



Living with heart failure

Information for the patient and his/her family

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You found out from your doctor your heart is not functioning properly: you suffer from heart failure or cardiac insufficiency. Heart failure is a disorder that develops gradually and treatment with medication should be started on time. You can also actively help to get better by leading a healthy lifestyle. Your doctor and the nursing staff have probably already explained a lot to you. We collected all this information in this brochure for you to read in the comfort of your home. If you still have questions or something is unclear, please don't hesitate to talk to a doctor or nurse of our team. We will gladly help you.

General Internal medicine, cardiovascular diseases

WHAT IS HEART FAILURE?

The healthy heart is a powerful pump that pumps blood around the body. When it doesn't do this properly anymore, it is referred to as heart failure or cardiac insufficiency. The blood pump is underperforming and no longer meets the body's needs.

The consequences soon follow: the blood flow slows down and the heart pumps less blood around your body. The blood that flows back to the heart accumulates in the veins, increasing the pressure there and this causes fluid to accumulate (oedema) in the tissues. Result: swollen feet, ankles and legs and sometimes water in the abdomen. When fluid accumulates in the lungs as well, shortness of breath occurs during activity and sometimes even at rest.

Signals of heart failure:

- shortness of breath during activity
- tiredness during activity
- fluid retention in the lower limbs
- shortness of breath at night

Do you have any complaints that could point to heart failure?
A thorough examination of the heart is recommended:

- because the complaints may also have another cause.
- to confirm the existence of heart failure.
- to determine the cause of the heart failure as accurately as possible.

CAUSE

Heart failure occurs as a result of damage or prolonged overexertion of the heart.

Possible causes of damage or overexertion of the heart:

- constriction of the coronary arteries.
- high blood pressure.
- deterioration of the heart valves.
- cardiac arrhythmia.
- deterioration of the heart muscle (caused by infection, alcohol, toxic substances).

If your heart is underperforming, your body tries to make up for this by giving the heart extra stimulation and retaining more fluid.

This solves the problem, because your heart is performing again, but only in the short term. Things will only get worse for your body: the fluid retention and extra stimulation damage the heart even more in the long term. This creates a downward spiral and the heart slowly uses up its reserves.

Your heart is an organ with considerable reserves. And precisely because of this it may already be irreparably damaged, while there are no obvious complaints yet. The cardiac insufficiency only becomes clear after the proverbial straw that breaks the camel's back. For example, some people have little or no complaints for a long time after a heart attack, but 'suddenly' get into trouble because of a stupid cold.

Why? In the years following the heart attack, the heart gradually lost its pump reserves. And now that your body is no longer in peak condition, it suddenly manifests itself.

In other words, heart failure is a disorder that develops gradually. That is why it is so important you start taking medication on time that protects the heart as much as possible. You may be asked to take medication even before you've experienced any limitations of your weakened heart. Your doctors will try to stabilise the heart failure and minimise the risk of complications.

Heart failure is divided into four levels of severity, according to the NYHA-class (New York Heart Association):

✓ **Class I: = no limitation**

Ordinary physical activity does not cause shortness of breath or fatigue.

✓ **Class II: = slight limitation.**

Ordinary physical activity causes shortness of breath and fatigue.

✓ **Class III: = marked limitation.**

Less than ordinary activity may cause symptoms; no complaints at rest.

✓ **Class IV = severe limitation.**

Any activity causes symptoms; complaints may also occur at rest.

DIAGNOSIS

EXAMINATION BY THE DOCTOR

The doctor has a suspicion of heart failure due to your history and your current symptoms. This is why the doctor performs a physical examination:

- He feels your ankles to check if they are swollen.
- He feels your jugular veins to see if they are swollen.
- He feels your abdomen to see whether your liver is swollen.
- He listens to your lungs to check whether fluid has accumulated.
- He listens to your heart, especially the closing of the heart valves and the murmur that may occur when a heart valve is not working perfectly.
- He feels your pulse and carotid arteries to determine the heart rate speed and rhythm.
- He checks your blood pressure with a blood pressure monitor.
- He asks you to monitor your weight by regularly weighing yourself.

OTHER EXAMINATIONS

Blood test

In case of (suspected) heart failure, a blood test is almost always performed. This may determine the cause of the heart failure, for example, a thyroid disorder or kidney disease. The blood test can also show whether other organs have already been damaged by the heart failure.

The treatment of heart failure involves many blood tests. Regular checks of your kidney function and sodium (salt) levels will tell your doctor how well your body is tolerating the medication and if the dose is correct.

Echocardiography

Images of the heart are made with ultrasound waves. This allows for a very precise examination: its size, wall thickness and valves. But also its pumping power, the speed and direction of the blood flow, the pressure in the heart and pulmonary arteries. This examination is completely painless and harmless. You just need to lie motionless.

Sometimes an echocardiography is made from the oesophagus (transesophageal echocardiography). This provides a better view, because the lung tissue does not disturb the image.

Electrocardiogram (ECG or EKG)

A number of electrodes are put on your arms, legs and chest. They record the electrical activity of the heart. The examination is painless.

Do you have cardiac arrhythmia?

For this, the heart must be monitored for 24 hours. This is done with the '24 hour holter registration' on a portable tape recorder.

How do the heart and blood circulation react during activity?

Fitness tests such as walking on a treadmill or cycling on an exercise bike can help answer this question. During and after the test, the ECG and blood pressure are measured regularly. Sometimes the amount of O₂ that is absorbed from the air is also measured.

What is your heart's pumping power?

The ejection fraction (EF) is a number that expresses your heart's pumping power. It can be measured in various ways, including echocardiography and scanner examination. Under normal circumstances, the EF is about 60 percent. It is lower in case of heart failure, for example after a major heart attack. If it drops below 40 percent, it is referred to as 'significant' cardiac insufficiency.

TREATMENT



Your medication, on time!

A number of health problems increase the risk of developing heart failure: high blood pressure, diabetes, constriction of the coronary arteries, a heart attack, a problem with the heart valves, cardiac arrhythmia, being overweight and fat content in the blood that is too high.

These same problems also increase the risk of complications. In addition to effective treatment with medication, a healthy lifestyle is recommended for everyone.

Correctly taking the prescribed medication, an optimal body weight, not smoking, limiting the amount of alcohol, a healthy diet and physical exercise are necessary.

The goals of the treatment of heart failure:

- lower the risk of complications.
- make the impact on daily life as small as possible.
- stabilise and possibly improve your heart's pumping action.
- help the heart to work less hard.
- reduce the symptoms (fatigue, shortness of breath, oedemas).
- combat a deterioration of the illness.

MEDICATION

Medication supports the weakened heart and lightens its work. This improves the symptoms of fluid retention, fatigue and shortness of breath and prolongs your life.

- Always take your medication at the same time of day and make sure you take the correct dose.
- Never stop taking one of the prescribed medicines without consulting your doctor. This may aggravate your condition.
- Use a one week medication box (available from your pharmacy).
- If you are admitted to hospital please bring the medication in the original packaging.

The treatment of heart failure almost always requires you to take several types of medication simultaneously. The basic treatment consists of four types of medication: diuretics, ACE inhibitors (sometimes replaced by angiotensin receptor blockers), beta blockers and aldosterone antagonists.

Here below is some essential information about these four types of medication:

DIURETICS

- **Brands:** Lasix[®], Burinex[®], Torrem[®].
- **Effect:** reduce the excess fluid in the body and protect the body from fluid retention.
- **Duration:** a couple of hours.
- **Side effects:** potassium deficiency, dry mouth, rash, gout, dizziness and muscle cramps (mostly in the legs).
- **Attention:** in case of muscle cramps, extra magnesium supplements may be taken (these are available without prescription from your pharmacist).

ACE INHIBITORS (HELP TO RELAX AND PROTECT THE HEART)

- **Brands:** Capoten[®], Renitec[®], Zestril[®], Coversyl[®], Tritace[®], Accupril[®].
- **Effect:** relax the heart by widening the blood vessels; reduce the expansion of the heart so that it can contract more efficiently.
- **Side effects:** tickling cough, dizziness (caused by low blood pressure) or rash.
- **Attention:** the dose is gradually increased to allow the body to adjust to the lowered blood pressure.

ANGIOTENSINE-II RECEPTOR BLOCKERS

- **Brands:** Cozaar[®], Loortan[®], Diovan[®].
- **Effect:** widen blood vessels in the same way as ACE inhibitors.
- **Side effects:** dizziness, rash.

BETA BLOCKERS

- **Brands:** Seloken[®], Selozok[®], Kredex[®], Emconcor[®], Isoten[®], Nobiten[®].
- **Effect:** slow down the heart rate so that the heart pumps more efficiently; better functioning of the weakened heart in the longer term.
- **Side effects:** particularly at the start of the treatment. Low blood pressure, dizziness, restless sleep, slight drowsiness, cold hands and feet, tiredness, erectile problems, vaginal dryness.
- **Attention:** the dose is gradually increased to allow the body to adjust to the lowered blood pressure.

ANGIOTENSINE RECEPTOR NEPRILYSIN INHIBITOR (ARNI)

- **Brand:** Entresto[®]
- **Substance name:** sacubitril and valsartan
- **Effect:** acts as a supplement when ACE inhibitors and Angiotensine-II receptor blockers do not have the desired effect.
- **Side effects:** dizziness, low blood pressure.

ALDOSTERONE-ANTAGONISTS

- **Brands:** Aldactone[®], Spironolactone[®], Eplerenone[®].
- **Effect:** diuretic effect and slow down the evolution of heart failure.
- **Side effects:** nausea, abdominal cramps, diarrhoea and headache.
- **Points of attention:** Aldactone[®] may result in painful breasts in women and swollen nipples in men (not-painful and non-disturbing swelling is acceptable).

SODIUM-GLUCOSE TRANSPORT PROTEIN 2 INHIBITORS (SGLT2)

- **Brands:** Forxiga[®], Jardiance[®].
- **Effect:** reduce the risk of heart failure and hospital admissions.
- **Side effects:** urinary tract infection or fungal infection of the genitals, dehydration.

The following medication supplements the basic treatment:

VASODILATORS

- **Brands:** Cedocard[®], Nitro-pleister[®], Hydralazine[®].
- **Effect:** widen the coronary arteries in case of complaints of angina (tightening of the chest).
- **Side effects in case of overdose:** dizziness, headache, racing pulse, blushing, nausea, restlessness, low blood pressure.

ANTIARRHYTHMICS

- **Brands:** Cordarone[®].
- **Effect:** influence the impulse conduction in the heart. Their use is limited as much as possible because of the risk of side effects.
- **Side effects:** Cordarone[®]: hypersensitivity to sunshine or bluish-purple discoloration of face, neck and arms.
- **Points of attention:** sun cream with high protection factor necessary, even when there is little sun; annual check-up at the optician, thyroid tests twice a year via a blood test at the GP; or your cardiologist.

ANTICOAGULANTS (BLOOD THINNERS)

- **Brands:** Marcoumar[®], Sintrom[®], Pradaxa[®], Xarelto[®], Lixiana[®], Eliquis[®].
- **Effect:** prevent the formation of blood clots.
- **Side effects:** inexplicable bruises or unusual bleeding. If this happens, contact your doctor or heart failure nurse.
- **Point of attention:** regular blood tests by the GP.
- In case of an operative procedure or intervention (dentistry, coronarography), the GP or cardiologist (Clexane[®], Fraxiparine[®]) will usually switch to Low Molecular Weight Heparins.

BLOOD PLATELETS-AGGREGATION INHIBITORS

- **Brands:** Aspirine Junior[®], Asaflo[®], Cardio Aspirine[®], Plavix[®], Triclid[®], Brilique[®], Efiend[®].
- **Effect:** prevent the formation of blood clots by slowing down platelet adhesion. Used chiefly after placing a stent in the blood vessels of the heart.
- **Side effects:** abdominal pain, heartburn, nausea.
- In case of an operative procedure you may be asked to stop taking this medication ten days beforehand.

CHOLESTEROL-LOWERING MEDICINES

- **Brands:** Zocor[®], Lipitor[®], Pravastatin[®], Crestor[®]
- **Effect:** reduce the fat content of the blood and protect the blood vessel wall; recommended in case of narrowing of the arteries.
- **Side effects:** muscle cramps, diarrhoea, nausea.
- **Attention:** brief muscle stiffness in the morning is acceptable. Preferably to be taken in the evening.

PROHIBITED MEDICATION

Never use the following medication without consulting your doctor due to the risk of dysregulation heart failure and/or kidney function:

- **Non-steroidal anti-inflammatory medication:** pain medication such as Brufen[®], Voltaren[®], Nurofen[®], Apranax[®], Brexine[®], Feldene[®].

PERMITTED PAIN MEDICATION: PARACETAMOL

Perdolan[®], Dafalgan[®] up to four times a day. If the pain doesn't get better, contact your doctor or heart failure nurse. Note: do not use effervescent tablets. They contain more salt.

HEALTHY LIFESTYLE



Eat healthy!

HEALTHY DIET

Avoid meals with many saturated fatty acids (animal fats). A diet rich in saturated fats can encourage arteriosclerosis, which increases the cholesterol level. However, unsaturated fats lower the cholesterol level. All types of oil, diet margarine and diet forms of cooking fats are rich in them.

If you are over the age of 75 it's important you take in sufficient calories. A diet low in saturated fats is less important in this case.

You can achieve a balanced diet by using the active food triangle. For more information, please contact the dietician.

OVERWEIGHT

If you are overweight, your heart has to work much harder. This increases

FLUIDS: 1.5 LITRE A DAY

- Heart failure deregulates the body's water balance. Fluid retention results in shortness of breath and swollen feet. It is important to limit salt intake and fluids.
- Fluid restriction is recommended for every patient with severe heart failure requiring diuretics.

The guideline for fluid intake is: 1.5 litres (1,500 ml) of fluids a day.



How do you 'count' the fluids you drink?

It is quite difficult to measure this. You measure how much is in a glass or a cup, and over the course of the day you count the number of glasses or cups you drink. You must also include soup in this 1.5 litres. Fruit (two pieces per day) and yogurt do not have to be included.

Still thirsty?

Spread your fluid intake over the day and leave some for the evening. Use small cups and glasses. Drink hot drinks: they will last you longer than cold or lukewarm drinks. Take your medication with your meal and not separately with a glass of water. Spreads (jam, syrup, cottage cheese) make sandwiches less dry than dry spreads (for example sliced cheese). Are you thirsty? Suck an ice cube or an acidic sweet. Lemon juice in tea or mineral water also quenches your thirst.

In a few exceptional circumstances you can have more fluids and in joint consultation with your GP even suspend your diuretic medication temporarily:

- during hot summer days, when you perspire more;
- if you have diarrhoea;
- if you have a fever.

WEIGH YOURSELF EVERY DAY

You must weigh yourself every morning to detect fluid retention. A weight gain of 2 kg in three days is an alarm signal and means you need to contact your doctor.

Write down your weight every day in your diary and bring this to every admission or consultation.

SALT RESTRICTION: AIM FOR ≤ 6 GRAMMES A DAY

The sodium in kitchen salt retains fluid and causes fluid retention in your body. The more severe the heart failure, the less salt and fluid you're allowed. Natural, unsalted food gives your body all the salt it needs. Adding salt is not only unnecessary, but also harmful. Salt restriction is very important if you need to take diuretics or after an admission with acute heart failure.



Don't pass the salt!

Tips:

- ✓ Don't add salt when preparing meals.
- ✓ Don't eat more than two slices of cheese or prepared meat a day or eat spreads you made yourself.
- ✓ Avoid processed products that contain added salt. For example ready-made (frozen) products, soup or sauce from a packet or tin, tinned vegetables or in jars, tomato juice, herb mixtures for meat, stock and snacks (!).

For detailed product info, please consult the dietician.

Did you know?

- Shellfish, such as shrimp and mussels, naturally contain a lot of salt.
- One salted herring equates to two grammes of salt. Pickled herring also contains salt.
- Even sweet products such as ice cream, chocolate and biscuits contain salt.
- Liquorice (both sweet and salted) contains another component that retains fluids. In other words, salted liquorice is twice as bad for you.
- Sea salt, aromatic salt, herbal salt, celery salt and onion salt contain just as much sodium as common kitchen salt.
- Mineral salt (for example Low salt) may contain less sodium than kitchen salt, but it is still too much.
- Salt substitutes contain a lot of potassium and are therefore not suitable either.

How can you flavour your food then? Try:

- garlic, onion, tomato.
- fresh, dried or frozen (garden) herbs (chives, cumin, coriander, thyme).
- spices such as pepper, paprika, curry and nutmeg.

Make sure you have a varied diet to ensure you get the most important vitamins, proteins and minerals. Talk to your doctor and dietician for more information.

SMOKING



Only chimneys smoke!

Smoking is the biggest risk factor for another heart attack. Tobacco smoke affects the vascular wall, causing constrictions in the blood vessels. It displaces the oxygen in the blood, which means the heart and the rest of the body do not get enough oxygen. But there is also good news: a year after you stopped smoking, the chances of a heart attack have halved!

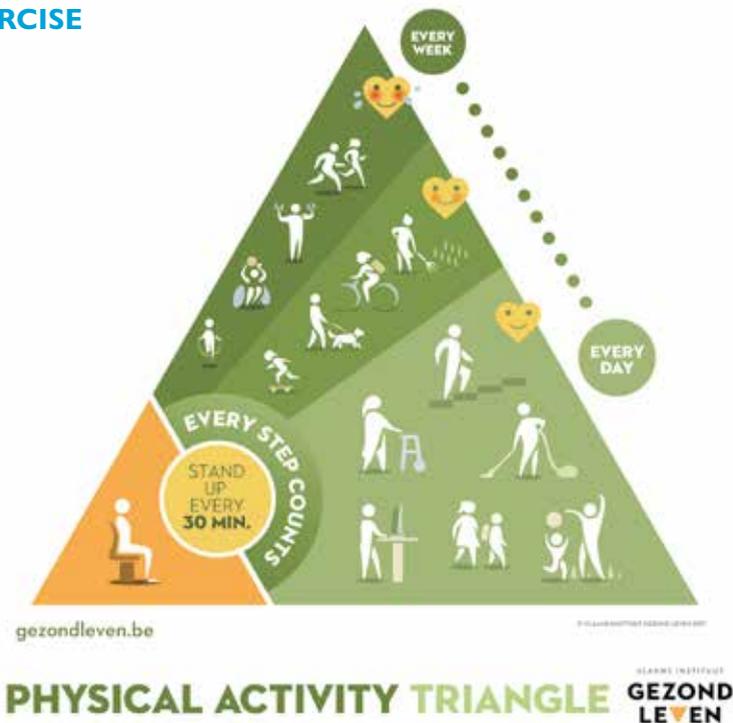
You can only quit smoking successfully when you are convinced you have to stop. All kinds of supporting means exist such as the smoke stop consultation, emergency stop programmes offered by the employer, the local medical insurance or via the GP with nicotine substitutes and medication.

ALCOHOL CONSUMPTION

Alcohol can lower the heart's contraction. In other words, you must limit your alcohol intake. One glass a day is fine, provided you don't have a history of alcohol abuse.

You must stop drinking alcohol all together if the heart failure was caused by alcohol. Alcohol also needs to be included in the fluid and calorie intake.

EXERCISE



**No lifts, but stairs,
no motorbikes, but bicycles!**

Physical exercise (for example walking, cycling, swimming, etc.) is good for you. It is important you work on and maintain a good basic condition. 30 minutes of moderate physical activity a day are recommended. You could also consider physiotherapy aimed at improving your condition, strength and stamina. Or you could join a sports club for heart patients where physical exercise is provided under expert guidance.

Some activities are not recommended:

- competitive sports;
- contact sports such as combat sports;
- weight-lifting (this includes lifting heavy bags for example);
- activities under extreme temperatures.

SEXUAL ACTIVITY

Sexual activity can be compared to normal activity and is therefore not dangerous. For most people the energy needed for this activity can be compared to going up two flights of stairs. Are you short of breath, in pain or are you having palpitations? It is advisable to stop and report it to your doctor or heart failure nurse.

ALARM SIGNALS FOR HIGHER RISK OF HEART FAILURE

Are you suffering one of the complaints in the list below, or has it got worse? Please contact your GP.

The following symptoms may indicate the condition of your heart is evolving negatively. If you contact us on time, together we can prevent any possible worsening of your cardiac insufficiency.

- You briefly lost consciousness.
- You wake up short of breath at night.
- You need to sit up at night in bed.
- You weigh 2 kg more in 3 days.
- Your legs, ankles or abdomen are swollen.
- You are short of breath more often.
- You get tired quicker.
- You can't get up the stairs anymore.
- You have been having palpitations.
- You have an annoying cough.

VACCINATIONS

A heart patient is more sensitive to infections.

In other words, make sure you have had the necessary seasonal vaccinations such as the flu vaccine (annual) and the pneumococcal vaccine (five-yearly).

DRIVING, HOLIDAYS AND TRAVEL

DRIVING

Ask your doctor whether it is safe to drive a car. Remember that public transport is a safe alternative.

HOLIDAYS AND TRAVEL

Ask your doctor or heart failure nurse about the possibilities for travel, also by plane.

If you are travelling, ask your GP or heart failure doctor for a document with useful information about your illness. In case of problems during your holiday, you can give this document to the local doctor.

Avoid holidays in seasons with extreme hot or cold temperatures.

HOW DO YOU LIVE WITH A CHRONIC ILLNESS?

PATIENT

Dealing with feelings

Heart failure not only causes physical complaints. You may also experience feelings and emotions, such as fear, anger, sadness or depression. Many people feel ashamed of this but they shouldn't. These feelings often occur in people with a severe medical disorder, such as heart failure. First try to determine what your feelings are and not to condemn.

If you find it hard to deal with your feelings, it's important you seek help and support from someone close to you. Sometimes talking about your worries or fears makes this feeling more manageable and less overwhelming.

Your loved ones may also experience these reactions, such as fear and concern for your health and safety. If you get closer to them by talking or spending more time together, it can make everyone feel better.

If your depression or fear is serious or does not get any better, talk to your doctor or nurse. It may also be useful to talk to the psychologist of the department. Medication also exists which safely reduces fear and depression in patients with heart failure.

Dealing with limitations

Usually, heart failure cannot be cured and implies many limitations. However, there are still many practical things you can do to enjoy life. Find out what you can do still. With the right care and support you can do most things, as long as you are aware of your limitations.

The people close to you are often the most important in terms of supporting you to live as actively as possible with heart failure. Allowing this help can have a positive effect on your health. Try not to exclude them and make it clear you appreciate their concern. At the same time, try to indicate what you like and tell your loved ones if you are in need of less help or support.

Dealing with therapy rules

On the one hand, your future health depends on how well your heart continues to function and how well it responds to treatment. On the other hand, your future also depends on yourself. How well you cooperate with your doctor or nurse to keep your complaints under control and how well you follow your treatment plan can make a huge difference for the result. If you have an active role in managing your condition, good support can help you control and stabilise your heart failure.

If you learn to change your lifestyle in a positive way in terms of diet, activity and not smoking, your complaints will improve, you slow down the progression of your heart failure and improve the quality of your daily routine. Therefore, build in a certain regularity in your life. It helps during your therapy and to follow all the medication rules.

CARER

Dealing with the role of carer and with your own feelings

In the same way that you provide valuable help and support to your partner or relative to help him or her live with heart failure, you may in turn need support in your role as carer. Don't hide away or give up on everything. You can't do everything on your own. Talk to your own doctor, or your partner or relative's doctor on time to find out what help is available through local services.

You may also have certain feelings about your partner or relative's illness. Don't be afraid to tell the patient how you feel. Talking can be the simplest and most effective support you need. If you feel you can't talk about certain things with your partner or relative, talk to another relative, a good friend, nurse or psychologist.

Dealing with the patient's feelings

If you notice your partner or relative is depressed or anxious, you can do several things to help. A listening ear is often the most important.

The following might help:

- Talk to the patient about his/her feelings and give him/her time and space to open up.
- Involve family and friends in the patient's care if appropriate so that your partner or relative has contact with others.
- Help the patient understand the treatment plan and support him/her to stick to it.
- Help the patient be more active and get exercise. Regular physical activity (even a few minutes a day) is an effective treatment for depression and fear. Ask your local cardiac rehabilitation centre whether they have any low intensity training programmes.
- Ask a doctor or nurse for help. Depression can be a side effect of some heart failure medication. If your partner's or relative's depression does not improve, or gets worse, the doctor or nurse can help by referring him/her to a psychologist.

INTERESTING WEBSITES

There is an interesting European website (English and French), specifically for patients with heart failure:

www.heartfailurematters.org.

Other interesting websites are:

www.hart-falen.be and www.insuffisance-cardiaque.be.

USEFUL TELEPHONE NUMBERS

In case of problems, contact your GP. If necessary, he/she will refer you to the hospital.

YOUR GP

Name:

Tel.:

YOUR CARDIOLOGIST

Name:

SECRETARIAT HEART FAILURE HTX

For making or moving appointments:

Address: UZ Leuven campus Gasthuisberg,
Herestraat 49, 3000 Leuven

Tel.: 016 34 42 63 or 016 34 42 68
(Monday to Friday from 8.00 to 16.00)

NURSING CONSULTANTS HEART FAILURE

Céline Spoormans

Jan Kennes

Tel.: via 016 34 42 63 or 016 34 42 68
(secretariat heart failure HTX)

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