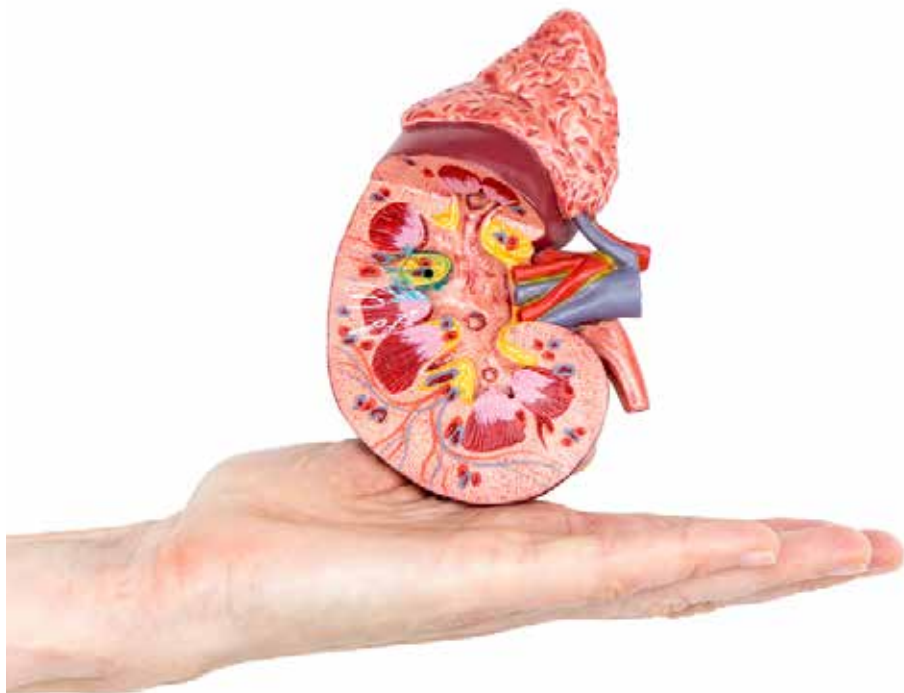




KIDNEY TRANSPLANTATION

LIVING WITH A KIDNEY TRANSPLANT

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01 CONTACT

Ghent University Hospital

- ▲ General number
09 332 21 11
- ▲ Transplant centre (entrance 12, route 1296)
09 332 32 90
- ▲ Nephrology nursing department (entrance 12, route 1447)
09 332 31 72
- ▲ Intensive care (entrance 12, route 1262))
09 332 27 86
- ▲ Nephrology outpatient clinic (entrance 12, route 1231)
09 332 45 09
- ▲ Accidents & Emergencies (entrance 12, route 1226)
09 332 27 42

Useful websites

Organisation	Website
Nephrology Ghent University Hospital	www.uzgent.be/nefrologie
Transplant coordination Ghent University Hospital	www.uzgent.be/transplantatiecentrum
Belgian government	www.beldonor.be
Eurotransplant	www.transplant.org

02 INTRODUCTION

Being well-informed about living with a kidney transplant is important. This booklet is meant to help you make your return home as easy as possible.

During your hospital stay, the multidisciplinary staff involved in your treatment (nephrologist, nurses, social worker, dietician, physiotherapist, psychologist and the study nurses) will help you so that you feel confident about going home.

In this booklet you will find information on transplantation, medication, how to recognize rejection or infection, dietary guidelines, physical activity, psychosocial aspects. You will also find information on items that require your attention when you go home and on follow-up consults at the outpatient clinic. We hope that this booklet will guide you and help you to talk to your doctor or nurses about any questions or concerns you might have.

The different doctors, nurses, transplant coordinators, the hospital pharmacist, dietician, and the social worker involved in the transplant program were all involved in the development of this booklet.

If you have questions or concerns after receiving a kidney transplant, do not hesitate to ask your nephrologist or nurse.

03 HELP US GUARD YOUR SAFETY



- 1 Provide us with any information on **health problems, medication you are currently using, allergies, lifestyle habits, etc.**



- 2 Always wear your **identification bracelet** and state your name and date of birth when a hospital caretaker asks you to.



- 3 Make sure that you know the **medication** you are taking. If they look different, or differ from what you usually take, please tell the nurse.



- 4 Being hospitalized may increase your **risk of falling**. Please wear shoes that fit well, use a walking aid if needed or ask the nurse to help you.



- 5 You can help us to **prevent infections**. Wash your hands before eating, after coughing or sneezing and after you have used the toilet. If there is a notice with isolation instructions on your door or bed, make sure that the people entering your room respect those instructions.



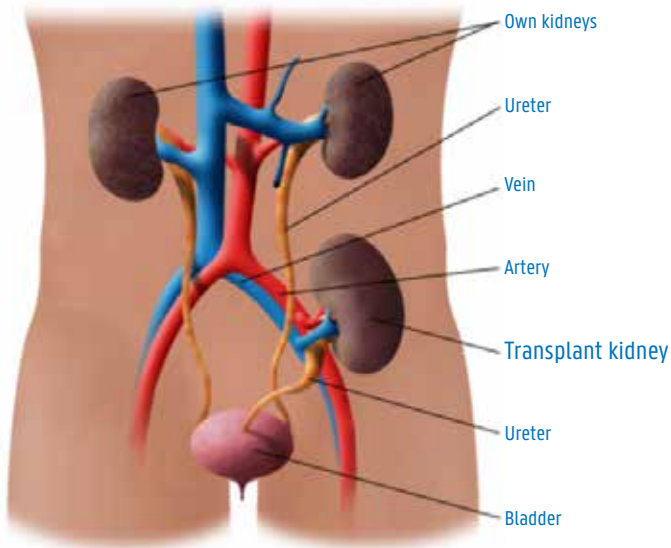
- 6 Feel free to **ask questions** about your operation, treatment, medication and discharge. Please pay attention to recommendations and adhere to them. If you need us to repeat information, please ask us to.

04 THE KIDNEY TRANSPLANTATION

A kidney transplant is inserted in the lower abdomen.

In this figure, the kidney has been inserted in the lower left side. However, insertion in the lower right side is also an option.

You may or may not feel your kidney through your abdominal muscles. Ask your nephrologist to show you where exactly the donor kidney is located and what it feels like under normal circumstances.



05 THE IMMUNE SYSTEM

We all have an immune system that protects us from diseases. It recognizes our own cells as 'good' cells and viruses, bacteria and fungal cells as foreign to our body and therefore 'bad' cells that it tries to eliminate. Your immune system will therefore identify your donor kidney as foreign and react to it.

This perfectly natural reaction is called 'rejection'. To prevent rejection, you need to take medication to suppress this type of reaction: immunosuppressants. Further on in this booklet, this will be described in more detail.

06 MEDICATION

General advice

You must always take your medication as prescribed by your nephrologist. Failing to take your medication will result in rejection of the transplanted kidney and/or other complications.

Your nephrologist decides which combination of the medication described in this booklet is right for you. The doctor prescribes that combination in a dose adjusted to the specific needs of your body.

Determining the combination and the correct dose demands particular expertise and frequent adjustments, especially in the first months after transplantation. Because of this, regular consultations with your nephrologist are required.

Learning to manage your medication

When you are in hospital, the nursing staff teaches you how to manage your medication. During this time, they are responsible for the medication you take. That is why they keep a close eye on you to see how you are managing - even if you do not make any mistakes - until the day you return home.

First, the nurse explains your medication schedule and the way in which the medication training is organized. After this, you receive information about the medication that prevents rejection. Finally, we discuss the other medication you need to take.

You will receive a supply of all the medication you need to take in order to practise. Each drug is put in a different bag, labelled with its name and a short explanation of why you need to take it. You can find the same explanation on your medication schedule.



Proper way of handling medication

It is important that you take your medication as instructed. If you fail to do so, the medication may become ineffective or you may develop side effects. Make sure that you are well informed on your medication. Let us know if there is anything you do not understand.

Below, we have included recommendations on how to handle your medication with care. They are meant for immunosuppressants in particular, but they also hold true for other medication.

How should I take my drugs?

Always take your medication as prescribed. Do not deviate from the instructions on your own behalf. Some drugs need to be taken on an empty stomach, some need to be taken with food. Make sure you know how and when to take each drug. A good absorption of the drug in your body is the first step towards getting an optimal effect.

What if I forget a dose?

Take the missed dose as soon as you can. If it is nearly time to take the next dose, then skip the one you missed, and take the following dose as scheduled. Do not take an extra dose or double your next dose. If you took the wrong dose, contact your nephrologist at the hospital.

What if I am sick?

If you throw up after taking your medication, contact your nephrologist.

What if I have diarrhoea?

If you have diarrhoea, your intestine is either absorbing too much or not enough of the medication. Contact your nephrologist if the diarrhoea continues for more than one day.

Blood test

Regular blood tests are needed to monitor the level of immunosuppressants in your body. The timing of this blood test is very important. In the hospital you are asked not to take your medication until **after** your blood has been drawn. The nephrologist needs the result of this blood test to determine your next dose of immunosuppressant.

Scheduling your medication

Knowing when to take which pill can become complicated: some need to be taken at certain intervals, others with food, others in-between meals. Ask your nephrologist for a schedule detailing all your medication and with information on how and when to take them. Always use this schedule to manage your medication.

Make sure that this schedule gets updated each time your prescribed medication changes.

Take your medication schedule with you whenever you see your GP or when you go to the hospital, to the pharmacist, on holiday, etc.

Can I open capsules or break or crush pills?

Never break, open or crush medication without checking with your doctor first. Some pills have a special outer layer. This layer has been designed for different purposes: to protect your stomach, to create a delayed release of the medication, or to prevent stomach acid from destroying the medicine.

By breaking, crushing or opening pills you will break this special layer and its intended effect. The medicine can become ineffective, which can result in severe side effects. You must therefore never open, crush or break immunosuppressants. It is not safe for the people around you. If you have trouble swallowing your pills, consult your nephrologist.

Hygienic measures

Observe normal hygienic measures for taking immunosuppressants. As already mentioned, you must under no circumstances open, break or crush this medication, unless otherwise indicated. Do not open the capsules.

Stopping medication

Never stop medication of your own initiative!

Always follow the advice of your nephrologist and make sure that you have sufficient prescriptions. Remember to take weekends and holidays into account. Inform your pharmacist of your continued use of some medication.

Starting medication

Never start new medication of your own initiative!

Some medicines can interact, causing a change in effectiveness. That interaction may lead to a reduced efficacy causing your therapy to fail, or it may lead to an enhanced efficacy causing severe side effects. Interaction can occur with prescribed medication, but also with over-the counter-medication.

Make sure to take your medication schedule with you when you go to your doctor or pharmacist. If possible, always get your drugs from the same pharmacist.

Avoid eating grapefruit or drinking grapefruit juice and do not use St John's wort, as they can respectively enhance or reduce the medication's efficacy, with possible serious side effects.

Storing medication

Always store your medication appropriately.

- ▲ Keep all your medication in the same place. Do not mix them up, keep them separate.
- ▲ Most medicines can be stored at room temperature. If they need to be stored in a cool place, it is mentioned on the pack or in the manufacturer's leaflet. Most immunosuppressants are to be stored in the original pack, in a dry place and well protected from light. At home, the bathroom is therefore the least suitable place.
- ▲ Take care that your medicines are out of reach of children and pets.
- ▲ Do not leave your medication lying in the sun.
- ▲ Check the expiration date regularly. This can be quite limited, e.g. for eye drops or syrups or for compound medicines. Medication past its expiration date should be returned to the pharmacist as soon as possible.

Staying in compliance with your therapy

Taking your medication as instructed is important. Some advice on how to remember to take your medication:

- ▲ Keep your medication in plain view (but away from small children).
- ▲ Link the moment you need to take your medication to a daily routine, e.g. breakfast, brushing your teeth, etc.
- ▲ Consider using a pillbox with subdivisions matching your medication schedule. If you do so, pay attention when your medication therapy changes. Keep the pills in their blister pack until the moment you need to take them.

Brand name and generic medication

Generic medicines are composed of the same active ingredients and have the same efficacy as brand name medicines. You must, however, not change your immunosuppressants from brand name to generic on your own initiative. Despite the fact that they consist of the same active ingredients, the use of generic medicines can lead to a different drug level in your blood.

What about my medication when I am readmitted to the hospital?

Take your medication schedule with you each time you come to the clinic. If you are readmitted to the hospital, bring your medication schedule and a medication supply for one day. The medication should still be in its original pack. Hand it over to the nurse, as the nursing staff manages your medication during your hospital stay.

See to it that you get an updated medication schedule and sufficient prescriptions when you are discharged.

Immunosuppressants

It is vital to take immunosuppressants exactly as instructed: the exact dose, at the exact time within the exact interval. Neglecting these instructions may lead to rejection of the transplant or other complications.

Anti-rejection medication or immunosuppressants suppress the immune system to prevent a reaction to the transplant. After the transplant, you are given a combination of 3 medicines to prevent rejection:

- ▲ Prograf® or Advagraf®: Dose depends on the drug level detected in your blood test
- ▲ Cellcept®: Fixed dose
- ▲ Medrol®: Dose gets reduced the first month after transplantation every 4 days according to a fixed scheme

Your daily doses vary a lot during the first months. Doses of Prograft® or Advagraf® are adapted according to the drug levels in your blood. Blood is drawn before you take your morning dose of Prograft® or Advagraf®.

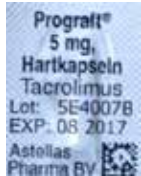
During your hospital stay, the nurses teach you to handle changed dose instructions. After your visit to the outpatient clinic for a follow-up consultation, the nephrologist informs you of your new medicine dose by phone. Always make sure that you understand the new instructions. If you do not, ask the nephrologist to repeat them.

Never hesitate to contact your nephrologist if you are unsure about your medication schedule.

During working hours, the transplant team can be contacted on the phone number of the Nephrology clinic (09 332 45 09). Outside working hours, dial the general phone number of the hospital (09 332 21 11). Never hesitate to contact us!

PROGRAFT® (Tacrolimus)

Appearance

Redgray capsules containing 5 mg		
White capsules containing 1 mg		
Yellow capsules containing 0.5 mg		

The active ingredient is tacrolimus.

Taking the medication

Take this medicine twice a day, preferably within a 12-hour interval. For instance: at 08.00 a.m. and 08.00 p.m., or at 09.00 a.m. and 09.00 p.m., etc. By taking it at regular intervals the level of tacrolimus in your blood remains stable. Always take these pills the same way: either on an empty stomach or with food.

Remarks

- ▲ Through regular blood tests, the nephrologist checks whether the tacrolimus level in your blood is sufficiently high. It is therefore important that you do not take Prograf® or Advagraf® until after your blood has been drawn. Based on the lab result of this blood test, the nephrologist decides what your next dose of Prograf® or Advagraf® will be. In medical terms this is called the blood level.
- ▲ If swallowing these pills is difficult for you, ask your nephrologist to prescribe a tacrolimus suspension. Always use the included syringe to measure the right dose. Shake the suspension well before using it.
- ▲ This drug should be stored in a dry place. Do not store it in the bathroom.
- ▲ This drug contains lactose.
- ▲ After you have been taking Prograf® for a few weeks or months, it is likely that your therapy will be switched to Advagraf®. Both medicines contain tacrolimus as an active ingredient. The daily dose of Prograf® is divided into two intakes (morning and evening with a 12-hour interval), while you only have to take Advagraf® once.
- ▲ Never drink grapefruit juice. It enhances the efficacy of Prograf® or Advagraf® and may cause severe side effects.
- ▲ Prograf® is a prescription drug that you can buy at the pharmacist. It is fully reimbursed.
- ▲ Tacrolimus suspension is prepared in the hospital pharmacy of the Ghent University Hospital (entrance 12, route 1570). When you come to pick it up, always bring the prescription leaflet and your ID with you.

Stopping Prograf® or Advagraf® causes rejection of the transplant kidney!

CELLCEPT® (Mycophenolaat mofetil)

Appearance

Lavender blue tablets containing 500 mg		
Blue-brown capsules containing 250 mg		

The active ingredient is mycophenolate mofetil.

Taking the medication

Take this medicine as instructed by your nephrologist. Take the first dose at breakfast and the next doses at the prescribed times.

Take the tablets or capsules with a glass of water.

Remarks

Cellcept® is a prescription drug that you can buy at the pharmacist. It is fully reimbursed.

Stopping Cellcept® causes rejection of the transplant kidney!

MEDROL® (Methylprednisolone)

Appearance

Oval white tablets containing 32 mg		 MEDROL® 32 mg METHYLPREDNISOLON COMPRIMES/TABLETTEN LOT 115CC EXP 10/2020 GTIN 05415062100103 
Oval white tablets containing 4 mg		MEDROL® 4 mg  Methylprednisolonum  LOT 520AB EXP 02/2020 GTIN 05415062100080

The active ingredient is methylprednisolone.

Taking the medication

Take this medicine with a glass of water at breakfast.

Remarks

- ▲ During the first weeks following the transplantation, you need to take a high dose of this medicine. Over the following months, you are instructed to reduce this dose until you reach a low dose that you have to continue taking. In rare cases, the nephrologist decides to stop this drug a couple of months after transplantation. To reduce the Medrol® dose we use a fixed scheme.
- ▲ We only prescribe Medrol® 32 mg and Medrol® 4 mg. By combining these two pills, you can reach your daily dose. (See scheme below)
- ▲ Medrol® 32 mg can be broken into two halves of 16 mg. Both halves can in turn be broken into two, creating 4 pieces of 8 mg.
- ▲ Medrol® 4 mg can be broken into two halves of 2 mg. Both halves can in turn be broken into two, creating 4 pieces of 1 mg.
- ▲ This medicine contains lactose.

Stopping Medrol® causes rejection of the transplant kidney!

Composing your daily dose

Use this scheme to compose your Medrol® dose. To break pills in equal pieces we recommend a pill splitter. Pill splitters are available at the pharmacist.

2 mg = ($\frac{1}{2}$ x 4 mg)	
4 mg = (1 x 4 mg)	
6 mg = (1 x 4 mg) + ($\frac{1}{2}$ x 4 mg)	
8 mg = ($\frac{1}{4}$ x 32 mg)	
10 mg = ($\frac{1}{4}$ x 32 mg) + ($\frac{1}{2}$ x 4 mg)	
12 mg = ($\frac{1}{4}$ x 32 mg) + (1 x 4 mg)	
14 mg = ($\frac{1}{4}$ x 32 mg) + (1 x 4 mg) + ($\frac{1}{2}$ x 4 mg)	
16 mg = ($\frac{1}{2}$ x 32 mg)	
18 mg = ($\frac{1}{2}$ x 32 mg) + ($\frac{1}{2}$ x 4 mg)	
20 mg = ($\frac{1}{2}$ x 32 mg) + (1 x 4 mg)	
22 mg = ($\frac{1}{2}$ x 32 mg) + (1 x 4 mg) + ($\frac{1}{2}$ x 4 mg)	
24 mg = ($\frac{3}{4}$ x 32 mg)	
26 mg = ($\frac{3}{4}$ x 32 mg) + ($\frac{1}{2}$ x 4 mg)	
28 mg = ($\frac{3}{4}$ x 32 mg) + (1 x 4 mg)	
30 mg = ($\frac{3}{4}$ x 32 mg) + (1 x 4 mg) + ($\frac{1}{2}$ x 4 mg)	
32 mg = (1 x 32 mg)	

Medication to prevent infections

Valcyte®

You have to take Valcyte® for 200 days in the following circumstances: if you have antibodies for the cytomegalovirus (CMV), or if you yourself have no antibodies for the CMV virus but your kidney donor has been in contact with the virus. By prescribing Valcyte® for 200 days, we try to prevent the virus, which is transmitted through the transplantation, from infecting you. It also protects you from herpes infection (cold sores).

If you have antibodies against CMV before the transplantation, you have to take Valcyte® for only 100 days.

Acyclovir

If neither you nor the donor have antibodies for CMV, you have to take acyclovir for one month to prevent herpes reactivation.

Bactrim® – Dapsone®

Bactrim® or Dapsone® are prescribed mainly to prevent pneumonia caused by *Pneumocystis jiroveci*, a fungal infection.

Bactrim® is partly reimbursed. It is a prescription drug you can buy at the pharmacist.

Dapsone® is a prescription drug that you can also obtain at the hospital pharmacy of the Ghent University Hospital (entrance 12, route 1570). Do not forget to bring your patient ID.

When treating infectious diseases, antibiotics are often prescribed to support a weakened immune system or to prevent potential complications. It is extremely important to duly follow the instructions and to take the pills for as long as the doctor prescribes them, even when you feel better. This prevents the growth of resistant germs that can no longer be treated by antibiotics.

Medication to prevent osteoporosis

The anti-rejection medicines you take may cause osteoporosis. To prevent this from happening, the nephrologist prescribes a combination of calcium pills and a vitamin D supplement.

Those medicines must be taken in between instead of during the meals (which differs from how you had to take them while you were on dialysis).

Medication to protect your stomach

The drugs you take can cause stomach irritation. In severe cases they can cause a stomach ulcer. When you are still on a high dose of Medrol®, the nephrologist prescribes a medicine that inhibits the secretion of stomach acid. Pantoprazole (Pantomed®) and Omeprazole are examples of these medicines.

Medication to lower your blood pressure

High blood pressure is a common problem in patients after kidney transplantation. Most patients have to take one or more drugs to treat high blood pressure and have to restrict their salt intake (your nephrologist will advise you on this). It is important to never stop taking these drugs without consulting your nephrologist first, as your blood pressure may rise significantly after stopping these drugs.

Other medication

Cholesterol levels may be too high in transplant patients due to the anti-rejection drugs. If so, anti-cholesterol medicines are prescribed and you have to follow dietary restrictions. Certain mineral supplements are sometimes prescribed temporarily. The most common supplements are: phosphate, magnesium, sodium bicarbonate and iron.

Medication and side effects

Taking medication in general, and anti-rejection medication in particular, can cause specific side effects.

Side effects do not always occur, and each medicine can cause its own manner of discomfort. The side effects or discomfort you might experience varies from person to person.

Tell your nephrologist about the side effects you are experiencing. We can try to find a way to make them bearable for you. For many medicines, one or more alternatives exist with the same efficacy.

The most common discomforts are diarrhoea, swollen gums, increased growth of body hair, accumulation of fat tissue around the cheeks and neck, acne, sensitive stomach, skin frailty, decrease of muscle tissue and high blood pressure.

Long-term effects include an increased risk of cardiovascular disease, raised blood sugar levels, problems with knee and hip joints, high blood pressure, cataract or clouded eye lens, skin tumour growth. Kidney transplant patients are more at risk of contracting infections. These might be minor but can also become severe. Always contact your nephrologist when you develop a fever, generally do not feel well or have painful muscles or joints. Those are often the first signs of an infection. Avoid any unnecessary contact with sick children or adults who are ill.

If you feel something is wrong, always contact your nephrologist first. They will explain what you need to do and tell you if you need further examination. If you need urgent treatment, you will be advised to go to A&E. The nephrologist will alert the A&E staff that you are on your way and instruct them on your treatment.

Medication interactions

The use of certain medication (including herbs or homeopathic medicines) can have a negative impact on the efficacy of your anti-rejection medicines or immunosuppressants. Certain herbs, such as St John's wort, reduce the efficacy of medication. Do not use this herb and consult your nephrologist if you are in doubt.

Always consult your nephrologist for the prescription or use of each new medicine or homeopathic treatment.

07 A HEALTHY DIET

Nutrition plays an important role after a kidney transplantation. You benefit from following a healthy diet, which includes a low salt intake.

A varied diet

In the long term a healthy diet is important:

- ▲ Eat plenty of fruit and vegetables, whole-wheat products, skimmed dairy products, nuts and legumes.
- ▲ Choose lean meats, fish or meat substitutes.
- ▲ Include high-fibre foods in your daily diet.
- ▲ Limit the use of sugary or fatty snacks.
- ▲ Do not add salt to your food, and limit the use of food rich in salt such as canned foods, ready-made meals, smoked meats or fish, salty cheeses, stock cubes, herb mixtures containing salt such as spaghetti herbs, mustard, ketchup, salty snacks, etc.

Specific dietary instructions

Anti-rejection drugs may cause side effects that require specific dietary instructions.

Food containing potassium

Take special care with foods containing potassium in the first few weeks after the transplantation. Even when your kidney is functioning well, some medicines may raise the potassium level in your blood. If you get instructions to lower your potassium intake, you can always turn to your dietician for advice.

Germs and fungi

Taking anti-rejection medicines increases the risk of infection by pathogenic organisms in food. These can cause gastrointestinal tract infections.

- ▲ In the first three months after the transplantation, avoid eating eggs, fish or meats that are raw or have not been cooked thoroughly.
- ▲ During the first months, avoid cheeses which are not pasteurized. You can recognize them by the remark 'contains raw milk' or 'au lait cru' on the label. When the label says 'pasteurized' or 'au lait pasteurisé', the cheese has been sufficiently heated and is safe for you to eat.

Equally important to what you eat is the way you prepare your food. Good hygienic habits are essential.

Corticosteroids

Taking corticosteroids (medication with cortisone) may increase your appetite and make you eat bigger portions, or make you crave more candy and sweets. To avoid obesity, try to exercise regularly, and use lean meats or skimmed dairy products and cheeses. Also limit eating fried food, cakes, biscuits, crisps, ice cream, chocolate, etc.

Another side effect of cortisone is bone loss. We advise you to eat food that contains sufficient calcium and vitamin D. The main sources of calcium are milk, dairy products and cheese. You should drink 0.5 l of semi-skimmed or skimmed milk and eat 1 slice of low-fat cheese (25 g) daily. Soy drinks enriched with calcium and vitamins B and D are another option, provided you choose the ones that contain no added sugar.

Vitamin D enhances the absorption of calcium in the body. Main sources of vitamin D in food are minarine, margarine and cooking fat (with the exception of oil).

Exercise is important because it slows down the process of bone loss.

Diabetes

Kidney transplant patients with diabetes need to maintain a diet that takes carbohydrates into account and is low in sugar. In some transplanted patients, the use of certain drugs increases the blood sugar level and ultimately causes diabetes. If you get diagnosed with diabetes, you are referred to a dietician who explains the dietary guidelines and advises you on adjusting your eating habits. Sometimes these dietary changes are temporary. Again, keeping your body weight under control and exercising regularly are part of the treatment.

Food - medicine interaction

Grapefruit, pomelo, pomegranate and blood oranges contain a substance that alters the efficacy of your anti-rejection medication. You must not use these fruits or their juices. Turmeric or ginger supplements should be avoided for the same reason. They may increase the drug levels in your blood.

Alcohol

After a kidney transplantation, we advise you to drink alcohol moderately. It is alright to drink a glass of wine, beer or champagne on special occasions, but never drink more than 10 units of alcohol per week. Ideally, you should keep some days of the week alcohol-free.

If you have diabetes and you take medication that lowers your blood sugar level or if you use insulin, remember that alcohol intensifies the effect of both medicines. This causes a drop in your blood sugar level, which can occur until 12 hours after having alcohol. Do not drink alcohol on an empty stomach or when your blood sugar is low. Eat a snack rich in carbohydrates (e.g. a pastry, roll, etc.) when you drink alcohol separate from a meal. Cheese cubes, sausages, dipping vegetables fill your stomach but do not raise your blood sugar if it drops after drinking alcohol.

08 FLUIDS

Fluid balance

In normal circumstances, the body excretes fluids all day long. These fluids need to be replenished.

- ▲ Fluids are replenished by drinking water or other beverages and by eating food.
- ▲ Fluid is lost as water vapour in exhaled air, through perspiration, through defecating and urinating.

Our daily intake of fluids must be in balance with the amount of fluids lost. If we lose more fluids than we have replenished, our body warns us: we get thirsty. This is a signal that we need to drink.

During your hospital stay, your fluid balance is monitored closely. We measure how much urine you produce and how much you drink.

How much and what should I drink?

In normal circumstances, we advise you to stimulate your kidney by drinking sufficient fluids.

It is recommended to produce 2 to 2.5 l of urine per 24 hours, and to adapt your fluid intake accordingly. This means that you should drink at least 2 to 2.5 l every day.

Some suggestions to help you:

- ▲ At the start of your day, take two one-litre bottles of water and drink those during the day.
- ▲ Put the bottles in plain view.

Fluids include water, coffee, tea, soup, milk, yoghurt, cottage cheese, pudding, ice cream, dairy products, soft drinks, alcohol, etc.

Remember that sports drinks and also some bottled waters (e.g. Vichy, Appolinaris, Gerolsteiner, San Pellegrino) contain a high amount of salt. Salt tends to lead to fluids being absorbed by the body, which causes high blood pressure and weight gain.

Unusual circumstances

Sometimes we lose a lot of fluids. On hot summer days, we may sweat a lot. Fever and perspiration may lead to loss of fluids, as can diarrhoea.

In those circumstances, we advise you to drink more than you usually would. Contact the nephrologist at the hospital if you feel too ill to drink sufficiently, or if you are nauseous or have to vomit.

Taking a sauna is allowed, provided that you drink sufficiently during and after.

If you do not urinate sufficiently, fluids remain in your body. You will gain weight and your ankles and legs will start to swell. Contact the nephrologist at the hospital if this happens.

Body weight

Weigh yourself daily and note down your weight.

Gaining weight several days in a row is an indication of fluids building up in your body. If this happens, contact the nephrologist at the hospital.

Always weigh yourself under the same circumstances and at the same moment. The ideal moment is in the morning, after getting out of bed and before having breakfast. Always use the same scales.

Keep track of your weight in your transplant booklet, which you bring with you to the clinic.

09 PHYSICAL EXERCISE

Starting mild physical exercise sometime after the transplantation enhances your quality of life. Exercise prevents bone and muscular complications caused by your treatment. As in any other person, it diminishes the risk of cardiovascular disease.

It goes without saying that your body and the operation wound need time to heal. In order not to hinder wound healing, we advise you not to lift heavy weights (>10 kg) in the first eight weeks after the transplantation. Neither should you train your abdominal muscles or perform hard labour during that time.

By training cautiously and patiently you steadily build up your strength and fitness again. To benefit from exercising, you need to do so twice a week.

Activities that we recommend are:

- ▲ Cycling (outside or using a stationary exercise bike)
- ▲ Swimming (in clean water!)
- ▲ Walking at a brisk pace (or Nordic walking)
- ▲ Jogging at your own pace

We discourage contact sports such as boxing, wrestling, judo, karate. Sports that put a strain on your joints (power training, weight lifting) are best avoided.

Chest pain during physical activities means that you need medical assistance.
You should also seek medical advice for joint pains that get worse during exercising.

You can choose to exercise under the supervision of physiotherapists affiliated with the Belgische Sportvereniging voor Getransplanteerden en Gedialyseerden (BSVGG) (<http://www.bsvgg.be>, info@asbtd.be). This is a sports organization for dialysis and transplant patients. Or you can join Transplantoux, an organization that encourages transplant patients to participate in physical exercise.

10 SEXUALITY AND FAMILY PLANNING

Sexuality

After the transplantation, hormonal functions and sex drive (libido) are mostly restored. Women begin to menstruate again after a few months up to a year, provided they are not yet menopausal. Men can experience an improved potency depending on the condition of the blood vessels.

If you experience any problems, do not be shy to talk about them with your nephrologist.

There is no risk of infection by kissing or cuddling, unless your partner has a cold or cold sores. When you resume your sexual relationship, use a reliable contraceptive. Preferred methods of choice are: the use of a condom or female condom or a pessary combined with a spermicidal gel, or using a coil. Methods such as coitus interruptus or the calendar method are less reliable.

Oral contraceptives (the pill) must be discussed with your nephrologist because of possible side effects.

If you have changing sexual partners, it is absolutely necessary to protect yourself (condom, female condom, pessary) because of the increased risk of infection. Using the pill or a coil does not protect you from contracting an STD.

Family planning

Getting pregnant

Pregnancy is possible a few months after a transplantation, but would be unwise and, if not planned, dangerous for mother and child. Each pregnancy should be planned, and both your nephrologist and your gynaecologist need to be consulted. A deterioration of your kidney function cannot be ruled out. Your medication schedule needs to be changed, because some drugs cause severe birth defects.

Ideally you should wait 2 years following the transplantation to become pregnant. By that time you will have a stable medication schedule and will have had no relevant health problems for some time.

Men can father healthy children after a transplantation.

Follow-up during pregnancy

During the pregnancy you need more frequent consultations. We need to detect pregnancy-related complications, which also happens for pregnant women who have not had a transplant. We also want to monitor the way your pregnancy affects your kidney function.

During the pregnancy, more blood and urine samples are taken. Your blood pressure is checked more regularly. The dose as well as the type of anti-rejection medication may change.

Rejection during a pregnancy can be treated without affecting the hormonal status and the unborn child. Transplanted patients more often have premature babies or children with a lower birth weight. There is a somewhat higher risk of miscarrying if your kidney function deteriorates.

Kidney transplant patients usually have healthy, normally functioning children, provided that there is no genetic disorder in the family. Having had a transplantation does not affect giving birth.

Breastfeeding

Consult your nephrologist if you want to breastfeed. Sometimes, breast milk can contain traces of your medication.

Pregnancy and parenthood are usually successful, provided you follow the advice of your nephrologist, gynaecologist and paediatrician.

11 TRAVELLING

During the first months following the transplantation, travelling should be avoided. Your body is still adapting to the new situation and you need regular appointments with the nephrologist at the outpatient clinic. The chance of rejection is still fairly high.

Later on, planning a trip should not be a problem. Mind the hygienic circumstances. Always discuss your destination with your nephrologist.

Medication

If you want to travel, you need to remember a few things. Drugs can have different names abroad or might not be available at all. Always take the manufacturer's leaflets with you. They provide useful information for a doctor or a pharmacist.

Take your medication schedule with you as well as a letter with information on your medical condition. If you ask for it a few weeks in advance, you can get such a letter at the outpatient clinic.

Always keep a small drug supply in your hand luggage when travelling by plane. The rest of your luggage might not arrive timely. To avoid problems during check-in, ask your nephrologist for a letter explaining that your medication is of vital importance to you.

Vaccinations

Contact your nephrologist every time you need a vaccine (e.g. for an exotic trip, after an accident). Not all vaccines are allowed after a transplantation. If you are planning to travel to an exotic destination after the transplantation, the equator in particular, you need to get a yellow fever vaccine **before** receiving a transplant and you need to inform your nephrologist about this. In the three months following this vaccination you cannot get a transplant.

Sun

Your skin becomes more vulnerable to radiation from the sun. Sunbathing is strongly discouraged. If you insist on spending time in the sun, use sunscreen with a high protection factor and wear a long-sleeved shirt. Always wear a cap or a hat.

Food and drink

Make sure that you drink sufficiently in tropical climates.

Beware of the quality of food and water in some countries. Contaminated food and water can cause diarrhoea. Only drink water from closed bottles (also use these to brush your teeth). Do not use ice cubes or eat fruit that has not been peeled.

Travel insurance and ID

You need a travel insurance that covers a swift repatriation. Discuss this with your insurance broker or travel agent.

Carry an ID in English and, if possible, in the language of your destination, which explains that you have had a transplantation and that you need your medication.

12 SKIN PROTECTION

Your skin is more fragile because of your medication and can easily get damaged. Clothes protecting your lower legs help prevent difficulties. You also have a higher risk of infection because of your drugs. Disinfect even the slightest wounds.

Warts are more common in transplant patients, but they can easily be treated with cold therapy.

Tattoos are best avoided. There is no clear scientific data about long-term exposure to ink in transplant patients. We also advise refraining from having a body piercing. If you do have one, take good care so it does not get infected.

Being a transplant patient increases your risk of developing skin cancer. This is especially true if you have pale skin and get sunburned easily, have red hair or if your occupation requires you to work in the sun.

Because of the anti-rejection medicines, you may already be at risk 3 to 7 years after the transplantation. If the symptoms are detected in time, they can be treated successfully. That is why the nephrologist schedules an annual skin check with the dermatologist.

The main cause of skin cancer is exposure to UV radiation from the sun or from indoor tanning.

What can I do to keep the risk low?

- ▲ We strongly advise against sunbathing. If you do want to spend time in the sun, or if you have to work in the sun, always apply sunscreen with a high protection factor (SPF 30 or more). Apply the sunscreen regularly (every hour) and do not forget to reapply it after swimming.
- ▲ Wear long-sleeved shirts and trousers rather than shorts. Also wear a hat or a cap. Wear decent sunglasses.
- ▲ Avoid being in the sun between 10 a.m. and 4 p.m. If you want to sit outside, find a spot in the shadow.
- ▲ Examine your skin every month (e.g. the first day of the month, perhaps with the help of your partner. If you notice new tiny pink spots with hardened skin which do not disappear, or brown spots (melanoma) that change shape or become irregular, have them inspected by a doctor. If this type of skin cancer is detected on time, it can be cured.

13 LIFESTYLE ADVICE

- ▲ Your new situation may be a cause of stress and anxiety. These feelings can be intensified by the medicines you take. It is good for your partner to know this. As a patient you should remember that the situation is new for your partner too, and that they also need time to adapt.
- ▲ Your face might get more round and you may gain weight. This is not always easy to accept. If people comment on your changing appearance, bear in mind that this says much more about that person than it does about you. Also remember that these changes are temporary and disappear over time.
- ▲ To benefit your kidney transplant and your health in general, do not smoke and consume alcohol only moderately.
- ▲ Brush your teeth twice a day with a soft toothbrush, as your gums are more sensitive. Inform your dentist during each appointment that you are using anti-rejection medication.
- ▲ Pets are allowed, but they can transmit diseases. Do not let them lick your face and always wash your hands after petting them. Wear gloves to clean litters or cages or have somebody else do this.
- ▲ Not all vaccines are allowed (see above), but we do advise you to consult your nephrologist about getting a flu vaccine every year.
- ▲ Wearing a seatbelt is still required.

14 COMPLICATIONS

Rejection

Acute rejection

The body's sudden reaction to a foreign, implanted organ is called acute rejection. It happens in about 1 in 5 to 10 patients.

Rejection can present itself as follows:

- ▲ Your body temperature is slightly raised (rare).
- ▲ In some cases the kidney, situated above the groin area, feels hard (uncommon).
- ▲ Sometimes you produce less urine despite drinking sufficiently.

To actually diagnose rejection, you need a blood test or a kidney biopsy at the hospital. The diagnosis is often made when serial lab tests show that the kidney function is deteriorating, which is then confirmed via a kidney biopsy.

Rejection usually occurs shortly after the transplantation. It can also occur if you do not take your medicines as instructed. After the first year, rejection is less likely to happen, but it is still possible up to 10 or 20 years after being transplanted.

Showing signs of rejection does not mean that the kidney is lost. It does mean that we have to act quickly, even in weekends and on holidays. To treat rejection, the nephrologist has different, stronger medicines at his or her disposal. On top of the medicines you already take, you temporarily receive extra medication.

Some of these medicines cannot be swallowed, but need to be administered directly into your veins. Because of this, you might be readmitted to the hospital. This treatment takes a few days, after which you are discharged again.

Chronic rejection

Rejection also exists as a slow process lasting several months or years. This is called chronic rejection. The kidney damage caused by this kind of rejection progresses more slowly. Unfortunately, chronic rejection is still difficult to treat. Sometimes patients with chronic rejection need dialysis again after a while. After a period of time, if your general health allows it (after medical examinations), you might be placed on the transplant waiting list again.

Infections

The anti-rejection medicines you take protect your kidney against rejection. Sadly they also weaken your body's entire defence mechanism. This puts you at a higher risk of getting an infection, especially in the first three months following the transplantation.

An inflammation or infection is the body's reaction against germs. You can recognize it through one or more of the following symptoms:

- ▲ Pain or a burning sensation when urinating
- ▲ Urinating often and in small amounts
- ▲ Smelly urine
- ▲ A persistent cough
- ▲ Shortness of breath or coughing up phlegm
- ▲ Diarrhoea
- ▲ Vomiting
- ▲ Fever or shivering
- ▲ Feeling like you have the flu
- ▲ Not feeling well in general

Importance of body temperature

The normal body temperature lies between 36°C and 37°C. A body temperature higher than 37°C means your body is signalling that something is wrong. Sometimes a raise in body temperature is preceded by cold shivers.

Fever in a kidney transplant patient can have two major causes: an infection (by bacteria, a virus or a fungal infection) or, less frequently, rejection of the kidney.

Both causes need treatment, though not the same. This often means that you are readmitted to the hospital, because you need medication that can only be administered intravenously.

Check your temperature if you do not feel well. If you have a fever or cold shivers, contact the nephrologist at the hospital. The correct way to check your temperature is to put a thermometer (preferably an electronic one) under your armpit and keep it there until it beeps. Make sure that you did not wash your armpit with cold water right before or that it was not exposed to cold air. This cools your armpit down, resulting in a wrong evaluation of your body temperature.

Read the manufacturer's instruction leaflet carefully before using your electronic thermometer.

When you return home, you receive a transplant notebook to write down your blood pressure, pulse, weight and temperature. Always bring this booklet with you to your clinic appointments. It helps to decide on the best treatment for you and your transplant kidney.

15 FOLLOW-UP AFTER DISCHARGE

Clinic consultations

Through clinic consultations, we monitor the evolution of your kidney function and make sure that there is no rejection. We also keep an eye on your health in general. Your treatment may change according to blood test results and medical examinations.

Clinic consultations take place at the Nephrology clinic (entrance 12, route 1231).

Frequency

The first three months following your transplantation, you need to attend the clinic on Mondays, Wednesdays and Fridays between 8 a.m. and 9 a.m. You do not need to fast before coming to the clinic. Depending on how well you recuperate, the frequency of your clinic visits will gradually be reduced to about once or twice every two months.

Registration and billing

When registering at the machine at entrance 12, always take a ticket and bring it to the clinic, even if you only need a blood test. Billing comes later, after settling with your health insurance.

Parking ticket

When you have to visit the clinic two or three times a week for a longer period of time, you can ask for a free parking ticket at the clinic reception.

Medication

If you take Prograf® or Advagraf®, you need to bring your morning dose to the clinic. **After** your blood has been drawn, you can take your morning dose. Blood samples are not drawn at the Nephrology clinic but by a specialized team of nurses in the Blood work department (entrance 12, route 1229).

You can take all your other medication at home before coming to the clinic, depending on the instructions by your nephrologist.

Clinic routine

The nephrologist conducts a physical exam, checks your blood pressure and your weight and discusses the problems or discomforts you may be experiencing. Bring your transplant notebook to the clinic. This gives the nephrologist an idea of the evolution of your blood pressure, temperature and body weight during the days you were at home. Patients who have diabetes should also bring the booklet they use to keep track of their blood sugar levels.

Also bring your latest medication schedule with you.

Urine collection

Sometimes the nephrologist asks you to bring a 24-hour urine collection. This is not done routinely. Containers for urine collection can be obtained at the Nephrology clinic or at the department where you have your blood drawn.

Prescriptions and certificates

Remember to ask the nephrologist for sufficient medication, prescriptions or certificates when you come to the clinic.

The nephrologist may contact you to inform you on a change in your medication therapy.

Your next clinic appointment may occasionally be moved to an earlier date. This usually means that extra blood tests or medical exams are needed.

Having your blood drawn when you take Prograf®, Advagraf® or Neoral®

To determine your next dose of Prograf®, Advagraf® or Neoral®, we need to determine the trough level. This is done when you have your blood drawn before you come to the clinic.

Do not take your morning dose until **after** the blood sample has been taken. Fasting is not necessary for this test, so you can eat or drink something.

Bring the following along to your clinic consultations:

- ▲ Morning dose of Prograf® or Advagraf®
- ▲ Medication schedule
- ▲ Transplant notebook

Ureter stent removal

To allow proper wound healing where the ureter is attached to the bladder, a tiny tube (called a ureter stent) is placed in the ureter during the transplantation. Three weeks after the transplantation, this stent is removed by inserting a tiny instrument through your urethra into your bladder.

This procedure takes place at the Urology clinic. The next day, an ultrasound and a consultation with the nephrologist are scheduled.

Routine biopsy after transplantation

We usually advise patients to undergo a surveillance biopsy three months after the transplantation. A biopsy provides us with extra information on the condition of your kidney. This information allows us to adjust your anti-rejection medication to your specific needs.

A kidney biopsy is performed under local anaesthesia. With a thin needle, a tiny fragment is taken from the kidney. This fragment is then studied under a microscope.

Because there are many blood vessels in a kidney, the needle may cause bleeding. This occurs in about 5 in 1000 cases. Other rare complications are pain, bloody urine, arteriovenous fistula, peritonitis, and hematoma adjacent to the kidney.

In our opinion, the advantages of detecting damage to the transplant kidney in an early stage outweigh the complications mentioned. During your clinic visit, the nephrologist discusses this procedure with you extensively. You get all the necessary information to make a well-informed decision about whether you want to undergo this procedure.

Undergoing a kidney biopsy requires observation. You are admitted to the hospital overnight. Bring your medication schedule and a two-day medication supply with you. During this hospital stay, you are responsible for managing your medication.

Annual medical examinations

Every year around the time of your transplant anniversary, several examinations are planned.

This long-term follow-up enables the nephrologist to assess the effect of the transplantation on your general health. These examinations are also precautionary, to detect negative drug effects and allow the doctor to tackle them.

The following examinations are planned:

- ▲ Fasting blood test
- ▲ ECG
- ▲ A chest X-ray
- ▲ 24-hour blood pressure monitoring
- ▲ Dermatology and Ophthalmology consult
- ▲ For female patients: Gynaecology consult
- ▲ Every three years: a bone density measurement

When scheduling your appointments for these examinations, the nurses at the clinic try to spread them across as few days as possible.

You are informed about the results of these examinations, as is your GP.

Patient assistance

After receiving a transplantation, you may not only have questions about medical but also psychological, social or financial aspects.

Social and psychological aspects

- ▲ What will life be like now that I do not need dialysis anymore?
- ▲ What will I feel like as a transplant patient?
- ▲ Can I go to a convalescent home after my hospital stay?
- ▲ Is it possible for me to get help around the house?
- ▲ What about work?
- ▲ How will I get to the frequent clinic appointments during the first few months? Can I use transport organized by volunteers?

Financial aspects

- ▲ What will the operation cost?
- ▲ Will my health insurance cover all costs?
- ▲ Will my health insurance cover transport costs for clinic appointments?
- ▲ If the costs are too high, can I spread payment over several months?

All these questions can be discussed with our social workers. They will help you find a solution. They are also available if all you need is to talk about being ill and everything that encompasses.

You can ask for an appointment with a social worker at the clinic.

You can find the Patient assistance department by taking entrance 12 and following route 1598.

Kidney patients peer group (Vzw Nierpatiënten Gent)

The aim of this organization is to offer counsel, information and advice to people with chronic kidney disease and their families, and to enable communication amongst patients.

We regularly organize gatherings and activities. You can find announcements in the clinic waiting room, or in our very own magazine 'Nierkrant'.

Try to regularly check the Nephrology website at www.uzgent.be.

The office of our organization is located at the Ghent University Hospital. Further information is available at the Nephrology clinic reception (entrance 12, route 1231).

16 DO NOT FORGET WHEN DISCHARGED

Medication

- ▲ Anti-rejection drugs or immunosuppressants after a kidney transplantation always consist of a combination of:
 - Cellcept®
 - Medrol®
 - Prograf® or Advagraf®
- ▲ You must never stop or change these medicines of your own initiative.
- ▲ When taking these anti-rejection drugs, it is vital that you respect instructions on dose, time and interval of taking. If you fail to do so, you risk rejection or other complications.
- ▲ The dose of Prograf® or Advagraf® changes according to the result of your blood test. Blood for this test is drawn before you take your morning dose of Prograf® or Advagraf®, both during your hospital stay as well as your visits to the clinic. Other drugs can be taken before the blood test.
- ▲ You should always take your anti-rejection medication, even when you are told to fast.
- ▲ Contact your nephrologist when you are sick.
- ▲ Contact your nephrologist when you have diarrhoea which lasts longer than one day.
- ▲ Never stop, start or change medication at your own initiative. Combining your medication with other medicines or herbs may cause side effects. Avoid using Saint John's wort. It increases the efficacy of immunosuppressants, making them toxic.
- ▲ You must not crush medication.

Blood test

The doses of Prograf® or Advagraf® you need to take are determined by the trough level of this medicine detected in your blood. Blood for this test is drawn before you take your morning dose of Prograf® or Advagraf®, both during your hospital stay as well as your visits to the clinic. Other medicines can be taken before the blood test.

The evening dose of Prograf® or Advagraf® depends on the result of your blood test. You will be contacted a few hours after the consultation to inform you of the dose.

Weight

Weigh yourself daily and note your weight in your transplant notebook. Contact the clinic if your weight exceeds your ideal weight by 2 kg.

Fluid intake

Drink at least 2 litres of water every day (other beverages not included).

Diet

Follow a healthy diet.

The following food can cause toxic tacrolimus levels and should be avoided:

- ▲ Grapefruit
- ▲ Blood oranges
- ▲ Pomelo
- ▲ Pomegranate
- ▲ Turmeric
- ▲ Ginger

Risk of infection

- ▲ Respect hygienic measures.
- ▲ Stay away from people who are ill.
- ▲ Disinfect wounds and have a doctor inspect them.

Sun

Always protect yourself from the sun by applying sunscreen with a high protection factor (SPF 30) and always wear a hat or cap.

Clinic consultations

Just before every clinic consultation, we determine the trough level of Prograf® or Advagraf® in your blood. Do not take Prograf® or Advagraf® **until after your blood has been drawn**.

Always bring your most recent medication schedule. When you are given a new schedule, throw away the old one to avoid confusion.

Readmission to the hospital

If you are readmitted to the hospital, always bring your medication schedule and a supply of drugs with you. The medication should still be in the original pack. During your hospital stay, the doctors and nurses manage your medication.

Only take advice from your nephrologist.

17 WHEN TO CONTACT THE NEPHROLOGIST?

Contact the nephrologist at the clinic on the number 09 332 45 09 in the following cases:

- ▲ You are out of medication.
- ▲ You forgot to take a dose.
- ▲ You were sick after taking medication.
- ▲ You are running a fever.
- ▲ Your feet are swelling.
- ▲ The feel of your kidney transplant is uncomfortable.
- ▲ You are gaining weight rapidly.
- ▲ Urinating causes a burning sensation.
- ▲ You are sick or you have diarrhoea.
- ▲ You want to travel abroad.
- ▲ You are admitted to another hospital.
- ▲ You detect a skin anomaly.

18 TRANSPLANT TEAM

Transplantation coordinators



Luc Colenbie



Pieter Lafaire



Nelly Mauws



Christel Walraevens

Nephrologists



Prof. dr. Wim Van Biesen



Prof. dr. Steven Van Laecke



Prof. dr. Evi Nagler



Dr. Patrick Peeters



Prof. dr. Marijn Speeckaert



Prof. dr. Jill Vanmassenhove



Dr. Floris Vanommeslaeghe



Prof. dr. Arjan Van der Tol



Prof. dr. Francis Verbeke



Prof. dr. Annemie Dhondt

Nephrology head nurses



Lizy Christelle



Tamara Leune

Nursing staff Nephrology ward



Nursing staff Nephrology clinic



Van links naar rechts: Nathalie Polfliet, Georges Smekens, Tamara Leune, Melanie Mouton, Clement Dequidt, Sandra De Geest

Social worker



Wim Moreels

Psychologist



Prof. dr. Carine Poppe

Pharmacist



Sarah Mertens

Dietician



Kim Van den Mergele



Elise Coppieters

19 QUESTIONS? REMARKS?

Our aim with this booklet is to inform you on life after receiving a kidney transplant. The different doctors, nurses, transplant coordinators and hospital pharmacists involved in the transplant program were all involved in the development of this booklet.

If certain items are not clear or if you think important topics are missing, please contact us at transplantatiecentrum@uzgent.be or at nephrodia@uzgent.be. With your feedback, we hope to keep improving this booklet.

This booklet is revised annually. We appreciate your patient input!

20 PERSONAL NOTES

21 SELF-MONITORING

Nephrology outpatient clinic

Entrance 12, route 1231

T +32 (0)9 332 45 09

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Volg ons op

