused by medications to prevent rejection or more commonly by prolonged cold storage of the kidney prior to transplantation.

### Adherence

The process of obeying the rules or sticking to an agreement. In the case of kidney transplant, medicine adherence means your responsibility to take your medications exactly as prescribed.

### Allograft

A transplant between two people with different genes. Allograft loss is when the transplant fails, most often because the organ is rejected.

### Anaemia

A condition in which the blood has a lower than normal amount of red blood cells.

### Analgesic

Any drug intended to alleviate pain.

### Anastomosis

A surgical connection, often between two blood vessels.

### Antibody

A protein made by the body's immune system in response to a foreign substance such as a blood transfusion, pregnancy or previous transplant. Because the antibodies can attack the transplanted organ, transplant recipients must take immunosuppressive medicine to ward off rejection of the organ.

### Antibiotic

A medicine used to treat infection.

### Antigen

A molecule or substance that is seen by the body as foreign, such as a transplanted organ, that triggers a response from the immune system. This response may be due to increased production of circulating antibodies.

### Antihypertensive

A medicine that lowers blood pressure.

### Anti-Thymocyte Globulin (ATG)

An immunosuppressive medicine used after transplantation to prevent and/or treat acute rejection.

### B cell

A specialised white blood cell responsible for the body's immunity. B cells play a central role in antibody production.

### Blood pressure

Force of the blood against the walls of a blood vessel or heart chamber.

### Blood urea nitrogen

A waste product normally excreted by the kidneys.

### Cellcept

An immunosuppressive medicine used after transplantation to prevent rejection (the trade name is Mycophenolate Mofetil).

### Cholesterol

A substance normally made by the body, but also found in foods from animal sources, like beef, eggs, and butter. Too much cholesterol in the body can lead to narrowing and blockage of the arteries, especially those that feed the heart and keep it healthy. High cholesterol can also cause the formation of gallstones. Ideally, blood cholesterol levels should be less than 200mg/dL.

### Complete blood count

A measurement of size, number, and maturity of different blood cells in a specific volume of blood.

### Compliance

Following instructions or a prescription, for example taking your medicine after a transplant.

### Contraindication

Any procedure that would not be in a person's best interest to be undertaken. By means of physical and psychological examination, physicians and healthcare team members are careful to identify any contraindication to kidney transplantation.

### Cyclosporine A

An immunosuppressive medicine used after transplantation to prevent rejection. This medicine comes in two formulations but they are NOT interchangeable (trade names include Sandimmune or Neoral and Gengraf).

### Cytomegalovirus (CMV)

A virus that lies dormant in the body and can be transmitted or reactivated after transplantation.

### Dehydration

When the bloodstream and the cells of the body contain less fluid than normal. The body's mineral balance may also be affected.

### Donor

The person who gives an organ to somebody else.

### Endotracheal tube

An airway tube inserted through the mouth leading to your windpipe to help you breathe during surgery.

### Glomerulonephritis

A type of glomerular kidney disease in which the kidneys' filters become inflamed, scarred and slowly lose their ability to remove wastes and excess fluid from the blood to make urine.

### Graft-versus-host disease (GVHD)

A condition that results when the immune cells of a transplant react against the tissues of the person receiving a transplant.

### Haematocrit

The measurement of the percentage of red blood cells found in a specific volume of blood.

### Immune system

The body system that serves as a defence mechanism and protects the body by fighting against foreign intruders into the body. These intruders include bacteria, viruses and foreign cells in the form of organ transplants. Antibodies may be formed against these foreign substances.

### Immunosuppressant medications

Medicines that lessen the action of the immune system, and therefore protect your transplanted kidney.

### Nephrectomy

Surgery to remove the kidney.

### Nephrologist

A physician who specialises in diseases of the kidneys.

### Nephrotic syndrome

A condition characterised by high levels of protein in the urine, low levels of protein in the blood, tissue swelling, and high cholesterol.

### Organ preservation

Immediately upon recovery from a donor, organs/tissues are placed in preservation fluid until just before they are ready to be transplanted into the recipient.

### Pathologist

A physician who specialises in diagnosis and classification of diseases by laboratory tests such as examination of tissue and cells under a microscope.

### Perforation

A hole in the wall of an organ.

### Prednisone

An immunosuppressive medicine used post-transplant to prevent rejection (a type of corticosteroid).

### Regimen

A specific plan, such as diet, exercise, or medicine, designed to achieve certain goals.

### Rejection

An immune system response to transplanted tissues or organs.

A rejection episode does not mean the transplanted kidney will be irreversibly rejected; most rejection episodes are reversed with medications. Immunosuppressive medications taken diligently for life are essential to preventing rejection of the kidney.

### Renal scan

An ultrasound procedure is used to check how well the transplanted kidney is working. An injection of dye into a vein helps the scanner translate the findings onto X-ray film.

### Sensitisation

Your regular blood samples are tested against a panel of proteins to assess the antibodies. Someone who reacts to less than 10% of the panel is unsensitised; those who react to more than 10% of the panel are said to be sensitised.

### Side effects

Unwanted responses to certain treatments.

### Sirolimus

An immunosuppressive medicine used after transplantation to prevent rejection (the trade name is Rapamycin).

### Stent

A small tube placed in the ureter during surgery to protect stitches and promote healing. Stents should be removed six weeks after surgery.

### Tacrolimus

An immunosuppressive medicine used after transplantation to prevent rejection (the trade name is Prograf, previously known as FK506).

### T cell

A type of white blood cell responsible for the body's immunity, T cells recognise and destroy cells infected by viruses, graft cells and other foreign cells.

### Transplant coordinator

A registered nurse with advanced training in the care of organ transplant patients, your coordinator manages the processes of evaluation, testing, and listing for a donor organ. After the transplant, your coordinator is your link to transplant doctors for post-transplant care.

### Transplantation

To transfer organs, tissues, or cells from one person to another, or from one area of the body to another in order to replace a diseased structure and to restore function.

### Urinalysis

Laboratory examination of urine for various cells and chemicals, such as red blood cells, white blood cells, infection, or excessive protein.



# Contact details and resources

**IMPORTANT TELEPHONE NUMBERS**

Name

---

My GP

---

My kidney specialist

---

My transplant team contact person

---

Transplant coordinator

---

Renal dietitian

---

Psychologist

---

Social worker

---

My Discovery Health Plan details

---

**Discovery Health: 0860 99 88 77**





## Resources

### CONTACT DETAILS FOR INFORMATION AND SUPPORT

#### National Kidney Foundation of South Africa

Telephone: 011 447 2531

Email: [nkfsa@mweb.co.za](mailto:nkfsa@mweb.co.za)

[www.nkf.org.za](http://www.nkf.org.za)

#### Southern African Transplantation Society

Email: [info@sats.org.za](mailto:info@sats.org.za)

<https://www.sats.org.za/resources>

#### Renal Care Society of SA

A professional association for improving patient care

Email: [www.renalcaresoc.org](http://www.renalcaresoc.org)

[www.renalcaresoc.org](http://www.renalcaresoc.org)

#### Diabetes SA

Telephone: 021 425 4440

Email: [national@diabetessa.org.za](mailto:national@diabetessa.org.za)

[www.diabetessa.org.za](http://www.diabetessa.org.za)

#### South African Heart Association

Telephone: 021 889 6129

[www.saheart.org](http://www.saheart.org)

#### Organ Donor Foundation

Telephone: 0800 226611

[www.odf.org.za](http://www.odf.org.za)

#### SA Depression and Anxiety Group (SADAG)

[www.sadag.org](http://www.sadag.org)

Suicide crisis line: 0800 567 567

#### KidneyBeanz Trust

Supporting children with life-threatening kidney disease [www.kidneybeanz.co.za](http://www.kidneybeanz.co.za)

#### Medicine Information Centre (UCT)

[www.mic.uct.ac.za](http://www.mic.uct.ac.za)

Telephone: 021 406 6829

### INTERNATIONAL INFORMATION AND SUPPORT

#### Renal Support Network

[www.rsnhope.org](http://www.rsnhope.org)

#### Davita

[www.davita.com](http://www.davita.com)

#### Renal Info

[www.renalinfo.com](http://www.renalinfo.com)

#### American Association of Kidney Patients

[www.aakp.org](http://www.aakp.org)

#### Nephkids

[cybernephrology.ualberta.ca/nephkids/](http://cybernephrology.ualberta.ca/nephkids/)

#### National Kidney Foundation (USA)

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

#### National Kidney Foundation (UK)

[www.kidney.org.uk](http://www.kidney.org.uk)

In case of emergency



# Medical Alert

Wearing a medical alert bracelet or necklace that identifies you as a transplant patient is useful in the case of an accident.

## HOW DOES MEDICALERT WORK?

When you join MedicAlert your medical details are recorded on a database: this will include your kidney transplant history, medications and any complications. First responders to an emergency will be able to contact the MedicAlert hotline to access your files, ensuring that you receive appropriate treatment.

Your identification from MedicAlert will alert first responders to your medical condition and enable them to act accordingly.

In an emergency, medical staff have immediate access to important medical information about you. This could help them to save your life.

## Contact the MedicAlert Foundation of Southern Africa

For more information:

Call: 086 111 2979

Email: [info@medicalert.co.za](mailto:info@medicalert.co.za)

Or visit: [www.medicalert.co.za](http://www.medicalert.co.za)

# My medicine schedule

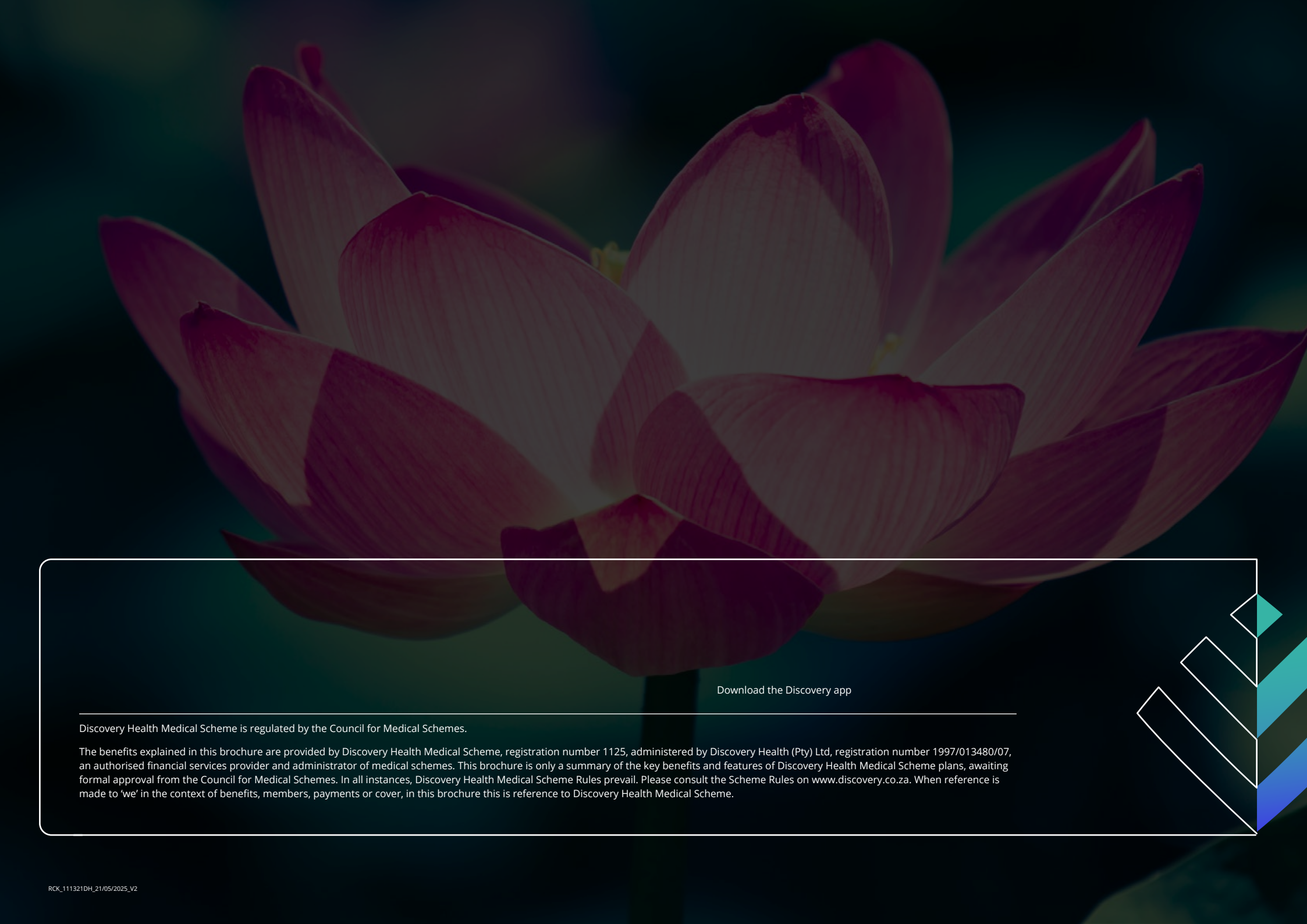




# My medicine schedule

[illegible]

In case of missed medicine, or medicine-related problems, call:



Download the Discovery app

---

Discovery Health Medical Scheme is regulated by the Council for Medical Schemes.

The benefits explained in this brochure are provided by Discovery Health Medical Scheme, registration number 1125, administered by Discovery Health (Pty) Ltd, registration number 1997/013480/07, an authorised financial services provider and administrator of medical schemes. This brochure is only a summary of the key benefits and features of Discovery Health Medical Scheme plans, awaiting formal approval from the Council for Medical Schemes. In all instances, Discovery Health Medical Scheme Rules prevail. Please consult the Scheme Rules on [www.discovery.co.za](http://www.discovery.co.za). When reference is made to 'we' in the context of benefits, members, payments or cover, in this brochure this is reference to Discovery Health Medical Scheme.