



# Life for children after an organ transplant

information for patients

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If your organ fails, your condition will deteriorate. An organ transplant makes it possible to lead an active, normal and quality life again. During their stay in the hospital, we offer transplant patients an educational programme, so that they can prepare themselves as best as possible for life with a new organ or new organs.

Want to find out more about organ transplants? Then ask for the booklet 'Look, my organs' by Noozi.



In this brochure, we aim to provide you with a tool to ensure that the transition from hospital to home goes as smoothly as possible. You will read more about possible rejection of the new organ and the medication that you need to continue to take at home to prevent any such rejection.



It also discusses how to identify problems such as rejection or infection. Finally, we offer some tips about healthy eating and practical guidelines about sport, school, travel, etc.

View this as a workbook for the whole family and part of the learning programme that we will be working through with you over the next few days.

If you have any further questions after reading this brochure, please don't hesitate to ask someone from our team. We will be pleased to give you a more detailed explanation.

We wish you a pleasant stay in the hospital.  
The hospital paediatric team A (E 345)

The paediatric transplant unit can be contacted day and night on the telephone number +32 16 34 58 05.



# THE IMMUNE SYSTEM

## Rejection



We all have an immune system that protects us against diseases. This immune system recognizes foreign cells such as bacteria, but also the cells in a donor organ. If there are foreign cells present in the body, the immune system will try to disable them.

For this reason, any body can reject a donor organ, which is considered a foreign organ. To prevent a transplant organ from being attacked, you permanently need to take medication after a transplant to suppress the immune system. We call these drugs immunosuppressants or anti-rejection medication. For optimal protection against rejection of the donor organ, you need to take this medication in the correct way and at the correct times.

Even if the medication is taken correctly, there is a chance that rejection symptoms may occur. There are two types of rejection: acute and chronic rejection.

- ❁ The **acute** form is a rapid and powerful rejection and occurs most frequently within three months of the transplant. Acute rejection may, however, still occur at a later date.
- ❁ The **chronic** form is a rejection process that occurs over the course of years and in which the transplant organ gradually works less effectively.



In order to rule out rejection, a biopsy of the donor organ can be taken. The doctor then uses a fine needle to remove a piece of tissue from the organ that is then studied under a microscope. The biopsy is performed under anaesthetic. The doctor may initiate a course of treatment based upon the result of the biopsy.

The occurrence of rejection symptoms does not mean that the organ is lost. A rejection can be treated effectively if it is detected in an early stage. That is why it is important that a transplant patient undergoes regular check-ups after being discharged from hospital.

Rejection cannot always be avoided. However, the risk of rejection can be significantly reduced by taking the prescribed medication correctly and on an on-going basis. At home, you can also adopt a number of practices following a transplant that help to quickly detect a rejection or other problems. For each organ, there are various signals that may indicate a rejection.

### **How can you recognize a rejection?**

It is not always immediately clear when there is a rejection. The patient usually feels weaker after a while because the organ is affected by rejection and therefore will not function properly. Only after a blood and/or tissue examination (a biopsy) can it be determined with certainty whether there is a rejection.

The following symptoms may indicate a rejection:

- \* Feeling generally unwell
- \* Persistent increase in temperature
- \* Pain and/or swelling around the donor organ
- \* Persistent gastrointestinal discomfort
- \* Persistent low or high blood pressure
- \* Heart palpitations
- \* Abnormal fatigue
- \* Chest tightness, shortness of breath or difficulty breathing (at rest, when exercising or at night)
- \* Swollen legs and feet
- \* Abnormal weight gain
- \* Sudden fall in blood pressure, fainting
- \* Less urination with normal fluid intake
- \* Increase in creatinine (after a kidney transplant)
- \* Jaundice (after a liver transplant)

Are you experiencing any of the above symptoms after the transplant? Then please get in contact the hospital.



## Tips and guidelines

### Body temperature

For the first six weeks it is important to measure body temperature every morning at the same time. After that, it is only necessary when the patient feels sick.

Leave the thermometer in place until you hear an audible signal or until the temperature stops rising.

- ★ Is the temperature higher than 38°C? Then contact the unit immediately.
- ★ Is the temperature between 37.5 and 38°C? Take the temperature again an hour later. Is it rising above 38°C? Then contact the unit.

A potential increase in temperature may be concealed as a result of taking certain medicines (corticosteroids). Contact the unit if your temperature is high.

- ! Only in consultation with the transplant doctor may antipyretic medication be administered.



## Body weight

The transplant doctor may ask the patient to weigh him/herself daily during the first three months following the transplant. After that, one weigh-in per week is sufficient.



The patient should always weigh him/herself at the same time and under the same conditions. This is preferably done in the morning after going to the toilet and before breakfast in nightwear, without shoes or a dressing gown. Record your weight in kilograms and grams and bring these notes to the consultation if the doctor requests this information.



If the patient suddenly puts on more than 0.5 to 1 kg, depending on the length of time, then contact the hospital.

## Measuring blood pressure

The transplant doctor may ask the patient to measure his/her blood pressure every day for the first three months following the transplant.



## Urine test

If the patient needs to urinate significantly less, even if they are taking in enough fluids, or if the urine changes colour or smell, then contact the unit.



It is useful to keep a note of this in a diary. To do this, you can just use a normal notebook or organizer, which you then bring with you to the consultation. A diary can also be kept using the MyNexuzHealth app, so that the data can be shared immediately from home. Bring the diary with you to the consultation.



# INFECTION

An infection is our body's response to being infected by a pathogen.

The medication that reduces the chance of rejection makes the body more susceptible to infections and inflammations. This susceptibility is greatest immediately after the transplant and after treating a rejection response. The quantity of anti-rejection medication is highest in the body at these times.

The doctor may prescribe antibacterial and antiviral medicines to prevent certain infections after the transplant.

## How do you recognize an infection?

In the event of an infection, one or more of the following symptoms will occur, depending on the site of the infection.

- ✿ Increase in temperature
- ✿ Feeling flu-like
- ✿ Feeling generally unwell
- ✿ Fatigue
- ✿ Persistent cough, coloured mucus
- ✿ Shortness of breath
- ✿ Diarrhoea and/or vomiting (for longer than 24 hours)
- ✿ Persistent or severe sore throat
- ✿ Swollen glands
- ✿ Skin rash
- ✿ Urinating frequently and with difficulty
- ✿ Burning sensation when urinating

Are you experiencing any of the above symptoms? Then please get in contact the hospital.

## Tips for preventing an infection

- ✓ Regular hand washing is very important for a transplant patient and the people around him/her. For example, wash your hands every time you have been to the toilet, after blowing your nose, after changing a nappy, when preparing a meal and before eating.
- ✓ Avoid contact with children and people who have a fever, the flu, colds or are unwell. Most infections with germs are propagated by air and hand contact.
- ✓ Good all-round body hygiene is important. Do you regularly have a full wash and do you pay sufficient attention to proper nail care and oral hygiene. Change your underwear daily and regularly put on clean clothes.
- ✓ Ventilate indoor areas every day that do not have ventilation. This is important for good air quality.
- ✓ Avoid contact with animals after the transplant. That's particularly important for the first six months. Are you thinking about getting a pet? You should first discuss this with your doctor. It's better not to keep reptiles, turtles, hamsters, guinea pigs and birds at home. These animals are more likely to cause an infection.



✓ During the first six months following the transplant, avoid large groups of people, such as in cinemas, department stores or cafés.

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✓ It is strongly advised that you do not smoke. Smoking increases the chance of cancer, pneumonia and cardiovascular conditions. Combined with the medicines that prevent the risk of rejection of the donor organ, this risk is made even more acute. Even passive smoking is harmful, so people shouldn't smoke at home or in the car.

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✓ After the transplant, it is better not to have a piercing or tattoo to minimize the risk of infections.

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✓ Make sure that the necessary vaccinations are up to date. Do you have any doubts or queries? Then please contact the unit.

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✓ Avoid contact with people who have recently been vaccinated.

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✓ Drink plenty of water every day. Particularly after a kidney transplant, it is best to drink 1.5 to 2 litres of water a day, unless the doctor has prescribed otherwise.

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✓ A healthy lifestyle can not only be achieved by eating a balanced diet, but also by exercising. Subject to approval by the doctor, you can resume exercise three months after the transplant.

More information about sporting activity after a transplant can be found from page 44 of this brochure.

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## Oral hygiene

After a transplant, good oral hygiene is important to prevent infections in the mouth. That's why it's important to brush your teeth three times a day for the first three months after the transplant: after each main meal and at bedtime. As soon as children acquire a good writing technique, they can then also usually start brushing. If in any doubt, please check with the dentist.

Do not brush immediately after eating or drinking something sweet or sour. Due to the combination of the acid and brushing, wear to tooth enamel occurs faster than normal. That's why it's best to wait an hour.

Preferably use an electric toothbrush or a toothbrush with a small head.



## How much fluoride should be in the toothpaste?

The amount of fluoride in toothpaste can vary. This information is often stated on the tube. Discuss with the dentist what is the best fluoride content to use.

The general recommendations are:

- ✧ From the first milk tooth breaking through to 2 years old:  
**1,000 ppm of fluoride**
  - The amount of toothpaste you need is about the size of a grain of rice.
  
- ✧ From age 2 to 6: **1,000 ppm of fluoride**
  - The amount of toothpaste you need is about the size of a pea.
  
- ✧ Age 6 and above: **1,450 ppm of fluoride**
  - The amount of toothpaste you need is about the size of a pea.

Brush your teeth for two minutes. Afterwards, rinse the brush thoroughly and allow it to dry.

Do not share a toothbrush with another person and replace your toothbrush every three months. An additional toothbrush replacement is required if the bristles of the toothbrush are splayed open or following a serious infection.

Also clean the space between your teeth once a day using floss or special sticks for flossing (*floss picks or tooth picks*).



Go to the dentist at least once a year. Tell the dentist about your transplant and what medication you need to take on a permanent basis. The dentist can always contact the transplant unit for additional information.

For the first three months following the transplant, you will use medication (Nilstat<sup>®</sup>) and a mouthwash (Perio-Aid<sup>®</sup>) for even better oral hygiene.



- **Nilstat®**

This medication prevents fungal growth. After brushing your teeth, put the liquid medicine in your mouth with a pipette and swallow. Then wait at least 15 minutes before drinking, eating or rinsing your mouth with Perio-Aid®.

- **Perio-Aid®**

This mouthwash prevents bacterial growth and thus prevents infections. After taking Nilstat®, wait at least 15 minutes before using Perio-Aid®. You should rinse for one minute.



### Oral hygiene:

#### For the first 3 months after the transplant

After every meal:

- Brush your teeth
- Take Nilstat®

After taking Nilstat®, wait for at least 15 minutes before eating or drinking.

Before going to bed:

- Brush your teeth
- Floss
- Take Nilstat®
- Wait for 15 minutes
- Rinse with PerioAid® (1 minute)

#### From the 4th month after the transplant

In the morning, brush your teeth for 2 minutes.

Before going to bed, brush your teeth and floss for 2 minutes.

## Sun protection

Avoid excessive exposure to sunlight. Protecting yourself from the sun is good advice for everyone, but even more important if you have pale skin, blonde hair, clear eyes or freckles.

How do you protect your skin when taking part in outdoor activities?

- ✓ Wear a T-shirt and a wide-brimmed hat.
- ✓ Use sunscreen with a high protection factor (+50).
- ✓ Apply the sunscreen liberally.
- ✓ Apply it half an hour before going into the sun then repeat every two hours and every time you've had a swim.
- ✓ UV radiation is strongest between midday and 4 pm (summer time). It is best to plan outdoor activities outside these hours, i.e. in the morning or after 4 pm.

Other ways of protecting your skin:

- ✓ Don't go on sunbeds.
- ✓ Provide additional protection in the mountains, because there is more UV radiation at high altitude than at sea level.
- ✓ Protect yourself especially well on the water or in the snow, as partial reflection of the UV rays can cause you to burn faster.
- ✓ Consult the dermatologist if a skin lesion appears or changes. The dermatologist will in any case examine your skin during the annual check-up.



# MEDICATION AFTER THE TRANSPLANT

Taking medication is an important part of life after a transplant. The time at which you take your medication is also important. There are many tools for remembering medication, such as a medication box, an alarm clock or an alarm on your mobile phone and handy apps that remind you to take your medication (e.g. the free MyTherapy app).

There are different types of medication that are important after a transplant:

- ❁ Immunosuppressants (prevents rejection / suppresses the immune system)
- ❁ Preventive medicines (antibiotics and antiviral medicines)
- ❁ Blood thinners
- ❁ Gastric protective medication
- ❁ Supportive medication
- ❁ Antihypertensives (countering high blood pressure)



## Immunosuppressants

These medicines weaken the immune system and prevent rejection of the transplanted organ. The post-transplant treatment will consist of a combination of different medicines that suppress the immune system and will be adjusted individually.



## What if you forget your medication?

If the patient forgets to take the anti-rejection medication, it is important that this medication is taken again as soon as possible using the correct regimen. You may only make up for a forgotten dose within 4 hours of the usual time the medication is taken. Suppose that you take your medication at 8 am, but forget about it and remember at 11:30 am, then you can still take that forgotten dose. From 12 o'clock onwards, you are no longer allowed the forgotten dose and you simply follow the instructions again.

### Never double a dose of medication to make up for a forgotten dose.

Always write a missed dose down in your medical diary and/or mention it during the next consultation in the hospital. This may be important for the amount of medication in your blood.

If your blood level needs to be checked at the consultation, you should not take a morning dose of immunosuppressants that particular day. They should not be taken until after the blood sample has been taken. Take this medication with you to the consultation at the hospital. Do you have any further questions? Then please contact the unit.

## What if you need to be sick?

For each medicine, you apply the same guidelines, depending on the time between taking your medication and vomiting.

- **Within 15 minutes** of taking the medication: take another **full** dose.
- **Within 30 minutes** of taking your medication: take another **half** dose.



- **Within 45 minutes** of taking your medication: take another **quarter** dose.
- **One hour** after taking your medication: **do not** take any further medication.

In case of vomiting, a new dose of medication needs to be taken as promptly as possible. If you don't manage to do so, then contact the unit.

## Dose

With immunosuppressants, the correct dose is very important. If in doubt, it is best to contact the unit.

## Immunosuppressants: types of medication

In addition to the different types of medication, for each type there are also different medicines that the doctor will prescribe. A combination of immunosuppressants is always required.

Below you can indicate which medicines apply:

Active substance	Brand name
<input type="checkbox"/> tacrolimus	<input type="checkbox"/> Prograft® <input type="checkbox"/> Advagraf®
<input type="checkbox"/> ciclosporin A	<input type="checkbox"/> Neoral-Sandimmun®
<input type="checkbox"/> mycophenolate/ mycophenolate mofetil (MMF)	<input type="checkbox"/> Cellcept® <input type="checkbox"/> Myfortic®
<input type="checkbox"/> corticosteroids	<input type="checkbox"/> Medrol® <input type="checkbox"/> Prednisolon® <input type="checkbox"/> Prednison®
<input type="checkbox"/> azathioprine	<input type="checkbox"/> Imuran®

Below you will find the required information for each type of medication, including the dose, administration, precautions for use and any side effects.

- **Tacrolimus (Prograf® and Advagraf®)**



#### General information

##### Prograf®

Medication consisting of 0.5 mg (yellow), 1 mg (white) and 5 mg (orange-red) capsules. Keep the capsules in the pack until they are taken. When taking the capsules, swallow them without biting or chewing them. The capsules should not be opened for any reason whatsoever. The capsules may be taken with any drink, **except** grapefruit or blood orange juice and derivatives thereof such as Agrum®. Prograf® also exists in syrup form, which contains 0.5 mg of tacrolimus per millilitre. Keep the medication at room temperature.

##### Advagraf®

Medication consisting of 0.5 mg (orange-yellow), 1 mg (orange-white), 3 mg (orange) and 5 mg (orange-red) capsules. Keep the capsules in the pack until they are taken. Keep the medication at room temperature.

#### Administration and precautions for use

The dose of tacrolimus is adjusted for the patient's body weight and the amount of medicine in the blood.

It is very important that the amount of tacrolimus in the blood is always constant. It is best to take this medication on an empty stomach, but the most important thing is that it is always taken at the same time (before, during or after meals) and always at the same time of day. 12 hours should be allowed to elapse



between taking the first and the second dose. For example, take the first dose at 8 o'clock in the morning and the second dose at 8 o'clock in the evening.

Always take the correct dose in the same way and at the correct time. Never alter the dose on your own initiative.

If you take this medication at the same time as certain other medicines, the amount of tacrolimus in the blood may vary. That's why new medicines should never be taken on your own initiative. The dose may not be altered either and the medication may not be discontinued. Always ask the transplant doctor for advice about this. Never take Prograft® together with an acid inhibitor such as Maalox® or Gaviscon®.

#### Reimbursement

These medicines will be reimbursed in full by your health insurance.



#### Possible side effects

Medicines containing tacrolimus can cause a number of side effects. Not everyone is equally susceptible to this medication. The doctor may prescribe additional medication to prevent or treat side effects. The most common side effects are listed below.

- **Headache and increased blood pressure**

This can occur especially at the start of treatment with tacrolimus (Prograf®). The headache usually disappears by itself after a number of days. In case of excessively high blood pressure, the doctor will prescribe medication to lower your blood pressure. A low-salt diet also helps to lower blood pressure.

- **Trembling hands**

This can occur especially at the start of treatment. Never adjust the dose of the medication on your own initiative, but notify the doctor if the patient is experiencing excessive discomfort.

- **Diarrhoea, nausea and vomiting**

This sometimes occurs at the start of treatment. Never adjust the dose of the medication on your own initiative, but notify the doctor if the patient is experiencing excessive discomfort.

- **Insomnia**

This sometimes occurs at the start of treatment. Never adjust the dose of the medication on your own initiative, but notify the doctor if the patient is experiencing excessive discomfort. Never take sleep medication on your own initiative.

- **Increased sugar level**

Tacrolimus may cause diabetes in the first months after the start of treatment. This is usually only a temporary side effect. It is sometimes necessary to follow a sugar-restricted diet temporarily.

- **Reduced renal function**

This occurs especially when the incorrect dose is taken. That's why it is important to keep the amount of tacrolimus in the blood constant by taking the correct dose of medication at the same time and to regularly come to the hospital for a blood test. The doctor will monitor kidney function regularly and adjust the dose of tacrolimus, as required.



- **Skin problems**

The medication makes the skin more sensitive to the sun. For this reason, you should not sunbathe as there is an increased chance of skin cancer. During the summer months, always use a high-factor protective sunscreen (+50).

- **Other possible side effects**

Some patients suffer hair loss as a result of the medication. Sometimes there may be an increased risk of epilepsy when under the influence of tacrolimus. The doctor will then prescribe appropriate epilepsy medication.



- **Ciclosporin A (Neoral-Sandimmun®)**

*General information*

There are two types of Neoral-Sandimmun®: a yellow, oily liquid and light grey 10, 25, 50 and 100 mg capsules.

*Liquid form*

The liquid form of the medicine is in a brown bottle: 1 ml of liquid contains 100 mg of Neoral-Sandimmun®. Keep the bottle at room temperature. The medicine must be taken within two months of opening the bottle. Draw the prescribed amount of Neoral-Sandimmun® from the bottle using a pipette and dissolve it in a glass of water, apple or orange juice or a soft drink. After taking the medicine, rinse the glass so that the full dose of Neoral-Sandimmun® is definitely taken. Prepare the solution just before taking it and never allow the solution to stand. Do not rinse the pipette with water, but only dry the outside of the pipette with a clean cloth.

## Capsules

The capsules are individually packed in aluminium foil. Keep the capsules in this pack at room temperature. When opening the pack, you may detect a slight smell:

this is normal and certainly does not mean that the medicine is out of date. When taking the capsules, swallow them without biting or chewing them. The capsules can be taken with or without a drink. They may be taken with any drink at room temperature, **except** grapefruit or blood orange juice and derivatives thereof such as Agrum®.

## Administration and precautions for use

The dose of Neoral-Sandimmun® is adjusted for the patient's body weight, kidney function and the amount of the medicine in the blood. It is extremely important that this quantity is always exactly the same. 12 hours should be allowed to elapse between taking the first and the second dose. For example, take the first dose at 8 o'clock in the morning and the second dose at 8 o'clock in the evening.

Always take the correct dose in the same way and at the same time. Never alter the dose on your own initiative.

If you take this medication at the same time as certain other medicines, the amount of Neoral-Sandimmun® in the blood may vary. That's why new medicines should never be taken on your own initiative. The dose may not be altered either and the medication may not be discontinued. Always ask the transplant doctor for advice about this.

## Reimbursement

Neoral-Sandimmun® can be obtained from the pharmacy on the doctor's prescription and is reimbursed in full by your health insurance.



## Possible side effects

Neoral-Sandimmun® can cause a number of side effects.

Not everyone is equally susceptible to this drug treatment. The doctor may prescribe additional medication to prevent or treat side effects. The most common side effects are listed below.

- **Headache and increased blood pressure**

This can occur especially at the start of treatment with NeoralSandimmun®. The headache usually disappears by itself after a number of days. In case of excessively high blood pressure, the doctor will prescribe medication to lower your blood pressure. A low-salt diet also helps to lower blood pressure.

- **More hair growth on body and face**

If this bothers the patient, the stiff hairs can be plucked out or a depilatory cream or bleach can be used to remove the downy hairs.

- **Reduced renal function**

This occurs especially when the incorrect dose is taken. That's why it is important to keep the quantity of Neoral-Sandimmun® in the blood constant by taking the correct dose of medication at the same time and regularly visiting the hospital for a blood test. The doctor will monitor kidney function regularly and adjust the dose of medication, as required.

- **Skin problems**

The medication often causes warts, which are best treated as quickly as possible. In addition, the medication makes the skin more sensitive to the sun. For this reason, you

should not sunbathe as there is an increased chance of skin cancer. During the summer months, always use a high-factor protective sunscreen (+50).

- **Trembling hands and a burning sensation in the hands and feet**  
This occurs, in particular, at the start of treatment. Never adjust the dose of the medication on your own initiative, but notify the doctor if the patient is experiencing excessive discomfort.
- **Thickening of the gums and an increased risk of fungal infections in the mouth and oesophagus**  
Effective oral hygiene is really important! Brush your teeth properly after each meal for at least two minutes. If the patient is taking antibiotics or has a fungal infection in the mouth, they should take Nilstat<sup>®</sup> four times a day. Do not forget to brush your teeth before you take Nilstat<sup>®</sup>.
- **Other possible side effects**  
Sometimes there may be an increased risk of epilepsy when under the influence of Neoral-Sandimmun<sup>®</sup>. The doctor will then prescribe appropriate epilepsy medication.

## Mycofenolaat/MMF (Cellcept<sup>®</sup>, Myfortic<sup>®</sup>)



### General information

#### Cellcept<sup>®</sup>

There are two different doses of this medicine. Cellcept<sup>®</sup> 250 mg are oblong capsules with one blue side and one brown side. On the top half of the capsule is the text 'Cellcept 250', on the bottom is the text 'Roche'.



Cellcept® 500 mg is available in oval, lavender-coloured tablets. For these, one side states 'CellCept 500' and 'Roche', on the other.

Cellcept® also exists in syrup form, which contains 1 g of Cellcept® per 5 ml.

Cellcept® is available from the pharmacy on prescription and subject to approval of the doctor. You will receive the request for approval from the doctor during your stay in the hospital.

### Myfortic®

There are two different doses of this medicine. Myfortic® 180 mg is available in round, lime-green tablets with the letter 'C' on them. Myfortic® 360 mg are oval, light orange-red tablets with the letters 'CT' on them.

### Administration and precautions for use

When taking tablets or capsules, swallow them with a glass of water without biting or chewing them. You should not break the tablets or ground them down.

When using the syrup, shake the bottle well for 5 seconds. Fill the syringe according to the instructions and inject the medicine directly from the syringe into the mouth. Rinse the syringe thoroughly with water and leave to dry on a clean cloth.

### Reimbursement

Medicines containing mycophenolate are reimbursed in full by your health insurance.



### Possible side effects of Cellcept®

Cellcept® can cause a number of side effects. Not everyone is equally susceptible to this drug treatment. The doctor may

prescribe additional medication to prevent or treat side effects. The most common side effects are listed below.

- **Diarrhoea**

This is a very unpleasant side effect. Never adjust the dose of the medication on your own initiative, but notify the doctor if the patient is experiencing excessive discomfort.

- **Increased chance of infections**

Decreasing the number of white blood cells in the body increases the chance of infections. Our body needs white blood cells to fight bacteria and viruses. For this reason by completing a blood test, the number of white blood cells in the body can be determined and, if required, the medication dose can be adjusted. Never adjust the dose on your own initiative.

- **Nausea, vomiting and lack of appetite**

Sometimes Cellcept® can cause an upset stomach, particularly during the early stages. If you vomit immediately after taking the medication, take the same dose again. Contact the transplant unit if vomiting persists.

- **Fatigue**

Decreasing the number red blood cells in the body can increase fatigue.

Possible side effects of Myfortic®

Myfortic® can cause a number of side effects. Not everyone is equally susceptible to this drug treatment. The doctor may prescribe additional medication to prevent or treat the side effects. The most common side effects are listed below.



- **Increased chance of infections**  
Decreasing the number of white blood cells in the body increases the chance of infections. Our body needs white blood cells to fight bacteria and viruses. For this reason, by completing a blood test, the number of white blood cells in the body can be determined and, if required, the medication dose can be adjusted. Never adjust the dose on your own initiative.
- **Fatigue**  
Decreasing the number red blood cells in the body can increase fatigue.
- **Bruising, haemorrhages**  
Decreasing the number of blood platelets can cause haemorrhages or bruising.
- **Headache**  
This can occur particularly at the start of treatment. The headache usually disappears by itself after a number of days.
- **Diarrhoea, nausea and vomiting**  
This sometimes occurs at the start of treatment. Never adjust the dose of the medication on your own initiative, but notify the doctor if the patient is experiencing excessive discomfort.
- **Other possible side effects**  
Some patients suffer hair loss as a result of the medication.

- **Corticosteroids (Medrol<sup>®</sup>, Prednisolon<sup>®</sup>, Prednison<sup>®</sup>)**

### General information

This medication is available in the form of breakable tablets in different doses. The slit in the tablets makes it easier to break them.



**Note:** the different doses of the tablets are very similar in appearance.

Medicines containing corticosteroids are available from the pharmacy on prescription from the doctor.

### Administration and precautions for use

A daily dose of less than 32 mg may be taken in one go.

Medicines containing corticosteroids are best taken with food to prevent an upset stomach.

The dose of corticosteroids is adjusted for the patient's body weight. If all goes well, the dose is slowly reduced after the transplant.

### TIP

Medrol<sup>®</sup> has a very unpleasant taste. If necessary, you can break the tablet into small pieces and insert it into an empty capsule.

### Reimbursement

Medicines containing corticosteroids are reimbursed in full by your health insurance.



## Possible side effects

Medicines containing corticosteroids can cause a number of side effects. Not everyone is equally susceptible to this medication. If the doctor reduces the dose of corticosteroids, the side effects will decrease. However, never adjust the dose on your own initiative. The most common side effects are listed below.

- **Full moon face**

The face may become fuller or swollen as a result of the medication. The adipose tissue on limbs decreases, but more fat will accumulate around the torso.

This side effect reduces as the doctor slowly reduces the dose.

- **Improved appetite**

Appetite can increase. Make sure that your body weight does not increase too quickly, because corticosteroids also promote the accumulation of fluid and salt. A balanced diet and sufficient exercise are also extremely important.

- **Mood swings**

Corticosteroids can affect mood and cause mood swings. The urge to laugh and cry can follow one another in quick succession.

- **Skin problems**

The medication can cause stretch marks on the skin, especially if you gain excessive weight. Acne and more hair growth on the face and back are also potential side effects. In addition, bruising can occur more readily and slows down healing. Any skin injury must be properly disinfected and cared for to prevent infection.

- **An upset stomach and increased risk of stomach ulcers**  
Corticosteroids can cause an upset stomach and even an ulcer. The doctor may prescribe Omeprazol® to prevent this.
- **Osteoporosis**  
If this side effect occurs, the doctor may prescribe calcium and/or vitamin D supplements.
- **Visual impairment**  
A high dose of corticosteroids can cause visual disturbances. If this is the case, then be sure to tell the doctor at your next check-up.
- **Increased risk of diabetes**  
Taking corticosteroids for a long time can lead to diabetes.
- **Increase in temperature**



- **Azathioprine (Imuran®)**

#### General information

Imuran® is available in the form of yellow 50 mg tablets and pinkish-brown 25 mg tablets (Imuran Mitis®). Imuran® is only taken once.

Imuran® is available from the pharmacy on prescription from the doctor.

#### Reimbursement

Imuran® is reimbursed in full by your health insurance.



### Possible side effects

Imuran® can cause a number of side effects. Not everyone is equally susceptible to this drug treatment. The doctor may prescribe additional medication to prevent or treat side effects. The most common side effects are listed below.

- **Increased chance of infections**

Decreasing the number of white blood cells in the body increases the chance of infections. Our body needs white blood cells to fight bacteria and viruses. For this reason by completing a blood test, the number of white blood cells in the body can be determined and, if required, the medication dose can be adjusted. Never adjust the dose on your own initiative.

- **Nausea, vomiting and lack of appetite**

In rare cases, Imuran® can cause an upset stomach. To prevent this, it is best to always take the medicine with food.

- **Fatigue**

Decreasing the number red blood cells in the body can increase fatigue.

- **Bruising, haemorrhages**

Decreasing the number of blood platelets can cause haemorrhages or bruising.

## Preventive medication

These medicines protect against infections caused by viruses, bacteria and fungi and may be prescribed temporarily after the transplant.

### Nystatin (Nilstat<sup>®</sup>) and chlorhexidine (Perio-Aid<sup>®</sup>)

Medication for good oral hygiene. You can find more information about this on page 16.

### Antibiotics (Eusaprim<sup>®</sup>)

To prevent specific pneumonia, the doctor may prescribe Eusaprim<sup>®</sup>. Too few white blood cells and itching may indicate hypersensitivity to this medication.

### Aciclovir (Zovirax<sup>®</sup>)

This medicine is an antiviral medicine that fights cytomegalovirus (CMV). Zovirax<sup>®</sup> is available in 200 and 800 mg tablets. Not all children need to take this medication.

### Valganciclovir (Valcyte<sup>®</sup>)

This medicine is an antiviral medicine that fights cytomegalovirus (CMV). Valcyte<sup>®</sup> is available in 450 mg tablets. Children can also take it in the form of syrup, which is made up in the hospital pharmacy.



## Blood thinners

These medicines improve the blood flow to the transplant organ.

### Asaflow® and Aspirin®

These medicines contain the active substance acetylsalicylic acid, which has both analgesic, antipyretic and anti-inflammatory effects. After the transplant, they are mainly prescribed for effective blood circulation to and from the transplant organ. This medication can be temporarily stopped by the doctor before and after a biopsy.

## Gastric protective medication

### Antacids (Omeprazol®)

A number of medicines have an adverse effect on the wall of the oesophagus, stomach and small intestine, which can cause an upset stomach or even an ulcer. Antacids offer protection against this. This medication should only be taken after consultation with the transplant doctor, as this may affect the effectiveness of other medication.



## Supportive medication

### Vitamin D droplets and calcium syrup or calcium tablets

These medicines are prescribed to reduce the adverse effects of steroids on the development of the bone system. The dose of the medication is determined individually. Vitamin D droplets are administered once a day; calcium syrup or calcium tablets are taken once or twice a day. It is best to do this in the evening, because the medicines are better absorbed then.

### Antihypertensives (countering high blood pressure)

If you have excessively high blood pressure after the transplant, the doctor may prescribe antihypertensives. This medication helps to keep blood pressure under control. Standard blood pressure is determined individually, on the basis of which customised medication is prescribed.

### Amlodipine® (Amlor®)

This medicine is available in the form of orange 5 or 10 mg capsules, which you must allow to melt under your tongue or bite and swallow. Amlodipine® works within two to three minutes and the effect remains for another six hours.



## HEALTHY EATING AFTER THE TRANSPLANT

A healthy and balanced diet is very important after the transplant. A dietician from the transplant team will come by during your stay in the hospital to discuss the adjusted diet and answer any questions.

Earlier in this brochure we told you that taking medication to suppress the immune system (immunosuppressants) can cause a number of side effects. To prevent or limit many of these side effects, specific nutritional advice is required.



## Specific nutritional advice for each side effect

### High blood pressure

Limit salt in your diet to prevent high blood pressure.

- ★ Prepare hot meals without adding extra salt. Do not use sea salt, iodine salt, celery salt or fleur de sel either. Use salt alternatives (e.g. CoSalt®).
- ★ Be careful about herbal mixes such as chicken herbs or spaghetti herbs, as they often contain a lot of salt. Use fresh, dried or frozen herbs.
- ★ Be careful about stock cubes, as they often contain a lot of salt. Use low-salt stock cubes (e.g. Damhert®, Verstegen®).
- ★ Eat processed meats such as sausages, minced meat, etc. as little as possible. Prepare meals yourself without salt or seasoning but with suitable herbs.
- ★ Bread contains a lot of salt. Bake your own bread without (or with less) salt or buy low-salt bread in the supermarket or at the bakery. By regularly replacing bread with low-salt breakfast cereals, muesli or oatmeal, you can immediately limit your salt intake to a large extent.
- ★ Avoid ready meals such as frozen pizza, deep-fried snacks... They often contain a lot of salt.
- ★ Do not eat smoked meat or smoked fish.
- ★ Avoid salty snacks such as crisps, olives and salty nuts.



What is the maximum amount of salt that can be found in low-salt foods?

Food category	Maximum amount of salt
Biscuits	0.5 g of salt/100 g
Savoury snacks	0.5 g of salt/100 g
Cheeses	1.5 g of salt/100 g
Meat products	2 g of salt/100 g
Salads	1.5 g of salt/100 g
Bread and cereal products	0.1 g of salt/100 g
Fats	0.2 g of salt/100 g
Tinned vegetables	0.1 g of salt/100 g
Tinned fish	0.6 g of salt/100 g
Sauces	0.6 g of salt/100 g
Water	50 mg of sodium/l litre
Herbs	0.1 g of salt/100 g

### Increased cholesterol

Make sure your diet contains the right fats to maintain your cholesterol levels.

Good choices are:

- ✓ minarine, margarine or oil without salt.
- ✓ skimmed or semi-skimmed milk and milk products.
- ✓ lean meat products such as chicken breast, turkey ham, cooked ham, lean beef or pork roast.

Try eating fish twice a week instead of meat and also opt for a vegetarian alternative at least once a week.

Regularly eat a handful of nuts as a snack.



### Increase in weight

A healthy and balanced diet is the basis for maintaining a healthy weight.

❁ Eat up to three snacks per day. In so doing, choose fruit or a skimmed milk product. Extra vegetables and low-fat, low-salt soup are also a good snack. Try to limit sweets to once a day.

❁ Always eat a large portion of vegetables with the hot meal. You can also provide extra vegetables with bread meals in the form of raw vegetables or low-fat, low-salt soup.



❁ Choose whole grain cereals (bread, pasta, rice). These contain more fibre and will make you feel fuller faster, which means that you will eat less of them.

❁ Do not place double amount of toppings on your sandwich.

❁ Choose skimmed or semi-skimmed milk, milk products and cheese.

❁ Choose lean meat products and lean meat with hot meals.



- ✿ Limit the use of cooking fats to one tablespoon per person for a full hot meal. With a bread meal, limit fat to one knob of margarine per sandwich.
- ✿ Drink plenty of water or unsweetened tea. Avoid soft drinks and fruit juices.

## Osteoporosis

Pay extra attention to getting sufficient calcium in your diet in the form of milk, milk products or calcium-rich soya, rice and nut drinks. Try to drink and/or eat half a litre of milk and milk products per day, preferably skimmed or semi-skimmed varieties. In addition, eat one or two slices of bread with (low-fat) cheese.

## Increased risk of food-borne infection

Always bear in mind the general basic rules regarding food safety and hygiene.

### In shops

- Do not buy food with damaged packaging.
- Always check the best-before date.
- Transport chilled and frozen products home as quickly as possible.

### In the kitchen

- Store and prepare meals in a hygienic environment.
- Keep raw and prepared food separate from one another.
- Store prepared products in sealed jars.

- Cook meat, fish, poultry and eggs thoroughly.
- Always wash fruit and vegetables carefully.

#### General hygiene

- Always wash your hands and dry them thoroughly before preparing, serving and eating meals.
- Use clean kitchen equipment. Change towels and tea towels daily.

It is better to avoid the following food products:

- Raw food products (meat, fish, poultry and eggs) and any cold preparations made using them (e.g. tiramisu, chocolate mousse).
- Raw milk
- Moulded cheeses and non-pasteurised cheeses. If in doubt, look at the packaging.
- Untreated nuts, which are not sold in a sealed pack.
- Avoid fruit and vegetables at restaurants or sandwich bars.
- Grapefruit, blood oranges and star fruit combined with certain medications can cause a reaction. While you are taking this medication, you should stop eating these fruits.

#### Other nutritional advice after a transplant

- ✓ Do not eat simmered or stewed meat dishes such as goulash and stewed meat the day before your consultation. They can affect the blood test results.



- ✓ Drink plenty, preferably alternate between water and unsweetened tea. The amount you should drink is specified by the doctor.



## EVERYDAY LIFE

### Sport

Enough physical exercise, especially combined with a balanced diet, is essential for staying in good shape. Research shows that physical activity also has many benefits for your health: less risk of cardiovascular diseases, being overweight, diabetes and high blood pressure. In addition, physical exertion has a positive effect on your state of mind.

After a transplant, your body needs some time to adapt, in which you can slowly rebuild your levels of physical activity. This recovery period should last at least six weeks.

The **first six weeks** after the transplant:

- ✿ you should not lift heavy weights, such as a heavy bag, so as not to damage the healing of the wound. In fact, you shouldn't lift more than a glass of water.
- ✿ it is best to avoid strenuous physical activity.

The **first three months** after the transplant:

- ❁ in the case of abdominal surgery, you should not undertake any abdominal exercises. After that, you can rebuild your abdominal muscles during physiotherapy.
- ❁ you shouldn't go swimming. After three months, this is allowed, provided that you have recovered well and everything is going well.

Certain contact sports are not recommended after a transplant because there is an increased risk of causing damage to the transplant organ. These include boxing, karate, BMX and judo, for example. When choosing a new sport, it is best to think about whether or not the transplant organ is in a vulnerable location. Always discuss the choice of sport with your doctor.



## School

Normally, six to eight weeks after the transplant, you can go back to school. The parents are best to inform the school about the increased risk of infections and ask to be informed if there are any infections amongst pupils or teachers at school. If necessary, the transplant team can also contact the school.



When you go back to school, in principle you can participate in all activities. There are a few restrictions, as long as you can take your medication at set times and you take on board the tips to prevent infection.

## Infections

Especially during the first six months following the transplant, you have a high risk of infections. That's why you should read the tips on page 11 of this brochure on how to prevent an infection.

## Pets

For the first few months after the transplant, you should avoid contact with animals. Are you thinking about getting a pet? You should first discuss this with your doctor. Also, have the animal regularly examined by a vet, so that you can be sure that it does not have any infections.

When in contact with animals, you should always thoroughly wash and/or disinfect your hands. Family and friends should also make it a habit to wash and/or disinfect their hands after contact with animals.

Never let a pet lick your face and do not change the litter tray yourself.

Some animals pose a greater risk for those with reduced immunity.

It's better not to keep birds or chicks, hamsters, guinea pigs, reptiles (e.g. snake, turtle, lizard), and exotic animals (e.g. monkeys) at home.



## Smoking and alcohol

It is strongly advised that you do not smoke or drink alcohol. Smoking increases the chance of infections, especially postoperative lung infections. It also increases the chance of cancer and cardiovascular diseases. Combined with the medicines that prevent the risk of rejection of the donor organ, this risk is made even more acute. Even passive smoking is harmful, so people shouldn't smoke at home or in the car.

After a liver transplant, alcohol consumption is forbidden.

## Fertility

After a transplant, the fertility of a young woman often returns to normal. In boys, fertility remains the same as before the transplant. Pregnancy is not recommended for the first two years after the



transplant. It is best to discuss the use of contraceptives with your doctor.

## Travel

You should not travel for the first three months after your transplant, because your body still needs to adapt to the new situation. The risk of rejection of the transplant organ is still quite high and you still have to undergo check-ups regularly.

You can travel again from fourth months after the transplant, but you should always discuss this first with your doctor. Always carry your medicines in your hand luggage. This way you can be sure not to experience difficulties should you lose your suitcases. Also



keep the phone numbers of the hospital at hand, as well as a short medical report and possibly also any necessary medication instructions. You can request this in advance from the doctor. In most

European countries, you can easily obtain prescription medication from a pharmacy.

It is best to take out travel insurance. The social worker will be able to provide you with more information on this.

In case of problems when travelling, always contact the hospital first. They may advise you to visit a local doctor. Be sure to bring along the short medical report. Be sure to state explicitly that the patient is a transplant patient.



# CONTACT WITH THE HOSPITAL AFTER DISCHARGE

## Admission

In case of illness or urgent questions, call the hospital paediatric unit A (E 345): Tel. +32 16 34 58 06.

The unit team will transfer you to the doctor, who will assess whether an admission is necessary. If an admission is necessary, after a telephone consultation you can come directly to the unit and you do not have to go to the accident and emergency department. Don't forget to bring sufficient medication to the hospital.

## Consultations and examinations

### Check-up consultations

Regular check-up consultations are required for the first year after the transplant.

During the first few weeks after being discharged from hospital, it is not unusual for you to have a check-up once or twice a week. During these check-ups, the treatment with anti-rejection medication (immunosuppressants) is refined. You do not have to have an empty stomach for the check-ups, unless specified otherwise by the doctor. On the morning of the consultation, however, you should not take any immunosuppressants. Take the morning dose with you to the consultation and only take them after the blood sample has been taken. You can take other medication at home before you come to the check-up.



The check-up consultation continues in the children's hospital, red arrow, gate 4, first floor. You can register in the reception hall, after which you can proceed to the paediatrics consultation. Usually, a blood sample is taken first and after this the anti-rejection medication can be taken. Sometimes the doctor calls after the consultation to adjust the medication regimen according to the blood results.

### Schedule a new appointment

Make a new appointment at each consultation. In this way you can plan everything well in advance. In the case of a compelling reason, such as an exam, a school trip or annual leave, the consultation can be moved to another date in consultation with the doctor.

To make or move an appointment, you can call +32 16 34 39 91.

### Annual check-up

There are also check-ups every year around the anniversary of the transplant. These take place during a short two- to three-day admission to the hospital paediatric unit A (E 345).



## Preparing for the consultation



Prepare yourself for the consultation at home:

- ★ Check your supplies of medication at home and ask for the prescriptions needed during the consultation.
- ★ Write down your questions in advance so as not to forget anything during the consultation. You can also always call upon the dietician, psychologist, social worker or nurses.
- ★ For the first few months after the transplant, we recommend that you wear a face mask when you come to the hospital. The doctor will indicate when this is no longer necessary.

The doctor may want to complete a **24-hour urine volume test**. This takes place as follows:

- ✿ You are given a special collection container and tube to take home with you. You can collect the urine the weekend before the consultation.
- ✿ The day on which you start collecting urine, you first pee into the toilet, for example at 8 am, so that your bladder is empty.
- ✿ From then on, you collect all your urine throughout the day and night in the collection container.
- ✿ The morning wee of the next day (up to 24 hours after your first wee, for example up to 8 am) is also collected in the collection container. This is the way to complete a correct 24-hour urine volume test.

- ❁ Properly close the container using the lid and mix the collected sample together by gently rolling the container a few times.
- ❁ Read off the total volume of urine (the flow rate) from the collection container and note down the volume on the label of the tube.
- ❁ Also write the number of hours on the label. Suppose you started at 8 am and you pee for the last time at 7 am the next day, then you have a total urine collection of 23 hours.
- ❁ Tilt the collection container with the insertion opening pointing down. Push the rubber stopper of the tube into the insertion opening. The tube now fills with urine. When the tube is full, carefully remove it from the collection container. You pour away the rest of the urine.
- ❁ Take the filled tube with you to the consultation and give it to the nurse who takes the blood sample. If there has been a spill or if the volume test is incomplete, please report this to the nurse.
- ❁ Afterwards, you can rinse out the container and reuse it for the next 24-hour urine volume test.



# PSYCHOSOCIAL AND FINANCIAL CONSIDERATIONS

## Psychosocial counselling

When the transplant is complete, you will gradually realise that a new phase of your life has begun. The waiting for the transplant is over and all sorts of new feelings and questions will come to you.

- \* How do we rebuild our lives?
- \* Who is the organ donor?
- \* What happens if the organ is rejected?
- \* How do we cope with this new situation?
- \* Will you be able to go back to school?

Do not hesitate to ask all of your questions to the doctors, nurses, psychologist or social worker. They are always available to help and guide you through this new phase of your life as best as possible. You can also find a lot of useful information on the website [www.overlevendoorgeven.be](http://www.overlevendoorgeven.be).

## Transition

We refer to the move from paediatrics to adult care as 'transition'. This transition often brings with it a lot of questions and uncertainties.



Preparations for this will begin from the age of about 12. Around the age of 18, it will be time for the actual transition. This period will be different for everyone. One patient will be ready for the transition more quickly than another. That's why we work with carefully adapted questionnaires to ensure effective follow-up. There are also regular discussions with the various disciplines to closely monitor the transition process. The transition to adult care will only take place when preparations have been completed properly and in full, and no earlier.

## Patient associations and organisations

### Parent Association for Kidney Patients (OVNP)

This association also organises holiday trips for dialysis and transplant patients. More information can be found on the website: [www.ovnp.be](http://www.ovnp.be).

### TACKERS (Transplant Adventure Camp for Kids)

TACKERS brings together transplant children from all over the world to take part in a winter camp. As the children try out new sports, such as skiing, snowboarding, scuba diving or paragliding, they learn to take responsibility for themselves and get to know children who are going through the same thing. These social contacts can be a real asset to both the children and their families. More information can be found on the website: [www.tackers.org/en](http://www.tackers.org/en).



## Young Transplantoux

In addition to Transplantoux, an association that organises sports activities for transplant patients, there is also Young Transplantoux. They focus on transplant children and young adults. More information can be found on the website:

[www.transplantoux.be/presentation-transplantoux-in-english/](http://www.transplantoux.be/presentation-transplantoux-in-english/).

## Belgian Sports Association for Transplant and Dialysis Patients (BSVGG)

Transplant and dialysis patients can join this not-for-profit organisation to practice a sport of their own choice. The Belgian team takes part in sporting events in the Netherlands and abroad, such as national, European and world games. At national level, they organise monthly training sessions, both to maintain and strengthen members' fitness and to forge and reinforce friendships. More information can be found on the website: [www.bsvgg.be](http://www.bsvgg.be).

## Child and Organ Transplant Fund

The main objective of this fund is to provide financial support for both scientific and psychosocial considerations of a transplant in children. The Child and Organ Transplant Fund aims to permanently improve the survival and quality of life of these children. In order to achieve this, the fund aims to promote research into and about transplants and to promote comprehensive prevention of organ failure in children with severe kidney, liver or intestinal disease. You can find more information about this at [www.kind-en-orgaantx.be](http://www.kind-en-orgaantx.be).

## VZW Bas, tough fighter

This not-for-profit organisation focuses both on providing information about organ donation and transplants and about supporting scientific research. In addition, the organisation supports families affected by an organ donation or transplant.

## Different organisations

There are many other organisations that work with young transplant patients and their families. These organisations offer support in a variety of areas. There are a number of initiatives that offer holidays, excursions and other residential opportunities. In addition, there are organisations that make wishes or dreams come true. Finally, there are also not-for-profit organisations that can offer help with support at home and financial assistance.

If you have any queries, you can contact the transplant team social worker.

## Financial support

You can always contact the unit's social worker with questions about the financial side of the transplant and everything that comes with it.



## Hospitalisation invoice

The hospitalisation invoice is split into two main parts. The majority of the costs are settled by the hospital through your health insurance fund. In addition, the hospital only charges for the personal surcharge and supplements. A cost estimate can always be requested from the unit's social worker or directly from the medical administration unit at the hospital. The health insurance fund usually provides for an allowance for (unreimbursed) supplements such as rooming-in, but this is only possible when the invoice is brought in after receipt. Hospitalisation insurance also often provides for this.

## Consultations

The invoices for the consultations can always be submitted to the health insurance fund or the hospitalisation insurance for inspection.

## Medication

When you are discharged from hospital, you will be given the necessary instructions about collecting medication from the pharmacy. Always keep a close eye on your supplies of medication at home. You can ask for new prescriptions from the doctor at one of the check-up consultations.

For some medicines, you will need to submit a test with which you have to go to the consulting doctor of your health insurance fund for approval and reimbursement of the medicine. By doing so you'll have to pay less in the pharmacy.

## Care allowance for children with specific support needs

For the first months or years after the transplant, a child with a specific support need is entitled to a care allowance.

The unit's social worker is happy to provide more information about this and can offer support with the application. More information can also be found on the growth package web site ([www.groeipakket.be/en](http://www.groeipakket.be/en)).

Depending on the decision about the care allowance, as a transplant patient you may still be entitled to a number of other social benefits (increased allowance, basic support budget, tax reduction, etc.). Find out about this by contacting the social worker. The social welfare department of the health insurance company can also help you with this.

## Transport

After the transplant, you must keep a list of visits to the hospital that need be signed by the doctor.

You can get such a list from the unit. The social worker can help you with this, if necessary. He/she will visit during your stay in hospital and provide the necessary certificates for the transport assistance.



## PRACTICAL INFORMATION



University Hospitals Leuven Gasthuisberg Campus,  
Herestraat 49  
3000 Leuven, Belgium  
Tel.: +32 16 33 22 11

→ At the UZ Leuven web site you can find out more information and the contact details of the various units and staff: [www.uzleuven.be/kindergeneeskunde](http://www.uzleuven.be/kindergeneeskunde).

### **Department of Paediatric Medicine**

Hospital paediatric unit A (E 345)  
Red arrow, gate 4, level 4.a  
Tel.: +32 16 34 58 05

### **Paediatric Consultation (E 302)**

Red arrow, gate 4, floor 1.a and floor 2.a  
Tel.: +32 16 34 39 91

### **Paediatric Outpatient Centre (E 305)**

Red arrow, gate 4, level 2.b  
Tel.: +32 16 34 31 41

### **Paediatric Nephrology and Organ Transplant Administration Office**

E-mail: [kindernefrologie@uzleuven.be](mailto:kindernefrologie@uzleuven.be)  
Tel.: +32 16 34 38 22

### **Paediatric cardiology consultation**

Red arrow, gate 4, floor I, waiting zone G

### **Centre for metabolic diseases**

E-mail: [mz@uzleuven.be](mailto:mz@uzleuven.be)

Tel.: + 32 16 34 38 27

### **Paediatric Cardiology Administration Centre**

E-mail: [kindercardiologie@uzleuven.be](mailto:kindercardiologie@uzleuven.be)

Tel.: +32 16 34 38 65

### **Medical assistants**

For non-urgent questions, please call between 14:00 and 16:00.

- ❁ Consultations and outpatient appointments medical assistant:  
tel. +32 16 34 06 63
- ❁ Hospital Unit E 345 medical assistant:  
tel. +32 16 34 06 55
- ❁ Cardiology medical assistant:  
tel. +32 16 34 06 60
- ❁ Accident and Emergency medical assistant:  
tel. +32 16 34 06 62







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via [nexuzhealth.com](http://nexuzhealth.com) or

