Module 1.1 - Information on Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD)

Theme	1.1 Stages of CKD, symptoms and eGFR definition
GOAL(S) AND OBJECTIVES	The goal of this module is to help learners to: • recognize the symptoms of Kidney Failure • better understand the progress of Kidney Disease • understand the difference between Chronic Kidney Disease and Acute Kidney Disease • be informed about the usefulness of eGFR test
LEARNING OUTCOMES	Learners will acquire basic information about the stages and progression of Kidney Disease but also instructions of how to prevent the progress of CKD
METHODS	Self-directed learning
DURATION:	1 hour online and 65 minutes face-to-face
RESOURCES NEEDED:	• lap-top with internet connection • mobiles phones with internet connection • Flipchart and markers • Papers, markers, pens
ORDER OF ACTIVITIES:	• E-learning module (1 H) Face to face: • Welcome process (10 min.) Worksheet 1 • Introduction to the contents of this module (30 min.) – Worksheet 2 • Role playing (25 min.) – Worksheet 3 • Conclusions (10 min.)
EVALUATION OF THE THEME:	• Self-assessment (e-learning module)
REFERENCES	•
WORKSHEETS	• Worksheet 1 • Worksheet 2 • Worksheet 3
HANDOUTS	None

Background information – e-learning:

Introduction

Kidney disease is defined as a heterogeneous group of disorders affecting kidney structure and function. It is recognized that even mild abnormalities in measures of kidney structure and function are associated with increased risk for developing complications in other organ systems as well as mortality, all of which occur far more frequently than kidney failure. Duration of greater than 3 months is defined as chronic, while duration of 3 months or fewer is termed acute. AKI is defined as a subgroup of acute kidney diseases and disorders (AKD) in which changes in kidney function evolve within one week. There is a complex relationship between AKI and CKD; AKI can lead to CKD, and CKD increases the risk of AKI.

The term "chronic kidney disease" means lasting damage to the kidneys that can get worse over time. If the damage is very bad, your kidneys may stop working. This is called kidney failure, or end-stage renal disease (ESRD). If your kidneys fail, you will need dialysis or a kidney transplant in order to live.

What causes chronic kidney disease (CKD)?

Anyone can get CKD. Some people are more at risk than others. Some things that increase your risk for CKD include:

- Diabetes
- High blood pressure (hypertension)
- Heart disease
- Having a family member with kidney disease
- Being over 60 years old

What are the symptoms of kidney failure?

You may notice one or more of the following symptoms if your kidneys are beginning to fail:

- Itching
- Muscle cramps
- Nausea and vomiting
- Not feeling hungry
- Swelling in your feet and ankles
- Too much urine (pee) or not enough urine
- Trouble catching your breath
- Trouble sleeping

How do I know if I have CKD?

CKD usually does not have any symptoms until your kidneys are badly damaged. The only way to know how well your kidneys are working is to get tested. Being tested for kidney disease is simple. Ask your doctor about these tests for kidney health:

eGFR (estimated glomerular filtration rate)

The eGFR is a sign of how well your kidneys are cleaning your blood.

Your body makes waste all the time. This waste goes into your blood. Healthy kidneys take the waste out of your blood. One type of waste is called creatinine. If you have too much creatinine in your blood, it might be a sign that your kidneys are having trouble filtering your blood.

You will have a blood test to find out how much creatinine is in your blood. Your doctor will use this information to figure out your eGFR. If your eGFR is less than 60 for three months or more, you might have kidney disease.

Urine test

This test is done to see if there is blood or protein in your urine (pee).

Your kidneys make your urine. *If you have blood or protein in your urine, it may be a sign that your kidneys are not working well.*

Your doctor may ask you for a sample of your urine in the clinic or ask you to collect your urine at home and bring it to your appointment.

Blood pressure

This test is done to see how hard your heart is working to pump your blood.

High blood pressure can cause kidney disease, but kidney disease can also cause high blood pressure. Sometimes high blood pressure is a sign that your kidneys are not working well.

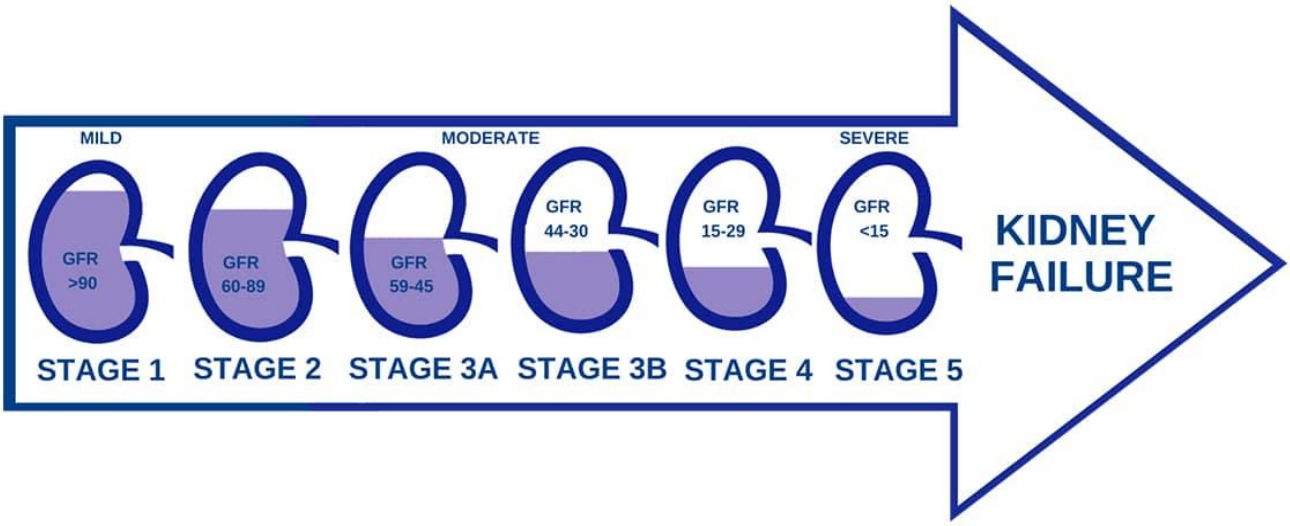
For most people a normal blood pressure is less than 120/80 (120 over 80). Ask your doctor what your blood pressure should be.

What is an eGFR test

GFR is a blood test our nephrologists use to measure the amount of creatinine in the blood. Creatinine is a normal waste product from the muscles that is filtered out through the kidneys. The higher the amount of creatinine found in the blood, the lower the amount of creatinine being filtered out by the kidneys, which tells us how well (or poorly) the kidneys are functioning.

Early detection of kidney disease is important to slow the progression of CKD and a nephorologist should be consulted. While you cannot reverse damage, *in stages 1 and 2, it is possible to prevent further damage and maintain kidney function.* Changes in lifestyle and diet, along with regular checkups, can help keep the kidneys from further deterioration. Stages 3, 4 or 5 CKD are when your kidney function is moderately to severly reduced. During these stages is most likely when you will experience physical changes. If you have not been seen by and evaluated by a nephrologist, it is extremely important that you make an appointment with a nephrologist, like the experienced, reputable physicians at Dallas Nephrology Associates.

Glomerular filtration rate (GFR) is calculated using the creatinine level in the blood, your age, ethnicity and gender. Creatinine is a normal waste product found in your body that can build up while your kidney function declines. Therefore, the higher level of creatinine, the lower your kidney function.



Stage 1 CKD: eGFR 90 or Greater
Stage 1 CKD means you have mild kidney damage and an eGFR of 90 or greater.
Most of the time, an eGFR of 90 or greater means your kidneys are healthy and working well, but you have other signs of kidney damage. Signs of kidney damage could be protein in your urine (pee) or physical damage to your kidneys. Here are some ways to help slow down the damage to your kidneys in Stage 1 kidney disease:

- Control your blood sugar if you have diabetes
- Control your blood pressure
- Eat a healthy diet
- Do not smoke or use tobacco
- Be active 30 minutes a day, 5 days a week
- Stay at a healthy weight
- Ask your doctor if there are medicines you can take to help protect your kidneys
- Make an appointment to see a nephrologist (kidney doctor) even if you already have a general doctor

Stage 2 CKD: eGFR Between 60 and 89
Stage 2 CKD means you have mild kidney damage and an eGFR between 60 and 89.
Most of the time, an eGFR between 60 and 89 means your kidneys are healthy and working well. But if you have Stage 2 kidney disease, this means you have other signs of kidney damage even though your eGFR is normal. Signs of kidney damage could be protein in your urine (pee) or physical damage to your kidneys. Here are some ways to help slow down the damage to your kidneys in Stage 2 kidney disease:

- Control your blood sugar if you have diabetes
- Control your blood pressure
- Eat a healthy diet

- Do not smoke or use tobacco
- Be active 30 minutes a day, 5 days a week
- Stay at a healthy weight
- Ask your doctor if there are medicines to protect your kidneys
- Make an appointment to see a nephrologist (kidney doctor) even if you already have a general doctor

Stage 3 CKD: eGFR Between 30 and 59
Stage 3 CKD means you have an eGFR between 30 and 59.
An eGFR between 30 and 59 means that there is some damage to your kidneys and they are not working as well as they should.

- Stage 3 is separated into two stages:

Stage 3a means you have an eGFR between 45 and 59
Stage 3b means you have an eGFR between 30 and 44

Many people with Stage 3 kidney disease do not have any symptoms. But if there are symptoms, there may be:

- Swelling in your hands and feet
- Back pain
- Urinating (peeing) more or less than normal

At this stage, you are also more likely to have health complications as waste builds up in your body and your kidneys are not working well, such as:

- High blood pressure
- Anemia (a low number of red blood cells)
- Bone disease
- To keep your Stage 3 kidney disease from getting worse, you can:
- Control your blood sugar if you have diabetes
- Control your blood pressure
- Do not smoke or use tobacco
- Eat a healthy diet
- Be active 30 minutes a day, 5 days a week
- Stay at a healthy weight
- Visit a nephrologist (kidney doctor), who will make a treatment plan that is right for you and tell you how often you will need to have your kidneys checked
- Meet with a dietitian, who will help you follow a healthy diet
- Ask your doctor about blood pressure medicines called ACE inhibitors and ARBs if you have diabetes or high blood pressure. Sometimes, these medicines can help keep kidney disease from getting worse

Stage 4 CKD: eGFR Between 15 and 29
Stage 4 CKD means you have an eGFR between 15 and 29.
An eGFR between 15 and 30 means your kidneys are moderately or severely damaged and are not working as they should. Stage 4 kidney disease should be taken very seriously – it is the last stage before kidney failure.

At Stage 4 kidney disease, many people have symptoms such as:

- Swelling in your hands and feet
- Back pain
- Urinating (peeing) more or less than normal
- At Stage 4, you will likely also have health complications as waste builds up in your body and your kidneys are not working well, such as:
- High blood pressure

- Anemia (a low number of red blood cells)
- Bone disease

To keep kidney disease from getting worse at this stage, your doctor will recommend that you:

1. Have regular appointments with a nephrologist (kidney doctor), who will make a treatment plan that is right for you and tell you how often you will need to have your kidneys checked
2. Meet with a dietitian, who will help you follow a healthy diet
3. Take special blood pressure medicines like ACE inhibitors and ARBs if your doctor says you should. If you have diabetes or high blood pressure, sometimes these medicines can help keep kidney disease from getting worse.

At Stage 4 kidney disease, this is the time to start talking with your nephrologist about how to prepare for kidney failure. Once your kidneys have failed, you will need to start dialysis or have a kidney transplant to live.

Stage 5 CKD: eGFR Less than 15
Stage 5 CKD means you have an eGFR less than 15.
An eGFR less than 15 means the kidneys are getting very close to failure or have completely failed. If your kidneys fail, waste builds up in your blood, which makes you very sick.
Some of the symptoms of kidney failure are:

- Itching
- Muscle cramps
- Feeling sick and throwing up
- Not feeling hungry
- Swelling in your hands and feet
- Back pain
- Urinating (peeing) more or less than normal
- Trouble breathing
- Trouble sleeping

Once your kidneys have failed, you will need to choose a type of Renal Replacement Therapy (RRT): dialysis or having a kidney transplant to live.

Preparing for dialysis: Dialysis helps clean your blood when your kidneys have failed. There are several things to think about, such as the type of dialysis, how to plan your treatments and how they will affect your daily life.
Preparing for a transplant: A kidney transplant is a surgery to give you a healthy kidney from someone else’s body. If you can find a living kidney donor, you may not need to start dialysis at all. It is possible to have a transplant when your kidneys are getting close to failure.

CKD stage	Description	Possible signs & symptoms	eGFR
Stage 1	Kidney damage with normal kidney function		90 or higher
Stage 2	Mild loss of kidney function	High blood pressure, swelling in legs, urinary tract infections or abnormal urine test	89–60
Stage 3	3a: Mild to moderate loss of kidney function; 3b: Moderate to severe loss of kidney function	Low blood count, malnutrition, bone pain, unusual pain, numbness or tingling, decreased mental sharpness or feeling unwell	3a: 59–45 3b: 44–30
Stage 4	Severe loss of kidney function	Anemia, decreased appetite, bone disease or abnormal blood levels of phosphorus, calcium or vitamin D	29–15
Stage 5 End stage renal disease (ESRD)	Kidney failure and need for transplant or dialysis	Uremia, fatigue, shortness of breath, nausea, vomiting, abnormal thyroid levels, swelling in hands/legs/eyes/lower back or lower back pain	Less than 15

Self-assessment test

Part A – Fill the gaps with the appropriate answer

Please reply to the following sentences to assess your knowledge of this unit. Note that only one option is correct.

1. A basic symptom of Kidney failure is muscle ______.
   a. cramp
   b. pain
   c. dystrophy

2. GFR is a blood test that nephrologists use to measure the amount of ________ in the blood.
   a. protein
   b. creatinine
   c. phosphorus

3. You are ate stage ____ of CKD when your eGFR test is between 30 and 59
   a. 4
   b. 3
   c. 1

Part B – drag & drop

Please match the correct answers:

Someone has to contact with his doctor if his blood pressure is over	1
Someone is at Stage 2 of CKD if his eGFR is	5
If someone has eGFR less than 15 then he is at stage .... of CKD.	120
How many are the stages of CKD?	70

Enrich your knowledge

Please visit the following websites:

- European Renal Association-European Dialysis and Transplant Association (ERA-EDTA): https://www.era-edta.org/en/
- European Kidney Patients Federation (EKPF): www.ekpf.eu
- International Society of Nephrology (ISN): https://www.theisn.org/
- Europrean Kidney Health Alliance (EKHA): www.ekha.eu
- Panhellenic Renal Patients Association: https://psnrenal.gr/
- Hellenic Society of Nephrology: www.ene.gr

- Nephron website: www.nephron.gr

Face2face part

Worksheet 1.1.1 – Welcome process

Objective: warm-up, start the session and encourage participants to get to know each other better.

Duration: 10 minutes

Implementation: At this point we will ask participants to present themselves, to explain the reasons in simple words for choosing attending this module. It's good to know the ''story'' behind each patient and caregiver. That will help the moderator to better understand the participant's level of information about CKD.

Worksheet 1.1.2 –Discussion on the contents of the module

Objective: Full-scale discussion on the contents of the online module

Duration: 30 minutes

Implementation: the moderator will ask each participant to give a detailed description of the modules' topics, to refer any comments or expressing any question. After that and for the dialogue to begin between the participants the moderator will ask:

- Do you think the information you obtained is useful for you or any close relative/friend?
- Please describe if you ever have been called to address and stand by persons who have symptoms of CKD?
- How likely is to share this piece of information with friends and relatives so to aware them about CKD?

Worksheet 1.1.3 – Role playing

Objective: Role play as a teaching strategy recognizing the symptoms of CKD

Duration: 15 minutes

Implementation: The facilitator will randomly select 5 participants to demonstrate the symptoms of the 5 CKD stages. The rest of the participants should recognize the stage and provide the necessary information to the performers. Additionally, the moderator with a volunteer will present the correct way to monitor someone's blood pressure at home. Then every participant will follow moderator's paradigm and will measure the BP of someone else (work in couples).

Role Play checklist

1. How difficult was to monitor yours or someone else blood pressure?
2. Were the participants/performers convincing in their roles?
3. The participants/audience worked toward to propose a solution?
4. The role play captured and maintained audience interest?

Module 1.2 - Information on Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD)

Theme	1.2 Renal Replacement Therapies (RRT)
GOAL(S) AND OBJECTIVES	Objective of this module is to: • Inform the learners about the existing types of RRT • Present the applied method of each therapy that a patient with ESKD has to follow • Explain in a simple way the surgical operations each therapy involves
LEARNING OUTCOMES	After completing this module the learners will have obtained the necessary knowledge to detect and describe the basic differences between renal replacement therapies
METHODS	Self-directed learning
DURATION:	1 hour online and 75 minutes face-to-face
RESOURCES NEEDED:	• lap-top with internet connection • mobiles phones with internet connection • Flipchart and markers • Papers, markers, pens
ORDER OF ACTIVITIES:	• E-learning module (1 H) Face to face: • Welcome process (10 min.) Worksheet 1 • Introduction to the contents of this module (40 min.) – Worksheet 2 • Role playing (15 min.) – Worksheet 3 • Conclusions (10 min.)
EVALUATION OF THE THEME:	• Self-assessment (e-learning module)
REFERENCES	•
WORKSHEETS	• Worksheet 1 • Worksheet 2 • Worksheet 3
HANDOUTS	None

Background information – e-learning:

Introduction

Renal Replacement Therapies

As chronic kidney disease (CKD) progresses, an essential component of care becomes educating and preparing patients for end stage renal disease (ESRD) and possible treatment options.

Renal replacement therapy (RRT) is called the therapy that replaces the normal blood-filtering function of the kidneys. It is used when the kidneys are not working well, which is called kidney failure and includes acute kidney injury and chronic kidney disease. Renal replacement therapy includes dialysis (hemodialysis or peritoneal dialysis, which is various ways of filtration of blood with or without machines. Renal replacement therapy also includes kidney transplantation, which is the ultimate form of replacement in that the old kidney is replaced by a donor kidney.

These treatments are not truly cures for kidney disease. In the context of chronic kidney disease, they are more accurately viewed as life-extending treatments,

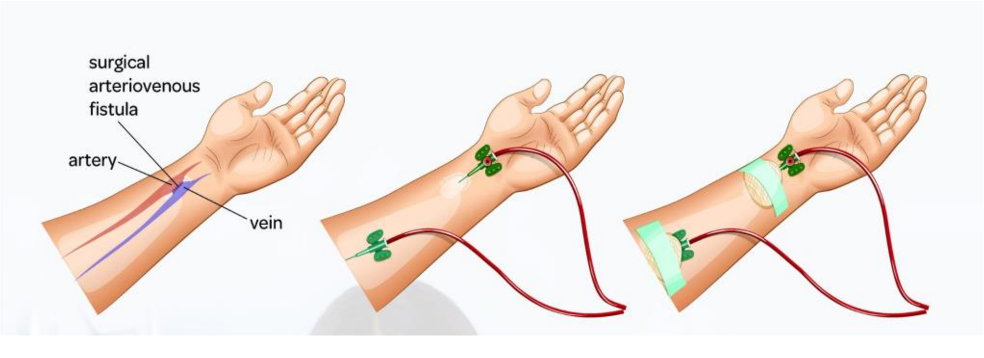
At this point we should mention that adequate preparation for RRT takes time and the timing of RRT initiation also affects the preparatory period. Patients initiated at higher levels of GFR may have decreased or increased opportunity to prepare for dialysis. However, while recent, studies have shown a trend in initiating therapy at higher levels of GFR these have not demonstrated evidence for improved outcomes although lead time bias may confound these data.

The 3 types of RRT are presented below:

1. Dialysis is a treatment to clean your blood when your kidneys are not able to. It helps your body remove waste and extra fluids in your blood. It does some of the work that your kidneys did when they were healthy. A healthy, working kidney can remove fluid and waste 24 hours a day. Dialysis can only do 10-15% of what a normal kidney does.

In hemodialysis, blood is removed from the body and filtered through a man-made membrane called a dialyzer, or artificial kidney, and then the filtered blood is returned to the body. The average person has about 10 to 12 pints of blood; during dialysis only one pint (about two cups) is outside of the body at a time. To perform hemodialysis there needs to be an access created to get the blood from the body to the dialyzer and back to the body. There are three access types for hemodialysis: arteriovenous (AV) fistula, AV graft and central venous catheter. The AV fistula is the vascular access most recommended by the dialysis community; however, you and your doctor will decide which access is best for you.

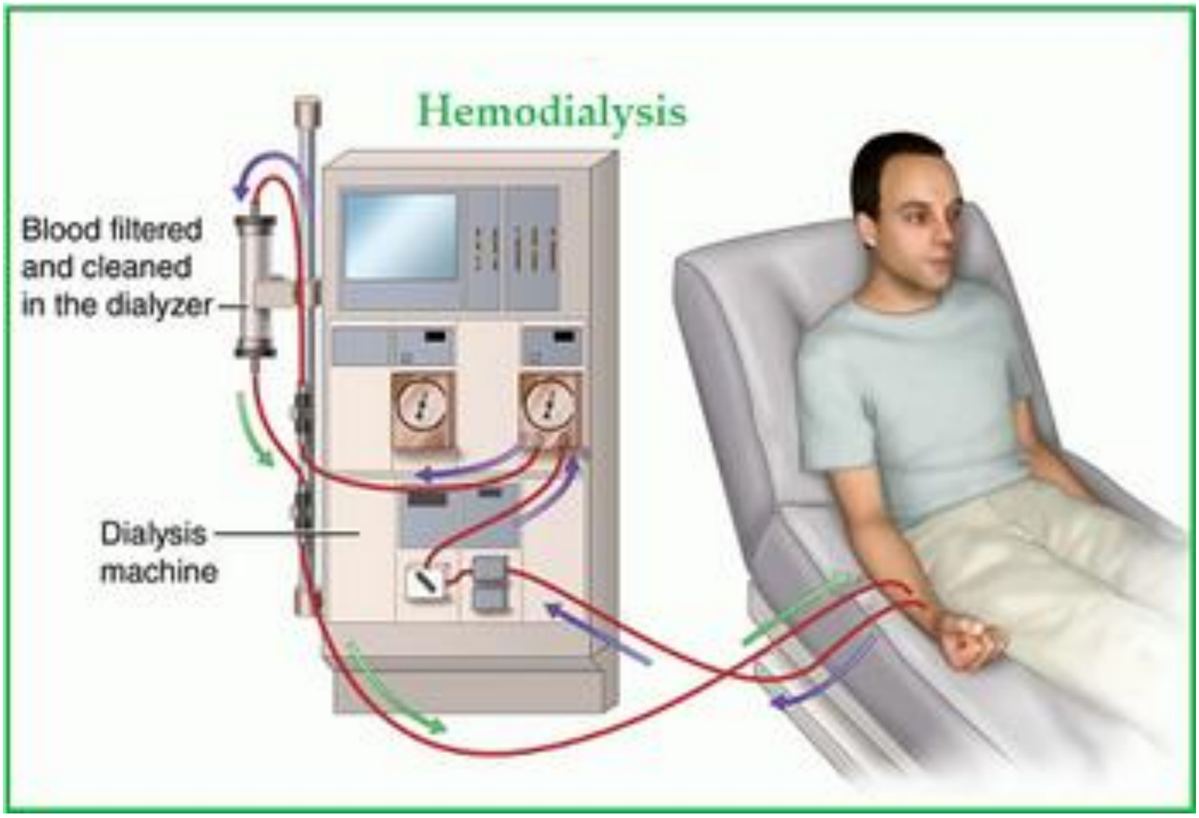
When a patient goes to hemodialysis, a nurse will check vital signs and get the patient's weight. The weight gain will tell how much excess fluid the patient has to have removed during the treatment. The patient is then "put on the machine". Patient with a vascular access (AV fistula or AV graft) will get two needle sticks in their access; one needle takes blood out of the body, the other needle puts it back. Patients with a central venous catheter will have the two tubes from their access connected to the blood tubes that lead to the dialyzer and back to the body. Once the patient is "put on the machine", the dialysis machine is programmed and then treatment begins.



Blood never actually goes through the dialysis machine. The dialysis machine is like a big computer and a pump. It keeps track of blood flow, blood pressure, how much fluid is removed and other vital information. It mixes the dialysate, or dialysis solution, which is the fluid bath that goes into the dialyzer. This fluid helps pull toxins from the blood, and then the bath goes down the drain. The dialysis machine has a blood pump that keeps the blood flowing by creating a pumping action on the blood tubes that carry the blood from the body to the dialyzer and back to the body. The dialysis machine also has many safety detection features. If you visit a dialysis center, you will likely hear some of the warning sounds made by a dialysis machine.

How does hemodialysis work?

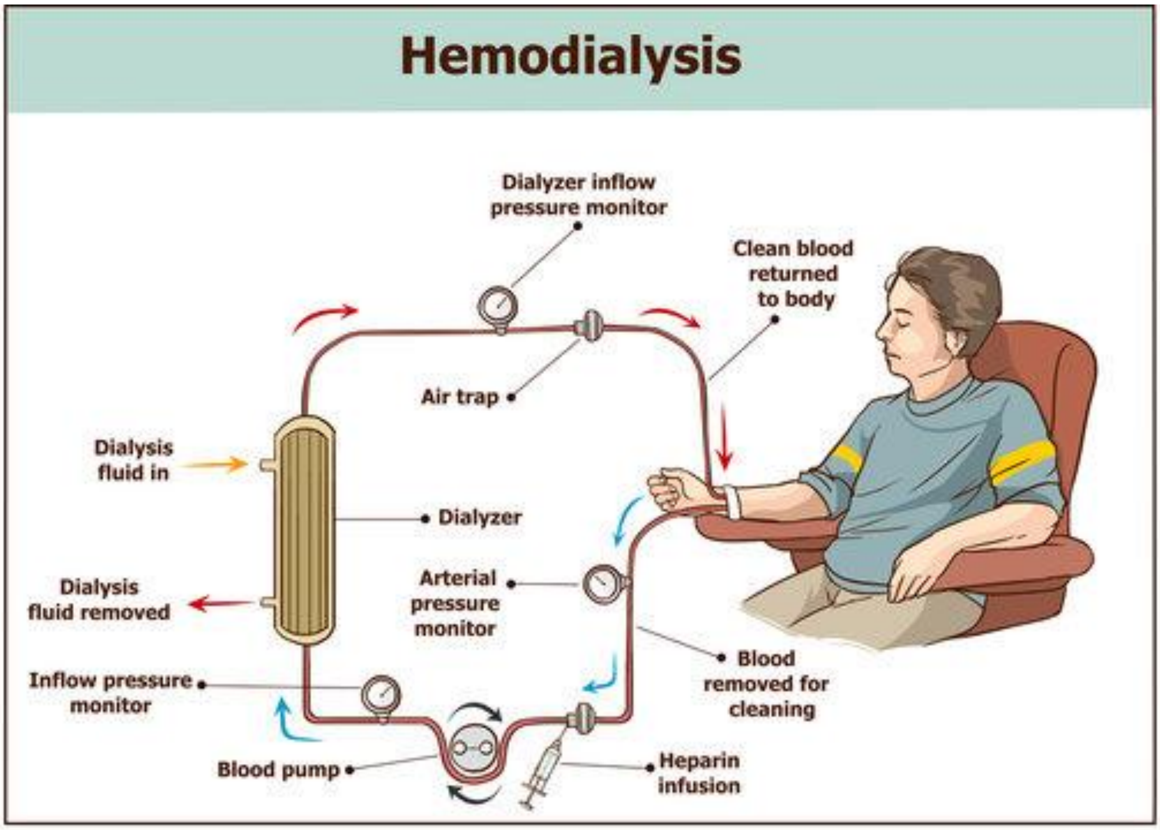
The dialyzer is the key to hemodialysis. The dialyzer is called the artificial kidney because it filters the blood — a job the kidneys used to do. The dialyzer is a hollow plastic tube about a foot long and three inches in diameter that contains many tiny filters. (Dialyzers are made in different sizes so doctors can prescribe the best one for their patients.) There are two sections in the dialyzer; the section for dialysate and the section for the blood. The two sections are divided by a semipermeable membrane so that they don't mix together. A semipermeable membrane has microscopic holes that allow only some substances to cross the membrane. Because it is semipermeable, the membrane allows water and waste to pass through, but does not allow blood cells to pass through.



Dialysate, also called dialysis fluid, dialysis solution or bath, is a solution of pure water, electrolytes and salts, such as bicarbonate and sodium. The purpose of dialysate is to pull toxins from the blood into the dialysate. The way this works is through a process called diffusion. In the blood of the hemodialysis patient, there is a high concentration of waste, while the dialysate has a low concentration of waste. Due to the difference in concentration, the waste will move through the semipermeable membrane to create an equal amount on both sides. The dialysis solution is then flushed down the drain along with the waste. The electrolytes in the dialysis solution are also used to balance the electrolytes in the patient's blood. The extra fluid is removed through a process called filtration. The fluid is pushed off by higher pressure on the blood side than on the dialysate side.

How often is hemodialysis done?

Blood needs to flow through the dialyzer for several hours to adequately clean the blood and rid the body of excess fluid. Traditional, in-center hemodialysis is generally done three times a week for about four hours each session. Your doctor will prescribe how long your treatments will be, usually between 3 to 5 hours, but most common is 4 hours. Talk to your doctor about how long you should be on hemodialysis. Some people feel that dialysis lasts a long time; however, healthy kidneys work 24 hours a day, 7 days a week and dialysis must do the job in only 12 or so hours a week.



In addition, people on dialysis often take the following medications and supplements:

i. A multivitamin preparation called B-complex, folic acid and vitamin C to offset the loss of these vitamins during dialysis
ii. Phosphorus binders to help keep phosphorous levels normal
iii. Stool softeners
iv. Pain medications
v. Blood thinners
vi. Cholesterol medicine
vii. Antihistamines for dry, itchy skin
viii. Iron or erythropoietin to manage anemia
ix. Active vitamin D to help balance calcium, phosphorus and parathyroid hormone (PTH)

2. Peritoneal dialysis is the second choice a treatment for kidney failure that uses the lining of your abdomen, or belly, to filter your blood inside your body. Health care providers call this lining the peritoneum. A few weeks before you start peritoneal dialysis, a surgeon places a soft tube, called a catheter, in your belly.

When you start treatment, dialysis solution—water with salt and other additives—flows from a bag through the catheter into your belly. When the bag is empty, you disconnect it and place a cap on your catheter so you can move around and do your normal activities. While the dialysis solution is inside your belly, it absorbs wastes and extra fluid from your body.
After a few hours, the solution and the wastes are drained out of your belly into the empty bag. You can throw away the used solution in a toilet or tub. Then, you start over with a fresh bag of dialysis solution. When the solution is fresh, it absorbs wastes quickly. As time passes, filtering slows. For this reason, you need to repeat the process of emptying the used solution and refilling your belly with fresh solution four to six times every day. This process is called an exchange.

You can do your exchanges during the day, or at night using a machine that pumps the fluid in and out. For the best results, it is important that you perform all of your exchanges as prescribed. Dialysis can help you feel better and live longer, but it is not a cure for kidney failure.

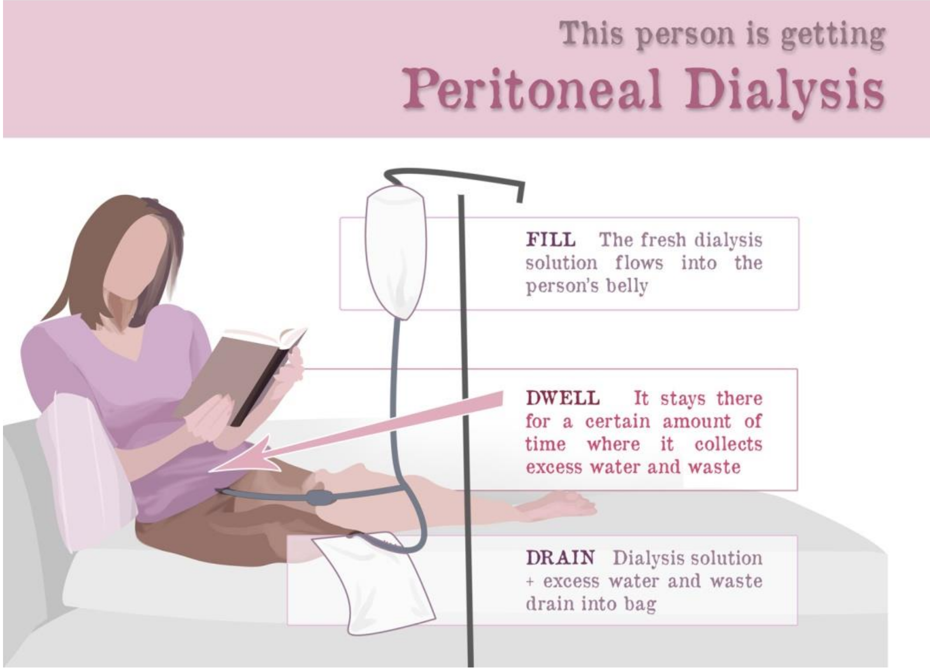
<u>What are the types of peritoneal dialysis?</u>

You can choose the type of peritoneal dialysis that best fits your life:

- continuous ambulatory peritoneal dialysis (CAPD)
- automated peritoneal dialysis
-

The main differences between the two types of peritoneal dialysis are:
the schedule of exchanges
one uses a machine and the other is done by hand

If one type of peritoneal dialysis doesn't suit you, talk with your doctor about trying the other type.



<u>CAPD</u> doesn't use a machine. You do the exchanges during the day by hand.
You can do exchanges by hand in any clean, well-lit place. Each exchange takes about 30 to 40 minutes. During an exchange, you can read, talk, watch television, or sleep. With CAPD, you keep the solution in your belly for 4 to 6 hours or more. The time that the dialysis solution is in your belly is called the dwell time. Usually, you change the solution at least four times a day and sleep with solution in your belly at night. You do not have to wake up at night to do an exchange.

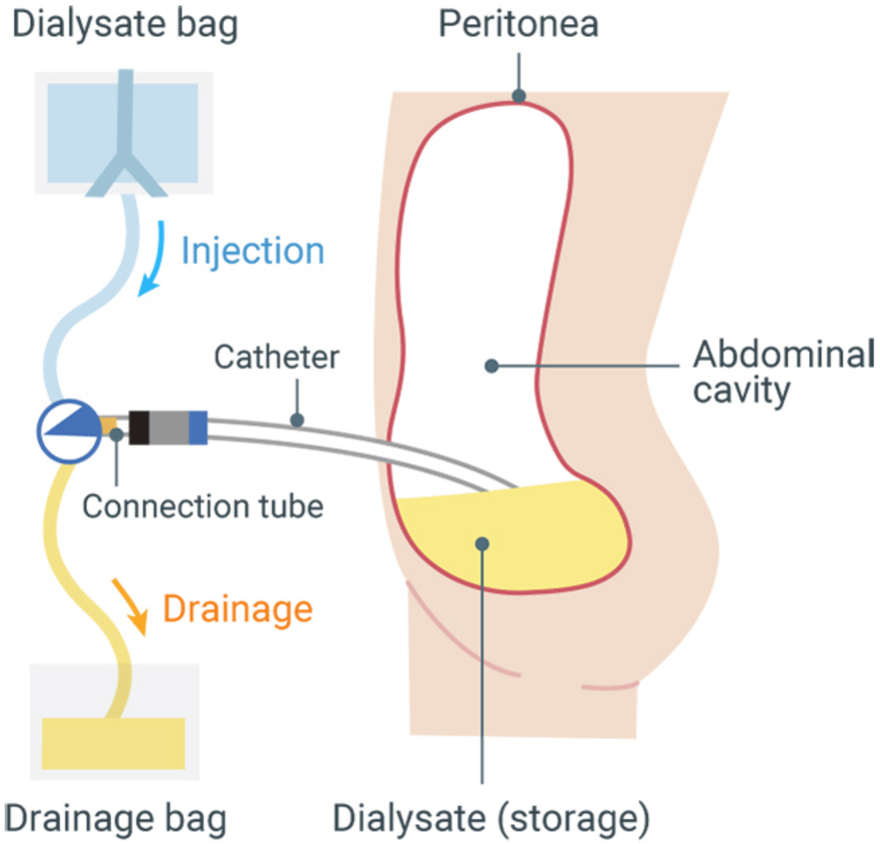
<u>Automated peritoneal dialysis</u>. A machine does the exchanges while you sleep.
With automated peritoneal dialysis, a machine called a cycler fills and empties your belly three to five times during the night. In the morning, you begin the day with fresh solution in your belly. You may leave this solution in your belly all day or do one exchange in the middle of the afternoon without the machine. People sometimes call this treatment continuous cycler-assisted peritoneal dialysis or CCPD.

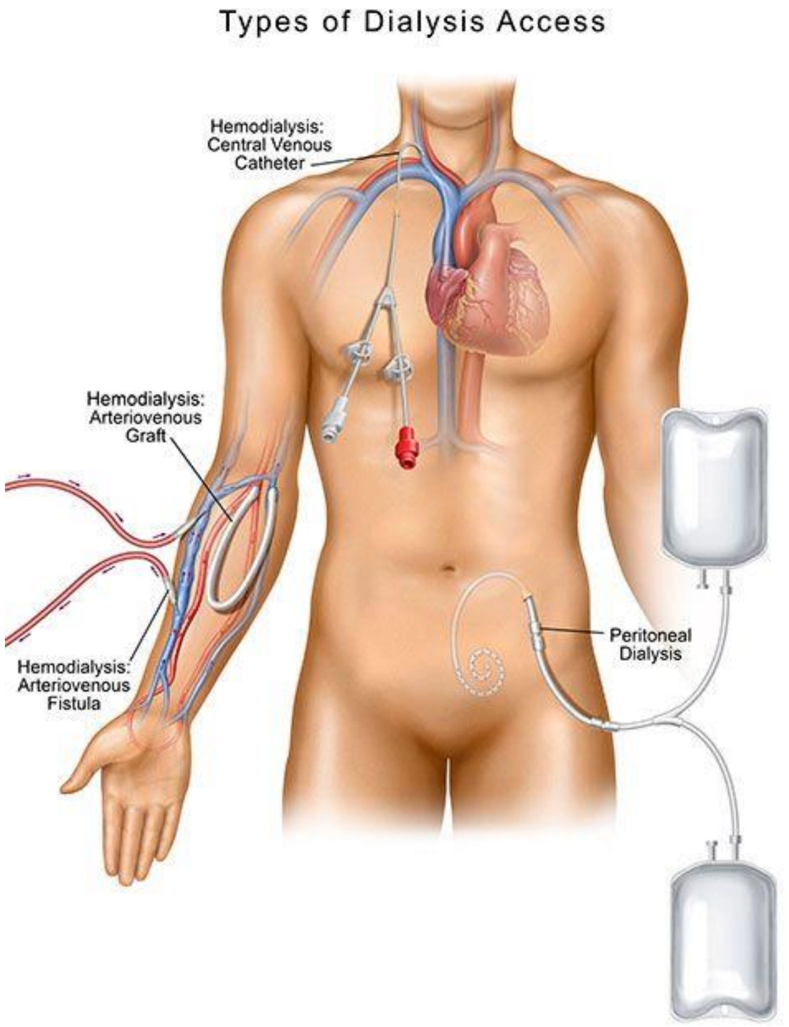
<u>Suggestions to protect your peritoneal catheter from infections:</u>

An infection in your belly, called peritonitis, is the most common problem that happens in people who do PD. If you do not clean the area where your catheter goes into your body, bacteria may get into your belly. Bacteria may also get into your catheter while you connect or disconnect from your dialysate bags.

You will need to take good care of your catheter and safely do your exchanges to prevent an infection. To help prevent peritonitis:

- ✓ Wash your hands very well before touching your catheter
- ✓ Clean the area where your catheter goes into your body every day
- ✓ Use an antibiotic spray on the area where your catheter goes into your body
- ✓ Keep your catheter dry at all times
- ✓ Store your PD supplies in a clean, dry area
- ✓ Wear a mask while you do exchanges
- ✓ Only do exchanges in clean, dry places
- ✓ Watch for signs of infection, including:
- ✓ Fever
- ✓ Redness or pain around the catheter
- ✓ Dialysate that looks cloudy or off-color when you drain it from your belly



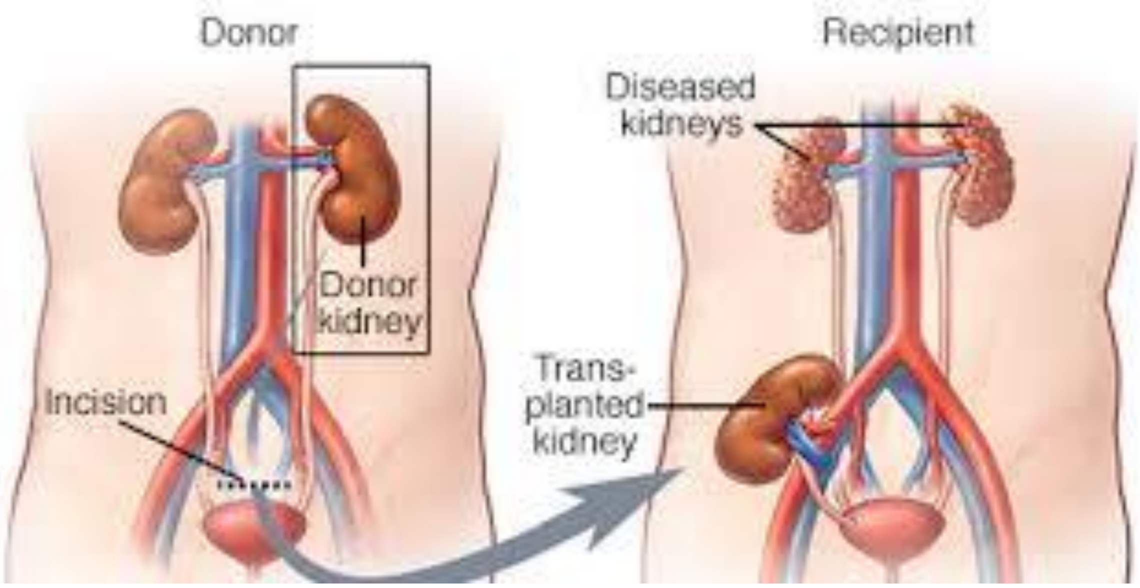


Types of Dialysis Access

3. A kidney transplant is a surgical procedure to place a healthy kidney from a living or deceased donor into a person whose kidneys no longer function properly.

During a kidney transplant, your surgeon will take a donated kidney and place it in your body. Even though you’re born with two kidneys, you can lead a healthy life with only one functioning kidney. After the transplant, you’ll have to take immune-suppressing medications to keep your immune system from attacking the new organ.

You’ll need to be healthy enough to have major surgery and tolerate a strict, lifelong medication regimen after surgery to be a good candidate for a transplant. You must also be willing and able to follow all instructions from your doctor and take your medications regularly. This medication ensures that your body does not reject the transplanted kidney. You will need to continue taking this medication for the rest of your life. The medication inhibits the immune response of the body. This means that you will also be more susceptible to infections. The medication increases the risk of cardiovascular disease and cancer (particularly skin cancer). You may also suffer from side effects. These side effects differ for different medicines.



If you have a serious underlying medical condition, a kidney transplant might be dangerous or unlikely to be successful. These serious conditions include:

- cancer, or a recent history of cancer
- serious infection, such as tuberculosis, bone infections, or hepatitis
- severe cardiovascular disease
- liver disease

A kidney transplant can free you from a long-term dependence on a dialysis machine and the strict schedule that goes with it. This can allow you to live a more active life. However, kidney transplants aren't suitable for everyone. This includes people with active infections and those who are severely overweight.

It is true that a kidney transplant has a positive impact on someone's future life. But there are also some disadvantages. After a kidney transplant, you will need to take medication.

What is a "preemptive" or "early" transplant?

Getting a transplant before you need to start dialysis is called a preemptive transplant. It allows you to avoid dialysis altogether. Getting a transplant not long after kidneys fail (but with some time on dialysis) is referred to as an early transplant. Both have benefits. Some research shows that a pre-emptive or early transplant, with little or no time spent on dialysis, can lead to better long-term health. It may also allow you to keep working, save time and money, and have a better quality of life.

Who can get a kidney transplant?

Kidney patients of all ages—from children to seniors—can get a transplant.

You must be healthy enough to have the operation. You must also be free from cancer and infection. Every person being considered for transplant will get a full medical and psychosocial evaluation to make sure they are a good candidate for transplant. The evaluation helps find any problems, so they can be corrected before transplant. For most people, getting a transplant can be a good treatment choice.

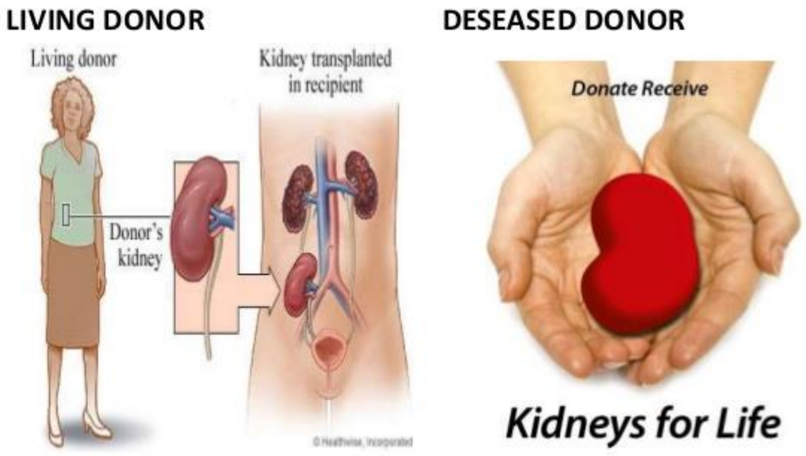
Deceased-donor kidney transplant

A deceased-donor kidney transplant is when a kidney from someone who has recently died is removed with consent of the family or from a donor card and placed in a recipient whose kidneys have failed and no longer function properly and is in need of kidney transplantation.

The donated kidney is either stored on ice or connected to a machine that provides oxygen and nutrients until the kidney is transplanted into the recipient. The donor and recipient are often in the same geographic region as the transplant center to minimize the time the kidney is outside a human body.
Only one donated kidney is needed to sustain the body's needs. For this reason, a living person can donate a kidney, and living-donor kidney transplant is an alternative to deceased-donor kidney transplant.

Living-donor kidney transplant
A living-donor kidney transplant is when a kidney from a living donor is removed and placed into a recipient whose kidneys no longer function properly.
Only one donated kidney is needed to replace two failed kidneys, which makes living-donor kidney transplant an alternative to deceased-donor kidney transplant.

TYPES OF DONORS



Your medication will change after your transplant with some tablets, such as phosphate binders and vitamin supplements stopping and new tablets starting. You will be given a list of new medication before you leave the hospital.

The most important new tablets you will be started on are called immunosuppressants. These tablets stop your immune system from rejecting the kidney and should be taken regularly every day you have a functioning transplant. Because these medications reduce your own natural immune system, you will also be given medication to prevent you getting some serious infections.

Initially you are likely to be on a combination of three medicines:

- Tacrolimus
- Mycophenolate Mofetil
- Prednisolone

If you do not take these medications as prescribed, it will result in rejection and the loss of your new kidney.

These drugs need to be finely tuned as too little may lead to rejection and too much may lead to infection. Early after the transplant the need for immunosuppression is high but this need lessens with time, so the drugs will be slowly reduced by your doctors. The level of these drugs have to be monitored in the blood. When you come to clinic, do not take your tablets until after you have had your blood taken. After the clinic, you may be telephoned to change the dose of the tablets you are taking or asked to return for further blood tests.

Self-assessment test

Part A – multiple choice

Please reply to the following questions to assess your knowledge of this unit. Note that only one option is correct.

1. We call artificial kidney:
   a. the dialyzer
   b. the dialysis machine
   c. the dialysate

2. During the Automated peritoneal dialysis the patient
   a. does the exchanges during the day by hand.
   b. usually sleeps, a machine does the exchanges
   c. has to watch the machine performing the exchanges

3. What is a kidney transplant?
   a. Is a surgical procedure to place a healthy kidney from a deceased donor into a person whose kidneys no longer function properly
   b. is the transfer of a healthy kidney a living donor into the body of a person who has little or no kidney function
   c. Both are true

4. What is a preemptive transplant?
   a. A kidney transplant prior dialysis
   b. A heart transplant
   c. A kidney transplant for patients on peritoneal dialysis

Part B – drag & drop

Please match the correct answers:

Peritoneal dialysis is the choice of treatment	the dialysis solution or bath
Dialysate we name	Includes water with salt and other additives
A/V fistula is a surgery	that filters your blood inside your body
Peritoneal dialysis solution	that creates an access point for the dialysis machine

Enrich your knowledge

Please visit the following websites:

- European Renal Association-European Dialysis and Transplant Association (ERA-EDTA): https://www.era-edta.org/en/
- European Kidney Patients Federation (EKPF): www.ekpf.eu
- International Society of Nephrology (ISN): https://www.theisn.org/
- European Kidney Health Alliance (EKHA): www.ekha.eu
- Panhellenic Renal Patients Association: https://psnrenal.gr/
- Hellenic Society of Nephrology: www.ene.gr
- Nephron website: www.nephron.gr

Face2face part

Worksheet 1.2.1 – Welcome process

Objective: warm-up, introduction of the topic

Duration: 10 minutes

Implementation: Participants will be asked to present themselves, to share with the rest of the team experiences they might have relevant to the topic of the module

Worksheet 1.2.2 – Open dialogue about the information participants obtained

Objective: the participants are free to express their thoughts, concerns, questions about this module

Duration: 40 minutes

Implementation: the moderator will ask each participant to give a detailed description of the modules' topics, to refer any comments or expressing any question. After that and for the dialogue to begin between the participants the moderator will ask:

- If this module's piece of information is adequate for a patient who is at stage 4 of CKD
- Which could be the interventions of a nephrologist to help his/her patients choosing the most suitable treatment for him/her?
- Would it be better the patients remaining without knowledge about RRT and allow their doctors to choose the best treatment for them?
- Is it easy for someone to decide becoming an organ donator?

Worksheet 1.2.3 – Role playing

Objective: Role play as a method to disseminate the information the participant obtained on this module

Duration: 30 minutes

Implementation: Each participant will try to reflect and disseminate, on his own words, what he has learned. The rest members of the team will interact as the ''patient or a caregiver'' who looks for information about available RRT. The moderator will conduct each partner so they to improve their technique of approaching and informing a patient or a caregiver about RRT.

Module 1.3 -Medication

Theme	1.3 Medication
GOAL(S) AND OBJECTIVES	Objective of this module is to: • Inform the learners about the existing types of RRT • Present the applied method of each therapy that a patient with ESKD has to follow • Explain in a simple way the surgical operations each therapy involves
LEARNING OUTCOMES	After completing this module the learners will have obtained the necessary knowledge to detect and describe the basic differences between renal replacement therapies
METHODS	Self-directed learning
DURATION:	20 minutes online and 25 minutes face-to-face
RESOURCES NEEDED:	• lap-top with internet connection • mobiles phones with internet connection • Flipchart and markers • Papers, markers, pens
ORDER OF ACTIVITIES:	• E-learning module (20 min.) Face to face: • Welcome process (5 min.) Worksheet 1 • Introduction to the contents of this module (15 min.) – Worksheet 2 • Conclusions (5 min.)
EVALUATION OF THE THEME:	• Self-assessment (e-learning module)
REFERENCES	•
WORKSHEETS	• Worksheet 1 • Worksheet 2
HANDOUTS	None

Background information – e-learning:

Introduction

Ensuring patient safety is a priority of medical care because iatrogenic injury has been a primary concern. Medications are an important source of medical errors, and kidney disease is a thoroughfare of factors threatening safe administration of medicines. Principal among these is reduced kidney function because almost half of all medications used are eliminated *via* the kidney. Additionally, kidney patients often suffer from multimorbidity, including diabetes, hypertension, and heart failure, with a range of prescribers who often do not coordinate treatments.

Take medicines as prescribed

Many people with CKD take medicines prescribed to lower blood pressure, control blood glucose, and lower cholesterol. Many people need to take two or more medicines for their blood pressure. You may also need to take a diuretic, sometimes called a water pill. The aim is to meet your blood pressure goal. These medicines may work better if you limit your salt intake.

Know that your medicines may change over time
Your health care provider may change your medicines as your kidney disease gets worse. Your kidneys don't filter as well as they did in the past, and this can cause an unsafe buildup of medicines in your blood. Some medicines can also harm your kidneys. As a result, your provider may tell you to:

- take a medicine less often or take a smaller dose
- stop taking a medicine or switch to a different one

Your pharmacist and health care provider need to know about all the medicines you take, including OTC medicines, vitamins, and supplements.

Be careful about the over-the-counter medicines or the antibiotics you take

If you take OTC or prescription medicines for headaches, pain, fever, or colds, you may be taking nonsteroidal anti-inflammatory drugs (NSAIDs). NSAIDs include commonly used pain relievers and cold medicines that can damage your kidneys and lead to acute kidney injury, especially in those with kidney disease, diabetes, and high blood pressure. NSAIDs medicines are sold under many different brand names, so ask your pharmacist or health care provider if the medicines you take are safe to use.

If you have been taking NSAIDs regularly to control chronic pain, you may want to ask your health care provider about other ways to treat pain, such as meditation or other relaxation techniques.

Tips for managing your medicines:

An informed patient is better equipped to handle kidney disease and more likely to stay healthy longer. As part of understanding chronic kidney disease, patients must talk with their health care team and get an understanding of all their prescribed medications. Learning the names of all the medicines being taken and how each one supports kidney health is vital to a person's well-being. It is vital to a person's well-being to:

- ✓ Learn the name of each prescribed medication
- ✓ Understand the function of each medication
- ✓ Know when to take different medications, i.e. before or after meals, at bedtime, etc.
- ✓ Know which medications can or cannot be taken together

Keeping medications organized is also important, and these tips should be considered:

Forming daily habits – It's suggested to get into the habit of taking medications at the same time each day. Link them to another daily event, such as a meal time or bed time, making it easier to stick to a schedule.
Pill organizers - A pill organizer is an effective way to divvy up pills to be certain to take the correct daily doses. An organizer that has separate sections for the days of the week and also different times of day can be helpful. For tech-savvy people, electronic versions of pill organizers may work best. To differentiate between medications and supplements, color-coded bottles can be useful, too.

Additionally, the next time you pick up a prescription or buy an OTC medicine or supplement, ask your pharmacist how the product may:

1. affect your kidneys
2. affect other medicines you take
3. have harmful interactions
4. And finally, Keep track of your medicines and supplements:

   Keep an up-to-date list of your medicines and supplements in your wallet. Take your list with you, or bring all of your medicine bottles, to all health care visits.

Self-assessment test

Part A – Fill the gaps with the appropriate answer

Please reply to the following sentences to assess your knowledge of this unit. Note that only one option is correct.

5. A patient with CKD should know that his physician may suggest him _________ the medicines he receives
    a. Buying and storing
    b. switching or stopping
    c. continuning and increasing the dosage of

6. A daily habit a patients should follow is to receive his medicines at the same ________ each day
    a. order
    b. time
    c. meal

7. It is really imprortant and vital for a patient's well-being to underastand the ________ of each drug

    a. name
    b. scheme
    c. function

Part B – drag & drop

Please match the correct answers:

OTC medicines or supplement	helps patients to take the correct daily doses
Pill organizers	may affect your kidneys
A well informed patient is necessary to	AKI (Acute Kidney Injury)
Nonsteroidal anti-inflammatory drugs (NSAIDs) it is likely to lead to	Know which medications can or cannot be taken together

Enrich your knowledge

Please visit the following websites:

- Hellenic Society of Nephrology: www.ene.gr
- Nephron website: www.nephron.gr

Face2face part

Worksheet 1.3.1 – Welcome process

Objective: warm-up, introduction of the topic

Duration: 5 minutes

Implementation: Participants will be asked to present themselves, to express their initial opinions about the topic of the module

Worksheet 1.3.2 – A practical session about correct medicines' organizing

Objective: The participants will have the opportunity to watch a lesson about correct medicines' organizing and then express their questions

Duration: 15 minutes

Implementation: the moderator will start presenting in a more detailed way paradigms of organizing the medicines patients take

Module 2- How to manage CKD and ESRD in daily activities

Theme	**2.1 Physical activity in CKD and ESRD patients**
GOAL(S) AND OBJECTIVES	Aim of this module is to provide to learners: • Useful information to adapt physical activity to people with CKD and ESRD • Practical tools that help careers to adapt physical exercises to ESRD patients and in each stage of CKD
LEARNING OUTCOMES	At the end of the section 2.1, learners will have obtained information and tools regarding how to adapt physical activity on CKD and ESRD patients
METHODS	Self-directed learning
DURATION:	30 minutes online and 1 hour face-to-face
RESOURCES NEEDED:	• lap-top with internet connection • projection screen and light cannon • hand dynamometer Note: advise participants in advance that they must wear comfortable clothing
ORDER OF ACTIVITIES:	• E-learning module (30 minutes) Face to face: • Welcome and introduction (10 min.)- Worksheet 1 • Theoretical session (20 min.) – Worksheet 2 • Practical session (40 min.) - Worksheet 3
EVALUATION OF THE THEME:	• Self-assessment (e-learning module)
REFERENCES	•
WORKSHEETS	• Worksheet 1 • Worksheet 2 • Worksheet 3
HANDOUTS	None

Background information – e-learning:

Introduction

People with chronic kidney disease (CKD) are often inactive and often have difficulty performing activities of daily living and have a health-related decrease in their quality of life compared to healthy people. It is also known that a sedentary lifestyle is a risk of morbidity and mortality in people with CKD. Currently, the promotion of physical activity among this group should be an integral part of the treatment and the positive benefits of regular exercise should be known. It benefits patients both physically and psychologically, increasing strength, aerobic capacity, and health-related quality of life. The exercise program must be adapted to the functional capacity and comorbidities of each person. Promoting the habit of exercise can lead to a better health-related quality of life.

Physical activity adapted CKD and ESRD patients

A moderate and continuous exercise maintained for 30 minutes and practiced between 3 and 5 days a week is something that we should maintain in our life as an essential healthy habit.

Many patients with chronic kidney disease (CKD) believe that they should not do physical exercise and maintain a certain amount of rest, but this is due to the lack of knowledge regarding what type of exercise they should do, how to do it and how often to do it. However, it is important that they know that moderate exercise will not only help them eliminate risk factors that can be linked to the disease over time, but that it will make them feel stronger in their day to day and with a better state. of courage to face the limitations and treatments that the disease requires.

As for the type of exercise that we should do, the ideal is to combine an aerobic exercise in which we work the large muscle groups for a while (30 minutes) while controlling our breathing well: walking, swimming, dancing, playing tennis, riding a bike (static or walking), etc., with strength or toning exercises in which we will use elements that provide resistance such as weights (no more than 1 kg), elastic bands, foam rubber balls, etc., always using little resistance but performing many repetitions to define our muscles well, achieving a good muscle tone but without fatigue.

When in doubt about when it is better to do physical exercise, the answer is that each person should look for the best time to do it, and the time when their other activities allow it. The advantages of exercising in the morning is that we help our metabolism to start up and accelerate the process of burning fat that remains during the hours following the practice of exercise, it also fills us with energy, activates circulation and prepares us to face daily activities.

The frequency when practicing exercise must be continuous, that is to say, perform aerobic exercise daily (even if it is a light walk of half an hour), and the strength exercise must be carried out on alternate days to allow the muscle groups that we have involved in exercise rest and recover from the effort made.

The limit of physical effort during exercise should be decided by each person according to their age and their physical condition. We must know how to control our effort and a very simple way to do it is to be able to have a conversation while we do the exercise, that way we will know that our heart rate is optimal so that the exercise is really beneficial and that our breathing is correct.

We must stop exercising when we feel that we cannot breathe well, that we have cramps in our legs, that we suddenly have an irregular heartbeat or an unknown prick in our chest, nausea or vomiting.

Always before starting an exercise routine we must consult our specialist doctor and if there is any change in our life such as having a fever, changing a treatment, having joint pain or excessive muscle fatigue we will have to avoid exercising and consult with the doctor

Physical activity in dialysis patients

Peritoneal dialysis (PD): exercise patients can improve dyslipidemia control, glucose metabolism, and excess weight. However, activities that increase intra-abdominal pressure should be avoided.

Stable Hemodialysis (HD): different programs can be proposed, such as home exercise programs, supervised exercise training, hospital gym, and exercise activity during the hemodialysis session. Home exercise programs, useful for people on PD and HD, can, on the one hand, motivate the person to increase the time and intensity of the usual activities of daily life, such as walking, using pedometers. We can also propose strength programs, these are more structured, consist of training sessions, two / three times a week, where people will follow exercise guidelines that will be controlled by the referral person at the hospital. These home sessions should be carried out on non-dialysis days for the HD modality (15). On the other hand, we can also find the modality of intra-dialysis physical exercise for patients on HD.

They are usually low intensity exercises where coordination, strength and resistance are worked. The most used material in these programs are medicine balls, rubber bands, dumbbells, weights and cycloergometers. These exercise sessions must be supervised and guided by trained professionals; the most effective is a physiotherapist, since many times we find that dialysis personnel observe the exercise program as a factor that alters their skills and workloads; however, some programs are currently operating successfully with the involvement of an experienced and trained nurse.

Physical activity in informal caregivers

Physical activity in caregivers is also a necessary habit to be able to face the challenges that caring for a person with kidney disease offers them.

The recommended tests will also help you adapt your physical exercise to your conditions, age, etc.

Physical activity will help you feel better and also improve your emotional situation, preventing other health problems

Key messages

- The promotion and advice on physical exercise, as well as the implementation of the exercise program, should be part of the clinical care of these people.

- Most people with kidney disease should be encouraged to progress in their daily activities, such as walking, dancing, and so on.

- An exercise program should include both strength, endurance and aerobic activities, with duration and intensity adjusted for each person, along with flexibility, mobility and stretching exercises.
- Exercise programs must be adapted to the comorbidities of each person and these must be controlled and supervised by trained professionals and experts.

Functional tests to help us start doing physical exercise:

"Short Physical Performance Battery" (SPPB).

It includes three tests:

1.- Balance: with the feet together, in a semi-tandem and tandem position, it is assessed whether the person can maintain each of these positions up to a maximum of ten seconds, the balance assessment ranges from 0 to 4 points .

A. Side-by-side-stand: Held for 10 sec: 1 point. Not held for 10 sec: 0 points. Not attempted: 0 points.

B. Semi-Tandem Stand Held for 10 sec : 1 point. Not held for 10 sec: 0 points. Not attempted: 0 points (circle reason above) If 0 points, end Balance Tests Number of seconds held if less than 10 sec: . sec

C. Tandem Stand Held for 10 sec.: 2 points Held for 3 to 9.99 sec: 1 point Held for < than 3 sec: 0 points Not attempted: 0 points (circle reason above).

2.- Walking speed in 4 meters at usual speed; Two timed attempts are made and the best of them is recorded, so that according to the second employees a score of 1 to 4 is assigned. If time is more than 8.70 sec: 1 point, If time is 6.21 to 8.70 sec: : 2 points, If time is 4.82 to 6.20 sec:: 3 points, and If time is less than 4.82 sec:: 4 points.

3.- Test "STS-5", which consists of measuring the time taken to get up and sit down from the chair five times; time stops when the person reaches the standing position on the 5th repetition and according to the time spent a score of 0 to 4 points is assigned. Participant unable to complete 5 chair stands or completes stands in >60 sec:: 0 points, If chair stand time is 16.70 sec or more: 1 points, If chair stand time is 13.70 to 16.69 sec:: 2 points, If chair stand time is 11.20 to 13.69 sec:.: 3 points, and If chair stand time is 11.19 sec or less:: 4 points.

Finally, all the points are added and we have a result that ranges from 1 to 12 points. A score of 0 to 3 indicates that the person has severe limitations; from 4 to 6, moderate; 7 to 9, mild; and from 10 to 12, minimal or without limitation.

The "Timed Up and Go" test (TUG):

From a standard-height chair with armrests, the person gets up, walks 10 feet, and returns to the starting position. The time and degree of difficulty are recorded according to the scale of perceived exertion (PSE).

- The “STS-10” and “STS-60” tests. The first one consists of measuring the seconds that the person needs to get up from a sitting position and sit down again ten consecutive times. The test is performed on a chair without armrests approximately 44.5 cm high, 38 cm deep leaning against the wall to minimize the risk of falling. The person is allowed one attempt, indicating that the arms must remain crossed in front of the chest. After performing the ten repetitions, the time used is recorded. The STS60 consists of performing the maximum number of repetitions of getting up and sitting back in the chair in a time of sixty seconds. After that time the repetitions are recorded.

The test "The six minutes walking test" (6MWT):

The person must wear comfortable shoes. Before the test, and after sitting for five minutes, the baseline heart rate and blood pressure were recorded using a digital sphygmomanometer in the arm without fistula. The patient is then instructed to cover the maximum distance at an active pace for six minutes. The order given is as follows: 'walk as far as possible in a time of six minutes'. It is allowed to carry out the test with aids for ambulation or to stop and restart the march in case of needing a rest. The information on the elapsed time, the form and the moments in which the person is encouraged according to the procedure is standardized. Immediately after the test, the pulse and blood pressure should be taken. The distance traveled in meters is recorded and the person is asked to describe EEP.

JAMAR Dynamometer:

Finally, muscle strength can also be recorded using the hand dynamometry test (JAMAR Dynamometer), since there are studies in people on dialysis that correlate the grip strength of the hand with their health status and it is a very simple test . People sit in a chair, with their feet resting on the floor and their knees bent 90º. The shoulder of the arm that is recording remains in neutral rotation, elbow in 90º flexion resting on the table, semi-prone wrist and forearm (0-30º) and an ulnar deviation between 0 and 15º. There are 3 consecutive repetitions with a fifteen second rest between them, in each of the upper limbs, starting with the dominant arm; finally, the maximum force value is recorded.

Conclusions

- Before starting any physical exercise program, a series of functional tests should be measured.
- These bump tests can be evaluated by several simple tests that do not require any special devices.
- Tests that assess functional capacity should be implemented in the routine clinical practice of people with kidney disease.

Self-assessment test

Part A – multiple choice

Please reply to the following questions to assess your knowledge of this unit. Note that only one option is correct.

1. Can any CKD and ESRD patient practice regular physical activity?
    a. Only transplant patients can perform physical activity
    b. Everyone except those with heart problems
    c. All CKD and ESRD patients, whatever their condition, although an evaluation and adaptation will be needed
2. How can I Adapt physical activity to a CKD and ESRD patients?
    a. Performing a strength test before, to check his/her limits
    b. Adjusted duration and intensity for each person, along with flexibility, mobility and stretching exercises.
    c. Opting for moderate exercises such as walking or small stretches.
3. Which of the following sentences is false:
    a. Haemodialysis patients should avoid exercises that offer intra-abdominal pressure
    b. A patient on peritoneal dialysis perform any physical activity with adaptation
    c. Transplanted patients can perform strength exercises

Part B – drag & drop

Please match the functional test with it measurement system

Short Physical Performance Battery	Maximum number of repetitions of getting up and sitting back in the chair in a 60 seconds
JAMAR Dynamometer	Walk as far as possible in a time of 6 minutes
"Timed Up and Go" test (TUG)	Recording the maximum force value
The test "The six minutes walking test" (6MWT)	Adding a score between 1 to 12 points to access the limitations.

Video

Example: Add a video- demonstration with an expert in physical activity performing exercises adapted people with CKD.

To learn more

To learn more, you can visit the following websites:

- ALCER, Spanish Kidney Patients´ Federation (official webpage): https://www.alcer.org
- ALCER, Spanish Kidney Patients´ Federation (educational webpage): https://www.personasrenales.org
- Proffesional experts in adaptation of phisical activity (Traïnsplant): https://www.trainsplant.com/

Face2face part

Worksheet 2.1.1 – Welcome and introduction

Objective: explain the development of the session; know the characteristics of the participants and analyse what we will need during it.

Duration: 10 minutes

Implementation: describe the session, which will consist of a theoretical and a practical part, where useful ways of adapting exercise to forgive with chronic kidney disease will be shown. Subsequently, each participant will be asked the characteristics of the people with CKD they attend to. It will end with a practical workshop on what was learned in the session.

Worksheet 2.1.2 – Theoretical session: physical activity in CKD and ESRD

Objective: acquire basic knowledge to help them identify the exercise needs of people with CKD and how to adapt them to their situation.

Duration: 20 minutes

Implementation: The speaker will explain the advantages of adapted physical activity in people with CKD. It will focus on the disease conditions of the participants, as reported in the introductory part (take up the e-learning theoretical material). An interactive session will be offered asking participants to clarify their doubts at any time during the explanation.

Worksheet 2.1.3 – Practical session: adapting physical activity to CKD people

Objective: provide participants with practical tools to help them in their daily life.

Duration: 40 minutes

Implementation: the monitor will ask a volunteer to carry out the exercise under his supervision and will guide him/her. It will be requested after each participant performs the exercise. At the end of each exercise the monitor will review the scores obtained and advise the participants based on each score.

The practical exercises will be executed in this order:

1. "Short Physical Performance Battery" (SPPB)
2. “Timed Up and Go” test (TUG)
3. The test "The six minutes walking test" (6MWT)
4. JAMAR dynamometer

Finally the session will end with a question and answer section.

Module 2- How to manage CKD and ESRD in daily activities

Theme	**2.2 Nutrition and fluid intake**
GOAL(S) AND OBJECTIVES	Aim of this module is to provide to learners: • Acquire the basics about adapting the diet for people with chronic kidney disease. • Know how kidney disease affects diet
LEARNING OUTCOMES	At the end of the section 2.2, learners will have obtained information and tools regarding how to adapt the diet and fluid intake on the different stages of CKD.
METHODS	Self-directed learning
DURATION:	2 hours online and 3 hour face-to-face
RESOURCES NEEDED:	• lap-top with internet connection • projection screen and light cannon • nutritional cards • different foods in different states: fresh, canned, cooked • cookware, some spices, olive oil, etc.
ORDER OF ACTIVITIES:	• E-learning module (2 hours) Face to face: • Welcome and introduction (10 min.)- Worksheet 1 • Theoretical session (30 min.) – Worksheet 2 • Nutritional games (50 min.) - Worksheet 3 • Cooking workshop (1 hour and 30 minutes) – Worksheet 4
EVALUATION OF THE THEME:	• Self-assessment (e-learning module)
REFERENCES	
WORKSHEETS	• Worksheet 1 • Worksheet 2 • Worksheet 3 • Worksheet 4
HANDOUTS	food composition tables

Background information – e-learning:

Why does chronic kidney disease (CKD) affect the diet?

The kidneys are responsible, among other functions, for cleaning the blood of our body. When kidney disease occurs and it significantly affects the function of both kidneys (the kidneys work less than 50%), some complications may begin to appear.

Goals in diet in CKD

- Trying to make this disease progress as slowly as possible
- Not increasing the levels of some toxins in the blood through the foods we eat
- Maintaining an adequate nutritional state.
- And, in general, keeping ourselves in the best possible conditions.

Don't forget: your nutritional status will depend, fundamentally, on the diet you eat. The person with kidney disease, over time, can go through several stages or treatments: pre-dialysis, dialysis and / or kidney transplantation.

The nutritional recommendations will vary in some aspects from one stage of the disease to another, likewise, within the same stage there may be differences according to sex, weight, height, activity level, etc. For any question or doubt, please ask your nephrologist or dietician.

Nutritional parameters

Protein:

Proteins are a necessary nutrient for the repair and formation of cells and tissues, as well as for the proper functioning of the defensive system. Proteins are formed by the union of small molecules called amino acids, some of these amino acids are produced within our body, however others must be taken from outside, with food. If we did not take these amino acids, we would be lacking, and we could become malnourished (these amino acids that are not produced in our body are called essential amino acids). Proteins that contain a large amount of essential amino acids are called proteins of high biological value and are found mainly in fish, meat, milk and eggs.

The amount of recommended proteins is different depending on the stage of the disease in which you are.

Sodium:

Sodium (salt) is a mineral found in almost all foods. Too much sodium can make you thirsty, which can lead to bloating and raise your blood pressure. This can cause more damage to your kidneys and make your heart work harder.

One of the best ways to stay healthy is to limit your sodium intake. To limit sodium in your meal plan:

- Don't add salt to your food when you cook or eat. Try cooking with fresh herbs, lemon juice, or unsalted spices.
- Choose fresh or frozen vegetables over canned vegetables. If you are using canned vegetables, drain and rinse them to remove the salt before cooking or eating.
- Avoid processed meats such as ham, bacon, hot dogs or red sausage, and lunch meats.
- Eat fresh fruits and vegetables instead of cookies or other salty snacks.
- Avoid canned soups and frozen meals that are high in sodium.

- Avoid pickled foods, like olives and pickles.
- Limit high-sodium condiments like soy sauce, barbecue sauce, or tomato sauce.

Potassium

It is one of the food components responsible for the proper functioning of the muscles and the nervous system. Potassium, like many other substances, is eliminated mainly by the kidney. In chronic kidney disease, due to this malfunction of the kidneys, there is an increase in potassium in our body.

The amount of potassium in our body will depend on two main factors:

- of kidney function
- and, if you are on dialysis, how often you are on dialysis.

For people who are not on dialysis, those who are in the so-called pre-dialysis stage or for kidney transplants, the amount of potassium that can be taken will depend on the function of their kidneys exclusively.

When kidney function is below 30%, it is usually necessary to start controlling the potassium that is taken, and as this kidney function is lower, it is even more important to take into account the recommendations to reduce potassium from food.

When kidney function drops to 15-10%, the recommended amount of potassium is the same as that of a person on hemodialysis. For people who are on dialysis it is advisable not to take more than:

- 2000 mg of potassium a day, if you dialyze three times a week.
- 2500-3000 mg of potassium per day, if you are on dialysis every day (peritoneal dialysis) or perform hemodialysis for at least 5 sessions.

The most important way to control potassium in the blood is by taking a small amount of it. It can be very useful to know which foods are high and low in potassium. Some drugs can increase potassium levels in the blood, they are usually drugs used to lower blood pressure while “protecting” the kidneys. Consult your health care provider if you are taking these medications, and if so, monitor your potassium levels.

All foods except pure sugar and oil have potassium in their composition, some in greater and others in less quantity.

Calcium

Calcium is a necessary element for the correct formation of bone and teeth. Milk and its derivatives (cheeses, yogurt, ...) are some of the foods rich in calcium.

When a person has chronic kidney disease, calcium is altered, and we find situations where it is low or high in the blood. When this happens, serious complications can appear, as happened with phosphorus, such as obstruction of blood vessels (vascular calcifications), heart involvement ... and death.

We do not usually talk about controlling calcium with food, unless it is a very extreme situation, since, in general, calcium levels will be controlled with medication and if the person is already on dialysis, also with this.

Some of the drugs used to lower phosphorus (phosphorus binders) provide calcium to the body, so you should not worry about low calcium in your blood. Sometimes calcium levels are high, so there are also phosphorus binders without calcium.

Milk and milk products contain large amounts of calcium. Fish, eggs, fruits, vegetables and bread contain it in a lower proportion and it is less absorbable. Foods rich in calcium are usually also rich in phosphorus. If you have chronic kidney disease, avoid foods called calcium-enriched.

Phosphorous

Phosphorous is a mineral that works together with other substances, such as calcium and vitamin D, in the formation of bones. Phosphorus is in almost all the foods we eat every day. The kidneys are in charge of eliminating the excess phosphorus. People with chronic kidney disease often have high levels of phosphorous in their blood (hyperphosphataemia).

These high levels of phosphorus in the blood are related to serious diseases, such as the weakening of the bones, the obstruction, little by little, of the blood vessels (this is what is usually called vascular calcifications), the affectation of the heart ... to cause death. Phosphorus has come to be called "The Silent Killer", because many times it causes these complications without the patient noticing anything. It is one of the nutrients less known to people with chronic kidney disease, although this is changing in recent years.

Advanced Chronic Kidney Disease Stage or Pre-dialysis and Dialysis Stage: the recommended amount of phosphorus is about 600-1000 mg per day, depending on physical activity, muscle mass, age and gender.

Transplant Stage: it will depend on the function of your kidney and the results of the analysis. Consult your healthcare provider to find out what the repaired amount is for you.

Almost all foods contain phosphorous. A normal diet usually provides about 1500 mg of phosphorus a day. This amount is much higher than what we have indicated as recommended in kidney disease. Controlling the amount of phosphorus you take with meals can be of great help to reach normal levels, but you will also need medication to achieve this. Only with diet or only with medication you cannot control phosphorous, you will need both, this is very important.

The sources of phosphorus are all foods rich in protein: meat, fish, eggs, milk, cereals and legumes. We must be very careful with pre-cooked meals, organ meats, dairy products and whole foods, they have a high phosphorus content. If you eat fish, avoid eating the spine (eg: fried anchovies).

Organic phosphorous:

It is naturally present in foods rich in protein. We can find it in foods of animal origin such as dairy, meat, fish and eggs, and in foods of plant origin, such as legumes, nuts and cereals, mainly.

Inorganic phosphorous:

It is a similar substance, which the food industry synthesizes and combines with other substances, with the objectives described above. It is also known as hidden phosphorus, since unless it is specified on the label, which is not always the case, we will not be able to know if that food contains it or not. We can find it in many foods already prepared for consumption (processed foods). A very important aspect to take into account is that depending on the type of phosphorus we take, our body will absorb more or less of it.

Thus, organic phosphorus is absorbed around 40-60%, taking into account that phosphorus from the plant world is absorbed in less quantity than that from the animal world. However, inorganic phosphorus is absorbed around 100%. We could say that the more processed a food is, the greater the probability that it contains an additive with phosphorus. Most processed foods have phosphorus additives, so for example, they are common products and they have a lot of phosphorus as an additive:

- Industrial pastries
- Cola-type soft drinks.
- Precooked meats.
- Frozen fish (especially battered ones).
- Preserves and semi-preserves.

There are many additives that contain phosphorus, although some of the ones that provide more phosphorus are:

- Phosphoric acid (E338)
- Sodium phosphate (E339)
- Potassium phosphate (E340)
- Calcium phosphate (E341)
- Magnesium phosphate (E343)
- Diphosphates (E450)
- Triphosphates (E451)
- Polyphosphates (E452)

How can we control the phosphorous we take?

As we have mentioned before, organic phosphorus is present in foods rich in protein. Although it could seem that the ideal would be to take very little protein in the diet, in order to lower the phosphorus intake, doing this would have a significant risk of malnutrition; in addition, people on dialysis are advised to increase their protein intake. Until a few years ago, the consumption or not of certain foods was recommended depending on the amount of phosphorus they had, however in recent years it is recommended that when choosing a food, the amount of phosphorus and proteins that are this food has. This is how the concept of phosphorus / protein index arises. People who have to control phosphorus intake should choose foods with a lower phosphorus / protein ratio. Foods that have 12-16 mg of phosphorus for every gram of protein, or less, are recommended.

To facilitate this task, there are lists, classified by food groups, where the phosphorus / protein ratio is reflected, in order to be able to choose among the most recommended of each group (see recommended documentation at the end of the article).

Analysing the phosphorus content according to the food group:

- **Dairy products** are foods with a high content of phosphorus and the phosphorus / protein ratio is usually high. In addition, many of the dairy products are processed, and the extra contribution of phosphorus that some additives suppose must be taken into account.
- **Meat and fish group**: it is recommended that they be ordered when cut at the time, avoiding the trays where they come pre-cut (since they may have added additives with phosphorus to favor their conservation).Regarding precooked meats or fish, they are usually added with inorganic phosphorus to avoid loss of water, improve their appearance and delay the rancidity of the product. Deep-frozen meats and fish are usually added with phosphorus as an additive to avoid loss of water and proteins due to the freezing process.
- **Egg**: it is the yolk that has a high phosphorus content. Egg white, however, is a very good choice as a high-quality protein source with little phosphorus.
- **Legumes and nuts** present most of the phosphorus in the form of phytic acid, being absorbed in less quantity, however its composition in other minerals, such as potassium makes these foods should be taken with caution in chronic kidney disease (using the recommendations to decrease the potassium intake).
- **Vegetables and fruits**: the contribution of phosphorus is usually low, however, if we talk about kidney disease, the potassium contribution of the same must be taken into account, which is usually high.

Pharmacological treatment is another of the fundamental aspects to control the contribution of phosphorus, the so-called phosphorus binders or chelators are drugs that bind phosphorus and do not allow our body to absorb it, for this reason they should be taken with food. If the treatment of phosphorus binders is not adequately followed, it is practically impossible for phosphorus levels in the blood to be controlled, just as if these drugs are taken well, but not properly fed, neither will it be possible to control phosphorus levels.

There are many doubts that can arise about food and medication in kidney disease, since not all people are in the same situation, and there are also important gastronomic differences according to the geographical area where they live. If you have any doubts, consult the health personnel of your center / hospital, as well as the nutrition professionals who work in the different associations of people affected by kidney disease, they will be able to provide you with more information adapted to your case. A diet as natural as possible in patients with kidney disease allow a much more exhaustive control of phosphorus, because its content can be known with greater precision. It should be conveyed that the diet should be as balanced, comprehensive and varied as possible. Food is one of the greatest existing pleasures, and we must do everything in our power to be able to continue enjoying it without posing risks to our health.

How to manage the fluid intake

Due to the loss of the function of the kidneys to eliminate excess fluid through the urine, in the dialysis phase one of the most important points of the diet is the restriction of fluid intake. Current recommendations tell us that the amount of liquid we can ingest is as follows:

- Haemodialysis: Urine volume + 500-700 ml. In case of total absence of urine,1000 ml / day

- Peritoneal dialysis: as it is a type of daily dialysis, there are fewer restrictions, so it is necessary to Individualize according to the fluid balance.

How to decrease the feeling of thirst:

- Drink only when you are thirsty and do it in a small glass.
- Don't drink as a habit.
- Take all the medicines with the liquids of the meals and not with more water.
- Use lemon wedges to stimulate salivation and moisten the mouth.
- Add a few drops of vinegar to the water.
- Chew sugarless gum.
- Make ice by adding a few drops of lemon before freezing.
- Freeze pieces of fruit.
- Reduce cola, orangeade, etc. because they increase the feeling of thirst. Substitute them for cold tea or homemade lemonade, as they relieve thirst better.
- Stay busy, this way you will not think so much about feeling thirsty.

Self-assessment test

Part A – multiple choice

Please reply to the following questions to assess your knowledge of this unit. Note that only one option is correct.

4. What mineral can easily pass from food to water?
    a. Calcium

   b. Potassium
   c. Phosphorous
5. Does diet influence the disease progression?
   a. No, unfortunately the disease will progress unchecked
   b. No, but it will allow us to feel better
   c. Yes, it can slow down or advance more quickly if it´s not adequate
6. Can I flavour my food without using salt?
   a. Yes, spices help us
   b. Yes, flavouring oils
   c. Both are true
7. What food contains the most phosphorus?
   a. Frozen fish battered
   b. Chicken meat
   c. Green beans

Part B – drag & drop

Please match the nutritional parameter with it function

Sodium	Nutrient for the repair and formation of cells and tissues
Potasium	Works in the formation of bones and vitamin D
Protein	Responsible for the proper functioning of the muscles and the nervous system
Phosphorous	Raise your blood pressure

Useful tips

How to flavour foods without adding salt

Reducing sodium, and therefore salt, is one of the great workhorses of many diseases, including chronic kidney disease. We must bear in mind that by not using salt we are going to discover a greater variety of flavours that were previously almost nullified by the taste of salt.

We advise that it´s necessary to reduce the salt intake gradually and, above all, we ask patient for a little patience. At the beginning is when we are going to notice this change in flavour the most, although little by little we will get used to these flavours. To make this process more pleasant, we advise you to use when cooking:

- Use of dressings: oil + garlic + parsley
- Seasoning vegetables: celery, garlic, leek, onion, tomato, carrot.
- Aromatic herbs and spices: they can be used alone or as a combination of several of them. Some of the most common are parsley, bay leaf, rosemary, oregano, basil, nutmeg, cumin, pepper, paprika, thyme, mint…. they all go well with food. If the

aromatic herb that we are going to use is dry, we recommend that you add it in the last minutes of the stew, in this way we will be getting more out of its flavour.
- Flavouring the oils: they can be useful in oils that we are going to use to dress salad, meat or fish, to cook with that oil or to accompany on a little bread in an aperitif.
- Macerate or infuse the aromatic components (aromatic herbs or spices) in the oil for at least 3 or 4 weeks. Example: put a dried pepper, a few garlic cloves and a thyme sprig in oil and let them marinate for about a month.
- Heat the oil in a bain-marie together with the spices or aromatic herbs at about 60 degrees for 30 minutes. Example: 5 cloves of garlic and 1 or 2 chillies.

How to remove potassium from food

One of the complications in CKD is the increase in potassium in the blood (hyperkalemia) due to decreased kidney filtration, which causes various complications such as muscle weakness, mental confusion, dizziness, thirst, heart disorders ...

One of the main strategies to avoid the increase in potassium in the blood in these patients is through an adequate dietary intervention, reducing the intake of those foods that contain more potassium.

The foods with the highest potassium content are fruits, vegetables, legumes, nuts and chocolate. It should be noted, as we will see later in this guide, that not all fruits and vegetables have the same amount of potassium, so some are more recommended than others.

Another measure to reduce potassium in our diet is determined by cooking techniques. Following the results obtained in the Project "Effects of cooking on potassium content in foods of plant origin" completed in 2015, there has been a change in the recommendations for vegetables and legumes for potassium control in Renal Patients. This change in the recommendations is aimed at increasing the variety of the diet, facilitating cooking methods and increasing the amount of fibre; having as final objective to improve the quality of life of the renal patient and his relatives.

When cooking with plenty of water, there is no difference in potassium loss between normal cooking and double cooking with or without pre-soaking. Therefore, IT IS NOT NECESSARY TO DO THE DOUBLE COOKING OF THE VEGETABLES.

- CANNED vegetables and legumes have a lower amount of potassium than fresh vegetables and legumes.
- FREEZING vegetables, followed by soaking and / or normal cooking, leaves potassium levels in the food suitable for kidney disease.

Next, we are going to explain how the dietary recommendations for potassium control would be based on the aforementioned conclusions.

We are going to give 3 options for consuming vegetables and legumes based on the cooking technique.

OPTION A

If we use canned legumes or canned or frozen vegetables we can follow the following distribution in the main meal of the day

- VEGETABLE: 3-4 times / week
- LEGUME: 1-2 times / week
- PASTA OR RICE: 1-2 times / week.

These days you can have vegetables for dinner.

This pattern of meal distribution closely resembles the indications of the main scientific societies for the general population.

OPTION B

If we use fresh legumes or vegetables, we can follow the following distribution in the main meals of the day:

- VEGETABLE: 2-3 times / week
- LEGUME: 1 time / week
- PASTA OR RICE: 2-3 times / week.

OPCION C

The vegetables or greens that we are going to consume raw or subjected to a cooking technique without the use of water such as the grill, roasted or as a sauce of a dish we have to cook them by following the following steps:

- Soak in plenty of water for 6-8 hours with a water change
- Eliminate the water used in soaking
- Cooking them

In this case, we are going to classify the vegetables by their potassium content (see Table 1), so we must use the ones marked with green. Use the yellow ones in less quantity, preferably to prepare stir-fries or as garnishes and the red ones, leave them for special occasions.

Highlight the case of garlic, although it appears as discouraged due to its potassium content, it is a very good alternative to flavor dishes, as long as we only use it to add flavor without consuming it later.

Tips for healthy eating in caregivers

Maintaining an adequate and healthy diet is the basis for helping a person with kidney disease to eat well. Being adequately fed will help to cope with the tasks of caring for these patients.

1. Eat a variety of foods

We need more than 40 different nutrients, and no single food can provide them all. Always choose foods in a balanced way!

2. Base your diet on foods rich in carbohydrates

Most of the people do not incorporate enough foods rich in carbohydrates such as bread, pasta, rice, potatoes and other cereals, considering them forbidden to avoid gaining weight.

However, this is not correct, more than half of the calories in your diet, that is about 60%, must come from these foods.

3. Eat lots of fruits and vegetables

Most people don´t eat enough fruits and vegetables that provide important protective nutrients.

4. Maintain a healthy body weight and feel good

The right weight depends on many factors such as gender, height, age, and genetics. Being overweight increases the risk of suffering from various diseases such as cardiovascular problems, bones, joints and cancer. Calculate your ideal weight with this simple formula: BMI = weight in Kg divided by height in metres squared: for example, a person who weighs 70 kg and is 1.74 tall has a BMI = 70 / (1.74 x 1.74) = 23.1. The Body Mass Index should remain within a range considered normal, between 18.5 and 24.9 according to the World Health Organisation.

5. Eat moderate servings: cut down, don't eliminate food

By eating the right servings of each food, it is easier to eat from all the food groups without eliminating any.

6. Eat regularly

Skipping meals, especially breakfast, can lead to uncontrolled hunger pangs, often causing overeating. Snacking can help curb hunger, but don't eat too much so you don't replace main meals.

7. Keep an adequate fluid intake

Adults need to drink at least 1.5 liters of fluids a day! And we need more if it is hot or if we do a lot of sport. Hydration is essential to live.

8. Move around

Moderate physical activity helps burn excess calories. It is also good for the heart, for the circulatory system, for general health and well-being.

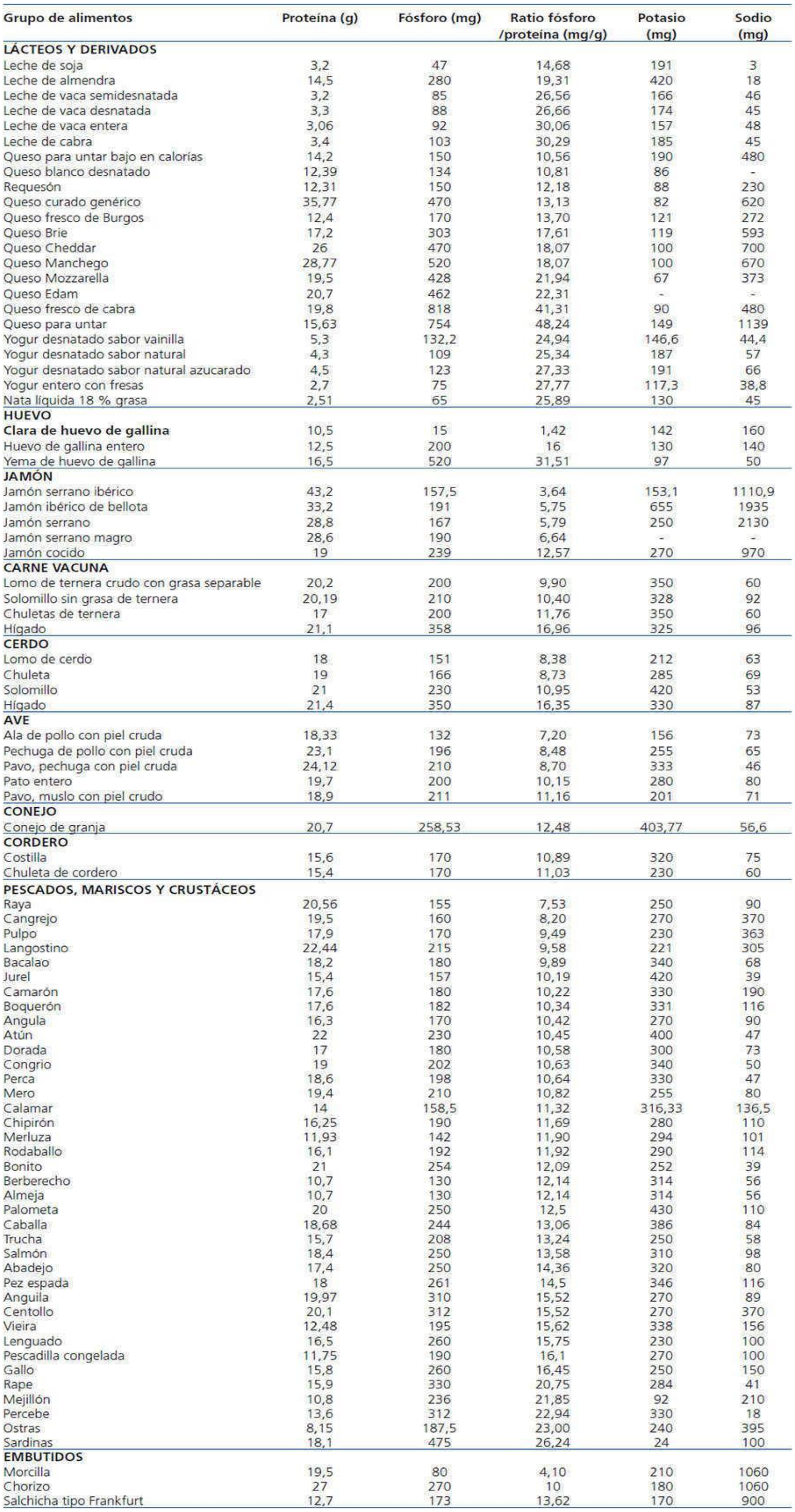
9. Get started now and make changes gradually!

Making your lifestyle changes gradually is much easier than making them suddenly.

10. Remember: it's all about balance

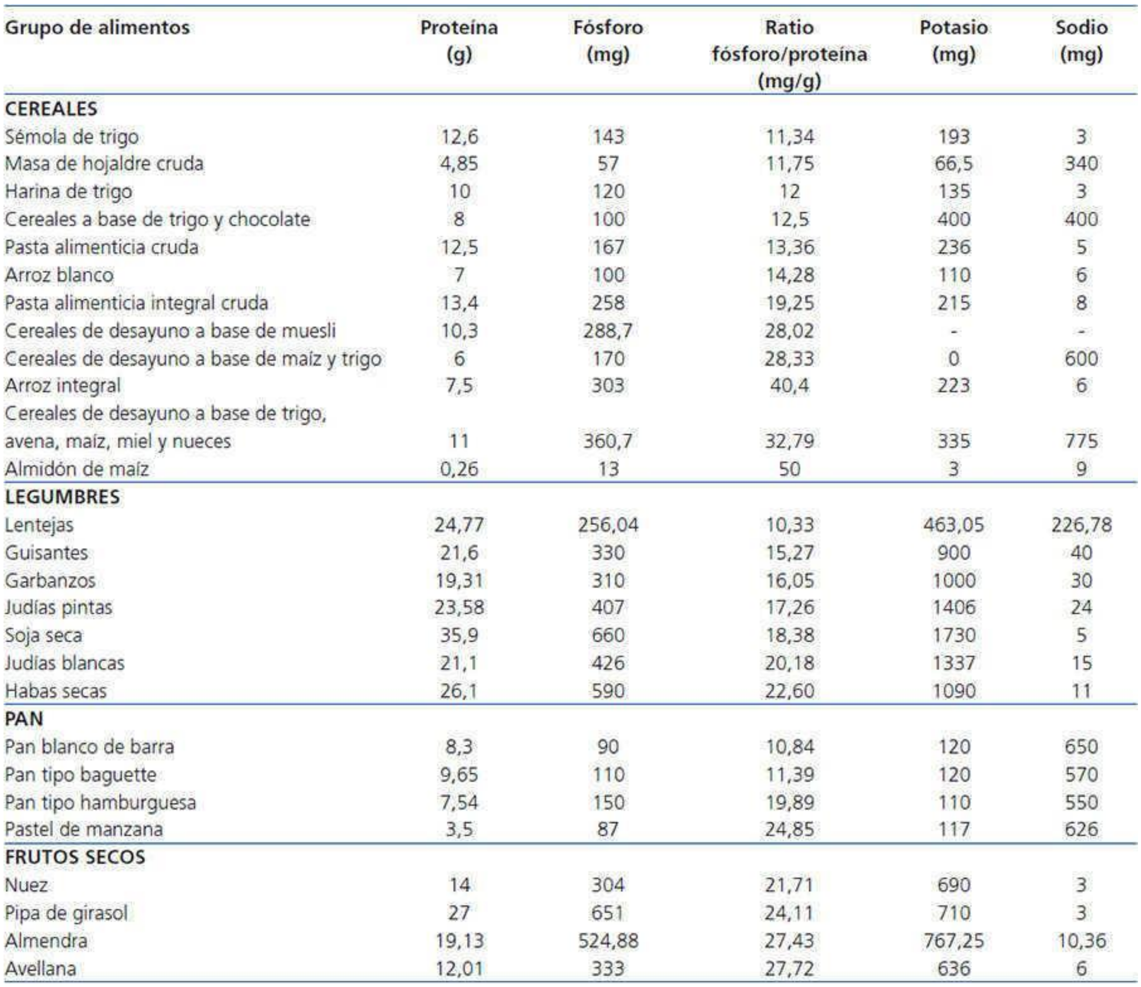
There are no "good" or "bad" foods, only good or bad eating plans.

Annex 1: table 1. Phosphorus / protein ratio per 100 g



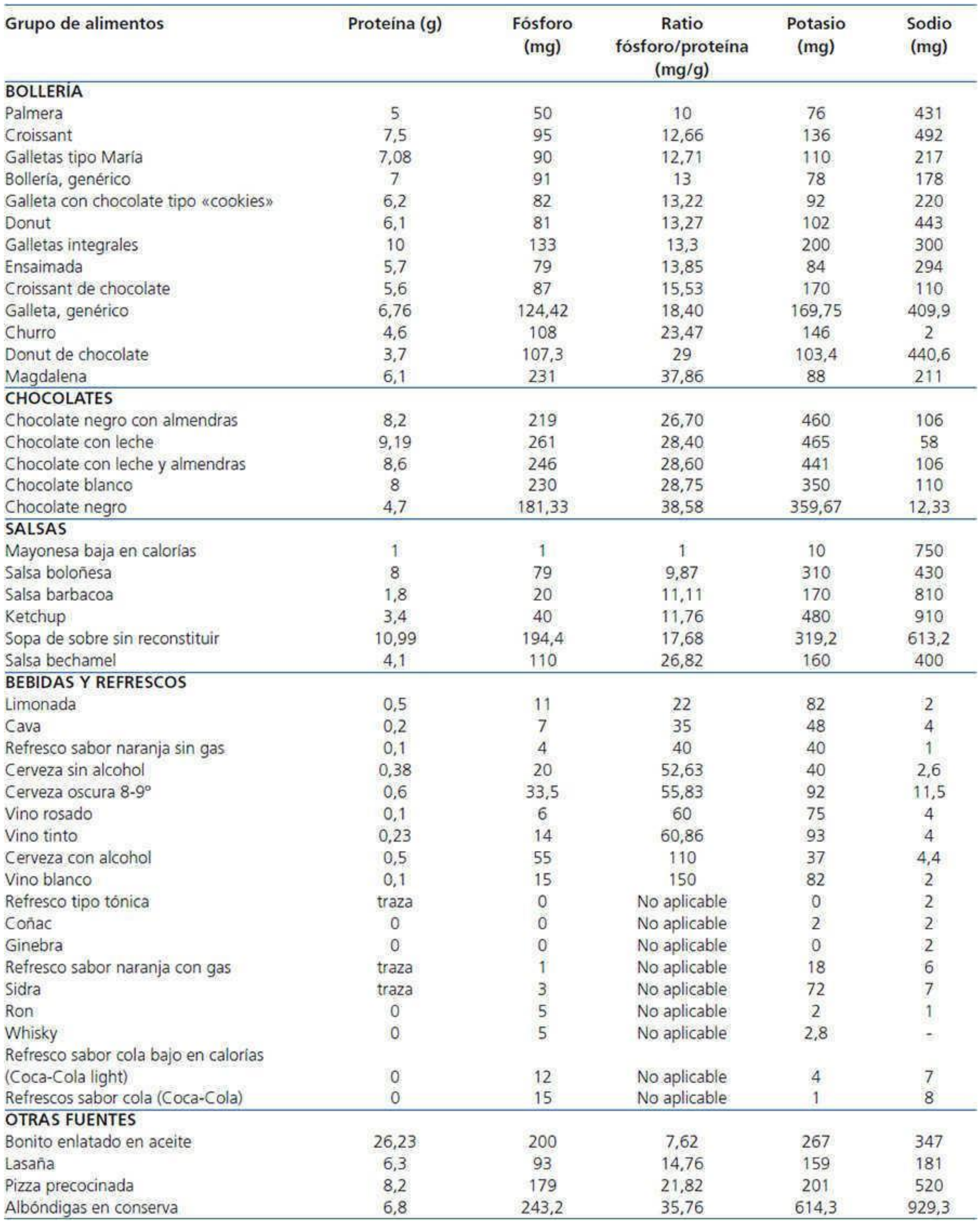
Grupo de alimentos	Proteína (g)	Fósforo (mg)	Ratio fósforo /proteína (mg/g)	Potasio (mg)	Sodio (mg)
LÁCTEOS Y DERIVADOS					
Leche de soja	3,2	47	14,68	191	3
Leche de almendra	14,5	280	19,31	420	18
Leche de vaca semidesnatada	3,2	85	26,56	166	46
Leche de vaca desnatada	3,3	88	26,66	174	45
Leche de vaca entera	3,06	92	30,06	157	48
Leche de cabra	3,4	103	30,29	185	45
Queso para untar bajo en calorías	14,2	150	10,56	190	480
Queso blanco desnatado	12,39	134	10,81	86	-
Requesón	12,31	150	12,18	88	230
Queso curado genérico	35,77	470	13,13	82	620
Queso fresco de Burgos	12,4	170	13,70	121	272
Queso Brie	17,2	303	17,61	119	593
Queso Cheddar	26	470	18,07	100	700
Queso Manchego	28,77	520	18,07	100	670
Queso Mozzarella	19,5	428	21,94	67	373
Queso Edam	20,7	462	22,31	-	-
Queso fresco de cabra	19,8	818	41,31	90	480
Queso para untar	15,63	754	48,24	149	1139
Yogur desnatado sabor vainilla	5,3	132,2	24,94	146,6	44,4
Yogur desnatado sabor natural	4,3	109	25,34	187	57
Yogur desnatado sabor natural azucarado	4,5	123	27,33	191	66
Yogur entero con fresas	2,7	75	27,77	117,3	38,8
Nata líquida 18 % grasa	2,51	65	25,89	130	45
HUEVO					
Clara de huevo de gallina	10,5	15	1,42	142	160
Huevo de gallina entero	12,5	200	16	130	140
Yema de huevo de gallina	16,5	520	31,51	97	50
JAMÓN					
Jamón serrano ibérico	43,2	157,5	3,64	153,1	1110,9
Jamón ibérico de bellota	33,2	191	5,75	655	1935
Jamón serrano	28,8	167	5,79	250	2130
Jamón serrano magro	28,6	190	6,64	-	-
Jamón cocido	19	239	12,57	270	970
CARNE VACUNA					
Lomo de ternera crudo con grasa separable	20,2	200	9,90	350	60
Solomillo sin grasa de ternera	20,19	210	10,40	328	92
Chuletas de ternera	17	200	11,76	350	60
Hígado	21,1	358	16,96	325	96
CERDO					
Lomo de cerdo	18	151	8,38	212	63
Chuleta	19	166	8,73	285	69
Solomillo	21	230	10,95	420	53
Hígado	21,4	350	16,35	330	87
AVE					
Ala de pollo con piel cruda	18,33	132	7,20	156	73
Pechuga de pollo con piel cruda	23,1	196	8,48	255	65
Pavo, pechuga con piel cruda	24,12	210	8,70	333	46
Pato entero	19,7	200	10,15	280	80
Pavo, muslo con piel crudo	18,9	211	11,16	201	71
CONEJO					
Conejo de granja	20,7	258,53	12,48	403,77	56,6
CORDERO					
Costilla	15,6	170	10,89	320	75
Chuleta de cordero	15,4	170	11,03	230	60
PESCADOS, MARISCOS Y CRUSTÁCEOS					
Raya	20,56	155	7,53	250	90
Cangrejo	19,5	160	8,20	270	370
Pulpo	17,9	170	9,49	230	363
Langostino	22,44	215	9,58	221	305
Bacalao	18,2	180	9,89	340	68
Jurel	15,4	157	10,19	420	39
Camarón	17,6	180	10,22	330	190
Boquerón	17,6	182	10,34	331	116
Angula	16,3	170	10,42	270	90
Atún	22	230	10,45	400	47
Dorada	17	180	10,58	300	73
Congrio	19	202	10,63	340	50
Perca	18,6	198	10,64	330	47
Mero	19,4	210	10,82	255	80
Calamar	14	158,5	11,32	316,33	136,5
Chipirón	16,25	190	11,69	280	110
Merluza	11,93	142	11,90	294	101
Rodaballo	16,1	192	11,92	290	114
Bonito	21	254	12,09	252	39
Berberecho	10,7	130	12,14	314	56
Almeja	10,7	130	12,14	314	56
Palometa	20	250	12,5	430	110
Caballa	18,68	244	13,06	386	84
Trucha	15,7	208	13,24	250	58
Salmón	18,4	250	13,58	310	98
Abadejo	17,4	250	14,36	320	80
Pez espada	18	261	14,5	346	116
Anguila	19,97	310	15,52	270	89
Centollo	20,1	312	15,52	270	370
Vieira	12,48	195	15,62	338	156
Lenguado	16,5	260	15,75	230	100
Pescadilla congelada	11,75	190	16,1	270	100
Gallo	15,8	260	16,45	250	150
Rape	15,9	330	20,75	284	41
Mejillón	10,8	236	21,85	92	210
Percebe	13,6	312	22,94	330	18
Ostras	8,15	187,5	23,00	240	395
Sardinas	18,1	475	26,24	24	100
EMBUTIDOS					
Morcilla	19,5	80	4,10	210	1060
Chorizo	27	270	10	180	1060
Salchicha tipo Frankfurt	12,7	173	13,62	170	900

Annex 2: Table 2. Phosphorus / protein ratio per 100 g of raw food from organic sources of plant origin



Grupo de alimentos	Proteína (g)	Fósforo (mg)	Ratio fósforo/proteína (mg/g)	Potasio (mg)	Sodio (mg)
CEREALES					
Sémola de trigo	12,6	143	11,34	193	3
Masa de hojaldre cruda	4,85	57	11,75	66,5	340
Harina de trigo	10	120	12	135	3
Cereales a base de trigo y chocolate	8	100	12,5	400	400
Pasta alimenticia cruda	12,5	167	13,36	236	5
Arroz blanco	7	100	14,28	110	6
Pasta alimenticia integral cruda	13,4	258	19,25	215	8
Cereales de desayuno a base de muesli	10,3	288,7	28,02	-	-
Cereales de desayuno a base de maíz y trigo	6	170	28,33	0	600
Arroz integral	7,5	303	40,4	223	6
Cereales de desayuno a base de trigo, avena, maíz, miel y nueces	11	360,7	32,79	335	775
Almidón de maíz	0,26	13	50	3	9
LEGUMBRES					
Lentejas	24,77	256,04	10,33	463,05	226,78
Guisantes	21,6	330	15,27	900	40
Garbanzos	19,31	310	16,05	1000	30
Judías pintas	23,58	407	17,26	1406	24
Soja seca	35,9	660	18,38	1730	5
Judías blancas	21,1	426	20,18	1337	15
Habas secas	26,1	590	22,60	1090	11
PAN					
Pan blanco de barra	8,3	90	10,84	120	650
Pan tipo baguette	9,65	110	11,39	120	570
Pan tipo hamburguesa	7,54	150	19,89	110	550
Pastel de manzana	3,5	87	24,85	117	626
FRUTOS SECOS					
Nuez	14	304	21,71	690	3
Pipa de girasol	27	651	24,11	710	3
Almendra	19,13	524,88	27,43	767,25	10,36
Avellana	12,01	333	27,72	636	6

Annex 3: Table 3. Phosphorus / protein ratio per 100 g of raw food from food sources with inorganic phosphorus



Grupo de alimentos	Proteína (g)	Fósforo (mg)	Ratio fósforo/proteína (mg/g)	Potasio (mg)	Sodio (mg)
BOLLERÍA					
Palmera	5	50	10	76	431
Croissant	7,5	95	12,66	136	492
Galletas tipo María	7,08	90	12,71	110	217
Bollería, genérico	7	91	13	78	178
Galleta con chocolate tipo «cookies»	6,2	82	13,22	92	220
Donut	6,1	81	13,27	102	443
Galletas integrales	10	133	13,3	200	300
Ensaimada	5,7	79	13,85	84	294
Croissant de chocolate	5,6	87	15,53	170	110
Galleta, genérico	6,76	124,42	18,40	169,75	409,9
Churro	4,6	108	23,47	146	2
Donut de chocolate	3,7	107,3	29	103,4	440,6
Magdalena	6,1	231	37,86	88	211
CHOCOLATES					
Chocolate negro con almendras	8,2	219	26,70	460	106
Chocolate con leche	9,19	261	28,40	465	58
Chocolate con leche y almendras	8,6	246	28,60	441	106
Chocolate blanco	8	230	28,75	350	110
Chocolate negro	4,7	181,33	38,58	359,67	12,33
SALSAS					
Mayonesa baja en calorías	1	1	1	10	750
Salsa boloñesa	8	79	9,87	310	430
Salsa barbacoa	1,8	20	11,11	170	810
Ketchup	3,4	40	11,76	480	910
Sopa de sobre sin reconstituir	10,99	194,4	17,68	319,2	613,2
Salsa bechamel	4,1	110	26,82	160	400
BEBIDAS Y REFRESCOS					
Limonada	0,5	11	22	82	2
Cava	0,2	7	35	48	4
Refresco sabor naranja sin gas	0,1	4	40	40	1
Cerveza sin alcohol	0,38	20	52,63	40	2,6
Cerveza oscura 8-9º	0,6	33,5	55,83	92	11,5
Vino rosado	0,1	6	60	75	4
Vino tinto	0,23	14	60,86	93	4
Cerveza con alcohol	0,5	55	110	37	4,4
Vino blanco	0,1	15	150	82	2
Refresco tipo tónica	traza	0	No aplicable	0	2
Coñac	0	0	No aplicable	2	2
Ginebra	0	0	No aplicable	0	2
Refresco sabor naranja con gas	traza	1	No aplicable	18	6
Sidra	traza	3	No aplicable	72	7
Ron	0	5	No aplicable	2	1
Whisky	0	5	No aplicable	2,8	-
Refresco sabor cola bajo en calorías (Coca-Cola light)	0	12	No aplicable	4	7
Refrescos sabor cola (Coca-Cola)	0	15	No aplicable	1	8
OTRAS FUENTES					
Bonito enlatado en aceite	26,23	200	7,62	267	347
Lasaña	6,3	93	14,76	159	181
Pizza precocinada	8,2	179	21,82	201	520
Albóndigas en conserva	6,8	243,2	35,76	614,3	929,3

Video

Example 1: Explanatory video of how kidney disease affects the diet: https://www.youtube.com/watch?v=Xy6Xr8dQF3c (What to eat and how to buy during hemodialysis:

The video first explains how kidney disease affects diet and then explains how to follow a specific diet, some tips for a healthy life and finally how to shop for food, a useful aspect for informal eaters)

.

Example 2: Video on tips for flavoring food without adding salt: https://www.youtube.com/watch?v=_zXJKPHTqaI&t=59s (Practical examples and tips for feeding people on hemodialysis including practical recipes).

Example 3: Tips for a healthy diet in caregivers: https://www.youtube.com/watch?v=NfjAtKF4LoM&t=394s (prevent obesity in caregivers and prevent kidney failure: the video presents tips and recipes to avoid obesity in the general population)

To learn more

To learn more, you can visit the following websites:

- ALCER, Spanish Kidney Patients´ Federation (official webpage): https://www.alcer.org
- ALCER, Spanish Kidney Patients´ Federation (educational webpage): https://www.personasrenales.org
- Nutritional paper of the Spanish Society of Nephrology: www.revistanefrologia.com/es-publicacionnefrologia-articulo-tablas-ratio-fosforoproteinaalimentos-poblacion-espanola-utilidad-enfermedad-renal-cronica-X021169951300319X
- Nutritional handbook for CKD patients (ALCER Ebro & Public Administration of Aragón-Spain): https://www.saludinforma.es/portalsi/documents/10179/2303825/Guia_pautas_dieteticas_en_ERC_2017.pdf/f9fce3fb-c3f6-429b-9e8a-6c3e910ad70c
- Consensus guide on nutrition for renal patients and SARS-CoV-2 (Spanish Society of Endichronology, Spanish Society of Nephrology, Spanish Society of Nephrology Nursing and ALCER) https://www.seen.es/ModulGEX/workspace/publico/modulos/web/docs/apartados/1500/010720_104836_8231075147.pdf

Face2face part

Worksheet 2.1.1 – Welcome and introduction

Objective: explain the development of the session; know the characteristics of the participants and analyse what we will need during it.

Duration: 10 minutes

Implementation: describe the session, which will consist of a theoretical part, a more playful to find the difference of foods by composition session and finally a workshop to put in practice the concepts learned.

Worksheet 2.1.2 – Theoretical session: how kidney disease affects the diet

Objective: acquire basic knowledge to help them

Material: lap-top with internet connection, projection screen and light cannon

Duration: 30 minutes

Implementation: The speaker will explain how kidney disease affects people with CKD diet, which are the minerals that the damaged kidney cannot eliminate and which, therefore, must be reduced as much as possible. [The trainer could use the video above: *Example 3 - Tips for a healthy diet in caregivers: https://www.youtube.com/watch?v=NfjAtKF4LoM&t=394s (prevent obesity in caregivers and prevent kidney failure: the video presents tips and recipes to avoid obesity in the general population)*]. The need for a healthy diet in caregivers will also be reinforced, to stay in good condition and thus help in their care of the patient.

Worksheet 2.1.3 – Nutritional game

Objective: help to differentiate the foods by its mineral composition

Duration: 50 minutes

Implementation: the monitor will divide participant into groups and distribute a cards with different foods. Each group of cards will have foods from the following groups:

- Vegetables
- Rice, cereals and pasta
- Eggs and dairy
- Fishes
- Meats

3 games will be played during the session:

- Game 1: classify foods based on their potassium content
- Game 2: classify foods based on their phosphorous content
- Game 3: compose daily food intake using the cards and calculate the sodium, potassium and phosphorus content using the food composition tables (listed as annex in the current document)

Worksheet 2.1.4 – Cooking workshop

Objective: acquire basic knowledge to help them

Duration: 1 hour and 30 minutes

Implementation: An expert in nutrition and a cook will collaborate to give a practical workshop. While the dietician explains the mineral reduction needs, the cook will carry out cooking techniques that allow this reduction. Later, the dietician will analyse the need to reduce sodium in food and the cook will apply tips to flavour foods with little salt. The workshop end with tips to consume less liquid: iced tea recipe, freezing fruits. The workshop will perform cooking techniques and show useful tips, but it´s not intended to execute specific recipes and after taste them.

Instead of that, if we cannot organize this type of show cooking, we can use the video Example 2: *Video on tips for flavouring food without adding salt:* *https://www.youtube.com/watch?v=_zXJKPHTqaI&t=59s* *(Practical examples and tips for feeding people on hemodialysis including practical recipes).* and comment it with caregivers

Module 2- How to manage CKD and ESRD in daily activities

Theme	**2.3 Psychosocial aspect and emotional management**
GOAL(S) AND OBJECTIVES	Aim of this module is to provide to learners: - Know the risks of emotional disorders in the patient and in the caregiver - Learn tips to prevent emotional disorders
LEARNING OUTCOMES	At the end of the section 2.2, learners will have obtained information and tools regarding how to adapt kidney disease and avoid emotional disorders.
METHODS	Self-directed learning
DURATION:	40 minutes online and 1 hour and 30 minutes face-to-face
RESOURCES NEEDED:	- lap-top with internet connection - projection screen and light cannon - floor mats
ORDER OF ACTIVITIES:	- E-learning module (40 minutes) Face to face: - Welcome and introduction (10 min.)- Worksheet 1 - Theoretical session (50 min.) – Worksheet 2 - Relaxiing workshop (30 minutes) – Worksheet 4
EVALUATION OF THE THEME:	- Self-assessment (e-learning module)
REFERENCES	- http://www.infocop.es/view_article.asp?id=6316
WORKSHEETS	- Worksheet 1 - Worksheet 2 - Worksheet 3
HANDOUTS	No

Background information – e-learning:

Introduction

When a person receives the news that they have a chronic disease and that they must receive dialysis treatment or be transplanted to continue living, the psychological impact that occurs both on a personal and family level is tremendous. The mixture of emotions that appear can be resolved in the best possible way through a psychology professional so that they do not lead to other types of pathologies.

Grief appears as a consequence of a loss, in this case the loss of health, and therefore a series of emotions are triggered, such as anxiety, stress and sadness.

Phases of acceptance of chronic disease

Taking as a reference the model of Kübler –Ross (1926-2004) we can describe the different phases of a process of mourning or loss, not all people go through all the phases, nor do they all reach the acceptance process:

First phase: Denial and isolation: In this phase the patient and / or her family does not accept the diagnosis, so they will do everything possible to deny reality. Thoughts such as: "the doctor has made a mistake", "this cannot be happening to me" etc can easily appear.

The control of their lives is diminished, and to regain it, many (especially if the diagnosis of the disease is made in adolescence) adopt defiant behaviors towards the guidelines that doctors propose. This type of rebellious behavior is called psychological reactance and represents an attempt by the psyche to regain lost freedom, although it is still an illusion that sooner or later ends up falling. This concept would be included within the denial behaviors, of not wanting to see reality, but it could be perfectly included in the next phase. An example in newly diagnosed patients would be not following the diet recommended by the doctor, abusing foods that have been especially restricted due to their harmful nature.

Second phase: Anger: this is the moment when questions such as "Why me?" or "Why him?" arises. An intense feeling of anger and hostility is generated, which can lead to active or passive aggression against any figure of power: God, doctors, nurses, parents. This phase is characterized by a difficulty for rational thinking that can impede adequate decision-making for an optimal future of the patient's life and her family. Being “blinded by anger” is not a good ally to face the disease, but it is necessary to go through it in the most assertive way possible to prevent it from harming both the patient and those closest to him.

Third phase: Pact: “If crying out against others does not get anything, perhaps asking humbly or offering something in return, things change”. The person begins to check what he is capable of doing, and in what projects he can invest his hope; he/she tries to take control of his/her life again, trying to repair what can be repaired. This phase is extremely dangerous, as in this period the patient may even search miracle cures/doctors. Do not confuse this phase with acceptance, since the change the person wants to obtain is the same: not having the disease. It would therefore be a “disguised denial”.

A clear example would be a person who says to himself: "If I get out of this, I promise to stop drinking alcohol."

Fourth phase: Depression: this phase prepares for acceptance, because it is aware that there has been a loss, the loss of health. At this time the patient begins to have depressive symptoms: feelings of guilt, worthlessness, emptiness, inability to act, etc.. In this phase the dejection and loss of energy typical of depressive symptoms is triggered, taking into account that in chronic patients depression is a reactive process in the face of the disease and that therefore a good differential diagnosis is necessary to ensure that depression is an effect of the disease and not a pathology that existed previously. In this sense, an adequate treatment is necessary to avoid a chronification of said mental state.

Fifth phase: Acceptance: if the patient and family have passed, or rather, have been helped to pass the previous phases, having been able to express their feelings, they will be able to face with greater serenity the new guidelines that will mark their future, establishing a higher quality of life. It is an expression of resilience of the patient and family members.

These phases do not necessarily occur in succession. It is also possible to return to an earlier stage, even if one is in a more advanced stage, or vice versa.

Practical tips for the caregivers

- **Understand reality and accept it:** chronic kidney disease is a pathology that cannot be cured, but that has substitution treatments that allow a long survival with a good quality of life, therefore when the situation is accepted before the negative effects will be limited on the emotional health of the patient. Caregivers can help with that process.
- **Foster social awareness and responsibility:** maintain empathy and be a good example for them.
- **Planning the new situation:** with kidney disease the routine will radically change and organizing well what the patient can do, when and how, is crucial. If you share space with people with kidney disease, good communication and respecting each other's times and needs is important.
- **Get informed properly:** look for official and reliable information, such as the one you can find at www.ecaris.eu. Don't constantly discuss the issue with the patient - talking to them about how they are coping can help.
- **Seize the moment:** talking to people who have been diagnosed with chronic kidney disease for a long time, they tell you that they live taking advantage more of the moment than before the diagnosis and that this helps them cope with the disease and its treatments. Help the patient to enjoy moments that were not possible before because of the rhythm of life they had. Make a list of things that you have been putting off due to lack of time: writing stories, reading, drawing pictures. The goal is for the patient to be mentally active.
- **Time to do physical exercise:** staying physically active is now more important for the person affected by kidney disease, encourage them to do physical exercise: walking, swimming, dancing, etc.
- **Take care of your state of mind:** take great care what you say and how you say it, taking care of our emotions and thoughts to be able to respond appropriately to moments of uncertainty and in which the spirit fails. Ask your support network for help if needed.
- **Stay positive:** it is normal to feel lost, sad or restless. Maintaining a positive attitude helps the patient feel better.

Self-assessment test

Part A – multiple choice

Please reply to the following questions to assess your knowledge of this unit. Note that only one option is correct.

How common are emotional problems in people with cone kidney disease?

a. They are less than 20%, but they are usually serious
b. They are very common in people on haemodialysis
c. They are given in all kidney replacement treatments equally

What are the most frequent psychological disorders in kidney disease?

8. Anxiety and Obsessive-compulsive Psychosis
9. Depression, anxiety and stress
10. Alterations in body perception?

Should caregivers consider patients emotional health?

a. Yes, although it has no impact on the care of the kidney **patient**
b. No, it is very unlikely that they may suffer from any psychological problems
c. Yes, it is necessary to be able to help the patient and protect their emotional health

Part B – drag & drop

Please match the phase with their definition

Anger	Is the situation in which you learn to live with the disease
Depression	It´s disguised denial
Acceptance	This phase prepares for acceptance
Denial and isolation	The moment when questions such as: "Why me?" or "Why him?"
Pact	the patient and / or her family does not accept the diagnosis

Video

Example 1: describes the phase of the acceptance process

Example 2: practical advice for relaxation in caregivers

To learn more

To learn more, you can visit the following websites:

- ALCER, Spanish Kidney Patients´ Federation (official webpage): https://www.alcer.org

- ALCER, Spanish Kidney Patients´ Federation (educational webpage): https://www.personasrenales.org
- General Council of Psichology in Spain: http://www.infocop.es/view_article.asp?id=6316

Face2face part

Worksheet 2.1.1 – Welcome and introduction

Objective: explain the development of the session; know the characteristics of the participants and analyse what we will need during it.

Duration: 15 minutes

Implementation: describe the session, which will consist of a theoretical part, a practical session in which a relaxation method for caregivers will be developed

Worksheet 2.1.2 – Theoretical session: how kidney disease affects the emotional health

Objective: acquire basic knowledge to help them

Duration: 25 minutes

Implementation: The speaker will explain how kidney disease affects mental health and the frequency of these disorders. The phases that the patient usually goes through will be analysed in order to treat the disease, based in the Kuber-Ross model.

Worksheet 2.1.3 – relaxation workshop

Objective: provide tools to avoid emotional disorders

Duration: 45 minutes

Implementation: The monitor will offer a training session to learn relaxation techniques that caregivers can implement for themselves and to help the patient reduce their distress and stress, with a practical session of mindfulness.

Then he/she can open a discussion session, where he/she can answer questions and invite the group to talk freely about what they have experienced.

Module 2- How to manage CKD and ESRD in daily activities

Theme	**2.2 Vascular access for hemodialysis**
GOAL(S) AND OBJECTIVES	Aim of this module is to provide to learners: • Useful information on fistulas for people with CKD who are going to receive hemodialysis treatment. • Practical tools for the CKD patient and her caregiver on fistula care.
LEARNING OUTCOMES	At the end of the section 2.4, learners will have obtained information about fistulas and tools on fistula care.
METHODS	Self-directed learning
DURATION:	30 minutes online and 45 minutes face-to-face
RESOURCES NEEDED:	• lap-top with internet connection • projection screen and light cannon
ORDER OF ACTIVITIES:	• E-learning module (30 minutes) Face to face: • Welcome and introduction (10 min.)- Worksheet 1 • Theoretical session (20 min.) – Worksheet 2 • Practical session (20 min.) - Worksheet 3
EVALUATION OF THE THEME:	• Self-assessment (e-learning module)
REFERENCES	•
WORKSHEETS	• Worksheet 1 • Worksheet 2 • Worksheet 3
HANDOUTS	Vascular access handbook for people with kidney disease (shortened edition)

Background information – e-learning:

Introduction

To carry out this haemodialysis treatment, you need to have what is called a
"vascular access for hemodialysis".
This vascular access allows the blood to be forced out of the body into the hemodialysis machine and return unhindered to the body.

There are three types of vascular access:

- **Native arteriovenous fistula**
- **Prosthetic arteriovenous fistula (arteriovenous graft)**
- **Central venous catheter**

Without none of these vascular access types, you CANNOT have hemodialysis treatment.

Selection of the best vascular access

As each person with kidney disease has its own characteristics that may be different from other people, the best type of vascular access to start the hemodialysis program must be personalized on a case-by-case basis. **The final decision on the type and location of the best vascular access in a specific person must lie in the hands of the health professionals who look after you and also the same person**. This is known as the multidisciplinary team, as represented below this paragraph, from left to right: dialysis nursing staff, nephrologist, kidney disease person, vascular surgeon and interventional radiologist.

Looking after the veins

The veins used to create a fistula in the arm are the same as those used when you have a blood test or when the nursing staff places an intravenous line. When this is done, there is always a risk of damaging these veins and if they are, they cannot be used to create a fistula. So it is very important to avoid needling in the veins of the arm where the fistula will be created and whenever possible, the veins in the hand must be used.

Fistula care just after operation

When you arrive home after the creation of the fistula, you must check the dressing that was put over the surgical wound. If you see that the dressing gets covered in more and more blood (bleeding), you must immediately apply constant compression with the fingers of the other hand and go to the Emergency Department of your hospital. At the same time, if you experience both intense pain in the hand and it also becomes cold and pale after having the fistula created, there may be insufficient blood reaching the hand, so you must go to the Emergency Department as well.

Fistula care during the maturation period

It is recommended that you perform exercises before and after fistula creation, for example by compressing a rubber ball with your hand. The aim of this exercise is to accelerate the fistula maturation process. Once the surgical stitches have been removed and the professionals in charge of you give their approval, it is very important that you do these exercises. Bear in mind that the more time you spend doing them each day, the better the fistula maturation process will be.

Care during the period of use of the fistula

Once you have a working fistula, it is important to know that you must not take your blood pressure in the fistula-bearing arm, have an intravenous line or take blood for a blood test through one of the veins in this arm or directly through the fistula. Bear in mind that, from now on, the veins in this upper limb "must not be touched" and that the fistula must only be used to do the hemodialysis treatment.

No compression must be placed on the fistula-bearing limb as it can obstruct normal blood flow and cause the fistula to stop working (thrombosis) so that it can no longer be used for hemodialysis. Therefore, it is important not to wear tight-fitting clothes, watches, bracelets and occlusive bandages. It is advisable not to lift heavy weights with the fistulabearing arm or do brusque exercises and impact sports with it, either. You must not lie on the fistula-bearing arm to sleep. You must avoid sharp changes in temperature (e.g. such as in saunas). Infections can get into the body when the fistula is needled. Thus, cleaning or asepsis measures of the fistula to eliminate microbes and avoid this must be stepped up.

To ensure this:

1. You must wash the fistula-bearing limb with soap and water before going into the dialysis room.

2. The nursing staff must disinfect the needling area using an antiseptic liquid that will be applied just before the needle's insertion.

Once the needles have been inserted, they are securely fixed on the limb, to prevent them from accidentally coming out during the dialysis session. This complication can be serious as it can cause an important bleeding.

The fistula must be routinely needled by specialized nursing staff working in the hemodialysis units (never by a nursing staff with no knowledge or specific skill). However, whenever there is an easily fistula for needling, all highly motivated people being treated in a hemodialysis unit or at home can choose to needle themselves **after a period of training** (selfneedling).

Fistula surveillance

In order to preserve the fistula for as long as possible to use it for haemodialysis, it is necessary to remain alert and keep an eye on it. Many people with kidney disease preserve their fistula in good conditions for years and do not need any other operation nor a catheter to be placed.

Types of catheter

Tunnelled catheter: this is called as such because the body of the catheter is attached using a cuff in a tunnel located beneath the skin. In this way, the risk both of infection and movement of the catheter is reduced.

Non-tunnelled catheter: here is no tunnel and the catheter body goes directly out of the body from the vein needling point. As a result, the risk of infection is higher than in the tunnelled catheter and it should not be left in place more than two weeks.

The ten commandments of the catheter carrier

- To maintain good hygiene habits and to know how to wash and bathe myself every day.
- To keep an eye on the dressing to make sure it is clean and dry and covers the whole catheter.
- Except for the dialysis staff, I must not allow anybody to take off my dressing or handle the catheter.
- To wear any kind of clothes as long as they do not compress the catheter and I should avoid brusque movements when I get dressed and undressed. I must wear clothes that open at the front when I go to the haemodialysis session.
- Have a shower as long as the catheter is protected by a waterproof dressing without directing the water jet at the catheter area.
- Cannot have a swim in the sea or in the swimming pool.
- Have to avoid pulls that can move the catheter and avoid sharp, cutting objects around it.
- If the patient get high fever and shiver, it is a sign of alarm that there may be a catheter infection and I have to go to Emergency at the hospital.
- If the patient have any problem with the catheter, I must get in touch as soon as possible with the staff at the dialysis unit.
- Must not try to solve any catheter-related problems on my own.

Self-assessment test

Part A – multiple choice

Please reply to the following questions to assess your knowledge of this unit. Note that only one option is correct.

11. To avoid any infections can get into the body when the fistula is needled:
    a. You must wash the fistula-bearing limb with soap and water before going into the dialysis room.
    b. The nursing staff must disinfect the needling area using an antiseptic liquid that will be applied just before the needle's insertion.
    c. Both a and b are correct.
12. If you carry a cateter:
    a. You have to maintain good hygiene habits, wear clothes that compress the catheter when I go to the haemodialysis session.
    b. You have to maintain good hygiene habits, wear clothes that do not compress the catheter and that open at the front when I go to the haemodialysis session.
    c. You have to maintain good hygiene habits, wash and bathe myself every day, wear clothes that compress the catheter and that open at the front when I go to the haemodialysis session.
13. If you carry a cateter:
    a. You can have a swim in the swimming pool but not in the sea.
    b. You can have a shower or a swim in the sea or in the swimming pool as long as the catheter is protected by a waterproof dressing without directing the water jet at the catheter area.
    c. You can have a shower as long as the catheter is protected by a waterproof dressing without directing the water jet at the catheter area and cannot have a swim in the sea or in the swimming pool.
14. Which of the following sentences is false:
    a. **In the tunnelled catheter,** the body of the catheter is attached using a cuff in a tunnel located beneath the skin.
    b. **In the tunnelled catheter,** the risk both of infection and movement of the catheter is reduced.
    c. Non-tunnelled catheter has no tunnel and the catheter body goes directly out of the body from the vein needling point.
    d. The non-tunnelled catheter, has the same risk of infection as the tunnelled catheter and it can be left in place more than two weeks.
15. Which of the following sentences is false:
    a. Patient have to avoid pulls that can move the catheter and avoid sharp, cutting objects around it.
    b. Patient must try to solve any catheter-related problems on his own, prior to go to Emergency at the hospital.
    c. If the patient get high fever and shiver, it is a sign of alarm that there may be a catheter infection and I have to go to Emergency at the hospital.
    d. If the patient have any problem with the catheter, I must get in touch as soon as possible with the staff at the dialysis unit.

Part B – drag & drop

Please match the type of catheter whit its characteristics:

Tunnelled catheter	the catheter body goes directly out of the body from the vein
	Is attached using a cuff in a tunnel located beneath the skin
Non-tunnelled catheter	The risk both of infection and movement of the catheter is reduced.
	The risk of infection is higher and it should not be left in place more than two weeks.

Video

Video1: Daily self-examination of the fistula: arteriovenous fistula with stenosis

Video2: Daily self-examination of the fistula: arteriovenous fistula without stenosis

To learn more

To learn more, you can visit the following websites:

- ALCER, Spanish Kidney Patients´ Federation (official webpage): https://www.alcer.org
- ALCER, Spanish Kidney Patients´ Federation (educational webpage): https://www.personasrenales.org
- Vascular Access Handbook (European Kidney Patients´ Federation): https://ekpf.eu/wp-content/uploads/2021/01/Handbook_ENGLISH-Extended.pdf

Face2face part

Worksheet 2.1.1 – Welcome and introduction

Objective: Explain the development of the session; know the characteristics of the participants and analyse what we will need during it.

Duration: 10 minutes

Implementation: Describe the session, which will consist of a theoretical and a practical part, where the characteristics of fistulas and catheters, the correct forms of care, and finally a practical workshop on what was learned in the session will be shown.

Worksheet 2.1.2 – Theoretical session: daily activity in CKD and ESRD

Objective: Acquire basic knowledge to help them identify the types of catheters and correct forms of care of the fistula.

Duration: 20 minutes

Implementation: The speaker will explain the characteristics of the fistula and types of catheters, their differences and their advantages (Using the theoretical material of the e-learning, specifically *Types of catheter and catheter and fistula care*). Then he will explain the correct forms of care, the fistula and the catheter to prevent infections. An interactive session will be offered asking participants to clarify their doubts at any time during the explanation.

Worksheet 2.1.3 – Practical session: adapting daily activity to CKD people

Objective: provide participants with practical knowledge to help them with the daily self-examination of the fistula: arteriovenous fistula with or without stenosis.

Duration: 20 minutes

Implementation:

The speaker will present two videos about the daily self-examination of the fistula: arteriovenous fistula with or without stenosis.

- Video 1

https://www.youtube.com/watch?v=jBNzN_am4sU

Daily self-examination of the fistula: arteriovenous fistula with stenosis. The process of exploring a fistula is described step by step, in this case with a narrowing or stenosis, which must be performed daily by the person with kidney disease.

- Video 2

https://www.youtube.com/watch?v=0RRpJ5xD6UY

Daily self-examination of the fistula: arteriovenous fistula without stenosis. The process of exploring a fistula is described step by step, in this case without any narrowing or stenosis, which must be performed daily by the person with kidney disease.

Finally the session will end with a question and answer section.

Module 2- How to manage CKD and ESRD in daily activities

Theme	**2.5 Other practical information**
GOAL(S) AND OBJECTIVES	Aim of this module is to provide to learners: - Acquire the necessary knowledge about some common problems in patients with kidney diseases.
LEARNING OUTCOMES	At the end of the section 2.5, learners will have obtained knowledge and tools to prevent co-morbidity in patient with CKD
METHODS	Self-directed learning
DURATION:	30 minutes online and 1 hour face-to-face
RESOURCES NEEDED:	- lap-top with internet connection - projection screen and light cannon - bust model and toothbrushes
ORDER OF ACTIVITIES:	- E-learning module (30 minutes) Face to face: - Welcome and introduction (10 min.)- Worksheet 1 - Theoretical session (20 min.) – Worksheet 2 - Practical session (40 min.) - Worksheet 3
EVALUATION OF THE THEME:	- Self-assessment (e-learning module)
REFERENCES	
WORKSHEETS	- Worksheet 1 - Worksheet 2 - Worksheet 3
HANDOUTS	None

Background information – e-learning:

Dental health

Preventive actions:

Reduce sugar consumption

There are foods especially harmful to the teeth: all those that contain sugar (cakes, chocolates, ice creams, chocolates, sweets, buns, soft drinks, packaged juices).

The association between sugar consumption and tooth decay is well established. Many of the foods we usually consume contain sugar (fruits, milk etc.) However, it is refined sugar, which is normally used to sweeten food and / or beverages, that has the greatest danger. There are foods that have added sugar in their composition, in the case of yogurts, jams, etc. This is what are called "hidden sugars" and their effect on the teeth it´s equally dangerous.

Brushing the teeth

Daily preventive care, such as brushing teeth, prevents later problems, and is less painful and less expensive than treatments for an infection that has progressed. To avoid cavities:

- Brush thoroughly and use dental floss at least twice a day.
- Eat a balanced diet and cut back between meals.
- Use dental products with fluoride, including toothpaste.
- Use fluoridated mouthwashes if your dentist tells you to.
- Make sure your children under 12 years of age drink fluoridated water or if you live in an area with non-fluoridated water you can give them fluoride supplements.

For effective cleaning, it is not necessary to fill the entire brush with toothpaste, a pea-sized amount is more than enough. This way we will avoid an excessive amount of foam in the mouth that is often annoying.

In order to have a healthy mouth, it is useful to acquire the habit of brushing your teeth and gums after each meal and, especially at bedtime, the last brushing being the most important. Each brushing should last 2-3 minutes minimum.

Visit the dentist regularly

The dentist is not a professional that we have to go to only when we have a toothache. It´s above all the professional who takes care of the dental health and who can help us keep it healthy. People with kidney disease are at higher risk for dental health problems, so these follow-up visits are more important.

Special situations:

Treatment with anticoagulants:

Those people who are taking any type of specific medication such as Adiro, Sintron or others should report this situation to be taken into account if it is necessary to remove a piece or if there are uninterrupted bleeding from the gums.

If bleeding occurs, it should be possible to locate the source of the bleeding. Fold a clean, damp tissue or bandage and place it over the site of the bleeding. You can bite into the tissue in order to stop the bleeding. You should not rinse your mouth and you should avoid physical exercise.

Kidney transplant:

In this situation, due to the immunosuppression that is part of the post-transplant treatment, it may be necessary to take extreme care of hygiene and monitor the oral cavity more carefully in case any complications arising from the treatment appear. Sometimes treatment with antifungal agents is recommended, always under medical prescription.

Dental prostheses

In those people who use some type of prosthesis, either partial or total, they must maintain the recommendations given by the professionals. Cleaning and monitoring of the deterioration of the same to avoid possible injuries that can cause infections.

Wound care after transplantation

Follow the following tips:

- Follow an appropriate diet to your personal characteristics.
- Recover the usual activity without making many physical efforts the first days after the intervention.
- Attend the reviews that have been scheduled.
- Wash surgical wounds with soap and water, dry well, disinfect and leave to air. Provide the family doctor with the discharge report for subsequent reviews.
- In case of pain, take painkillers prescribed by your doctor.
- Reduce alcohol consumption and avoid tobacco use.
- Avoid direct sun exposure or use highly protective creams.
- Go to the hospital if you notice any warning signs such as decreased urination, edema, sudden weight gain, discomfort when urinating, vomiting or nausea.

Prevention of visual problems

Currently there is no effective treatment capable of reversing the visual deterioration caused by optic nerve ischemia, although it´s possible to act on the risk factors that can precipitate it, ensuring good control of blood pressure, cholesterol and triglycerides, and secondary hyperparathyroidism.

Uremic optic neuritis secondary to severe acute renal failure usually disappears when the patient undergoes acute hemodialysis, although it is unknown whether an earlier onset of renal clearance is associated with a more favorable outcome.

Corticosteroid treatment could have theoretical benefits due to its anti-inflammatory effect on neural tissue to reduce optic nerve edema. However, the dose to be administered and the time interval is also not established. Posterior reversible leukoencephalopathy, evolves towards complete resolution of the lesions after correction of hypertension and predisposing metabolic factors. In the case of patients with kidney failure, the condition usually reverses after the start of dialysis

Self-assessment test

Part A – multiple choice

Please reply to the following questions to assess your knowledge of this unit. Note that only one option is correct.

1. What foods contain hidden sugar?
    a. Chocolates and sweets
    b. Yogurt and jam
    c. Fish and chips
2. In what special situations should we take more care of dental hygiene in patients with CKD?
    a. in people with a kidney graft
    b. in those taking anticoagulants
    c. the two above are true
3. What should you control to prevent visual problems in people with CKD?
    a. Blood pressure a cholesterol and triglycerides, and secondary hyperparathyroidism.
    b. Diet and blood pressure
    c. Weight bearing, triglycerides and cholesterol

To learn more

To learn more, you can visit the following websites:

- ALCER, Spanish Kidney Patients´ Federation (official webpage): https://www.alcer.org
- ALCER, Spanish Kidney Patients´ Federation (educational webpage): https://www.personasrenales.org

Face2face part

Worksheet 2.1.1 – Welcome and introduction

Objective: explain the development of the session; know the characteristics of the participants and analyse what we will need during it.

Duration: 10 minutes

Implementation: Implementation: describe the session, which will consist of a theoretical and a practical part, where tips will be shown to prevent common problems in people with CKD. It will end with a practical workshop on how

Worksheet 2.1.2 – Theoretical session: other common issues in patients with CKD

Objective: Objective: to acquire basic knowledge that will help them to know the most frequent risks in kidney patients in dental health, take care of transplant surgery, visual problems and how to position the patient in bed

Duration: 30 minutes

Implementation: The speaker will explain why CKD patients are at higher risk in relation to the proposed points and how to prevent its appearance..

Worksheet 2.1.3 – Practical session: dental health and best patient positions in bed

Objective: provide participants with practical tools to help CKD patients in their daily life.

Duration: 30 minutes

Implementation: an expert dental health monitor will conduct a practical tooth brushing session assisted by a bust model, followed by a question and answer section.

Alternatively, a video on correct tooth brushing can be viewed with audio in English and subtitles in different languages.
https://www.youtube.com/watch?v=7k3wjTOhYwY

Module 3

Theme	Creating an alliance with professionals - How healthcare professionals and caregivers can accompany the patient - Establishing an honest communication between patient-caregiver and healthcare professionals - How a caregiver can receive psychological support
Goals and objectives	- Introducing knowledge for both caregivers, patients and healthcare professionals on good communication and exercises to strengthen the participants communication skills and positive thinking abilities.
Learning outcomes	For professionals - Active and attentive listening for both verbal and nonverbal communication - Understanding patient/family problems and working together to find manageable solutions - Use of open questions where possible to elicit patient thoughts and ideas. - Learn and understand the barriers to communication For patients and caregivers - To gain the knowledge skills and confidence to be an active self-helper and improve communication skills - To identify and address issues that impact upon everyday life beyond clinical outcomes - To increase both patients and caregiver's knowledge about positive thinking
Content	- **A theoretical part**, which can be adapted into e-learning training - **A quizz at** the end or during the theory section, to test knowledge (assessment test) and/or 'entertain' the student. - A part to be carried out **in face to face, with at least one exercise** to be proposed to the participants (AS it is important to keep the session interactive). - **A video** (created by us or from other authoritative sources) to aid the comprehension of the module and to lighten it up. - Any additional and interactive elements: images, additional resources such as recommended books, sites, experiences etc.
References	Nyreskolen – Livet med Nyresygdom, Undervisningsmanual, Komiteen for Sundhedsoplysning Positivity, Barbara Fredrickson Learned Optimism, Martin E. P. Seligman

Introduction

When a person is affected by a long-term illness or disability, the social relationships change gradually or suddenly for the family and others who have a close relationship with the patient. Some caregivers experience that they have developed a chronic illness as a result of having to care for a close family member or friend. But also depression, sleep problems, eating disorders and stress are some of the disorders that relatives of a person with a serious chronic or life-threatening illness experience as a result of the extra strain in everyday life.

This module contains information for both caregivers and patients. In the first text, we describe how caregivers and health professionals can accompany the patient through an open listening and communication-based approach. In this chapter we also introduce the active self-helper.

In the second part of the module, we introduce the topic of how caregivers and patients can use communication techniques focused on the use of You and I-messages.

In the third part of the module, we also introduce the symptom circle which is a tool for both caregivers and patients and exercises on positive thinking.

1. How healthcare professionals and caregivers can accompany the patient

Being proactive by providing information and anticipating questions is the first step toward better caregiver-patient communication. Clinicians should actively seek patient participation by asking whether they have questions and whether anything has been overlooked from their viewpoint. The more caregivers do this, the more patients will engage in the dialogue.

Caregivers can partner with patients in numerous ways. First, patients should be told what is being done for them and asked whether they have any questions. It is important to refrain from using unfamiliar medical terms or acronyms during these discussions. Clinicians should encourage patients to speak up when something is not right and be prepared to respond appropriately when they do.

A key factor in improving communication with patients is to listen carefully and seriously consider what the patient is saying (even if the message is uncomfortable). Caregivers must avoid blocking behaviors that only serve to set up communication barriers.

Below are some approaches that can foster open communication between caregivers and patients:

- Focus on listening to the patient’s words and the intended meaning. Hear the patient out and acknowledge their input.
- Listen without interrupting. Listening is not just a skill but also an attitude. If the caregiver appears preoccupied with other issues, the patient will sense they are not being heard.
- Pay attention to your nonverbal behavior. By using positive body language, such as facing the patient and sitting down at their level, caregivers communicate interest in what the patient is saying. It is also helpful to provide for privacy and discourage interruptions during discussions.
- Be careful not to rush the patient, respond defensively, or change the subject.
- Take the time to acknowledge valid points. If the patient rambles or makes ambiguous statements, try rephrasing or paraphrasing or ask clarifying questions.
- Try to understand the patient’s message through both their verbal and nonverbal communication. How are they sitting or standing? What is their expression? Do they appear sad? Angry? Nervous?
- Take time to sort out what the patient is saying before responding, then summarize what you’ve heard.

The active self-helper

There are two parties who both play an active role in relation to the collaboration between patient and health professional and thus also to the optimal course of treatment. Adding to this collaboration, the cooperation and the involvement of the caregiver can be crucial to an optimal course of treatment and the overall wellbeing for both patient and caregiver.

It is important for a course of treatment that both the patient and the healthcare professional is committed and cooperate. When the patient is engaged, the patient can be described as being an active self-helper. This also goes for the caregiver, as the caregiver can take an active approach to taking care of their own health.

The role of an active self-helper implies the following:

The active self-helper

1. **Take care of your health** - such as taking medication, exercising, going to the doctor, eating healthy, taking part in planning your course of treatment by keeping an eye on and informing your doctors and other healthcare professionals about how your disease develops and what wishes and goals you have in relation for your treatment.

2. **Continue with your daily activities** - household chores, work, socializing with others, maintaining the things in life that matter to you. This may mean that you must find another way to continue your daily activities. For example, use a chair with wheels for gardening or have ready meals in the freezer for the times when you do not have the strength to cook.

3. **Pay attention to illness and pay attention to your emotions** - you can experience emotional changes due to your illness, such as anger, uncertainty about the future, changed expectations and goals as well as sadness and sometimes depression. There may also be changes in your relationship with your family and friends. To be aware that there will be emotional ups and downs, and that the downturns are a natural part of having a chronic illness and being a carer for one who is affected by chronic illness.

A good collaboration with the health staff is one of the things you can help to influence in order to have a good treatment course for the patient. This list of tips is something that you as a caregiver can use with your own health professional or when you accompany your relative to an appointment, but it may also be important to propose it to your relatives, so that he/she actively takes responsibility for his/her own care.

Prepare yourself

- **Keep an eye on the symptoms – both caregiver and patient**
  Be aware of what happens between the visits to the outpatient clinic. For example, the symptoms have lessened, worsened or are unchanged; the changes have occurred slowly or suddenly; has something happened in your life that has affected you?

- **Tell about your symptoms – for patient only**
  Changes, and patterns that you have observed between the controls. Also tell the healthcare professional which medicines or other types of treatment you are receiving and how they work.

- **Make a list of your main concerns and questions - both caregiver and patient**
  Ask your questions at the beginning of the meeting with your healthcare professionals. If you have more than 2-3 questions, give the entire list to your doctor, but do not expect answers to more

than 2-3 of them during the consultation.

- Ask - both caregiver and patient
  Ask questions about your diagnosis, tests, treatments, and follow-up.

- Repeat- both caregiver and patient
  Repeat to the health personnel the key points you have talked about during the consultation/control, diagnosis, prognosis, next step, treatment, etc.
  This gives both of you the opportunity to correct any misunderstandings.

- Take the initiative - both caregiver and patient
  If anything prevents you from following the instructions given to you by your healthcare professional, say so. Ask for written instructions if you need it.

- Get in touch- both caregiver and patient
  Call or make an appointment if you are in doubt or have questions.

2. Establishing an honest communication between patient-caregiver and healthcare professionals

Communication plays an important role in all relationships. Communication is important and good communication is even more important. Good communication matters to our relationships with other people, where poor communication can ruin our relationships with other people.

For example, it is crucial to be able to pass on information about one's condition and how one feels and ask for help. In terms of having to deal with one's illness, it is also an important trait in terms of how and where to seek information. Good communication skills can make one's course of illness easier and have an influence on the maintenance and building of good social relationships, which are indispensable in a course of illness. Communication is an important part of the relationship with one's relatives, health professionals, etc.

Exercise 2.1

Materials

- Note-pad, a pen
- If possible, someone to discuss and roleplay the exercise with.

We need to take a closer look at some communication techniques that can help us become better at expressing feelings and desires, and which can help prevent communication problems, for example in relation to our relatives. We need to talk about you - and I-messages.

- **I-messages:** provide an opportunity to express some of the difficult emotions we had in the last activity, such as worries or emotions such as anger and frustration, without blaming, exploding, or making others go into a defensive position.
- **You-messages** tend to do just that (e.g. blaming, exploding, or making others go into a defensive position), and it can make communication more difficult.

A good way to express anger and frustration in a constructive way is by using I-messages.

In this roleplay exercise we would like to give you an example of the two types of messages. You should try to notice the differences in the two dialogues and note what emotions they bring out in you and what they make you think.**Assign roles to two people in the group and read the following dialogues out loud.**

Example with "you-messages"

Spouse 1: Come on, let's buy tickets for that concert so we can get out together.
Spouse 2: Can you not understand that it is too much for me right now?
Spouse 1: You never want to do anything you are always too tired!
Spouse 2: Can't you just go yourself, instead of picking on me!
Spouse 1: If you could just go with me instead of always saying no, then we would not have this discussion every single time!
Spouse 2: Do not blame everything on me! You should try feeling the way that I feel!

Example with "I-messages"

Spouse 1: It's been a long time since we've done something together. Would you like us to try to arrange something?
Spouse 2: I'm just very tired right now. Dialysis is difficult to get used to. So, I do not feel like saying yes to anything right now. I am afraid that I am going to cancel and then you will be disappointed.
Spouse 1: O.k. I did not know. I just really miss doing activities with you. Should we plan something that you feel you have the strength to do?
Spouse 2: Can you possibly arrange a picnic? Then we can go out into the woods together, and if I am too tired that day, we can just do the picnic at home in the garden.
Spouse 1: That's a good idea, then we do not have to cancel anything, but can just adapt the plans, and then you do not feel you disappoint me.

Questions

- Which differences did you notice about the two conversations?
- Write them down – did something make a difference between the conversations?
- Discuss the differences that you noticed with your partner or the group.

Summary

Use of I-messages: expresses what the problem is, without blaming the other. Makes it possible to find a solution to it.

Use of you-messages: seem more aggressive and hostile - they make the recipient go on the defensive. It blocks the communication and inhibits finding a solution to the problem.

Moving forward

It can be difficult to use I-messages in the beginning. To address this, try changing the way you present the problem a little, and then tell how you feel about it.

For example:

- When you get home late, I get restless
- When you do not want to hold on to me, I get upset

They may be reminiscent of you-messages, but they differ from them by emphasizing a fact, and then elaborating on how to deal with it. They open the possibility of expressing emotions and are not as aggressive and hostile as you-messages.

Identifying the communication problem

Sometimes it can be difficult to identify a communication problem. For it may not always be about what we say or the way it is said, but it may also be what is not said that is the problem.

Listen to this conversation between two friends and decide if there is a problem and if so, what it is.

Tip: read the conversation out loud.

Friend number 1: Hi. I am very sorry, but I cannot go out to lunch with you today. I am simply too tired.
Friend number 2: It is okay. I know that your illness is often unpredictable. Is there anything I can do?
Friend number 1: No. There is nothing to do. That is just the way it is, I have to live with it.
Friend number 2: Well, okay. Well, then I am slipping away again. We will talk soon.
Friend number 1: Okay. Goodbye.

Questions

- Do you think that there was a problem in this conversation?
- What did you notice?
- If you are doing the exercise with a partner, discuss what you noticed about the conversation.

Now listen to this conversation, you can also read this one out loud.

Friend number 1: Hi. I am very sorry, but I cannot go out to lunch with you today. I am simply too tired.
Friend number 2: It is okay. I know that your illness is often unpredictable. Is there anything I can do for you?
Friend number 1: I am very glad you are asking. Can you be persuaded to bring some food over and have lunch at my house instead? I need something to eat, and I also want a little visit.
Friend number 2: That is a good idea. I would very much like to come by. What kind of food would you like?
Friend number 1: A sandwich or some chicken salad would be fine. What about you?
Friend number 2: Chicken salad sounds good. See you in a little while.

Questions

- What did you notice about this conversation?
- Did something make a difference?

Write down and discuss your observations with your partner or the group.

Summary

Family and friends usually want to help. But to be able to help, they need to know what to do. It is therefore one's own task to tell them how they can help or what it is that one needs. You can and should not expect your relatives to figure out exactly what you need.

Moving forward

Everyone has at some point experienced communication problems that create misunderstandings and unpleasant experiences. A lot of communication problems can probably be avoided if we learn to communicate more openly and effectively. Here are some suggestions on how to improve your own communication skills.

These techniques and tips can be used to improve communication between you and your family, friends and healthcare professionals.

Communication

1. **Identify** what is really going on with you and how you feel about it

2. **Express your feelings constructively**

Use "I-messages". An example: “I do not feel heard” is better than “you never hear what I say”. In the beginning, when using I-messages, one must watch out for hidden “You-messages” that just put “I feel” in front - such as “I feel frustrated when you behave like an idiot”. I-messages are also a great way to express positive emotions towards others, which helps to improve one's relationships.

When xxx happens, I feel zzz. An example: “When I cannot get in touch with you, it makes me feel abandoned and lonely”. For some, this way of expressing emotions may be easier because correlations between cause and effect are explained.

3. **Listen carefully**. We can be so eager to respond that we do not really hear what the other person is saying to us. We are too busy thinking about what to answer. When the other person has finished speaking, try to wait a few seconds to answer.

4. **Clarify** - repeat in your own words what you think you heard, then ask a question to get things clarified. For example: "When you answer 'yes’ to my question, is it because you agree - or do you just do not feel like talking right now?"

Quiz

1) As a carer should you write the patient’s symptoms down as they experience them?

- Yes
- No

Answer: You can write the symptoms down as they experience them. But remember, that a part of being an active self helper is for the patient to take action and take control over their own situation. They can write these things down, and also write down what they did to deal with the symptoms, as well as whether it worked or not. It will help both them and you to spot trends and patterns in their condition.

2) What is the use of I-messages?

- The use of I-messages expresses what the problem is, without blaming the other. When you use I-messages it possible to find a solution to the issue.
- T use of I-messages expresses how you really feel about the situation, and makes it clear to your partner what your intentions and needs are.

3) What is the use of you-messages?

- The use of you-messages makes it clear that the issue is about the person whom you are talking to, it helps them understand the issue from your point of view.
- The use of you-messages seems more aggressive and hostile - they make the recipient go on the defensive. It blocks the communication and inhibits finding a solution to the problem.

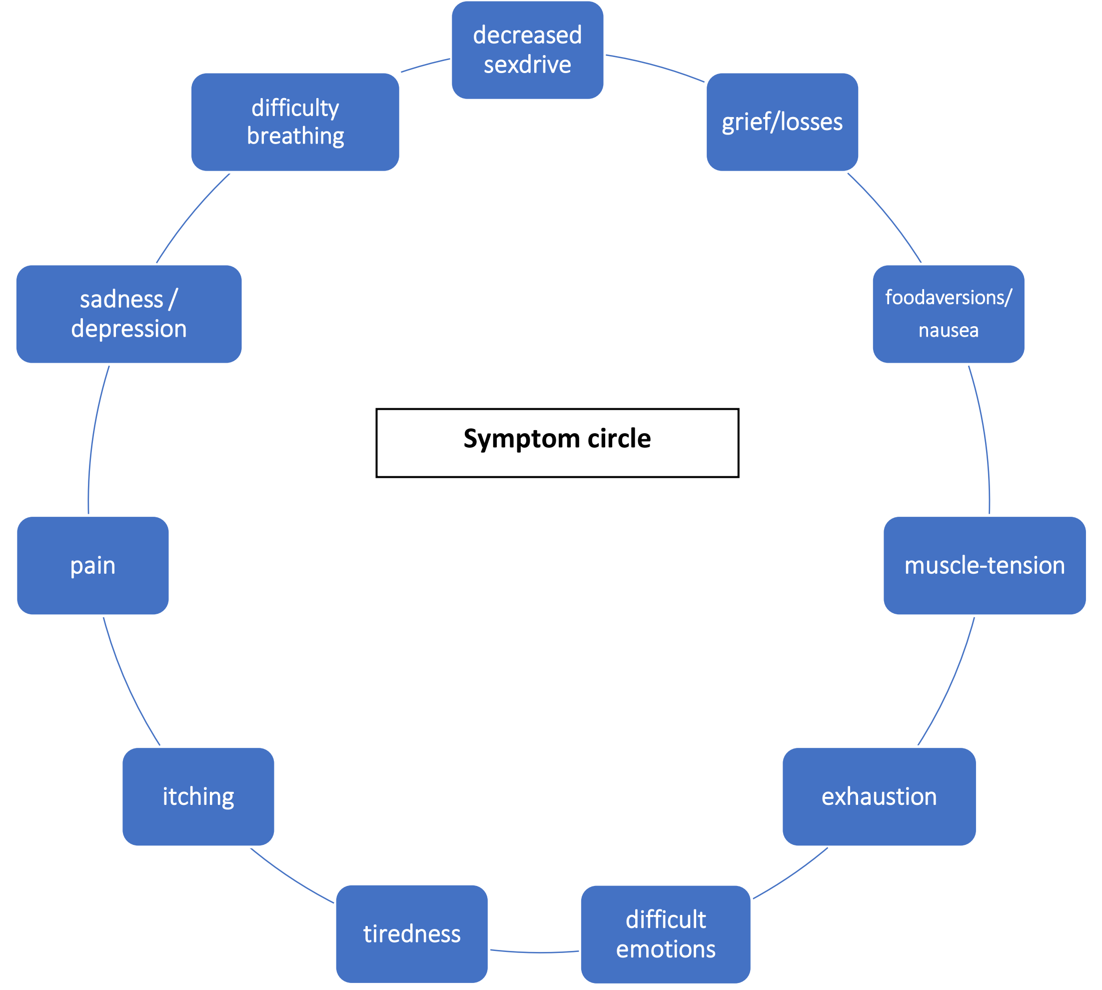
3. How a caregiver can receive psychological support

An important thing in relation to the symptoms that can occur in connection with suffering from kidney disease is to know when you can manage your symptoms yourself and when it requires the help of a professional.

When a person is affected by a long-term illness or disability, the social relationships change gradually or suddenly for the family and others who have a close relationship with the patient. Some caregivers experience that they have developed a chronic illness as a result of having to care for a close family member or friend. But also depression, sleep problems, eating disorders and stress are some of the disorders that relatives of a person with a serious chronic or life-threatening illness experience as a result of the extra strain in everyday life.

There is a big difference between experiencing sadness and depression and having a depression. Being affected by long-term illness and being a caregiver to one who is affected, can make one depressed and sad, which can affect the other symptoms we know in the symptom circle.

Symptom circle



Depression and sadness are still some symptoms we have to deal with - such as pain or fatigue. These feelings are part of life's normal ups and downs that everyone experiences and that we must learn to cope with. But it is important to be able to distinguish this from depression, which requires professional help.

Positive thinking

The way we think has a big impact on how we feel. Thinking very negatively can make one act inappropriately and make your symptoms worse. One develops a negative point of view both on oneself and the surroundings, and this in turn can pave the way for low self-esteem, depression and passivity. You feel like giving up. And all this aggravates one's symptoms and health.

An example is when we wake up in the morning and think about how hard it is to get out of bed.

Negative thought paths can make our everyday life and state of health reminiscent of a long hill that only goes uphill and is filled with obstacles. Learning to change your thinking pattern from being negative to being positive is an important tool when dealing with your health and the associated challenges.

A good example of positive thinking is the strip: "I think I can, I think I can… I know I can…"

Examples of positive and negative thinking

Here are some examples of the same statements formulated as negative and positive thoughts, respectively:

Example 1:

Negative: “I would like to go for a bike ride and visit my friend, but I can’t. I get so tired, just at the thought. And if I ride a bike, I know I will get tired when I get there that I'm not going to be very good company. There is no need to try. I know I can’t.”

Positive: “I could start biking over there, and if I think it's too hard on the road, I can sit on a bench and take a short break. When I am with my friend, I can ask rest if I get too tired. That way I can move and at the same time get a visit out of it.”

Example 2:

Negative: “I'm worried about the future. My life will never be the same again.”

Positive: “There are still many things I can do. I want to focus on that.”

3.1 Exercise with a partner

Materials

- notepad and pen

Write down 2-3 examples of something negative you say to yourself - or hear others say to you.

Examples of negative thoughts:

- “I will never be able to do that task; it is far too difficult.”
- "I'm too tired."
- "I will never be able to do the same things as before."

Now try and change the examples that you have written down into positives.

Here is an example of the previous negative thoughts changed into positive thinking/statements

Examples of positive thoughts:

- "I must have gotten a lot done yesterday since I'm so tired today."
- "I can overcome a little every day and take on a little at a time."
- “It's good enough because I do it as best as I can”

Question:

- Was it difficult changing your own negative statements?
- Discuss with your partner what each of you found difficult or easy during the task.

Summary

Especially in the beginning, it can be difficult to change or directly translate negative thoughts into positive ones. If this happens, it can be beneficial to have some ready-made positive or affirmative statements ready, especially for those times when you think everything is going bad. Make sure you have something good to say about yourself or the situation, such as “you feel good!”, “It gets better with each passing day” or “I do the best I can and that's good enough.”

Changing one's thought pattern is like changing any other habit. First, we must be conscious and very attentive. With practice, both positive thoughts and a brighter outlook on life become an automatic reaction - just like when we learn to ride a bike or drive a car.

Be patient.

If after trying to think positively for a few weeks you still do not think it works for you, do not worry.

Worksheet

How to turn negative thoughts into positive ones

1. Write down negative thoughts
2. Turn them into positive thoughts
3. Practice - use them in real situations
5. Be patient. It takes time to change habits.

If you want to read more about positive thinking, then here are two recommendations for you:

- Positivity by Barbara Fredrickson
- Learned optimism – How to change your mind and your life by Martin E. P. Seligman

Remember, if you feel depressed for more than two weeks, or it is seriously interfering with your ability to function at work, with your family, and in your social life, or is causing you to contemplate or plan to commit suicide, you need to consult with a mental health professional as soon as possible.

Module 4- Rights and opportunities for CKD patients and their carers

Theme	**Rights and opportunities for CKD patients in Denmark**
GOAL(S) AND OBJECTIVES	Aim of this module is to provide to learners: • Information on counseling, unemployment benefits and support provided by the municipality and state for CKD patients and their carers • Useful services for carers of kidney patients and their carers (e.g. how to travel while a patient suffers from CKD or ESRD) • Labor rights for kidney patients at national level
LEARNING OUTCOMES	At the end of the module, learners will have obtained basic information on the support services available at national level to support CKD patients and their carers and on rights and entitlements recognized to them.
METHODS	Self-directed learning

Background information – e-learning:

Introduction

Living with a long-term illness such as chronic kidney disease can turn anyone's world upside down. Managing a chronic kidney disease can be exhausting and stressful for patients, carers, families, and loved ones.

We all go through times of worry, fear and uncertainty when facing changes in our lives - especially ones that involves our health. At these difficult and uncertain times, it is important to acquire information about support services available in our local context, which can provide relief and respite as well as practical and economic support. It is also important to explore which certain rights and opportunities you have to seek help and counseling. You can also seek certain economic benefits from your municipality.

If you are a member of the Danish Kidney Association, you can also contact them for guidance and speak with a social worker (nyreforeningen.dk).

Support options for caregivers

There are plenty of support options that are important to know. It can be coverage of additional expenses and transport, lost earnings if you have a kidney-sick child or relief and psychological support. Relief may be necessary, e.g. after a prolonged hospitalization. A relief stay can be in a nursing home, and if you have a kidney-sick child, it can be with a relief family. Your family or network may also be financially compensated by the municipality for being a relief family. It can be difficult to send one of your loved ones on relief stays, but that's all right, because it can be really hard to live with kidney disease so close, and you as a relative have to take care of yourself, so you can continue to be there for the sick.

It can be difficult to get family life and work life connected, especially during the periods when the patient is hospitalized. Here it may be appropriate for you to lower your work hours or take a leave. However, the availability of leave options that match your situation is limited.

You can read more about different support options for both kidney patients and caregivers here: https://nyre.dk/dine-rettigheder/

Relevant professionals

In this module we will guide you through some basic information, but don’t forget to always check in with your health and social support workers for further information and guidance. These are the professional profiles that might help you the most to exercise your rights and obtain your entitlements:

Your primary care doctors

A primary care doctor is the person you can rely on to help you manage your health. They can help you with preventive care, like your routine physicals, screenings and immunizations, and also diagnose and manage many common chronic conditions. Besides prescribing medications, diagnostic examinations and specialist counselling, they can provide certificates you need to apply for specific benefits.

Your primary care doctor is an important point of contact and he or she can help you with your healthcare and counseling.

Social worker

Social Workers performs a great diversity of tasks to help people who are struggling with some aspect of their live. For example, social workers are trained to support clients and communities who are living with disabilities and chronic diseases. If you need help with your or a relative's illness there are several options in the municipality: time-limited home help, diet guidance, patient education or rehabilitation after surgery or hospitalization.

These are some of the areas where a social worker can help you navigate on how to apply.

Some kidney departments have their own social worker with special experience in counseling kidney disease. Remember that it is important to contact the social worker early on in the treatment course.

When you become ill, it also affects your work situation and your connection to the labor market. If your illness affects your ability to work, you can contact your local Jobcenter.

Jobcenter

At all Jobcenters, there are job retention consultants with special insight into the inclusive labor market and with knowledge of the many support schemes. For example, you can get help with tools and special design of the workplace, if it is necessary to take on a job. You can also get job training or training in a company where you are paid according to special rules.

You can read more about the rules here: www.bmhandicap.dk

Patient advisor

When you as a patient or relative need information, advice or guidance in connection with the contact to the hospital, you have the opportunity to get help from the hospital's patient advisor. The patient advisor can help you clear up misunderstandings or other problems that have arisen between you and the hospital staff. The patient advisor is neutral and of course has a duty of confidentiality. You can also contact them anonymously.

The patient advisor can also provide information and guidance on:

- Examination, treatment and care
- Free choice of hospital
- Treatment guarantee
- Replacement options
- Opportunities for appeal
- The right of access to documents
- Waiting times etc.

Legal expert

Among legal experts, you can find those specialised in supporting you with social security, welfare and employment benefits. They can also help you challenging decisions made by local and state agencies, if you think they have acted unlawfully. These professionals can work as private practitioners but most often you can contact them through dedicated agencies and non profit institutions such as Ældresagen.

Work

If you are already working prior to your illness, you can contact your union to seek counseling on how to fit work-life balance with a chronic illness.

If you are unable to work and is a member of an A-kasse (unemployment insurance), you may also be entitled to receive unemployment benefits such as Dagpenge or Sygedagpenge.

Read more about unemployment benefits with insurance here: https://www.borger.dk/arbejde-dagpenge-ferie/Dagpenge-kontanthjaelp-og-sygedagpenge/Sygedagpenge/Sygedagpenge-hvis-du-er-loenmodtager

Unemployment benefit and education assistance (kontanthjælp og uddannelseshjælp)

- Anyone can apply for cash benefits if they are unable to support themselves and their family (spouse and children under the age of 18).
- If you are under 30 years of age and do not have a vocational qualification, you may be entitled to educational assistance.
- However, you cannot receive unemployment benefits and education benefits if your spouse can support you, or if you or your spouse have assets that you can live on.

You can read more about unemployment benefits and education assistance here: https://star.dk/ydelser/ledighed/kontanthjaelp-og-uddannelseshjaelp/

Job clarification process (ressourceforløb)

You are entitled to a job clarification course from your municipality if it is not possible to have your unemployment benefits extended. A job clarification course is a holistic effort that aims to get you back in the job market or in the process of an education. A job clarification course can consist of the following offers:

- Guidance and upskilling
- Company internship
- Employment with wage subsidy
- Mentor
- Other efforts that can help to stabilize or improve work ability can also be initiated after a specific assessment

A job clarification course can last up to 2 years. Several courses can be initiated one after the other if you are still unable to work due to your illness and if you do not belong to the target group for resource courses, flex jobs or early retirement. The assessments are made by your local Jobcenter.

Early retirement (førtidspension)

Early retirement pension can be granted to persons with significant and permanent reduced ability to work. It is possible to work to a certain extent at the same time as receiving an early retirement pension. However, the pension is reduced if the early retiree or the pensioner's spouse or cohabitant has supplementary income of a certain amount.

It is the municipality that grants early retirement.

Read more about the rules here: https://star.dk/ydelser/pension-og-efterloen/folkepension-og-foertidspension/foertidspension-ny-ordning/

Extra expenses

Additional expenses due to illness

If there are many additional expenses due to illness, the patient can apply for them to be covered according to the Service Act § 100. Additional expenses are expenses that the patient would not have had if he / she was not ill. As a starting point, the total additional expenses must exceed DKK 6,804 annually (2021).

The additional expense benefit is tax-free and not dependent on income and can be applied for by new early retirees and others with disabilities.

For children and young people under the age of 18, special rules apply for subsidies for additional expenses and lost earnings for parents. The Kidney Association has published a booklet: Kidney Disease Children

Contact your local municipality for help on how to apply.

You can also read more in depth about what expenses the service act typically covers here: https://nyre.dk/merudgifter-2/

Medication supplement

Health insurance subsidies are granted for prescription medicines if they exceed DKK 1,010 during a year (2021 figures). The subsidy then amounts to the following for persons over 18 years of age:

- 50% of the part that exceeds DKK 1010, but not DKK 1,685
- 75% of the part that exceeds DKK 1,685, but not DKK 3,660
- 85% of the part that exceeds DKK 3,660

If there is a large, lasting and well-documented need for medicines that exceed the deductible of DKK 4,270 per year, a 100% subsidy is granted for the part of the deductible that is in addition to DKK 4,270 annually (chronic allowance).

Chronic illness grants and other grants

Chronic illness grant per. 010116 runs automatically (previously your own doctor had to apply to the Danish Medicines Agency). Retirees who do not have significant assets or special income can apply to the municipality for medicine subsidies in accordance with the rules on health allowances and personal allowances.

People with low incomes and tight finances, e.g. students and early retirement recipients, can seek help for their medical expenses in accordance with section § 82 of the Assets Act (Aktivloven).

Transportation

You may be entitled to a transport subsidy if you meet one of the following conditions:

- you receive a pension (Folkepension) or early retirement pension (Førtidspension)
- you live more than 50 kilometers from the hospital where you are to be examined or treated
- you are not able to take public transport to the hospital and you have to be in an outpatient course at the hospital more than once, or are sent home by the hospital on weekends or a short holiday

If you meet one of the conditions, you can contact your examination or treatment site to find out about your options for obtaining a transport subsidy.

Read more about the rules here: https://www.regionh.dk/Sundhed/Patientguiden/undersoegelse-for-en-sygdom/rettigheder-naar-du-skal-undersoeges/Sider/Transport-og-transporttilskud-dine-rettigheder.aspx

Home dialysis

The cost of dialysis treatment is a hospital expense. If you need minor home changes to your house, there is a possibility that the hospital will cover the cost.

You need to contact your dialysis unit at the hospital where you receive treatment if you want home dialysis.

Travelling when in dialysis

In Denmark

To a limited extent, you can get guest dialysis at a department in Denmark near the place where you want to vacation. Talk to your hospital staff about it. Remember that you must apply well in advance for the sake of planning. Dialysis treatment is free as the treatment is paid for by your region.

In relation to payment for driving to and from dialysis, when you visit another dialysis center, you can contact your home region and ask for a refund. Some regions provide it, others do not, but it is becoming more and more common to provide an amount equal to what your transportation from your home to the dialysis center costs the region.

See list of dialysis sites in Denmark on Nyreforeningens website https://nyre.dk/ferie/#:~:text=Du%20kan%20sagtens%20tage%20p%C3%A5,i%20b%C3%A5de%20ind%2D%20og%20udland.

In Europe

Dialysis patients are covered by the blue EU health card when traveling in Europe. Everyone who needs treatment abroad bring the blue card. The card makes it possible to cover the costs of necessary medical and hospital treatment on the same terms as the citizens of the country in question.

Expenses for repatriation are not covered by the blue EU health card.

The annulment of public travel health insurance also means, in principle, that only expenses for treatment at public hospitals, clinics and the like are covered. Dialysis treatment at a private hospital or clinic is therefore generally not covered.

It is recommended that kidney patients take out insurance if they become ill outside Denmark and need any medical treatment and repatriation. It is important to contact / examine your private travel insurance before departure both within and especially outside the EU.

Dialysis patients must always bring the blue health card, which is used as payment for dialysis treatment at most hospitals / clinics in EU countries.

https://pri.rn.dk/Sider/18205.aspx

Self-assessment test

Part A – multiple choice

Please reply to the following questions to assess your knowledge of this unit. Note that only one option is correct. Please insert a self-assessment related to what explained before

Video

Example: Add a video-interview with a legal expert from your country explaining the rights of a person with CKD.

To learn more

To learn more, you can visit the following websites:

https://www.kidney.org/

https://www.kidney.org.uk/