

# Living with a new kidney

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Welcome to the kidney transplant unit. You have recently undergone a kidney transplant. This information brochure is meant as a manual and support tool to ensure that the transition from hospital to home proceeds as smoothly as possible. The brochure is part of a learning programme aimed at preparing you as effectively as possible for your life with a new kidney. You will be taken through the programme in the coming days. Your physician, nurse, social worker, dietician, physiotherapist, psychologist, clinical nurse and pastor are ready to provide support.

This brochure comprises information on the transplant and medication, recognising signs of rejection and/or infection, the diet you will have to adopt, physical activity, psychological/ social aspects and other tips or areas of specific attention following your discharge from hospital and during consultations.

Should you have further questions after reading this brochure, please do not hesitate to contact a healthcare professional. We are ready to provide support. We wish you a speedy recovery and comfortable stay at our unit and in the hospital.

The kidney transplant team

## IMMUNE SYSTEM

The human body's immune system, which protects us from disease, is able to recognise cells that are foreign to the body – not only viruses, bacteria, fungal infections, but also cells originating from a donor organ. When these foreign cells are present in the body the immune system will attempt to disarm them. Rejection is your body's reaction to the kidney, which is perceived as 'foreign'. You will have to permanently take medication to suppress your immune system in order to prevent the transplanted kidney from being attacked. This medication is referred to as immunosuppressant or anti-rejection medication.

There are two types of rejection, acute and chronic. Acute rejection is a rapid and intense form of rejection, which usually occurs within three months of a transplant, although it can also manifest itself later.

Chronic rejection is a process that continues for years during which the transplanted kidney gradually deteriorates.

Signs of rejection may still occur, even though you dutifully take your immunosuppressant medication. More than 20% of kidney transplant patients show signs of rejection during the first three months following a kidney transplant. After that the risk of rejection decreases, but can never be completely eliminated. Taking appropriate medication in the correct manner at the right time will reduce the risk of rejection. The average survival rate for a transplanted kidney is fifteen years.

The appearance of signs of rejection does not mean that you will lose your new kidney. Rejection can be treated successfully providing it is detected early. It is important, therefore, to attend regular check-ups following your discharge from hospital. Initially this will be three times during each two week period. A routine kidney biopsy will be carried out three months after your kidney transplant to look for minor signs of rejection. These kidney biopsies will be repeated one and two years after the transplant.

If you were monitored before the transplant in another nephrology centre rather than UZ Leuven, you will be able to return to your own centre after three months. However, routine kidney biopsies are always done at UZ Leuven and take place three months, one year and two years after transplantation. Afterwards, we strongly recommend continuing to come for annual consultations at UZ Leuven for follow-up. Annual check-ups give us the opportunity to fine-tune the long-term policy for your immunosuppressant treatment to the evolution of your individual medical profile and, if necessary, adjust the treatment in consultation with your treating nephrologist. This will benefit the long-term survival of your kidney.

# MEDICATION

## IMMUNOSUPPRESSANTS OR ANTI-REJECTION MEDICATION

This type of medication aims to suppress the immune system and prevent rejection of the transplanted organ. Controlled studies are continually being conducted in order to develop new drugs, create different combinations or lower the required doses. This chapter provides information on existing immunosuppressants, their doses and [side effects](#). You will be prescribed a combination of different medications of this type. [Each patient's medication programme is unique and geared to his/her specific requirements.](#)

In addition to the [side effects](#) associated with a specific immunosuppressant, there are also [general consequences following long term administration](#) of this type of medication. The immunosuppressants required to prevent rejection suppress the immune system. This results in an increased risk of infection, sometimes from viruses, bacteria or fungal infections that don't affect people with a healthy immune system and are, therefore, more difficult to treat. [Not only is the risk of infection higher](#), these infectious diseases are also frequently more serious than in people not taking immunosuppressants.

Moreover, taking immunosuppressants for the rest of your life can also [increase the risk of some cancers](#) such as, for example, skin cancer and lymphoma. Hidden cancers that may have been present before the transplant but are growing very slowly, can start to [grow faster](#) when immunosuppressants are taken, which could lead to problems. This requires extra vigilance, which is why you will be monitored more closely.

The anti-rejection medication ticked below is applicable to you:

- Tacrolimus (Advagraf<sup>®</sup>, Prograf<sup>®</sup> of FK506)
- Cyclosporine A (Neoral Sandimmun<sup>®</sup>)
- Everolimus (Certican<sup>®</sup>)
- Azathioprine (Imuran<sup>®</sup>)
- Mycophenolaat Mofetil (MMF, CellCept<sup>®</sup>)
- Mycophenolaat natrium (MPA, Myfortic<sup>®</sup>)
- Corticosteroids (Medrol<sup>®</sup>)

## TACROLIMUS (ADVAGRAF<sup>®</sup>, PROGRAFT<sup>®</sup>)

- **Type**



**Prograf<sup>®</sup>:** capsules of 0.5 mg (yellow), 1 mg (white) and 5 mg (red). Store the capsules in their packaging until you need to take them. Store at room temperature. A 0.5 mg/ml syrup is also available.



**Advagraf<sup>®</sup>:** capsules of 0.5 mg (orange/yellow), 1 mg (orange/white), 3 mg (orange) and 5 mg (orange/red). Store the capsules in their packaging until you need to take them. Store at room temperature.

- **Purpose**

Prograf<sup>®</sup> and Advagraf<sup>®</sup> suppress the immune system to prevent the transplanted organ from being rejected.



- **Dose**

The dose of Prograft® or Advagraf® will be adapted to your weight and the amount of medication in your blood (blood concentration level). It is extremely important, therefore, that you take this medication **always in the same way**, e.g. on an empty stomach, and **always at the same time!**

The difference between these two drugs is the duration of action. Prograft® works for 12 hours (take twice a day) and Advagraf® works for 24 hours (take once a day).

### Prograft®

- The full daily requirement is taken in two doses. For example, if you need to take 6 mg in total, you will have to take 3 mg in the morning and 3 mg in the evening.
- There has to be a 12 hour interval, e.g. you should take 3 mg at 8.00 hrs and 3 mg at 20.00 hrs.
- Remove the capsules from the packaging just before taking them.
- Swallow the capsules whole without chewing them.
- Take the capsules with fluids, but not grapefruit or blood orange juice or derivatives such as Agrum®.
- **What should you do in the event of vomiting?**  
If you vomit within half an hour of taking the medication, you will have to take the full dose again. If you vomit between half an hour and an hour after taking the medication, you should take half the prescribed Prograft® dose. For example, if you usually take 3 mg at 8.00 hrs in the morning, you should now take 1.5 mg. Contact the nephrologist if vomiting persists.

- **What should you do in the event of diarrhoea?**  
If you are suffering from diarrhoea the medication may not be properly absorbed via the intestine. In that case always inform the nephrologist.
- **What if you have forgotten to take your medication?**  
It is extremely important that you take your medication always at the same time. If fewer than 4 hours have elapsed between the usual time of taking the medication (e.g. 8.00 hrs) and the time you remember you haven't taken it (e.g. before 12 hrs), you can still take the normal dose. However, if more than 4 hours have elapsed, you should no longer take the forgotten dose. You should now revert back to the usual prescription instructions. Always record this in your medical diary to ensure that your physician is notified accordingly. It may be important with respect to the amount of medication in your blood (blood concentration level).
- **What should you do when attending a consultation?**  
DO NOT TAKE Prograft® at home on the day of a consultation. Bring the medication to the hospital and take Prograft® with a glass of water after the necessary blood sample(s) have been taken. Always inform the physician if you have already taken Prograft® at home.

### Advagraf®

- You must take **the full daily dose in the morning.**
- Remove the capsules from the packaging just before taking them.
- Swallow the capsules whole without chewing them.
- Take the capsules with fluids, but not grapefruit or blood orange juice or derivatives such as Agrum®.

- **What should you do in the event of vomiting?**

If you vomit within half an hour of taking the medication, you will have to take the full dose again. If you vomit between half an hour and an hour after taking the medication, you should take half the prescribed Advagraf® dose. For example, if you usually take 6 mg at 8.00 hrs in the morning, you should now take 3 mg. Contact the nephrologist if vomiting persists.

- **What should you do in the event of diarrhoea?**

If you are suffering from diarrhoea the medication may not be properly absorbed via the intestine. In that case always inform the nephrologist.

- **What if you have forgotten to take your medication?**

It is extremely important that you take your medication always at the same time. If fewer than 12 hours have elapsed between the usual time of taking the medication (e.g. 8.00 hrs) and the time you remember you haven't taken it (e.g. before 16.00 hrs), you can still take the normal dose. However, if more than 12 hours have elapsed, you should no longer take the forgotten dose. You should now revert back to the usual prescription instructions. Always record this in your medical diary to ensure that your physician is notified accordingly. It may be important with respect to the amount of medication in your blood (blood concentration level).

- **What should you do when attending a consultation?**

DO NOT TAKE Advagraf® at home on the day of a consultation. Bring the medication to the hospital and take Advagraf® with a glass of water after the necessary blood sample(s) have been taken. Always inform the physician if you have already taken Advagraf® by mistake at home.

- **Tacrolimus (Advagraf<sup>®</sup>, Prograft<sup>®</sup>) side effects**

Medication can be associated with a number of side effects. Sensitivity to these side effects varies from person to person. **Never alter your dose on your own initiative!** Your physician may adapt your existing medication, or prescribe additional medication, to prevent or treat side effects.

You may suffer from any of the following side effects: trembling hands, diarrhoea, nausea, vomiting, insomnia, diabetes, headaches and raised blood pressure, visual disturbances.

Other side effects are monitored on the basis of blood samples: low phosphate, low magnesium and high potassium levels in the blood, impaired kidney function.

- **Repayment?**

Prograft<sup>®</sup> and Advagraf<sup>®</sup> are fully compensated by the health insurance fund and are available from pharmacies on prescription.

## CYCLOSPORINE A (NEORAL SANDIMMUN®)

- **Type**



**Neoral Sandimmun®:** gelatine capsules of 10 (paediatrics), 25, 50 and 100 mg. Store at room temperature and keep in the packaging until you are ready to take them. A 100 mg/ml oral solution, which must be diluted, is also available.

- **Purpose**

Neoral Sandimmun® suppresses the immune system to prevent the transplanted organ from being rejected.

- **Dose**

### Gelatine capsules

- The full daily requirement is taken in two doses. For example, if you need to take 100 mg in total, you will have to take 50 mg in the morning and 50 mg in the evening.
- There has to be a 12 hour interval, e.g. you should take 50 mg at 8.00 hrs and 50 mg at 20.00 hrs.
- Store the gelatine capsules in the packaging until you are ready to take them. You will notice an unusual odour when opening the aluminium packaging. This is a storage compound, which does not affect the quality of the medication or indicate that it has exceeded its use by date.
- Swallow the gelatine capsules whole without chewing them.

- Take the gelatine capsules with fluids, but not grapefruit or blood orange juice or derivatives such as Agrum®.
- **What should you do in the event of vomiting?**  
If you vomit within half an hour of taking the medication, you will have to take the full dose again. If you vomit between half an hour and an hour after taking the medication, you should take half the prescribed Neoral Sandimmun® dose. For example, if you usually take 100 mg at 8.00 hrs in the morning, you should now take 50 mg. Contact the nephrologist if vomiting persists.
- **What should you do in the event of diarrhoea?**  
If you are suffering from diarrhoea the medication may not be properly absorbed via the intestine. In that case always inform the nephrologist.
- **What if you have forgotten to take your medication?**  
It is extremely important that you take your medication always at the same time. If fewer than 4 hours have elapsed between the usual time of taking the medication (e.g. 8.00 hrs) and the time you remember you haven't taken it (e.g. before 12.00 hrs), you can still take the normal dose. However, if more than 4 hours have elapsed, you should no longer take the forgotten dose. You should now revert back to the usual prescription instructions. Always record this in your medical diary to ensure that your physician is notified accordingly. It may be important with respect to the amount of medication in your blood (blood concentration level).
- **What should you do when attending a consultation?**  
**DO NOT TAKE** Neoral Sandimmun® at home on the day of a consultation. Bring the medication to the hospital and take Neoral Sandimmun® with a glass of water after the necessary blood sample(s) have been taken. Always inform the physician if you have already taken Neoral Sandimmun® at home.

## Syrup

- The yellow oily liquid is drawn up using a graduated pipette.
  - 1 ml = 100 mg, 0.1 ml = 10 mg
  - The bottle must be stored at room temperature, away from daylight.
  - After use the pipette should be wiped with a tissue and put back.
  - Dilute the liquid in milk or fruit juice, but do not use grapefruit or blood orange juice or derivatives such as Agrum<sup>®</sup>. Because it is an oily substance it should never be diluted in water.
  - Thoroughly rinse the glass with water or fruit juice before emptying it completely, to ensure that you have ingested the full dose.
- 
- **Cyclosporine A (Neoral Sandimmun<sup>®</sup>) side effects**

Medication can be associated with a number of side effects. Sensitivity to these side effects varies from person to person. **Never alter your dose on your own initiative!** Your physician may adapt your existing medication, or prescribe additional medication, to prevent or treat side effects.

You may suffer from any of the following side effects: headaches and raised blood pressure, trembling hands, burning sensation in the hands and feet, increased hair growth on the body and face, thickening of the gums, increased risk of fungal infections in the mouth and oesophagus, sensitive skin.

Other side effects are monitored on the basis of blood samples: high fat and potassium levels and low magnesium levels in the blood, impaired kidney function.

- **Repayment?**

Neoral Sandimmun® is fully compensated by the health insurance fund and is available from pharmacies on prescription.



## EVEROLIMUS (CERTICAN®)

- **Type**

0.25; 0.5 and 0.75 mg tablets.



- **Purpose**

Certican® suppresses the immune system to prevent the transplanted organ from being rejected.

- **Dose**

### Tablets

- The full daily requirement is taken in two doses. Half the dose is taken in the morning, the other half in the evening.
- There has to be a 12 hour interval, e.g. you should take one tablet at 8.00 hrs and one at 20.00 hrs.
- Take the tablets whole, do not grind them down and always take them in the same way.
- Take the medication with adequate fluids, but not grapefruit or blood orange juice or derivatives such as Agrum®.
- **What should you do in the event of vomiting?**  
If you vomit within half an hour of taking the medication, you will have to take the full dose again. If you vomit within be-tween half an hour and an hour after taking the medication, you should take half the prescribed dose. Contact the nephrologist if vomiting persists.

- **What should you do in the event of diarrhoea?**

If you are suffering from diarrhoea the medication may not be properly absorbed via the intestine. In that case always inform the nephrologist.

- **What if you have forgotten to take your medication?**

It is extremely important that you take your medication always at the same time. If fewer than 4 hours have elapsed between the usual time of taking the medication (e.g. 8.00 hrs) and the time you remember you haven't taken it (e.g. before 12.00 hrs), you can still take the normal dose. However, if more than 4 hours have elapsed, you should no longer take the forgotten dose. You should now revert back to the usual prescription instructions. Always record this in your medical diary to ensure that your physician is notified accordingly. It may be important with respect to the amount of medication in your blood (blood concentration level).

- **What should you do when attending a consultation?**

**DO NOT TAKE Certican<sup>®</sup> at home on the day of a consultation.** Bring the medication to the hospital and take Certican<sup>®</sup> with a glass of water after the necessary blood sample(s) have been taken. Always inform the physician if you have already taken Certican<sup>®</sup> at home.

- **Everolimus (Certican®) side effects**

Medication can be associated with a number of side effects. Sensitivity to these side effects varies from person to person. **Never alter your dose on your own initiative!** Your physician may adapt your existing medication, or prescribe additional medication, to prevent or treat side effects.

You may suffer from any of the following side effects: mouth ulcers, acne, redness, swelling of the hands and feet, delayed wound healing and raised blood pressure.

Other side effects are monitored on the basis of blood samples: anaemia (red and white blood cells, blood platelets), disrupted metabolism.

- **Repayment?**

Certican® is fully compensated by the health insurance fund and is available from pharmacies on prescription.

Do not combine the intake of Certican® with Zyloric® (allopurinol) or Adenuric® (febuxostat).

## AZATHIOPRINE (IMURAN®)

- **Type**

25 and 50 mg tablets. Tablets should be stored at room temperature.



- **Purpose**

Imuran® suppresses the immune system to prevent the transplanted organ from being rejected.

- **Dose**

- The medication should be taken daily with fluids.
- Take the tablets whole, do not split them.
- **What should you do in the event of vomiting?**  
If you vomit within half an hour of taking the medication, you will have to take the full dose again. If you vomit between half an hour and an hour after taking the medication, you should take half the prescribed dose. Contact the nephrologist if vomiting persists.
- **What should you do in the event of diarrhoea?** If you are suffering from diarrhoea the medication may not be properly absorbed via the intestine. In that case always inform the nephrologist.
- **What if you have forgotten to take your medication?** It is extremely important that you take your medication always at the same time. If fewer than 12 hours have elapsed between the

usual time of taking the medication (e.g. 8.00 hrs) and the time you remember you haven't taken it (e.g. before 20.00 hrs), you can still take the normal dose. However, if more than 12 hours have elapsed, you should no longer take the forgotten dose. You should now revert back to the usual prescription instructions. Always record this in your medical diary to ensure that your physician is 24 notified accordingly. It may be important with respect to the amount of medication in your blood (blood concentration level).

- **Azathioprine (Imuran®) side effects**

Medication can be associated with a number of side effects. Sensitivity to these side effects varies from person to person. **Never alter your dose on your own initiative!** Your physician may adapt your existing medication, or prescribe additional medication, to prevent or treat side effects.

Additional side effects may occur, i.e. sensitive skin, gastric and intestinal complaints.

Other side effects are monitored on the basis of blood samples, i.e. anaemia.

- **Repayment?**

Imuran® is fully compensated by the health insurance fund and is available from pharmacies on prescription.

## MYCOPHENYLATE MOFETIL (MMF, CELLCEPT®)

- **Type**



**CellCept®** is available in 250 mg capsules and 500 mg tablets. Tablets must be stored at room temperature. Remove them from their packaging when you are ready to take them and do not split them. Always take them in the same way. Also available in oral solution, powder to be diluted to ratio of 1g/5 ml.

- **Purpose**

CellCept® suppresses the immune system to prevent the transplanted organ from being rejected.

- **Dose**

### CellCept®

- The full daily requirement is taken in two doses. Half the dose is taken in the morning, the other half in the evening.
- There has to be a 12 hour interval, e.g. you should take one dose at 8.00 hrs and one at 20.00 hrs.
- Swallow the tablets whole without chewing them.

- Take the medication with adequate fluids, but not grapefruit or blood orange juice or derivatives such as Agrum®.
- **What should you do in the event of vomiting?**  
If you vomit within half an hour of taking the medication, you will have to take the full dose again. If you vomit between half an hour and an hour after taking the medication, you should take half the prescribed dose. Contact the nephrologist if vomiting persists.
- **What should you do in the event of diarrhoea?**  
If you are suffering from diarrhoea the medication may not be properly absorbed via the intestine. In that case always inform the nephrologist.
- **What if you have forgotten to take your medication?**  
It is extremely important that you take your medication always at the same time. If fewer than 4 hours have elapsed between the usual time of taking the medication (e.g. 8.00 hrs) and the time you remember you haven't taken it (e.g. before 12 hrs), you can still take the normal dose. However, if more than 4 hours have elapsed, you should no longer take the forgotten dose. You should now revert back to the usual prescription instructions. Always record this in your medical diary to ensure that your physician is notified accordingly. It may be important with respect to the amount of medication in your blood (blood concentration level).

- **Mycophenylate Mofetil (MMF, CellCept®) side effects**

Medication can be associated with a number of side effects. Sensitivity to these side effects varies from person to person. **Never alter your dose on your own initiative!** Your physician may adapt your existing medication, or prescribe additional medication, to prevent or treat side effects.

This medication is mainly associated with gastro intestinal complaints, i.e. nausea, vomiting, lack of appetite, diarrhoea, constipation, abdominal cramps. The problem can usually be solved by adapting the dose or changing the medication.

Other side effects are monitored on the basis of blood samples: anaemia (red and white blood cells, blood platelets), increased risk of CMV infections.

- **Repayment?**

CellCept® is fully compensated by the health insurance fund and is available from pharmacies on prescription.



## CORTICOSTEROIDS (MEDROL®)

- **Type**



4, 16 and 32 mg tablets with a groove to make it easier to split them into four. This medication must be stored at room temperature.

- **Purpose**

Medrol® is an anti-inflammatory, anti-allergy and immunosuppressant drug.

- **Dose**

- This medication should be taken once a day at breakfast time in order to prevent gastric complaints.
- The tablets should be taken with fluids.
- The tablets can be split (into maximum 4 sections) to obtain the correct dose.
- **Warning!** These tablets are available in different doses, which all look very similar. Always check that you are taking the correct dose.

- **Corticosteroids (Medrol®) side effects**

Medication can be associated with a number of side effects. Sensitivity to these side effects varies from person to person. Never alter your dose on your own initiative! Your physician may adapt your existing medication, or prescribe additional medication, to prevent or treat side effects.

You may suffer from any of the following side effects: gastric complaints and an increased risk of gastric ulcers, risk of developing diabetes, water and salt retention, moon face, increase in weight and appetite, mood fluctuations, slow wound healing, brittle/dry/thinning skin, osteoporosis, visual disturbances (hazy vision), cataract and glaucoma.

- **Repayment?**

Medrol® is available from pharmacies on prescription. 32 mg tablets are repaid in full by the health insurance fund. Other doses are partly refunded by the health insurance fund.

## OVERVIEW OF IMMUNOSUPPRESSANTS

The aim of all the medication in the following scheme is to suppress the immune system to prevent rejection of the transplanted organ. Medrol® also has anti-inflammatory and anti-allergic effects. Never adjust your dose on your own initiative!

	TACROLIMUS Prograf®	TACROLIMUS Advagraf®	CYCLOSPIRINE A Neoral Sandimmun®
Type	<b>Capsules:</b> <ul style="list-style-type: none"> <li>• 0,5 mg (yellow)</li> <li>• 1 mg (white)</li> <li>• 5 mg (red)</li> </ul>	<b>Capsules:</b> <ul style="list-style-type: none"> <li>• 0,5 mg (yellow-orange)</li> <li>• 1 mg (white-orange)</li> <li>• 3 mg (orange)</li> <li>• 5 mg (red-orange)</li> </ul>	<b>Capsules:</b> <ul style="list-style-type: none"> <li>10 mg, 25 mg, 50 mg and 100 mg</li> </ul>
Intake	Works for 12 hours: take 2x/day	Works for 24 hours: take 1x/day	Works for 12 hours: take 2x/day
	Take this medication at set times.		
	Never break tablet and never open capsule. Never crush or chew this medication.		
Vomit or diarrhoea	<b>In case of vomiting:</b> <ul style="list-style-type: none"> <li>• up to 30 min after intake → take whole dose again</li> <li>• 30 - 60 min after intake → take half a dose again</li> <li>• more than one hour after intake → do not take again</li> </ul> In case of persistent vomiting, inform your nephrologist. <b>In case of diarrhoea:</b> inform your nephrologist.		
Forgot medication	<b>Within 4 hours:</b> take forgotten dose	<b>Within 12 hours:</b> take forgotten dose	<b>Within 4 hours:</b> take forgotten dose
	<b>More than 4 hours later:</b> do not take the forgotten dose, take the next dose at the right time	<b>More than 12 hours later:</b> do not take the forgotten dose, take the next dose at the right time	<b>More than 4 hours later:</b> do not take the forgotten dose, take the next dose at the right time
Consultation	<b>Do not take before you come for consultation.</b> Bring the medication with you and take it <b>after the blood collection.</b> Did you take the medication before the consultation anyway? Inform your nephrologist.		
Store	Store this medication at room temperature.		
Refund	This medication is fully reimbursed by the health insurance fund and is available on medical prescription from the pharmacy.		

EVEROLIMUS Certican®	AZATHIOPRINE Imuran®	MYCOFENOLAAT MOFETIL CellCept®	CORTI- COSTEROIDS Medrol®
<b>Tablets:</b> 0,25 mg, 0,5 mg and 0,75 mg	<b>Tablets:</b> 25 mg and 50 mg	<b>Capsules:</b> 250 mg  <b>Tablets:</b> 500 mg	<b>Tablets:</b> 4 mg, 16 mg and 32 mg
Works for 12 hours: take 2x/day	Works for 24 hours: take 1x/day	Works for 12 hours: take 2x/day	Take 1x/day with food
Take this medication at set times.			
Never break tablet and never open capsule. Never crush or chew this medication.			Tablet may be broken via slots.
<p><b>In case of vomiting:</b></p> <ul style="list-style-type: none"> <li>• up to 30 min after intake → take whole dose again</li> <li>• 30 - 60 min after intake → take half a dose again</li> <li>• more than one hour after intake → do not take again</li> </ul> <p>In case of persistent vomiting, inform your nephrologist. <b>In case of diarrhoea:</b> inform your nephrologist.</p>			
<b>Within 4 hours:</b> take forgotten dose  <b>More than 4 hours later:</b> do not take the forgotten dose, take the next dose at the right time	<b>Within 12 hours:</b> take forgotten dose  <b>More than 12 hours later:</b> do not take the forgotten dose, take the next dose at the right time	<b>Within 4 hours:</b> take forgotten dose  <b>More than 4 hours later:</b> do not take the forgotten dose, take the next dose at the right time	<b>Within 12 hours:</b> take forgotten dose  <b>More than 12 hours later:</b> do not take the forgotten dose, take the next dose at the right time
<b>Same as</b> Prograft®, Adva- graf® and Neoral Sandimmun®			
Store this medication at room temperature.			
This medication is fully reimbursed by the health insurance fund and is available on medical prescription from the pharmacy.			The tablets of 32 mg are fully reimbursed by the health insurance, the other doses partly.

## BLOOD PRESSURE LOWERING MEDICATION

High blood pressure is controlled by taking blood pressure lowering drugs and sticking to a low salt diet.

## MEDICATION TO PROTECT THE STOMACH

Some medicines you take can irritate your stomach and, in the worst case, cause an ulcer. Therefore, you will be prescribed gastroprotective medication that inhibits the production of stomach acid. Examples include Ranitidine and Omeprazole (Omeprazole<sup>®</sup>, Losec<sup>®</sup> and so on).

Gastroprotective medication that you can obtain without a prescription (self-care medication), such as Rennie<sup>®</sup> and Antagel<sup>®</sup>, should not be taken together with immunosuppressants. There should be at least two hours between the intake of these medications and the intake of Cellcept<sup>®</sup>, as these gastroprotective medications inhibit the absorption of Cellcept<sup>®</sup> in the intestines and thus interfere with its action.

## PREVENTIVE MEDICATION TO FIGHT INFECTION

Up to three months after the transplant you will have to take medication specifically to prevent infection.

- **Valcyte<sup>®</sup> (valganciclovir)**

If you do not have CytoMegalovirus (CMV) antibodies and your donor has previously been affected by this virus, your physician will prescribe Valcyte<sup>®</sup> to prevent the virus from establishing itself. You

may/may not qualify for repayment depending on specific conditions. The physician or social worker will be able to provide more details on this subject. Check before being discharged whether you can obtain it from your pharmacist or from your clinical nurse.

- **Zovirax® (aciclovir)**

Zovirax® is given preventively for the first three months as a protection against herpes infections (if you or your donor contracted an infection in the past).

- **Eusaprim® Forte (Bactrim®) or Dapsone®**

Eusaprim® Forte (Bactrim®) tablets are prescribed to prevent *Pneumocystis Carinii Pneumoniae* (a specific lung infection). A low level of white blood cells and itching can indicate hypersensitivity to this medication, in which case the medication will be changed to Dapsone® tablets.

- **Nilstat® mouth wash (nystatine)**

Because your immune system is being suppressed to prevent the transplanted kidney from being rejected, you will be more prone to fungal infections in your mouth and oesophagus. As a preventive measure you will be asked to rinse your mouth with Nilstat® for the first three months. If you wear dentures you will have to remove them before rinsing your mouth. This should be done four times a day, after every meal and before going to bed (clean your teeth half an hour later). Use 2 ml (2 pipettes) of the product to rinse your mouth and then swallow it, don't spit it out.

## **MEDICATION TO PREVENT OSTEOPOROSIS**

Your kidney disease and some of the anti-rejection drugs may cause osteoporosis, which is why you will be prescribed additional calcium tablets if necessary.

## **PAIN MANAGEMENT THERAPY**

Every patient will be prescribed painkillers. If you are still in pain you can ask for additional medication. Do not hesitate to tell the physicians and/or nursing staff that you are in pain. Before being discharged from hospital ask your physician which medication you can take at home if you are in pain. Avoid the use of anti-inflammatories such as Ibuprofen® or Brufen®.

## **TROMBOSIS PROPHYLAXIS**

To prevent deep vein thrombosis as a result of the operation and from being bed ridden you will be given a Clexane® injection each day. Once you are at home this is usually no longer necessary.

## **DIABETES MEDICATION**

In patients with no history of diabetes an OGTT (oral glucose tolerance test) is provided. Then in the morning after the blood draw, you will be given a bottle of sugar water to drink. One and two hours afterwards, blood will be taken again. During this examination, you will remain sober.



This test can be used to determine whether or not the blood sugar level in your blood has not been disturbed by the medication (tacrolimus, cortisone, cyclosporine ...). If so, your diet will be adjusted, the dietician will visit you and during your hospitalisation, your glycaemic profile will be monitored by finger pricking before meals. Three months after transplantation, your blood sugar level will be re-evaluated and the doctor will decide whether you should continue the diet.

You may experience a permanent disruption of your blood sugar levels, which we call NODAT (New Onset Diabetes After Transplantation) or PDTM (Post Transplant Diabetes Mellitus). Both these terms are used. In this case medication will be started (via tablets or injections with insulin) and a diabetes educator will visit you during your stay in hospital. He or she will give you further information. For a better follow-up, we try to have the control consultations coincide with the presence of our endocrinologist at the kidney transplant consultation, every first and third Wednesday of the month.

## SELF MANAGEMENT AND THERAPY COMPLIANCE

The kidney transplant will enable you to regain a quality of life you might have lost. However, you will have to take into account certain issues.

A kidney transplant does not offer a cure; it remains a chronic condition requiring life long monitoring. You are responsible for your daily care once you have been discharged from hospital.

You will have **three important self management tasks**:

- ✗ the management of your disease and its symptoms, which includes consistent therapy compliance and adopting a healthy lifestyle;
- ✗ creating or maintaining purposeful roles in your everyday life;
- ✗ dealing with the emotions associated with our chronic illness.

This implies that, after the kidney transplant, you must consistently comply with your medication therapy, be able to manage symptoms associated with the side effects of immunosuppressants, be able to prevent infection and engage in your day to day activities again, maintain a healthy diet, do not smoke, take sufficient exercise and learn to manage emotions such as depression, anxiety and stress.

Non compliance with your therapy (even for a brief period) can lead to:

- complications;
- rejection of the transplanted organ;
- loss of the transplanted organ.

## MEDICATION EDUCATION TOOLKIT AND TIPS

### MEDICATION BOX

As soon as you start feeling better after the kidney transplant you will be given information on how to take your medication and provided with a medication box. It is allocated to you personally and will be labelled with your name, first name and date of birth. Your personal medication list will also be stored in the box. Always bring this box with you to consultations and whenever you are admitted to hospital.

You must store your medication in its original packaging to guarantee optimum storage and comply with the use by date.



You will start to lay out your medication ready to be taken whilst still in hospital, initially with assistance from a nurse and possibly a family member. Thereafter you will manage your medication independently. If this doesn't work out permanent assistance from a family member or home nurse may be useful. Managing and taking your medication correctly is of vital importance to ensure that your kidney transplant is successful.

## TRANSPLANT DIARY

When you come to the hospital for monitoring of your kidney function, that visit is just a snapshot in your daily life. It is important to also monitor your health at home too. Specifically, we ask you to closely monitor your blood pressure temperature, weight and urine flow rate and to keep a diary. This allows us to detect any deterioration of kidney function in good time. In addition, we will also ask you to note the daily dose of your anti-rejection medication so that the changes communicated over the phone remain clear. In case of questions, symptomatic complaints and comments, there will be space to be able to evaluate and adjust the therapy if necessary. All these data are thoroughly checked by our doctors during your consultation.

You can complete the diary either on paper or digitally.

You bring a paper diary to each consultation.

## Mynexuzhealth app

You can complete the diary digitally via mynexuzhealth, a website and app that gives you access to your online medical record. The data you register via mynexuzhealth are then also immediately in your medical record. Based on this, a healthcare provider at the consultation can monitor the evolution of your health even better.

Besides keeping a diary, you can also use mynexuzhealth to view information brochures and educational videos and fill in questionnaires. Furthermore, you can, among other things, keep track of your consultations, invoices, lab results (after 4 to 7 days) and final medical reports (after validation).

More info on the general applications of mynexuzhealth can be found in the brochure. Ask for it or consult the brochure online via [www.uzleuven.be/en/brochure/701200](http://www.uzleuven.be/en/brochure/701200).



## TIPS

Always take your medication at the same time and in the same circumstances, e.g. always on an empty stomach, or always with meals or always after meals.

Stick to this even if your daily routine is different, e.g. during a holiday or a significant life event.

**Ask for support if you are having difficulty coping with this.**

Never take non-prescribed medication at your own initiative. Simultaneous use of immunosuppressants and other medication can affect the blood concentration level of your antirejection medication.

Inform any physician/dentist who wants you to start or stop with specific medication that you are a kidney transplant patient taking vital medication for a chronic condition.

It isn't always easy to take your medication correctly. If you find this problematic please do not hesitate to discuss this with your physician and/or nurse. Together we can try to find solutions to make your life easier, e.g. by using your mobile phone or watch, simplifying your medication schedule, linking the administration of your medication to routine activities.

## REJECTION

Earlier in this brochure we already described how our body's immune system works and what rejection means. This chapter mainly focuses on possible symptoms associated with rejection, and diagnosis and treatment options.

## Signs of rejection you can monitor yourself:


- fever and shivering (rare);
- pain in the kidney area;
- a kidney that feels swollen;
- unusual weight increase;
- swollen legs and feet;
- less frequent urination with normal fluid intake.

## Additional rejection symptoms

- an increase in creatinine in the blood.

If rejection is suspected you will have to be admitted to hospital where the physician will conduct a kidney biopsy. This is the only way to determine the onset of rejection for certain. You will have to stay in bed after the biopsy because of the risk of bleeding from the puncture site. The biopsy will be followed by an ultrasound scan. If this is satisfactory you will be allowed to get up. Depending on the results of the biopsy, the physician will start treatment with high dose cortisone injections. This will require hospital admission and will take approximately twelve days. An increase in creatinine in the blood can also be caused by excessively high doses of Prograft<sup>®</sup>, Neoral Sandimmun<sup>®</sup> or as a result of eating too much casseroled meat in the days prior to a consultation. In sufficient fluid intake can also cause an increase in creatinine, particularly during warm weather or when you have suffered from diarrhoea.

If it occurs, rejection cannot be avoided, but you can reduce the risk by taking the prescribed medication correctly and constantly, and by contacting your physician as soon as possible if you notice signs of rejection.

A close-up photograph of a person's hand holding a white digital thermometer. The hand is positioned at the top right of the frame, with the thumb and index finger gripping the handle. The thermometer is held vertically, pointing downwards. The digital display on the thermometer shows the number '37.5'. The background is plain white.

It is also advisable to check your temperature daily, preferably in the morning and always at the same time. Place the digital thermometer in your armpit and wait for the audible signal. If your temperature exceeds 37.5 °C, contact your physician or the transplant unit. If your temperature is between 37 and 37.5°C, check it again one hour later. If your temperature stays at 37.5°C or continues to rise, contact your physician or the transplant unit. Taking Medrol® may disguise a possible rise in temperature.

Check your weight daily during the first three months after the transplant. After that once a week is fine, unless instructed otherwise. Always check your weight at the same time (preferably in the morning before breakfast), in the same circumstances (wearing your nightwear, without shoes or dressing gown, after urinating). Record your weight in kg and g. In the event of a sudden increase in weight of more than 1 kg immediately notify your physician or the nephrology secretariat on 016 34 45 93.

If you are clearly urinating less even though your fluid intake was sufficient, or in the event of changes in the odour, colour or appearance of your urine, contact your physician or the transplant unit.

Touch the site where the new kidney was implanted with the palm of your hand. If you notice pain, sensitivity, hardening or enlargement of the kidney please do not hesitate to contact your physician or the transplant unit.

Always record the signs you notice yourself during your daily check-ups in the transplant diary and bring it with you to consultations.



Routine biopsies will be conducted three months, one and two years after your kidney transplant to trace early signs of rejection. This topic will be described in more detail in the next chapter.

## HYGIENE AND INFECTION PREVENTION

The immunosuppressants you need to take protect the kidney from rejection. Unfortunately this medication also weakens your body's immune system, making you more prone to infection, particularly during the initial three months after the transplant or during treatment for acute rejection when the medication doses are at their highest. This doesn't imply that you will be affected by every germ you come into contact with. Most infections in transplant patients are caused by infectious agents they already harbour before the transplant. You will be prescribed additional medication, e.g. Eusaprim<sup>®</sup>, to prevent specific infections following the transplant. This medication can only be stopped subject to your physician's approval.

### SIGNS

An infection is your body's reaction to contamination with a specific infectious agent. This infectious reaction can be recognised by one or more of the following symptoms: pain or a burning sensation when urinating, frequent urination in small quantities,

urine with an unpleasant odour, persistent cough, phlegm or shortness of breath, diarrhoea, vomiting, fever and shivering, flu like symptoms or generally feeling unwell.

## GENERAL PERSONAL HYGIENE

You can help prevent infection. Below are a few guidelines that remain important even after your transplant.

- Maintain good personal hygiene and take a bath or shower every day.
- Showers are preferable to baths.
- Look after your nails.
- Change your underwear daily and other clothing on a regular basis.
- Drink 1.5 to 2 litres per day, unless prescribed otherwise.
- Check your temperature daily.

## ORAL HYGIENE

Good oral hygiene is important to prevent infection.

Guidelines:

- Nilstat® must be used to rinse your mouth four times a day for the first three months after the transplant. This yellowy liquid prevents fungal infections in the mouth. After every meal and before going to bed rinse your mouth with two pipettes of 1 ml of Nilstat® and then swallow it (don't spit it out!). Clean your teeth approximately 30 minutes later. This will create an anti-fungal environment and prevent tooth discoloration.

- Clean your teeth after every meal (30 minutes after using Nilstat®) with a small, soft toothbrush and fluoride toothpaste.



- Thoroughly rinse your toothbrush after cleaning your teeth and leave it to dry. Replace your toothbrush every three months.
- Clean the gaps between your teeth once a day with dental floss or toothpicks, preferably before cleaning your teeth. Ask your dentist for instructions if necessary.
  - Choose high fibre foods without added sugar because sugar can attack tooth enamel.
  - Dentures must also be cleaned on a regular basis. To do so remove the dentures from your mouth and also clean your palate and the surface of your tongue with a soft toothbrush. Remove your dentures before rinsing your mouth with Nilstat®. Remove your dentures at night to lighten the load on your gums. Your dentures may no longer fit properly as a result of weight fluctuations. Consult your dentist, who can adjust them for you.
  - Visit your dentist at least every six months. Inform him/her that you are a transplant patient and are taking medication to suppress your immune system. Your dentist can always contact the transplant team for more detailed information.
  - Always consult your physician immediately in the event of infection, irritation or a wound becoming septic.

## CONTACT WITH OTHER PEOPLE

- Avoid contact with people suffering from a cold or flu, because most infections are airborne or transmitted via hand contact.
- Avoid contact with children suffering from childhood diseases.

## SMOKING

Smoking increases the risk of cancer, pneumonia and cardiovascular disease. In your situation smoking is not acceptable.

## PETS

Maintain good hygiene practices when coming into contact with pets. Don't allow pets to sleep in your bed, be vigilant with animal faeces and thoroughly wash your hands after coming into contact with them. Thoroughly disinfect wounds inflicted by pets (e.g. scratches from cats).

## WOUND CARE AND HEALING

A donor kidney is implanted in the lower abdomen, not in the same location as your own kidneys. To this end a curved incision is made to the left or right of the lower abdomen.

It is advisable to wear an abdominal support belt near the wound during the first few days. Once the drains have been removed this will no longer be necessary.

Long term use of an abdominal support belt can lead to weakening of the abdominal muscles. Always consult the surgeon for advice.

Providing the wound heals successfully the stitches will be removed after 14 days. If the wound was sutured subcutaneously the stitches will not have to be removed.

## SURGICAL COMPLICATIONS

Despite the fact that the results of the kidney transplant are successful, complications specifically related to the operation may still occur. These surgical complications are rare and can occur soon after the transplant or much later. Serious complications can result in the kidney not functioning properly or loss of the donor kidney, leading to a need for another surgical intervention.

### Early complications (within the first few days of the transplant)

- ✓ Bleeding, requiring another operation (5%).
- ✓ In rare cases (1%) a blood clot may develop in the artery to the transplanted kidney (supplying blood to the kidney, the arteria renalis) or in the renal vein (draining blood from the kidney, the vena renalis). The blood clot prevents blood and oxygen from reaching the kidney resulting in the kidney dying off (similar to a heart attack). This also necessitates another urgent operation during which the blood clot can sometimes be removed. However, in many cases the damage to the transplanted kidney is such that it has to be removed.

- ✓ Urine leakage near the connection with the ureters of the transplanted kidney and bladder is rare (1%). This problem can often be solved by temporarily diverting urine via the bladder catheter and an external drain near the kidney. Sometimes another operation may be required to deal with this leakage problem, during which the ureter of the transplanted kidney is connected to the ureter of the own kidney or the ureter is reimplanted on the bladder.

### **Later complications (months to years after the transplant)**

Many of these complications can be traced during a routine ultrasound scan. The most frequent complications occurring later on are:

- ✓ Lymphocele or an accumulation of lymphatic fluid around the transplanted kidney (less than 10%): if this fluid puts pressure on the transplanted kidney it can impair kidney function. The fluid can be removed via an external drain or during an operation (keyhole or traditional 'open' surgery).
- ✓ Narrowing at the site of the connection between the ureter and bladder is rare (less than 5%) because of the plastic stent which is inserted during the transplant. The plastic stent is removed six weeks after the transplant during a consultation at the urology clinic; it does not require surgical intervention.
- ✓ Vesicoureteral reflux or backwards flow of urine from the bladder to the transplanted kidney: if this reflux results in repeated kidney infections an operation may be required to connect the

ureter of the transplanted kidney to the ureter of the own kidney or to reimplant the ureter on the bladder.

- ✓ Narrowing of the kidney artery usually requires treatment involving a balloon and metal stent being inserted in the artery to open it up.
- ✓ Incisional hernia: poor wound healing around the muscles and tendon of the abdominal wall can lead to weakening and swelling near the scar in the abdominal wall. This can usually be repaired with a sheet of synthetic mesh.

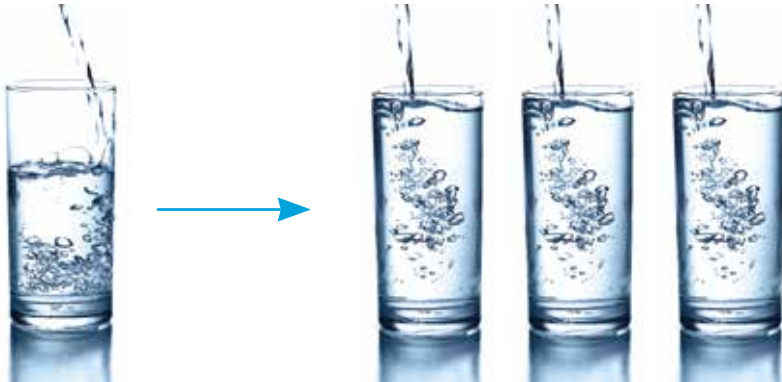
Please contact your physician if you have any further questions relating to these quite rare complications.

## NUTRITION

Even after transplantation, it is imperative that you follow certain dietary guidelines and hygiene guidelines. A healthy diet forms the basis, but due to the intake of immunosuppressive medication (immunosuppressants), a number of side effects can occur that require special dietary advice. A salt restriction and attention to the use of healthy fats are usually indicated.

## DRINKS

In contrast to fluid restriction during dialysis, it is indeed important to take sufficient and even extra fluids after transplantation. Choose mainly low-calorie drinks such as water, coffee and tea (without additives). Avoid sugary drinks such as soft drinks and fruit juice. Ask your doctor or dietician for advice.



during dialysis

after transplantation

During your stay in hospital the dietician will visit you on a regular basis to discuss nutrition and give recommendations about your diet at home.



## POSSIBLE SIDE EFFECTS OF THE MEDICATION:

- raised blood pressure, your salt intake will be limited to maximum 5 to 6 g;
- raised cholesterol and triglyceride levels in the blood;
- weight increase;
- osteoporosis;
- development of diabetes mellitus;
- increased risk of food poisoning requiring the observance of basic rules of food safety and hygiene;
- some fruits such as grapefruit, blood orange (and derivatives such as pomelo, sweetie and mineola) and pomegranate may interfere with the action of certain medications (immunosuppressants). As a result, these fruits, as well as juices and drinks based on these fruits are banned.

## SMOKING AND ILLEGAL DRUGS

You will have to have refrained from smoking for at least six months before you qualify for a kidney transplant. Smoking is a significant risk factor for heart and cardiovascular disease, which is the main cause of death following a transplant and is responsible for approximately half these fatalities. Tobacco also increases possibly already raised blood pressure after a kidney transplant and exacerbates arteriosclerosis.



Smoking also increases the risk of infection, particularly post-operative lung infections. Recurring bronchitis (frequent coughing and phlegm production leading to shortness of breath) and emphysema (lungs becoming less elastic leading to severe shortness of breath).

Smoking also raises the risk of cancer, including lung, larynx, oral, lip, bladder, kidney cancer etc. Combined with the medication you need to take to suppress rejection of the kidney the risk increases even more.

Vaping without nicotine is also not recommended, as it can cause a toxic effect and irritation at the level of the lungs. E-cigarette smoking or vaping can only be done for a short period as a temporary smoking cessation aid.

If you need help to stop smoking please do not hesitate to contact your physician and/or nurse. They can provide information on specific tools to help you stop smoking, refer you to a smoking cessation specialist or the health insurance fund, and/or make an appointment with the stop smoking clinic in the hospital.

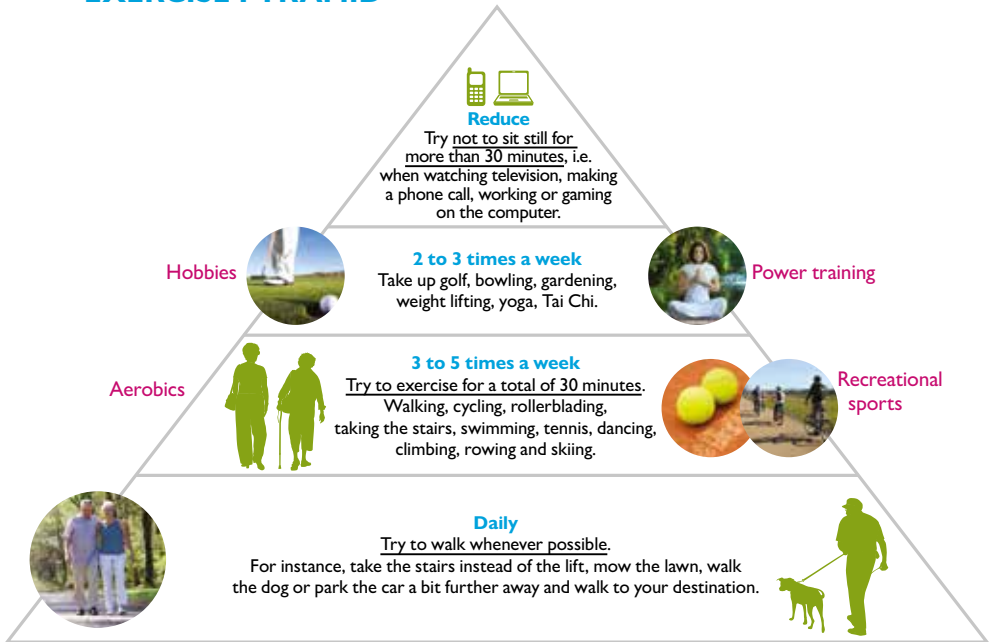
Taking illegal drugs is against the law and associated with serious medical risks, not just for transplant patients but for everyone.

## EXERCISE

Exercise – combined with a balanced diet – is extremely important to maintain your health. Scientific research shows that exercise has a whole range of important health benefits, such as a reduced risk of developing cardiovascular disease, obesity, diabetes and high blood pressure. Moreover, exercise has been shown to have positive effects on quality of life and mental well-being.

You may have lost strength and felt weak and tired as a result of your kidney disease even before your transplant. As a result, you may have been doing fewer physical activities, which may have reduced your quality of life and physical fitness. By physical fitness, we mean your endurance, strength, balance and flexibility. After transplantation, you may feel better as you recover from the procedure and from the complications of your kidney disease. However, many people suffer from reduced fitness and strength loss even after transplantation. Therefore, it is extremely important for your health that you exercise more so that your physical fitness improves. Below are some important guidelines.

## EXERCISE PYRAMID



### Basics of the movement pyramid: how can you move more daily?

The base of the pyramid consists of daily activities. Regular exercise is also important in the long term in order to maintain good health. It is important, therefore, to find opportunities for activity throughout the day.

#### A few simple examples:

- ✓ take the stairs instead of the lift;
- ✓ cycle to the bakery;
- ✓ walk the dog;
- ✓ get off the bus or tram one stop earlier;
- ✓ park your car a bit further away;
- ✓ take a walk during your lunch break.

## 2nd and 3rd steps of the movement pyramid: how to build fitness and strength?

On the second step of the movement pyramid are aerobic efforts and strength exercises.

By aerobic exercises, we mean efforts where you build your endurance or fitness capacity. To increase the number of aerobic efforts, you could, for example, try going out walking for 15 minutes five times a week or cycling on the exercise bike. Once you feel this is going smoothly going, you can expand this schedule to, say, three times 30 minutes. Depending on your physical condition before the transplantation you will make faster progress in this.

Any physical activity, even a small increase in exercise, will benefit your health. Follow the recommendations below to get the maximum health benefits from your physical activity.

We would recommend that you engage in moderately intense training three to five times a week, for example, by taking up cycling, walking or dancing. Each session lasts ideally at least 30 minutes.







Choose aerobic activities that you enjoy doing so that you can easily build them into your daily routine and enjoy them too. These can be different types of exercise: cycling, walking, dancing, playing tennis, or swimming. Swimming should only be done after the wound has fully healed, consult your nephrologist first.

Always listen to your body. Do you feel you have exerted too much effort? Then slow down next time and try to build up gradually.







In addition to aerobic efforts, strength exercises are also important, which you should ideally do two to three times a week. Below are some simple exercises that can help you in the beginning.

## Leg exercises

### Lying down

-  • rotate your feet;
-  • pull your feet up towards you;
-  • bend you knee keeping your heel flat on the bed;
-  • push your knee into the mattress (place a towel under your knee);
-  • lift your leg and move it sideways and back again;
-  • bend your knees, lower your leg sideways and bring it back again.

### Sitting position

-  • lift you knees alternately;
-  • stretch your knee;
-  • straighten your leg and rotate;
-  • straighten your legs and cross and uncross;
-  • stand on your toes;
-  • stand on your heels.

## Standing up



- bend your knees → maintain this position for 10 seconds;
- lift your knee;
- lift your leg sideways;
- lift your leg backwards but keep your back straight;
- straighten your leg and rotate;
- stand on your toes;
- stand on your heels;
- step forwards and bend the forward leg.  
Step back;
- stand on one leg and bend your knee;
- step up and down one stair;
- sit down and get up again.

## Arm exercises

- use a weight (e.g. a small bottle of water, initially 0.5 l and then 1 l) and bend your arm;



- stretch and lift your arm;



- stretch and lift both arms sideways;

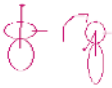


- stretch your arms and rotate;

- stretch your arms sideways, bend your elbows, bring your arms forwards, bend your elbows;



- use a small weight, lift your arm, bend your elbow moving the weight behind your shoulder and stretch your arm again;



- do push ups against the wall.

Start by repeating each exercise ten times and gradually increase it to fifteen times.



### Guidelines:

- ✓ Avoid heavy physical work immediately after the transplantation.
- ✓ During the initial six weeks you must not lift any heavy weights, e.g. a bucket full of water, otherwise you may interfere with the wound healing process.
- ✓ Neither should you do any abdominal exercises during the first eight weeks. Once the first eight weeks have passed we would recommend that you do abdominal exercises for about ten minutes a day in order to strengthen the lower abdominal muscles.
- ✓ You should be ready to take up sports again after a recuperation period of a few months. Certain sports are not recommended because of the risk of being kicked in the stomach (the site of the transplanted kidney) including, for example, boxing, karate, rugby, basketball and horse riding. Playing football is not recommended either, unless your nephrologist says it's ok. Always discuss your choice of sport with him/her.

### **Top of the movement pyramid: avoid sitting still for long periods of time**

The top of the movement pyramid aims to reduce sedentary behaviour or sitting still for long periods of time. This includes all activities that involve sitting or lying down and using little energy consuming. Examples include watching TV, sitting at your desk and lying on your sofa. Sleeping is not included.

Sedentary behaviour is detrimental to your health. You should therefore break long periods of sitting by standing up regularly or going for a walk, doing this every half hour if possible.



## LONG TERM EXERCISE: WHAT TO DO WHEN THE ROUTINE GETS BORING?

As you recover more and get back to your daily routine up, it can be difficult to find time to exercise.

It is important that you plan your exercise in advance and that exercise becomes part of your daily routine: think ahead and plan. Make deals with yourself as well as with others. This makes it easier for many people to effectively sit less and move more. In addition, variation is the key to a successful exercise programme. It is important to find things you enjoy doing and incorporate enough variety.

### Tips on building your exercise plan

- ✓ **What** am I going to do? (e.g. go for a walk)
- ✓ **Where** am I going to do my activity? (e.g. in your residential area)
- ✓ **When** will I do my activity and for how long?
- ✓ **With whom** will I do the activity or do it alone (e.g. with my family)?
  - Exercising together is motivating and more enjoyable, especially as a family. Encourage your partner, children and even pet and set a good example.
- ✓ Think in advance about **possible difficulties** and also solutions to these.

# FOLLOW-UP AND ROUTINE KIDNEY BIOPSIES

## FOLLOW-UP

Regular check-ups, carried out during consultations, are an absolute necessity after a successful kidney transplant. Frequent check-ups, approximately three every two weeks, are necessary during the first three months, depending upon your recovery rate. Once your kidney function allows it and the concentration of medication in your blood is satisfactory, the number of consultations can be reduced. After a couple of months you will be referred for further check-ups to your original nephrology centre. Physicians use a shared computer dossier to ensure that this follow-up process runs as smoothly as possible. This way the transplant centre keeps up to date at all times with your recovery process and problems that may occur.

If problems occur after having been referred back to your original nephrologist, contact him/her initially. Your physician will then decide whether or not to refer you to UZ Leuven for further investigation and/or treatment. Always bring your medication box with you if you have to be admitted to hospital. In the event of practical questions please call the transplant unit.

## WHAT SHOULD YOU DO THE DAY BEFORE ATTENDING A CONSULTATION?

### 24 hr urine collection

We ask you to keep a record of your urine flow for 24 hours the day before the consultation and bring one tube of urine sample. On it, we would like to see your name and the amount of the total 24-hour urine collection noted.

To collect urine, proceed as follows:



- ✓ On the day before the consultation urinate in the toilet when you get up in the morning.
- ✓ From then on, i.e. for the rest of the day and all of the following night, collect all urine in the container.
- ✓ Also add urine collected the following morning. You will now have a complete 24 hr urine sample collection.
- ✓ Close the container lid securely.
- ✓ Measure the total urine quantity, in the urine container (which shows the necessary gradations). Make a note if you have accidentally spilled urine or urinated in the toilet.

- ✓ Check that the urine container is properly sealed and tilt it a few times to mix it.
- ✓ To take a sample of the collected urine proceed as follows.
- ✓ Remove the white label from the lid.
- ✓ Carefully remove the tube from the container when it is full.
- ✓ Push the tube into the insertion opening (insert rubber stopper into the insertion opening).
- ✓ Note on the tube your name, the amount of urine and/or any any urine lost. Bring this sample with you to the consultation. Pour the remaining urine down the toilet. After use, rinse the canister out with tap water and let it dry in an inverted open position.



Ask for additional urine tubes or containers at the consultation.

Do you have further questions on this subject? Do not hesitate to ask a nurse for information.

## Nutrition

It is advisable not to eat casseroled meat from about two days before the consultation, as this can affect blood analysis results.

## Medication

Check your medication stock at home and record all your questions. Ask the physician for the necessary prescriptions during the consultation. You can also contact a transplant nurse for additional information during a consultation visit. The same applies to the nutritionist and social worker.

Do not take Prograf<sup>®</sup>, Advagraf<sup>®</sup>, Sandimmun Neoral<sup>®</sup>, Imuran<sup>®</sup> and/or Cellcept<sup>®</sup> the morning of a consultation. Bring your morning doses with you to the consultation and take them after the necessary blood samples have been taken. It is ok to have breakfast in the morning.

## HOW DOES THE CONSULTATION PROCESS WORK?

The consultation takes place on Monday and Wednesday mornings (sometimes on Friday mornings) between 8 and 11 am. You must register in advance at the reception desk via the registration kiosk or via the mynexuzhealth app. Once your registration is complete, you will receive a QR code that you will need to sign in at the orange gate, level 1, waiting rooms L and M. We ask you to be present between 8 and 9 a.m. to have the necessary blood and urine samples taken and dissected. Through the screens in the waiting rooms, you will be called to go to the examination room for blood collection and a second time to go to the doctor's consultation.

On Friday, only blood will be drawn and you cannot be seen by a doctor. Only after the blood draw will you be allowed to take your daily dose of immunosuppressants as prescribed (Prograf<sup>®</sup>, Advagraf<sup>®</sup>, Neoral Sandimmun<sup>®</sup> and Certican<sup>®</sup>). Are you unable to come to your appointment? If so, please report this as soon as possible by calling 016 34 45 93.

When you are discharged, you will be told clearly when you must come for your first check-up appointment. Afterwards, you will ask for a new appointment for each subsequent consultation. Ask for a new urine tube to take a urine sample.

Bring your transplant diary to the consultation. This will give the doctor an overview of your parameters over the past few days (blood pressure, temperature, urine flow rate, weight). You can also go over your medication with the doctor; you will be given a medication list to check while you wait. Do not hesitate to ask and discuss other questions too.



Sometimes the nurse will call you at home after the consultation to adjust your medication schedule according to your blood results. It is therefore important that your telephone details are always correct. Communicate any changes immediately. Make sure there is paper and stationery next to the phone. To change an appointment, contact us on tel 016 34 45 93.

In the event of a consultation being brought forward it is advisable to take your medication box to ensure that you have it with you if you unexpectedly need to be admitted to hospital again.

## **ROUTINE KIDNEY BIOPSIES FOLLOWING THE TRANSPLANT**

Once you are discharged from hospital your new kidney will need to be monitored for the rest of your life. Consultations with your nephrologist will regularly involve a blood analysis, urine analysis and physical examination. If necessary other techniques such as ultrasound and/or other radiological scans will be carried out.

Major successes have been booked in recent years in the development of new medication to prevent acute rejection in the first year after a transplant. Nevertheless, the long term survival of a new kidney has not changed in the past twenty years, meaning that on average a transplanted kidney doesn't function much longer than it used to. The main reasons for this include the toxic effect of medication on the kidney in the long term, narrowing of the small

blood vessels in the kidney, damage to the kidney filters (glomeruli), viral kidney infections, a return of the original kidney disease, raised blood pressure.

These different types of damage may be affecting your transplanted kidney for years before becoming apparent in blood and urine analyses (increase in creatinine in the blood, protein in urine). In some cases precious years have elapsed during which irreversible damage has been inflicted on the transplanted kidney undetected.

Research has shown that this damage can be identified early if control biopsies are carried out at regular intervals after the transplant. These biopsies will be repeated three months, one and two years after the transplant. In many cases the biopsy results will facilitate early intervention, for example, with changes in the dose and/or nature of the medication, so that the transplanted kidney can continue to function longer with timely and appropriate therapy.

During a biopsy a fine needle is inserted under local anaesthetic to remove a tiny piece of tissue from the kidney, which is examined under a microscope. This procedure can result in bleeding because the kidney is subject to a high blood flow. It is important, however, to put this risk into context. There is only a 0.05% risk of serious bleeding necessitating an intervention or blood transfusion. Only in one of a total of 2127 biopsies was the kidney lost because of bleeding that could not be stemmed in time. Other complications reported following a kidney biopsy include pain, blood in the urine, arteriovenous fistula, peritonitis and hematoma around the kidney. However, these rare complications do not outweigh the advantage of tracing and correcting damage to the transplanted kidney at an early stage.

To prevent or detect rare complications, you must lie flat in bed with a sandbag on your abdomen (at the puncture site) for four hours after the biopsy. Afterwards, we perform an ultrasound to check. If the result is good, you may get out of bed again and walk around. We strongly advise against lifting objects or strenuous physical activity for the week after the biopsy. Any blood thinners you are taking will be restarted after the biopsy, if your attending nephrologist also recommends positively.

## STUDIES

Whilst you are admitted to hospital the nephrologists may ask you to participate in a kidney transplant related study focused on ongoing scientific development. Participation is entirely without obligation, voluntary and non-binding.

If you decide to participate in a study you may have to undergo additional examinations. Where possible we try to plan these examinations to coincide with times when you are already attending the hospital.

For further questions relating to these studies please contact our study nursing staff on 016 34 56 75.

## PSYCHOLOGICAL/SOCIAL SUPPORT

When the transplant is several days behind you, you will gradually come to realise that you have entered a new stage in your life. You are no longer anxiously awaiting a new kidney, are dealing with new impressions and will be facing many questions, including the following:

- Who donated my kidney?
- How do I start to rebuild my life?
- What happens if this kidney is rejected?
- How will those around me react to this new situation?
- Will I miss contact with my fellow dialysis patients?
- Will I be able to return to work?
- How do I fill the spare time that has become available now that I no longer require dialysis?

Being discharged from hospital can also lead to conflicting emotions such as happiness, anxiety, insecurity about the future, etc.

If these and other questions are on your mind, please do not hesitate to consult your physicians, nursing staff, social worker, psychologist and other team members. They are ready to guide you through this new stage in your life in the most effective way.

## SOCIAL-FINANCIAL ASPECTS

### DRIVING

For the first four to six weeks after your transplant, you will have a driving ban. That period starts from the day on which the transplant is performed. Your nephrologist will decide when you are fit to drive again. One month after the transplant you can ask your physician for a driving ability certificate.

You will have to take this certificate to your local council offices to apply for an updated driving licence. The physician and social worker will provide further information on this subject.

Also inform your car insurance broker that you recently underwent major surgery and submit a copy of the driving ability certificate. Your insurance premium will not increase.

Remember that you may suffer from hazy vision as a result of taking high doses of Medrol®. Tell your physician if this is the case.

### TRANSPORT FOR CHECK-UP CONSULTATIONS

It is advisable to contact your health insurance fund about transport for check-up consultations. During your dialysis period the health insurance fund was legally obliged to provide a transport subsidy. Your health insurance fund is not obliged to continue to refund transport costs for consultations after the transplant. If your

health insurance fund does provide refunds you can ask the physician monitoring you during check-up consultations to complete the form stating the consultation dates.

If you have hospital treatment insurance cover it is advisable to ask your provider whether it covers transport for check-up consultations. Usually insurance providers do not cover transport costs.

In the event of problems you can always contact the transplant unit social worker.

## WORK

Providing your nephrologist, health insurance medical advisor and employer agree, you will be able to start work again after a recuperation period of approximately three months. Patients frequently return to work part-time to start with and then go back to full-time after a number of months.

Also discuss with your nephrologist whether special protective equipment will be required when you start work again, e.g. for painters or people working with hazardous materials.

Unfortunately, not everyone is fit enough to return to work. This may be due to the actual working conditions or to the extent to which you have recuperated after the transplant. Sometimes retraining can offer a solution.

The social worker may be able to help you look for new employment and/or put you in touch with various organisations such as VDAB Werkwinkel (a group of organisations that help people find suitable employment), expert career planning and guidance, etc.

Students should consult their physician about when to return to their studies.

## FINANCIAL ASPECTS

### Admission

Several weeks after your discharge from hospital you will be sent an invoice for your stay in hospital, with the full amount you will have to pay yourself.

If you have taken out hospital treatment insurance these costs may be refunded in part or in full by your insurer.

### Consultations

You will be invoiced for each consultation after the transplant. Usually the invoices for two or three consultations will be combined. These invoices must be paid in full. They will include a green form that will entitle you to a partial repayment of the consultation cost from your health insurance fund. You will have to pay your own share in full.

If you have hospital treatment insurance cover it is advisable to ask your provider whether it covers aftercare (check-up consultations and home medication).

## Medication

When you are discharged from hospital you will be issued with the necessary prescriptions for your medication to take to your pharmacy. Always monitor how much medication you have at home and ask your physician for new prescriptions at the next consultation. Some drugs require approval from the medical advisor of your health insurance fund. The physician will give you a prescription you can take to your health insurance fund for repayment approval. Certain medicines are refunded in full by your health insurance fund, or you pay less.

## SEXUALITY, FERTILITY FOLLOWING A TRANSPLANT AND CONTRACEPTION

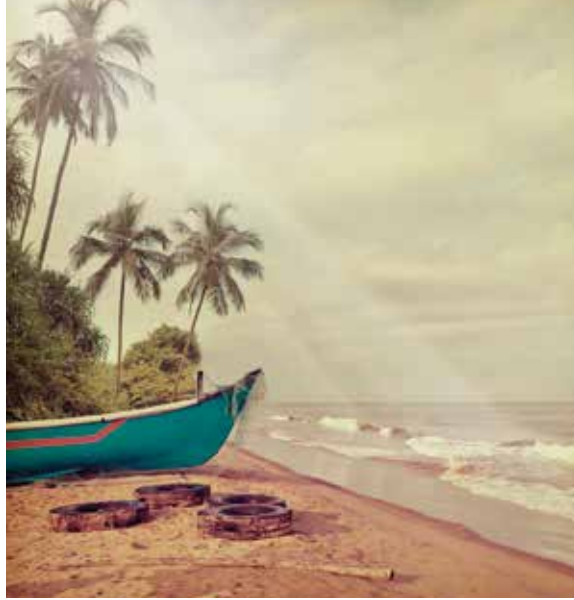
Sexual activity is fine if you and your partner feel that way inclined.

Female fertility will frequently go back to normal following a transplant. The menstrual cycle will resume and rebalance itself during the course of the first year after the transplant. Pregnancy is not advisable for female patients during the first two years after a transplant, not least because of the high doses of medication still required. It is best, therefore, to discuss the use of contraceptives with the physician in charge of your treatment before being discharged from hospital. Always discuss your desire for children with your nephrologist [first](#).



## TRAVEL

It is advisable not to travel during the first few months after the transplant because your body still needs to adapt to the new situation. There is still a significant risk of rejection and you still have to come for check-ups at regular intervals. After this initial period it is usually safe to plan a trip abroad. Always take into account local hygiene conditions and discuss your destination with your nephrologist.



Always carry your medicines in your hand luggage. Also put some of your medicines in your travel case. This will prevent problems if your hand luggage or travel case gets lost. Bring the phone number of your transplant centre and the necessary prescriptions for your medication with substance name. Ask your kidney specialist for these prescriptions, as well as a certificate stating that you should keep your medication with you at all times. This is especially useful when travelling by plane. It is also interesting to know whether there is a major transplant centre near where you are staying where you can go in case of any problems. Ask your doctor about this too.

Arrange travel insurance. The social worker will be able to provide additional information on the above.

# VACCINATIONS

	Can be administered before the transplant	Can be administered after the transplant
Flu	Yes	Yes
Pneumococcus	Yes	Yes
Tetanus (diphtheria)	Yes	Yes
Hepatitis A	Yes	Yes
Hepatitis B	Yes	Yes
Polio (non live form)	Yes	Yes
COVID-19 (AstraZeneca, Pfizer, Johnson)	Yes	Yes
Measles	Yes	No
Mumps	Yes	No
Rubella	Yes	No
Whooping cough	Yes	No
Yellow fever	Yes	No

You should not be vaccinated with live vaccines (e.g. yellow fever, measles, rubella, chicken pox).

Flu and covid vaccines can be administered from two weeks after transplantation. A (booster) vaccine for tetanos (tetanus) can also be administered from two weeks after surgery, in case a sudden a high-risk wound develops.

All other non-live vaccines are rarely urgent, so administration is best waited until three months after transplantation.

Check blood titres	Annually	Repeated
/	yes	
/		Every five years
/		Every ten years
yes		
yes		
/		
yes		
yes		
yes		
yes		



## SUNBATHING

Skin cancer tends to affect transplant patients more frequently because the immune system is unable to repair sun damage. You should, therefore, avoid or limit direct exposure to the sun as much as possible. Wear appropriate clothing and a sun hat. A long sleeved shirt and lightweight long trousers instead of a skirt or shorts.

Also use sun protection cream (minimum factor 50). It should be applied liberally to the face and other exposed body parts several times a day. Remember you can use self tanning creams/lotions but they do not provide protection from the sun.

Sun beds are prohibited.

Consult your skin specialist annually for a check-up.



## CONCLUSION

If, after reading this brochure, you have further questions please do not hesitate to contact a healthcare professional at the unit to discuss your concerns.

Even after your discharge from hospital, you can discuss your questions with your doctor during the consultation. If necessary, an appointment can be made with a healthcare provider for a consultation.

In case of questions, you can always contact the nursing consultant kidney and pancreas transplantation during the day on 016 34 45 93. In case of urgent problems at the weekend or at night, you can reach the transplantation department on 016 34 66 20.

Transplantation gives you the chance for regained autonomy. Despite stopping dialysis, regaining a better physical condition, being able to go on outings and holidays again... however, you are still a patient. Stay aware of this and react to the limitations created by the whole event, but also enjoy it to the full. It is up to you to find a new balance in what you can and want to do, and to ask a caregiver or confidant for help in time.

As one of our patients beautifully said it, “I have been given a new life, a second chance, and yet everything remains different. The risk of complications and infections remains, follow-ups are lifelong, but as you get ready for the transplant: with the roses, take on the inevitable thorns too. Only then will the future remain balanced.”

We wish you a speedy recovery and comfortable stay at the hospital.

# PRACTICAL INFORMATION

## UZ Leuven campus Gasthuisberg

Herestraat 49  
3000 Leuven  
tel. 016 33 22 11  
[www.uzleuven.be](http://www.uzleuven.be)

### Abdominal transplant unit

- Nephrologists: Prof. Dr. Dirk Kuypers (Head of Department), Prof. Dr. Bert Bammens, Prof. Dr. Kathleen Claes, Prof. Dr. Pieter Evenepoel, Prof. Dr. Bjorn Meijers, Prof. Dr. Maarten Naesens, Prof. Dr. Katrien De Vusser, Prof. Dr. Amaryllis Van Craenenbroeck
- Surgeons: Prof. Dr. Jacques Pirenne (Head of Department), Prof. Dr. Diethard Monbaliu, Prof. Dr. Ina Jochmans, Dr. Mauricio Sainz Barriga
- Head nurse: Carine Breunig, tel. 016 34 03 27
- Deputy head nurses: Vincent Vandebossche, tel. 016 34 03 38 and Viona Luyts, tel. 016 34 49 95
- Hospitalisation unit: tel. 016 34 66 20 or 016 34 03 25

## **Nephrology secretariat (consultation appointments)**

- Joke Gorter, tel. 016 34 45 97

## **Paramedic team (during office hours)**

- Social worker: Mirte Leurs, tel. 016 34 21 02
- Dieticians: Veerle Ressler, tel. 016 34 14 60  
and Kim Mees, tel. 016 34 10 85
- Physiotherapist: Leen Schepers, tel. 016 34 05 85
- Transplant nursing consultant (pretransplant):  
Katleen De Bondt, tel. 016 34 13 80
- Transplant nursing consultant (post-transplant):  
Eva Vanhoutte, tel. 016 34 68 60
- Pastoral services: Tel. 016 34 86 20
- Psychologist: Tania Rogach, tel. 016 34 06 70
- Study nursing staff: Tel. 016 34 56 75

## DO YOU REQUIRE FURTHER INFORMATION ON KIDNEY TRANSPLANTS?

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

[www.transplant.be](http://www.transplant.be)

[www.nierstichting.nl](http://www.nierstichting.nl)

[www.overlevendoorgeven.be](http://www.overlevendoorgeven.be)





## STANDARD SCREENING TESTS AFTER TRANSPLANTATION

	Year 1:	Year 2:	Year 3:	Year 4:	Year 5:	Year 6:
	.....	.....	.....	.....	.....	.....
Annual consultation kidney transplant + blood sampling (campus Gasthuisberg)						
Dentist (2x/year)						
Dermatologist (1x/year)						
Ophthalmologist (1x/year)						
For females: gynaecologist (1x/year)						
For patients > 50 years: colonoscopy (1x/5 years)						
Vaccination: pneumococcus (1x/5 years)						
Vaccination: flu (1x/year)						



	Year 7:	Year 8:	Year 9:	Year 10:	Year 11:	Year 12:
	.....	.....	.....	.....	.....	.....
Annual consultation kidney transplant + blood sampling (campus Gasthuisberg)						
Dentist (2x/year)						
Dermatologist (1x/year)						
Ophthalmologist (1x/year)						
For females: gynaecologist (1x/year)						
For patients > 50 years: colonoscopy (1x/5 years)						
Vaccination: pneumococcus (1x/5 years)						
Vaccination: flu (1x/year)						



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#### Design and implementation

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