### **Patient Information**

A Guide for Dialysis Patients





## **Patient Information**



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## 1. Kidney function and chronic kidney disease

### **1.1 KIDNEY FUNCTION**

The kidneys are a pair of bean-shaped organs located at the rear of the abdomen close to the abdominal wall. Each is approximately the size of a fist. In order to protect them from injury they are situated under the lower ribs, one on each side of the spinal column.

#### **Excretory functions**

Waste product removal

Excess fluid removal

Acid-base balance regulation

Electrolyte level regulation

### Secretory functions

Blood pressure regulation Regulation of red blood cell production Regulation of calcium uptake Kidneys are vital for the excretion of waste products from the body, the regulation of the composition of body fluids and the production of some important hormones. Thus, their function is both excretory and secretory.

Kidney

Ureter

Urinary bladder

### 1.2 CHRONIC KIDNEY DISEASE (CKD) AND ITS SYMPTOMS

Kidney disease occurs when kidneys can no longer perform their functions at full capacity. Permanently decreased kidney function is referred to as chronic renal failure. Chronic renal failure can be the result of a gradual decrease in the efficiency of the kidneys over a long period or might be the consequence of a sudden kidney failure (i.e. acute renal failure). In the case of chronic kidney failure, the kidneys are irreversibly damaged.

Many conditions can lead to chronic renal failure; the most prominent include diabetes, chronic kidney inflammation (glomerulonephritis) or hypertension and vascular damage. When the kidneys fail, the production of urine is reduced and the urine components, i.e. water and waste products, accumulate in the body and thereby result in a syndrome referred to as uremia. Common symptoms of uremia are fatigue, anorexia, nausea and itching skin. If uremia is left untreated, it can lead to severe consequences and even death.

# 2. Treatment modalities

## There are three main types of treatment modalities:

Haemodialysis (HD)

Peritoneal dialysis (PD)

Kidney transplant

Some of these treatment types are only suitable for certain patients and not all treatments are available at every dialysis centre.

Dialysis is a way of replacing the function of the kidneys; it cleans and filters your blood by getting rid of waste, extra salt and fluids and keeps the blood pressure and electrolytes, such as potassium, sodium and chloride in balance.





To decide which treatment option is best for you, various medical, social and psychological factors have to be considered. Your doctor will help you and give you advice on choosing the most adequate treatment modality for you.

#### TIP

Learn as much as possible about all treatment options to become an educated and active patient. Consider your habits and lifestyle when choosing your optimal treatment option. Please do not hesitate to consult your doctor or healthcare team about these issues.









## **2.** Treatment modalities



### 2.1 HAEMODIALYSIS (HD)

### Haemodialysis uses a dialyzer (this is a special filter) to clean your blood.

1   Arterial line	5   Dialysis inlet
2   Pump	6   Air retainer
3   Dialysis outlet	7   Purified blood
4   Dialyzer	8   Venous line



The dialyzer is connected to the dialysis machine which pumps your blood through bloodlines into the dialyzer. In the dialyzer, waste products and extra fluids are filtered out and the cleaned blood is guided through bloodlines back into your body. The cleaning process is pain-free. Depending on the individual medical condition, patients usually have three haemodialysis sessions per week, each lasting on average between 4 and 5 hours. This amount of time is necessary to sufficiently clean the blood, i.e. the longer the better.

Haemodialysis is the most common method used to treat chronic kidney failure. It is usually performed at a dialysis center under the supervision of experienced and well-trained medical staff. It requires a coordinated effort from the whole healthcare team, including your nephrologist, dialysis nurse, dialysis technician, dietitian, and social worker. However, the most important members of the healthcare team are you and your family. By learning about your treatment, you can work together with your healthcare team to achieve the best possible treatment results and thereby improve your quality of life. 9

# 2. Treatment modalities

### 2.2 PERITONEAL DIALYSIS (PD)

Peritoneal dialysis is another procedure for cleaning your blood which can be done at home or at work by yourself.

1   Fresh dialysis solution	5   Peritoneum
2   Tubing	6   Abdominal cavity
3   Transfer	7   Drainage bag
4   Catheter	

This treatment modality uses the lining of your abdominal cavity, to filter your blood. The peritoneal dialysis solution flows through a tube into your abdominal cavity, where waste products and excess water are filtered out of the blood through the peritoneum into the dialysis solution. The peritoneal dialysis fluid is a sterile solution consisting of glucose and other electrolytes.



#### 2.2 PERITONEAL DIALYSIS (PD)

After several hours, when the dialysis solution is saturated with waste products from the blood, it gets drained from your abdomen and is replaced by fresh solution in order to start the cleaning cycle again. This cycle is repeated about four times a day and must be done carefully to avoid an infection, called peritonitis.

Before you can start performing PD treatment, you need to undergo an operation where a soft tube (or catheter) is permanently placed to your belly. This exit site serves the purpose of transporting the peritoneal dialysis solution to and from your peritoneum. It takes approximately 10–21 days for the wound to heal after the operation. The PD medical staff will train you how to use the PD system properly.

As PD is a treatment option which can be done at home, it is crucial that you have all the necessary equipment and disposables available for performing the treatment appropriately. Therefore, dialysis fluid and treatment disposables will be delivered to your home on a regular basis.

## 2. Treatment modalities

### 2.3 KIDNEY TRANSPLANT

Kidney transplantation is a procedure where a healthy kidney from another person is implanted into your body by surgery. The new kidney replaces the function of your own failing kidneys.

New kidneys may come from a deceased donor or a live-related donor. For the success of the transplantation it is very important that the donor has a similar tissue type as the recipient. Your physician will discuss with you whether you are suited for a kidney transplant and which transplantation programs are available.

Kidney transplantation may offer you the highest quality of life. However transplant kidneys are scarce and special medical requirements need to be met before a patient may undergo such a surgery. Special transplant programs exist for potential transplant candidates. The chance of your body accepting the new kidney depends on your age and medical condition.

Although a successful transplant can help return you to a good state of health, you will still need to take medication daily and see your doctor regularly. For further information concerning transplant programs and regimens please ask your medical staff.



# 3. Vascular access for haemodialysis (HD)



Before starting your first HD treatment, an access to your bloodstream has to be prepared. This vascular access allows your blood to be easily taken from a vein in order to flow through the bloodlines to the dialyzer and back through bloodlines into the body. Therefore, such an access has to be surgically created in the arm, leg or near the collarbone.

#### The three main types of vascular access for HD are

#### the AV fistula

- the vascular access graft and
- the central venous catheter.

## 3. Vascular access for haemodialysis (HD)

### 3.1 AV FISTULA | 3.2 VASCULAR ACCESS GRAFT

An arteriovenous fistula (AV fistula) surgically joins your artery and vein. It is the treatment of choice for chronic dialysis. When you first get a new AV fistula, it will take a few weeks or months to mature (i.e. to heal and develop full functionality). A properly formed fistula is less likely than other kinds of vascular accesses to form clots or become infected. Also, fistulas tend to last many years, longer than any other kind of vascular access.

If a patient's veins are too small or weak for an AV fistula to be created, a synthetic graft (made from synthetic material) may be used to form a connection between an artery and a vein. It is placed under the skin like a natural vein. Compared with fistulas, grafts tend to have more problems with clotting or infection and need replacement sooner, but a well cared for graft can last for years. The graft as well as the AV fistula lie beneath the surface of the skin.



### 3.2.1 CARING FOR YOUR AV FISTULA AND VASCULAR ACCESS GRAFT

In order to avoid infections of your AV fistula and vascular access graft and to enhance their lifetime, proper care of your access is vital. Therefore, the following guidelines should be observed:

Avoid having blood samples taken from the arm with the AV fistula (except during HD treatment or with the dialysis centre's approval).

Check that the AV fistula is working every day as you have been shown by your healthcare team. Avoid wearing tight clothing or a wristwatch on the vascular access arm. Advise the dialysis centre immediately if you are worried that the AV fistula may not be working.

Always wash your vascular access arm before each dialysis treatment just as your healthcare team has taught you. Therewith you can avoid infections. Avoid activities that might impair the blood flow to your AV fistula such as sleeping on the AV fistula arm, carrying heavy shopping bags or having your blood pressure taken on the AV fistula arm.

## 3. Vascular access for haemodialysis (HD)

### 3.3 CENTRAL VENOUS CATHETER

### 3.3.1 CARING FOR YOUR CENTRAL VENOUS CATHETER:

### A central venous catheter is a flexible tube placed into a central vein in the neck or chest by a dialysis physician.

Sometimes it is not possible to wait until an AV fistula is ready before starting dialysis; that is when a central venous catheter is needed. Temporary catheters are held in place with stitches. Permanent catheters, intended for long-term use, may be held in place by a special cuff under the skin and a few stitches. Catheters can clog, become infected, or cause narrowing of the veins in which they are placed. With good care, a catheter can be a helpful "bridge" while your fistula or graft is healing or can allow you to have dialysis when other forms of vascular access are not available.

As catheters are prone to infections, it is highly recommended that the following principles are considered:

It is very important to always keep your catheter clean and dry. This means you must not swim, shower or bath with the catheter.

Watch for signs of infection: redness, swelling, pain, high pulse or fever. Call your dialysis centre right away if you notice any of these signs.

Never use scissors or other sharp objects near or around your catheter for any reason.

## 4. Medication



If you need dialysis — either haemodialysis or peritoneal dialysis — your doctor will prescribe various medications that serve various purposes (e.g. promoting the production of red blood cells to prevent anemia). The most common medications are described below:

#### **Phosphate binders**

Phosphate is found in your dietary intake and is normally excreted by the kidney. In renal failure, phosphate levels rise in your body. Together with other substances, this may lead to skin and eye irritation. A further consequence is arteriosclerosis; i.e. calcification of the vessels which can lead to heart disease. As dialysis only helps to remove some but not all of the excess phosphate, phosphate levels in the body have to be controlled additionally by restricting their intake orally (low phosphate diet) and by taking a medicine called a phosphate binder. Phosphate binders help to pass excess phosphate out of your body, reducing the amount of phosphate that gets into your blood. These medicines "bind" the phosphate in your digestive tract by combining with it to form a compound that is not absorbed into your blood.

### 4. Medication

#### Vitamin D

Vitamin D is normally activated in the kidneys to help us absorb calcium from food, which is necessary to keep our bones strong and healthy. People with kidney disease may be given vitamin D in an already activated form, which helps the body absorb more calcium and thereby reduces the risk of bone disease.

#### Iron substitution

Iron is a vital structural component of haemoglobin, a key protein found in normal red blood cells, which transport oxygen. Without iron, anemic patients' bodies have difficulties replenishing adequately healthy red blood cells and improving haematocrit levels. Clinical management of iron deficiency involves treating patients with iron replacement products while they undergo haemodialysis. Iron is usually supplied by intravenous infusion at the dialysis centre.

#### Erythropoietin

Erythropoietin, often referred to as EPO, is a hormone produced by the kidneys which stimulates the bone marrow to produce red blood cells. As the production of erythropoietin in chronic kidney disease patients is low, the level of red blood cells is reduced, which leads to renal anemia. Synthetic erythropoietin can be given intravenously or through the skin as a substitute for natural erythropoietin in order to keep the level of red blood cells stable.

#### Antihypertensives

The kidneys are involved in controlling blood pressure and most patients with renal failure have high blood pressure (hypertension). High blood pressure leads to heart disease and strokes. It is therefore very important to control your blood pressure. There are several drugs that lower blood pressure and need to be taken regularly.

## 5. Dietary advice

Dietary advice differs according to the stage of kidney failure and the type of treatment given. Adequate nutrition is very important and it should be an integral part of your treatment along with your dialysis and medication. Please follow the dietary advice of your doctor or dietitian.

#### Protein

Protein is needed for the repair and maintenance of body tissue, growth and for fighting infections. It is also a vital component of body fluids, including blood. When on dialysis, you have to make sure that the amount of protein in your diet is sufficient. Your dietitian will calculate the recommended amount of protein intake and teach you about the right nutrition.

#### **Protein-rich foods:**

- Fresh meat
- Poultry (chicken and turkey)
- Fish and other seafood
- Eggs or egg whites
- Small servings of dairy products

Compile a food diary or a list which includes your daily food intake and discuss this with your dietitian. This will help to establish your protein intake and can result in further dietary advice.

## 5. Dietary advice

#### Calcium

Calcium is a mineral that is important for strong bones and, in combination with potassium, is needed for healthy muscles and skeletal system. However, foods that are rich sources of calcium are also high in phosphorus. To prevent the loss of calcium from your bones, you need to follow a low phosphorus diet and take phosphate binders. To keep your calcium and phosphorus in balance and to prevent bone disease, your doctor may prescribe a special form of vitamin D.

Only buy vitamin D recommended by your doctor or dietitian because you need a special form of this vitamin. Do NOT take calcium supplements.

### Sodium (salt)

Salt is naturally found in most foods and is also used to add flavor to meals. Please always check the ingredients of the food you buy to avoid eating hidden salt. Sodium controls the fluid balance in your body; so restricting the intake of sodium (mostly from salt) becomes important to avoid fluid accumulation if your production of urine has decreased.

- Keep informed about your sodium restrictions
- Keep an accurate food diary
- Read the ingredients of your food
- Limit the amount of processed and canned foods in your diet
- Watch your beverage intake
- Try using fresh herbs and other spices to flavor food instead of salt
- Add a dash of hot pepper sauce or a squeeze of lemon for intensive flavor
- Be cautious when eating in restaurants

#### Potassium

Potassium is a mineral that supports nerve and muscle function and is also found in food. It helps your muscles and heart work properly. If your potassium level is too high (hyperkalemia) or too low (hypokalemia), these organs can be affected. If your kidneys fail, you will probably need to limit your intake of high-potassium foods. Your blood level of potassium will be checked regularly and your dietitian will give you advice on a proper diet with the right amount of potassium.

- Talk to your dialysis dietitian or physician about creating an eating plan with the right balance of potassium
- Watch your diet. Limit foods that are high in potassium
- Limit fruit and vegetables to the amounts recommended by your dietitian
- Limit milk and milk products or replace with non-dairy substitutes recommended by your dietitian
- Avoid fruit juices
- Avoid salt substitutes and other seasonings that contain potassium

#### Phosphate

Phosphate is a mineral found in all foods that is needed for the maintenance of healthy bones. However, the body only needs a certain amount of phosphate. Our kidneys usually keep the balance right by excreting phosphate whenever there is too much in the body. If your kidneys fail, you have to control the levels of phosphate in your body by restricting your intake orally (low phosphate diet) and by using a medicine called a phosphate binder that is taken with meals and snacks.

- Reduce the amount of phosphate you eat
- Take a medicine called a phosphate binder
- Take the active form of vitamin D as prescribed

## 5. Dietary advice

#### Fluid balance control

One of the main functions of the kidney is to balance fluid in the body. In kidney failure, the most common problem is that the body does not get rid of the excess fluid, a condition called fluid overload. In its extreme form, fluid will settle in the lungs, causing pulmonary edema and shortness of breath. The goal of treatment is to achieve a fluid balance that is close to normal. The weight after dialysis, in which the excess fluid is removed and the normal fluid balance is achieved, is called "dry weight."

The fluid allowance for each patient is determined by the amount of urine produced in a 24-hour period. Most people are limited to 700-1000 ml of fluid per day plus urine output. Fluid allowances vary from person to person and also depend on how much residual kidney function is left and on the individual's body size. Weight gain should not exceed 1-1.5 kg within one dialysis-free day, and 1.5 - 2.5 kg over 2-3 days. If large amounts of fluid need to be removed during dialysis it can make you feel ill; your blood pressure may fall and you might feel light-headed or sick.

- Avoid salty and spicy food
- Be aware of hidden fluids in foods (gelatin, watermelon, soup, gravy and ice cream)
- Stay cool. Keeping cool will help reduce your thirst, especially in warmer weather. Try drinking cold liquids instead of hot beverages
- Sip your beverages. Sipping will let you savor the liquid longer. Use small cups or glasses
- Try ice. Many patients find that ice is more satisfying than liquids
- Battle dry mouth. Dry mouth can be uncomfortable. Instead of drinking fluid to refresh your mouth, try using mouthwash or brushing your teeth. Sucking on hard candy or a wedge of lemon or lime will also help



## 6. Living with chronic kidney failure and dialysis

Adapting to dialysis can be difficult at times; it is also normal that you will have fears about living with chronic kidney failure. Dialysis is not problem free but it affords you the chance of a good quality of life.

Please discuss all issues with your medical staff; this can be helpful in dealing with your feelings for you and your family. Being a dialysis patient does not imply that you are unable to work or join your leisure activities. A good support system of medical staff, friends and family will help you cope with the new adjustments you face. Including dealing with administrative and insurance issues or filling in the necessary forms to ensure you receive the appropriate financial benefits.

#### Exercise

Your general health will benefit from regular exercise. Many people with chronic kidney disease say exercise was the key to helping them feel "normal" again after they started dialysis treatments. Before beginning any exercise program, please consult your doctor for approval and so that he can determine the "right" kind of exercise for you. The exercise program should meet your special needs and interests. Learn how exercise can help you feel better physically and be more in control of your emotions.

#### Driving

Kidney failure in itself does not affect your ability to drive. If you have heart disease, eye trouble or do not feel well after the treatment, please ask your physician for advice.

#### Smoking

While we are all familiar with the health risks smoking has on the lungs and heart, studies have shown that smoking also aggravates kidney disease. Smoking is a burden on your blood vessels and heart. On dialysis, you should quit smoking. Whether you are in the early stages of kidney disease or are on dialysis, your physician will discuss with you the different ways to help you stop smoking.

#### Work

Many patients with chronic kidney disease (CKD) are in full-time or part-time jobs. With your doctor's permission and an open discussion with your employer about all relating issues, you will be able to continue your work. Your doctor will try to schedule your treatment conveniently; please discuss details with the medical staff.

#### Sexual relationships

Sexuality does not only mean the act of sexual intercourse, it also includes feelings, communication and how willing you are to build a relationship. Physical and emotional changes caused by your disease may affect your sexuality. Kidney disease can cause physical and emotional changes that may lower your sexual interest and/or sexual ability. People with end stage renal disease may feel tired after their haemodialysis treatment. Ongoing fatigue should be discussed with your doctor and renal dietitian. Men with renal disease may experience changes in their hormone levels that affect their sexual interest. Please discuss this issue with your doctor so that he can get the right help for you.

## 6. Living with chronic kidney failure and dialysis

### Traveling

Everybody needs a break from time to time, and kidney patients are no exception. However, traveling for kidney patients on dialysis does require more planning, so last minute bookings are not a realistic option. Please ask the medical staff to assist you with the planning process and to help make sure you have a nice holiday. Your physician will help you arrange holiday dialysis treatments in different countries. For patients on PD treatment, traveling is much easier. Inform your physician where you want to go; he will arrange for your dialysis supplies to be delivered to your preferred holiday destination.





### Glossary

Acute renal failure – is the sudden and temporary loss of kidney function. Acute renal failure can be caused by diminished blood supply to the kidneys, obstructed urine flow or traumatic damage to the kidneys caused by, for example, major surgery or a car crash. Acute renal failure is treated with continuous renal replacement therapy, usually at the intensive care unit in a hospital.

Arteriovenous (AV) fistula – is a blood vessel that is made by surgically sewing together an artery and a vein (often in the forearm) to create the rapid blood flow needed for efficient haemodialysis treatment. It is also commonly called a native fistula.

**Blood pressure** – is the pressure exerted by the blood against the walls of the blood vessels, especially the arteries. Too high blood pressure increases the risk of heart attack and stroke and is treated by blood pressure medication (antihypertensives). **Catheter** – is a flexible plastic tube for insertion into a body cavity used to allow the passage of fluids.

**Chronic kidney disease** – is the slow and progressive loss of kidney function over several years, resulting in permanent kidney failure. People with permanent kidney failure need dialysis or a kidney transplant to replace the work of the diseased kidneys.

**Chronic kidney failure** - means less than 10% of kidney function.

**Creatinine** – is a breakdown product of creatine phosphate in your muscles. Your physician can test your creatinine clearance and check how efficiently the kidneys remove creatinine. Low creatinine clearance indicates impaired kidney function.

**Diabetes** - is a disease in which abnormal carbohydrate metabolism causes high glucose levels and can lead to kidney failure. About 20% of all patients with diabetes develop kidney failure. Dialysis fluid – constitutes a mixture of water, glucose and electrolytes used in dialysis to fulfill the body's needs. Dialysis fluid usually contains sodium, magnesium, chloride, potassium and calcium. During dialysis, waste products in the blood pass through the semipermeable membrane of the dialyzer into the dialysis fluid.

**Dialysis treatment** – is an artificial medical treatment process by which the toxic waste products and water are removed from a patient's body.

**Dialyzer** - is the filtering unit of a dialysis machine. The dialyzer removes waste products and excess water from the blood.

**Dwell time** – is length of time peritoneal dialysis patients keep fresh dialysate in the abdomen. After the dwell time is over, the used dialysate is replaced with fresh dialysate either by the patient themselves or by a cycler machine.

**EPO** - is a commonly used abbreviation for erythropoietin.

**Erythropoietin** – is a hormone produced by healthy kidneys that tells the bone marrow to produce erythrocytes (red blood cells). Synthetic hormone versions are available for kidney patients. Lack of this hormone may lead to renal anemia.

Haemoglobin – is the substance in erythrocytes which carries oxygen around the body. The iron contained in haemoglobin is responsible for the red color of the blood. A decreased level of haemoglobin is known as anemia. Anemia causes tiredness, shortness of breath and paleness.

**Immunosuppressive drugs** – are drugs used to make the immune system less effective, so that a transplanted kidney will not be rejected.

Kidney transplant – means replacement of a diseased kidney with a healthy one. A kidney transplant may come from a living donor, usually a relative, or from someone who just died. Satellite haemodialysis centre – is a centre that is located away from the main hospital dialysis centre.

The dialysis centre – is the place where a team of healthcare professionals treat kidney patients who need dialysis.

**Ultrafiltration** – means the removal of excess water from the blood.

Urea - is a waste product found in the blood and caused by the normal breakdown of protein in the liver. Urea is normally removed from the blood by the kidneys and then excreted in the urine. Urea accumulates in the body of people with kidney failure and tells us the level of kidney function.

Vascular access – is a method of gaining entry to the bloodstream so that dialysis can be performed. AV fistula is one form of access for haemodialysis.

Vascular access graft – is an access that is made by connecting one end of a piece of artificial vein to the patient's vein and the other end to the patient's artery. The graft is a larger vessel that allows the rapid blood flow needed for efficient haemodialysis. It is commonly called a graft.



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