KidneyCare
My health status and support
In an emergency

“A MedicAlert bracelet helps first responders to assess an emergency situation – it speaks for you when you cannot,” says Bruce Kimbrey, CEO of MedicAlert South Africa. “Everything a paramedic needs to know can be available with a phone call to our emergency room, which is staffed 24 hours a day by qualified personnel. All your medical details will be instantly on hand and can help first responders save your life.” Bruce explains that medics are not allowed to look in your wallet or handbag for information about you, but with a unique membership number they can get everything they need to know to give you the best possible treatment, without wasting any valuable time.

MedicAlert is for you if...

MedicAlert is right for you as a dialysis patient, and if you:
- have any type of hidden medical condition, including co-morbidities like cardiovascular disease or diabetes
- have an allergy
- have had a kidney transplant, or any type of implant, pacemaker, heart valve or joint replacement
- take regular medicine
- would like your blood group to be recorded
- have a living will or wish to be an organ or body donor
- simply want someone else to know if you have been involved in an emergency.

Making sure everyone knows about my condition in case of an emergency

When you live with a chronic condition and get ongoing treatment like dialysis, it’s important to take steps to make sure you are properly taken care of in an emergency situation.

What you need is to be able to give a lot of very important medical information to the people first on the scene so they can act quickly, and act right.

MedicAlert is a non-profit organisation designed to give emergency medical staff immediate access to important medical information that could help them save your life.

How it works

When you become a member of MedicAlert all your medical information is recorded on a database. Your records will include your kidney disease, what kind of dialysis you are on, whether you had a kidney transplant, or are waiting for a donor organ, your blood type, any medicine you are on, allergies, any linked health issues or emergency needs, and the details of your close family members. You are given a unique membership number that a medical professional can use to get these records in an emergency situation.

Your membership number and very important information, like your chronic condition, are engraved on a bracelet or necklace that you should wear at all times.

Also engraved on your bracelet is the 24-hour phone number that paramedics or other emergency staff can call to get the detailed information on the database.

“The more organised you are the easier it is to enjoy your holiday.”
Terms used by doctors and other medical staff

Understanding the meaning of these terms

- **Abdominal cavity**: open space in your belly where they put a donor kidney during a transplant operation.
- **Anaemia**: the word means “lack of blood” and is a decrease in the normal number of red blood cells, or less than the normal quantity of haemoglobin in the blood.
- **Acute tubular necrosis (ATN)**: When the internal structures of the kidney, mainly the tissues of the kidney tubule, become damaged or destroyed.
- **Antibodies**: Acting as the body’s army, antibodies are proteins generally found in the blood that pick up and destroy invaders, like bacteria and viruses.
- **Anaesthetic**: A specially trained doctor called an anaesthesiologist or anaesthetist will put you in a deep sleep so that you will feel no pain.
- **Artery**: is an elastic blood vessel that transports blood away from the heart.
- **AV fistula (or arterio-venous fistula)**: is the access point for haemodialysis. The AV fistula is created internally and used for a long time. To create it, the surgeon joins the artery and vein under the skin, usually in your forearm.
- **Calcitriol**: a hormone that is converted from vitamin D by the kidneys, which maintains normal calcium levels for healthy bones.
- **Catheter**: A flexible tube inserted through a narrow opening into a body cavity.
- **Chest x-ray**: a test that shows the doctor what is going on inside your chest.
- **Chronic kidney rejection and failure**: Chronic rejection is a response of the patient’s immune system and is usually not reversible. A patient’s white blood cells make special proteins called antibodies that are made specifically to “latch onto” the transplanted organ. While attached to the organ, the antibodies alert the rest of the immune system to attack the organ slowly and continuously. Because chronic rejection is usually not reversible, the best defence is to prevent it from happening in the first place by taking the anti-rejection medicines exactly as prescribed.
- **Complications**: things that go wrong.
- **Crossmatch**: During this test your blood cells are mixed with those of the donor. If your blood cells do not react to those of the donor, the crossmatch is negative and the transplant can go on. If your cells react to the donor cells, the crossmatch is positive, showing that the donor kidney is definitely going to be rejected.
Peritoneal cavity: The peritoneal cavity is a fluid-filled gap between the walls of the abdomen (belly) and the organs in the abdomen.

Peritoneal dialysis: uses the body's own abdominal cavity to clean the blood.

PCA pump: patient-controlled analgesia pump which is connected to your drip (IV). If you feel pain, simply push the button and the pump releases pain medicine into your bloodstream which stops the pain very fast.

Peritoneum: lining of the inside of the abdomen that is porous to waste products in the blood.

Peritonitis: infection of the abdominal cavity.

Physiotherapist: a healthcare professional who improves your physical condition by restoring normal body functions and prevents disability that may happen due to disease, trauma or injury.

Renal osteodystrophy: bone disease.

Renin: a hormone system that regulates blood pressure and water (fluid) balance.

Transplant: Organ transplantation is the moving of an organ from one body to another or from a donor site on the patient's own body, for the purpose of replacing the recipient's damaged or absent organ.

Ureter: a tube made of smooth muscle fibres that drain urine from the kidneys to the bladder.

Uraemia: a condition when the kidneys stop filtering the blood altogether and waste products build up, leading to symptoms like poor appetite, nausea, vomiting, fatigue or difficulty in concentration.

Vein: an elastic blood vessel that transports blood from various regions of the body to the heart.

- **Cyst:** a closed sac-like structure – an abnormal pocket of fluid, like a blister – that contains liquid, gaseous, or semi-solid substances.

- **Dialysis:** process of artificially removing waste products from the blood.

- **Dialyser:** filter for haemodialysis machine.

- **Donor:** a person who gives you a kidney.

- **ECG:** is an electrocardiogram, which is a test that measures the electrical activity of the heart.

- **End-stage renal disease:** term for total chronic kidney failure.

- **Erythropoietin:** also called EPO. The kidneys normally produce this hormone that tells the body to produce red blood cells. If you do not have enough EPO, you get anaemia.

- **Feeling for thrill:** putting your finger on the AV fistula area to feel if blood is flowing through it.

- **Glomerulus:** A network of very small blood vessels (capillaries) that forms the basis of filtration of blood in the nephron.

- **Haemodialysis:** use of an external filter to clean the blood when the kidneys have failed blood is taken out of the body, passed through the filter and then put back into the body.

- **Hirsutism:** abnormal growth of hair.

- **Hypercholesterolaemia:** raised cholesterol levels.

- **Iliac fossa:** Small space in the abdomen where the donor kidney is placed.

- **Immunosuppressant:** medicines used to prevent activity of the immune system thereby preventing the rejection of a transplanted kidney.

- **Laparoscopic surgery:** a modern method in which operations in the belly are performed through small cuts (usually 0.5 – 1.5cm long).

- **Nephron:** The nephron is the functional unit of the kidney, responsible for the actual cleansing and filtration of the blood.

- **Nephrologist:** medical doctor who treats kidney problems.

- **Organ rejection:** when the body does not accept the transplanted kidney and the body's immune system attacks the organ.

- **Osteoporosis:** medical term for thinning of the bones where bone mineral density is lost, leading to a high risk for fractures (bone breaks).

- **Parathyroid gland:** four small glands in the neck that produce parathyroid hormone. The glands control the amount of calcium in the blood and within the bones.
Contact details and resources

Ask about specific support groups in your area at your hospital. Or use this reference guide to services, help and information for kidney patients:

My healthcare providers

- My GP
- My kidney specialist
- My dialysis clinic
- My dialysis educator
- My dietitian
- Other

Local and international organisations

South Africa
- National Kidney Foundation: www.nkf.co.za
- SA Renal Society (for medical professionals): www.sa-renalsociety.org

International
- Renal Care Society of SA (A professional association for improving patient care): www.renalcaresoc.org
- Cape Kidney Association: www.capekidney.org
- KidneyBeanz (Supporting children with severe kidney disease): www.kidneybeanz.co.za
- International Renal Support Network: www.rsnhope.org
- Beat Kidney Disease: Taking control of kidney disease the natural way www.beatkidneydisease.com
- Davita: Health and medical information: www.davita.com
- Renal Info Support and resources for people with kidney disease: www.renalinfo.com
- Society for Kidney Support: www.societyforkidneysupport.org
- Global Dialysis Empowerment for patients wanting to travel: www.globaldialysis.com
- American Association of Kidney Patients: www.aakp.org
- Nephkids Cyber support group: http://cybernephrology.ualberta.ca/nephkids/
- Kidney Space Community of renal support network: www.kidneyspace.com
- Daily Strength Online support group: www.dailystrength.org/c/Dialysis/people

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- International Renal Support Network: www.rsnhope.org
- Beat Kidney Disease: Taking control of kidney disease the natural way www.beatkidneydisease.com
- Davita: Health and medical information: www.davita.com
- Renal Info Support and resources for people with kidney disease: www.renalinfo.com
- Society for Kidney Support: www.societyforkidneysupport.org
- Global Dialysis Empowerment for patients wanting to travel: www.globaldialysis.com
- American Association of Kidney Patients: www.aakp.org
- Nephkids Cyber support group: http://cybernephrology.ualberta.ca/nephkids/
- Kidney Space Community of renal support network: www.kidneyspace.com
- Daily Strength Online support group: www.dailystrength.org/c/Dialysis/people
Support groups

Ask about specific support groups in your area at your hospital.

- Hospice Association
  Telephone: 021 531 2094 (Head office)
  Website: www.hospicepalliativecare.co.za for more information or the number of a Hospice in your area

- SA Depression and Anxiety Group (SADAG)
  Website: www.sadag.co.za
  To find a support group in your area call 011 262 6396

- Suicide crisis line
  Telephone: 0800 567 567 or sms to 31393

Linked organisations – for medical information

- National Kidney Foundation of South Africa
  Telephone: 011 447 2531
  Website: www.nkf.co.za

- Diabetes SA
  Telephone: 086 111 3913
  To get a number of a branch near you, visit the website
  Website: www.diabetessa.co.za

- South African Heart Association
  Telephone: 021 931 8210
  Website: www.saheart.org

- Organ Donor Foundation
  Telephone: 0800 22 66 11
  Website: www.odf.org.za

- SAVES: Living Will Society
  Telephone: 031 266 8511
  Website: www.livingwill.co.za

Medicine and poison information

- Medicine Information Centre (UCT)
  Telephone: 021 406 6829
  Website: www.mic.uct.ac.za

- Poisons Information Centre (Red Cross Children’s Hospital)
  Telephone: 021 689 5227

- Netcare Poison Centre
  Telephone: 0800 333 444

- Drug and Poison Information Centre (University of the Free State)
  Telephone: 082 491 0160
My appointments

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Who the appointment is with?</th>
<th>Address</th>
<th>What is the appointment about (check-up, dialysis, blood tests, etc)</th>
<th>What should I take with me (x-rays, blood results, etc.)</th>
<th>Note (do not eat before the appointment, someone must take and collect me, etc)</th>
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What questions should I ask my doctor?

No two people are alike. Asking questions is the best way to find out about your health. If you write down your questions and show the list to your doctor, you may be more likely to get them answered. Write down the answers, too — or have someone come along to help you remember the answers.

Sample questions:

- What percent of kidney function do I have now?
- What is the cause of my kidney problem?
- What are my lab test results right now?
- What can I do to keep my kidneys working as long as possible?
- What treatment can I get for my symptoms? (List symptoms)
- What are the next steps for my treatment?
- Will I need dialysis or a transplant? If so, how long might it be until I get a donor kidney?