

Living with  
Chronic Kidney  
Disease

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# 1. Prolog

The diagnosis of kidney failure strikes most people in the middle of life. They got married, had children, built houses, made careers and, suddenly, nothing is the way it was.

Unexpectedly, they have faced with a disease that has a profound impact on their lives. Yet, a disease that will never leave them again. Some despair of this challenge. Others punish it with contempt and continue to live as if they would not notice the “uninvited guest”. Yet, there are also those who - nevertheless - lead a fulfilled life.

In the course of my 30 years of working with people with chronic kidney disease, I have met them all: the happy and the unfortunate, the resigned and the satisfied. Yet, I have often wondered what makes the difference. Which are the important aspects why people despair of the challenge of this disease, even though, from a purely external point of view, they hardly encounter any complications. Yet, on the other hand, which are those ailments, which let people find their life to be satisfactory despite chronic illness and often, adverse circumstances and complications.

In the search for answers, I watched, read, listened and tried out countless interventions and support offers. I have experienced and recognized a lot in the past 30 years and I would like to share this wealth with you.

The book you are now holding in your hands is the English translation of the book "Leben mit Niereninsuffizienz - Trotzdem" published in 2018. I have long considered whether I really want to translate the book into English, because I am very aware that my knowledge relates to the Swiss way of life with the disease. Meanwhile, "Leben mit Niereninsuffizienz - Trotzdem" was very quickly sold internationally and I received repeated feedback on how valuable the content has perceived. Not only in Switzerland, but in other countries as well. Then, as the book started selling in America too, I decided to translate it into English anyway.

At the same time, I would like to point out: I do not know about healthcare in America. I also have no knowledge of healthcare in Norway or India. The present book is written from the extensive knowledge within the framework of the Swiss healthcare system and I ask you to be aware of this at all times and to ask your considering kidney doctor in case of any uncertainties.

Yet, the disease of kidney failure behaves similarly, in every person affected by it and the related holistic challenges behave similarly across borders, too. Therefore, I am convinced that this book serves everyone affected and every member of his or her family, regardless of the country and continent in which they live. Nevertheless, please be aware that this is a book

written out of the context of the Swiss healthcare system.

The book is not an operating manual that has to be read through once and then everything is understood. Rather, it is written as an appreciative companion who would like to support you on your path of living with kidney failure. A companion who invites you to learn about the diverse challenges that kidney failure can entail. The book is an invitation to getting involved with the topics related to the disease of kidney failure and actively dealing with them. For then, finding your own good way in living with this huge challenge.

"Living with Kidney Disease" would like to introduce you to the sometimes, confusing "country of kidney failure" and shows you with various practical case studies how different the several challenges can be handled. People deal with challenges differently and that is precisely where the power and strength of each individual lie. The book also contains an abundance of strategies and tools that have been tried and tested over many years and are designed to equip you and help you to be on the road well.

May the book serve you!  
Susanne Edlmann

## 2. Introduction

Illness is an imposition. A disease, such as kidney failure, that accompanies for the rest of life and thus, affects life as a whole, is a double imposition.

The present book shows kidney failure with great openness and thus with all its ugliness. Yet, seen in this way, it is perhaps an imposition too.

Especially for people who are new to the subject. I am very aware of that. At the same time, however, I believe that part of the "nonetheless" is to face challenges honestly and to actively deal with them. Even and especially when the topic is uncomfortable and sometimes, painful. Dealing with the uncomfortable often leads to reconciliation, dissolution and healing. Which in turn, means that you can find your very own and good ways. People benefit of an active discussion and an active dealing, when they are on the go with the challenge of renal insufficiency. It is, in my opinion, one of the basic requirements to continue living a fulfilling and satisfying life.

Yet, the active discussion is a work that only you as the person concerned can do and for that, you need comprehensive information:

*Section A* provides you with the purely biological and medical aspects of kidney failure. It introduces the possible renal replacement therapies and addresses for the first time, possible challenges in this regard.

*Section B* is devoted to the very practical changes that those affected can encounter in the first phase of the disease.

*Section C* discusses possible long-term consequences of a chronic illness and offers a variety of suggestions for dealing with these challenges in advance. If one is aware of the cliffs, they can have circumnavigated calmly with the appropriate knowledge.

*Section D* deals with situations in which the soul begins to suffer and thus stresses life. Something that not only people with kidney failure can encounter. Yet, something that can be resolved successfully with the appropriate knowledge and sometimes also with the appropriate technical tools.

*Section E* has intended for relatives of people with kidney failure. Relatives are also affected. Otherwise. Yet, still, they are affected.

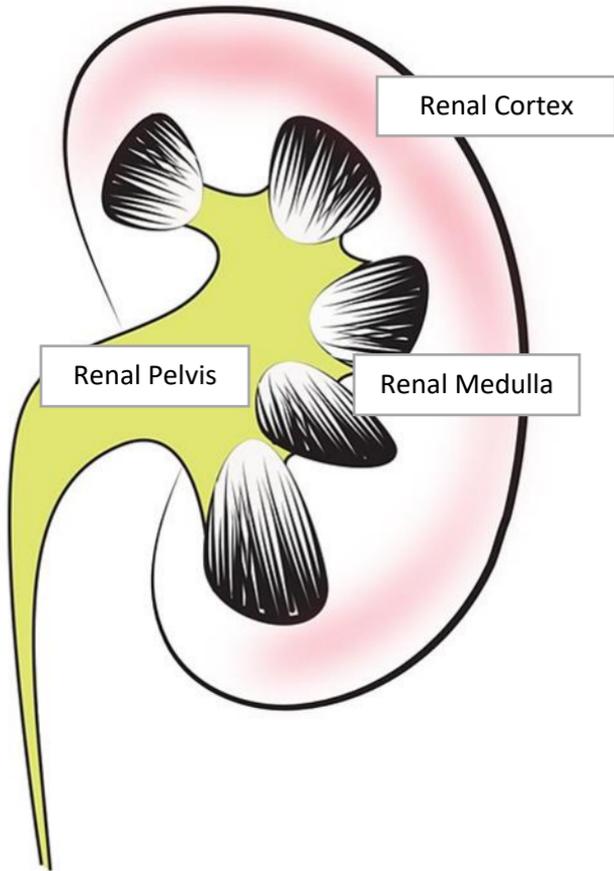
## SECTION A: BASIC KNOWLEDGE OF RENAL FAILURE

### 3. The Kidneys

The first chapter of the book is deliberately devoted to the kidneys and the medical aspects of kidney failure. A disease loses its threat if you deal with it and learn to understand it and its mechanisms. Adequate and detailed knowledge makes the disease tangible, understandable and thus more manageable. In addition, the knowledge of the specific events in the body is an invaluable support in contact with the treating doctors.

#### 3.1 Position and structure of the kidneys

The two bean-shaped kidneys lay in the lumbar region, behind the peritoneum and next to the spine. Their size depends on the size of the person: an average kidney is approx. 11 cm long, approx. 6 cm wide and weighs approx. 150 g.



The kidneys can have compared to the washing machine of a large family: one of their main tasks

is to clean the blood of a man. Therefore, two large artery branch off from the large body artery (aorta) to supply the kidneys with blood. Approx. 1200 ml of blood flow through them every minute.

The kidneys themselves have surrounded by a kind of protective cover, the renal capsule. The actual organ mass is then divided into kidney cortex, renal medulla (pyramids) and kidney pelvis.

Each of the two kidneys consists of approximately 1 million nephrons (functional units). To make it more understandable, the following comparison may help you: A kidney could have compared to a factory that produces urine. The production department of the factory consists of approximately 1 million subdivisions, all of which have the same task and the same goal, but function largely autonomously in themselves.

Such a nephron looks something like a pin and it has made up of a round ball of blood vessels (glomerulus) and a longer line system (renal tubule). The primary urine (approx. 170 liters per day), consisting of water, organic solutes (such as urea and creatinine, for example), inorganic ions (such as salts and glucose, for example.) and has filtered out of the blood in the renal corpuscle (glomeruli). This primary urine then, flows through the tubules, in which a large part of the water and inorganic ions has reabsorbed back into the bloodstream.

The remaining liquid only makes up approx. 1% of the primary urine (approx. 1.7 liters) and mainly consists of water, organic solutes and inorganic ions. It has now passed on from the renal medulla into the kidney pelvis and then, flows through the ureters to the bladder. From there, it has excreted through the urethra as urine.

### 3.2 Functions of the kidneys

The tasks of the kidneys are by no means limited to the excretion of fluids. How diverse and important these tasks are usually only then become aware when the kidneys are no longer working properly or their function wears off.

#### **Tasks of the kidney:**

- Filtering out certain metabolic waste products, flushing them out of the body with the urine.
- Regulation of water balance in the body.
- Maintaining electrolyte balance.
- Regulation of the acid-base balance in the body.
- Activating Vitamin D, excretion of calcium and phosphate, and thus playing an important role in bone metabolism.
- Producing the enzyme "Renin", which helps regulate blood pressure.

- Producing the hormone "erythropoietin", which is involved in the formation of red blood cells.

## 4. Chronic kidney disease

### 4.1 What does chronic kidney disease mean?

If the kidneys are working insufficiently one speaks of renal insufficiency (the term "insufficiency" comes from the Latin and means "weakness". Renal insufficiency therefore means renal weakness). Renal insufficiency then has referred often to chronic kidney disease. This means a weakness of the kidneys, which mostly, worsens over the years.

Possible causes of kidney failure include the long-term consequences of long-standing high blood pressure but also long-standing diabetes. Chronic kidney infections or autoimmune diseases can also cause kidney failure.

Unfortunately, there is also a family-related kidney disease (ADPKD - autosomal dominant polycystic kidney disease), which is inherited within certain families.

About a fifth of all people who suffer from chronic kidney disease do not know the actual cause of their disease. Sometimes, the diagnosis has made at a stage when the kidneys have already shrunk so that they can no longer have

examined. Sometimes, however, the causal challenge cannot have determined.

If the kidney function declines, the kidneys can no longer perform their tasks sufficiently and, among other things, this increases the concentration of urinary metabolic products in the blood. This fact has been used by medicine, which now measures the concentration of these metabolic products in the blood. One of these products is the so-called creatinine. Creatinine is a chemical waste, originated as by-product of a normal muscle function. It is completely excreted through the kidneys and thus; if the concentration of creatinine in the blood increases, it can be assumed that the kidney performance has decreased. The normal value, (which means the value for healthy kidneys) is  $<110 \mu\text{mol} / \text{L}$ .

Yet, the blood value depends on age, gender and muscle mass of a person and is thus, to handle individually. Therefore, the medicine works with the value of creatinine, but much more with the so-called GFR ("glomerular filtration rate"), which shows the actual "washing power" of the kidneys regardless of the age or muscle mass of the related person. The GFR is usually calculated using a predetermined formula from the measured creatinine blood value, age, gender and weight of the person concerned and then handled in practice as follows:

## **A GFR of 40 corresponds to a kidney function of 40%.**

According to this GFR, renal failure becomes international classified into disease stages (based on the so-called DOQI guidelines<sup>1</sup>).

### **4.2 Stages of chronic kidney disease (CDK)**

<b>Stages of renal failure according to DOQI guidelines</b>		
<u>Stages</u>	<u>GFR</u>	<u>Wich means</u>
Stage 1	90 or greater	kidney disease with normal kidney function
Stage 2	60 - 89	mild renal failure
Stage 3	30 - 59	renal failure
Stage 4	15 - 29	severe renal failure
Stage 5	< 15	terminal renal failure

If you read one of your medical reports, you will be able to read there that you suffer from chronic kidney failure, stage XY CDK. If you know the stage of your kidney disease, you can estimate where your kidney performance is in relation to a general course of the disease. Based on this stage, your treating doctor also decides, among other things, which current medical therapies you need. Each stage of the disease has its own focus of treatment.

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<sup>1</sup> Dialyses Outcome Quality Initiative - Guidelines International guidelines for the definition and classification of chronic renal failure, developed by the "National Kidney Foundation" 2002

### **Kidney function 60 - 90%**

Means **stage 2 CDK** or **mild renal failure**. At this stage, the medical focus is on the diagnosis, the clarification of possible causes for the renal function impairment and the reduction of risk factors (for example a high blood pressure, poorly adjusted blood sugar in diabetics or nicotine consumption). The aim of the respective treatment is to maintain the current kidney function as long as possible.

### **Kidney function 30 - 60%**

Means **stage 3 CDK** or **moderate renal failure**. At this stage, too, the focus of medical treatment is on supporting the long-term preservation of the current kidney function (for example still minimizing the risk factors of high blood pressure, excessive HbA1C, nicotine consumption, but also therapy for any additional diseases or complications such as prostate hyperplasia or others).

### **Kidney function 15 - 30%**

Means **stage 4 CDK** or **advanced stage kidney failure**. Again, attempts have made to maintain the current kidney function for as long as possible. In addition, possible follow-up