Provided by Miami-Biscayne Bay (FL) Chapter of the Links Incorporated

The Links, Incorporated

CHRONIC KIDNEY DISEASE (CKD)

INFORMATION RESOURCE GUIDE

block K.A.R.E.

The Links, Incorporated™

Linked in Friendship, Connected in Service

Miami-Biscayne Bay (FL) Chapter

On June 30, 2010, 31 of South Florida's most accomplished professional women were inducted as charter members of the Miami-Biscayne Bay Chapter of The Links, Incorporated. On Saturday, June 14, 2014, we expanded our circle of friendship by welcoming eight formidable, educated and engaged women to our Chapter. On Sunday, June 18, 2016, we once again strengthened our circle of friendship and dedication to service by embracing eleven amazingly talented, socially conscious, and community-minded women. We were so grateful to extend our friendship circle with six dynamics, civically engaged and educated women on Sunday, June 9, 2019.

The Miami-Biscayne Bay (FL) Chapter of the Links, Incorporated has been selected to receive a black K.A.R.E. Initiative sub-grant from The Links, Incorporated.

THE LINKS, INCORPORATED

black K.A.R.E. INITIATIVE

According to the National Institutes of Health, Black Americans are almost four times as likely as White Americans to develop kidney failure. While Black Americans make up about approximately 13 percent of the population, they account for approximately 35 percent of the people with kidney failure in the United States.

The primary goal of the black K.A.R.E. Initiative is to raise awareness of chronic kidney disease (CKD) in Black communities, with a focus on its risk factors, complications, treatment – and how to reduce the risk of kidney failure and/or improve outcomes for people living with the condition.

black K.A.R.E.

KIDNEY AWARENESS RESOURCES & EDUCATION

Mission of black K.A.R.E

The mission of black K.A.R.E. is to raise awareness and prevention of chronic kidney disease.

K.A.R.E. stands for Kidney Awareness Resources Education Initiative, which is focused on preventing chronic kidney disease, particularly in African American communities.

Black Americans are almost four times as likely as White Americans to develop kidney failure. While Black Americans make up about approximately 13 percent of the population, they account for approximately 35 percent of the people with kidney failure in the United States. National Institutes of Health.

Chronic kidney disease (CKD) affects about thirty-seven million people in the United States (more than 1 in every 7 adults).Around 90 percent of people who have this condition are unaware they have it.

Two out of five adults who have CKD do not know they have severe chronic kidney disease.

People with CKD can live for years without knowing, as it does not always have the most clearly defined symptoms.

The two leading causes of chronic kidney disease are high blood pressure and diabetes.

Many individuals are not aware they have CD until the disease has progressed to an advances stage.

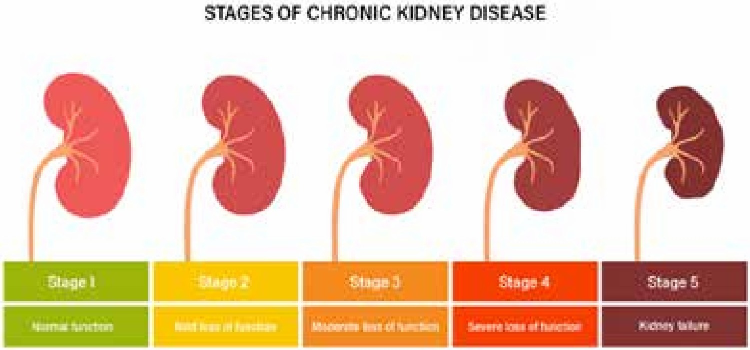
What Is Chronic Kidney Disease?

About thirty-seven million American adults have chronic kidney disease (CKD) and most don't even know it. CKD includes conditions that damage your kidneys. The word "chronic" refers to the gradual, but lasting, loss of kidney function over time. Healthy kidneys remove the waste that your body naturally produces out of your blood. With unhealthy kidneys, you are unable to filter waste and excess fluid from your blood as well as you should.

CKD is different from kidney failure. CKD refers to all five stages of kidney disease, from mild loss of kidney function at stage 1 to complete kidney failure at stage 5. The stages of kidney disease is based on how well your kidneys are able to remove waste and excess fluid from your blood. In the early stages of kidney disease, many people don't have any symptoms.

As the disease progresses, you may begin to show or notice symptoms that you may not associate with kidney disease until your kidneys begin to fail. Greater than 30% of CKD patients have never seen a kidney specialist, or nephrologist, by the time their kidneys fail. This is why CKD is often referred to as the "silent killer."

CKD can be treated. Although you cannot reverse kidney damage, you can potentially stop or slow its progression. The earlier detected and treatment started, the better. Understanding more about CKD—what it is, what the risk factors are, how the disease



progresses, and how to get screened—will help you protect your kidney health.

To fully understand CKD, we must first understand what kidneys do and why they are important.

Why Are My Kidneys Important?

Normal healthy kidneys...

1. **Remove excess fluid and waste**

   Your kidneys filter about two hundred quarts of blood each day to make about 1 to 2 quarts of urine. The urine contains excess fluid and waste. This process keeps excess fluid and waste from building up in your body.

2. **Control blood pressure**

   Kidneys need a certain level of pressure to work properly. They use hormones and fluid levels to control this pressure. For example, if the pressure inside the kidneys is too low, the kidneys make a hormone that causes blood vessels to constrict. This has the effect of increasing blood pressure. The kidneys maintain normal blood pressure to keep your heart, brain, and other organs healthy.

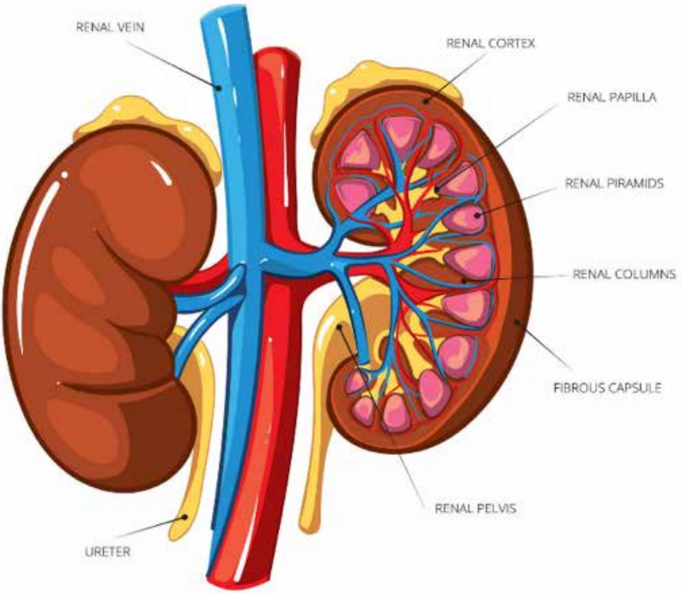
3. **Help make red blood cells**

   Your kidneys make a hormone called erythropoietin. Erythropoietin tells bone marrow to make red blood cells. Red blood cells carry oxygen from your lungs to your brain and vital organs. Red blood cells provide the energy you need for daily activities. If you do not have enough red blood cells, you develop anemia. Anemia can make you feel weak and tired.

4. **Help keep bones healthy**

   The kidneys make an active form of vitamin D. You need vitamin D to absorb calcium and phosphorus. Calcium and phosphorus are important minerals for bone health. The kidneys also balance calcium and phosphorus, so your body has the right amount. For example, your heart needs potassium to function properly.

5. **Control pH levels**



Importance of Kidney's

Your body functions best with a healthy balance of acids and bases in your blood. As cells break down, they make acids. The foods you eat can either increase or lower the amount of acid in your body. pH level is a measure of acids and bases. Your kidneys balance your pH level by either removing or adjusting the amount of acid and buffering agents.

What Happens When Kidneys Slow Down or Stop Working?

When your kidneys slow down and cannot do their job effectively, toxins build up and make you feel sick. CKD develops over time. In the initial stages of CKD, your kidneys are still able to filter out waste from your blood. Early detection and treatment often can keep CKD from getting worse. In the final stage of kidney disease, you need dialysis or a transplant to live.

Where Are Our Kidneys?

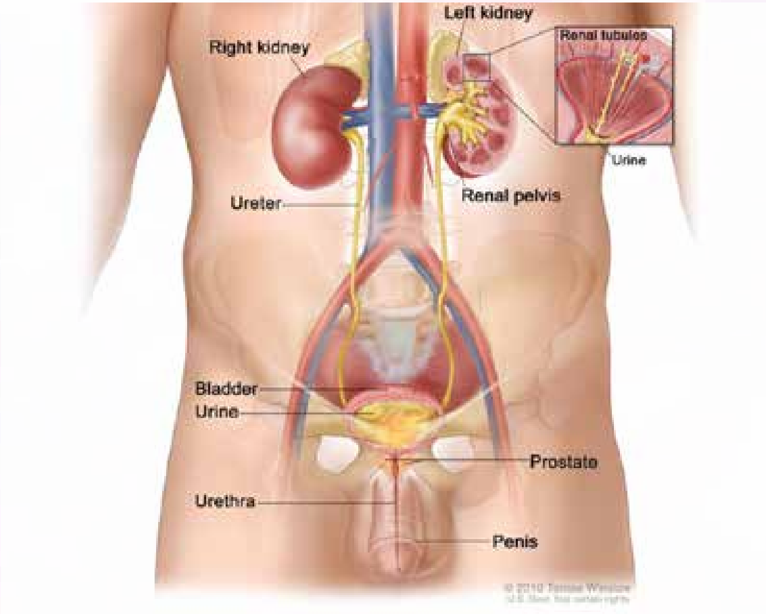
Kidneys play a vital role in maintaining your health. Learn more about where your kidneys are, what your kidneys do, and why they are important.

The kidneys are located below the rib cage, one on each side of the spine, toward the back of the body. They are protected by the lower part of your rib cage.

Each bean-shaped organ is about 4 to 5 inches long, about the size of an adult fist. Although they are small, your kidneys work hard to keep the rest of your body in balance.

Your kidneys work to keep you healthy. The main job of your kidneys is to filter your blood. All the blood in your body goes through the kidneys several times a day. The kidneys remove waste from the blood and adjust salts, fluid, and minerals. This waste is turned into urine, which then travels to the bladder and is eliminated.

Most people have two kidneys. But your body can function well with only one kidney.



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Normal Healthy Kidneys

Your kidneys filter blood and make urine. Urine contains excess fluid and waste. Filtering your blood helps keep excess fluid and waste from building up in your body.

Kidneys need a certain level of pressure to work properly. They use hormones and fluid levels to control this pressure. For example, if the pressure inside the kidneys is too low, the kidneys make a hormone that causes blood vessels to constrict. This has the effect of increasing blood pressure.

The kidneys work to maintain normal blood pressure. This keeps your heart, brain, and other organs healthy.

Your kidneys make a hormone called erythropoietin. Erythropoietin tells bone marrow to make red blood cells. Red blood cells carry oxygen from your lungs to your brain and vital organs. Red blood cells provide the energy you need for daily activities. If you do not have enough red blood cells, you develop anemia. Anemia can make you feel weak and tired.

The kidneys make an active form of vitamin D. You need vitamin D to absorb calcium and phosphorus. Calcium and phosphorus are important minerals for bone health. The kidneys also balance calcium and phosphorus, so your body has the right amount.

Your body functions best with a healthy balance of acids and bases in your blood. As cells break down, they make acids. The foods you eat can either increase or lower the amount of acid in your body.

High Blood Pressure and Chronic Kidney Disease

High blood pressure is a leading cause of chronic kidney disease (CKD) in the United States. About 1 in 2 American adults (about 108 million people) have high blood pressure. High blood pressure and CKD are often linked. A diagnosis of one often precedes a diagnosis of the other. About 1 in every 5 adults with high blood pressure may have CKD.

What is High Blood Pressure?

Blood pressure is the force of blood pushing against the walls of your arteries. Arteries carry blood from your heart to other parts of the body. Normal blood pressure is a reading of less than 120/80 mmHg. Blood pressure normally rises and falls throughout the day. If blood pressure stays high for a long time, it can lead to kidney disease. Most people with high blood pressure do not have any symptoms. In rare cases, it can cause headaches. You can have high blood pressure for years without knowing it. The only way to find out if you have high blood pressure is to have it measured.

What Does High Blood Pressure Do to the Kidneys?

High blood pressure can constrict and narrow the blood vessels in your kidneys. This reduces blood flow so the kidneys cannot do a good job of removing excess fluid and waste from your body. Excess fluid in the blood vessels can raise your blood pressure even more.

What are the Symptoms of Kidney Disease in People with High Blood Pressure?

Many people in the early stages of kidney disease do not have any symptoms. As kidney disease gets worse, some people may have swelling. This happens when the kidneys cannot get rid of extra fluid and salt. Swelling typically occurs in the legs, feet, and ankles. Swelling typically occurs in the legs, feet, and ankles. Swelling occurs less in the hands or face.

Symptoms of Kidney Disease in People with High Blood Pressure

- Increased or decreased urination
- Loss of appetite, nausea, or vomiting
- Weight loss
- Drowsiness, feeling tired

- Trouble sleeping
- Headaches or trouble concentrating
- Generalizing itching or numbness, dry skin, or darkened skin
- Muscle cramps
- Chest pain or shortness of breath

Drugs that can damage the kidneys include:

- Antihistamines
- Pain Killers

In diabetes, your kidney health matters

Diabetes is **the leading cause** of kidney disease in Canada[1]

As many as **50%** of people with diabetes may show signs of kidney damage[2]

Diabetes is a Major Risk Factor

Diabetes is major risk factor for CKD when the body does not make enough insulin, the body makes a normal amount of insulin, but the body does not use it effectively and when the sugar in the blood is too high.

Prevalence of Chronic Kidney Disease in Black Americans

The rates of kidney disease and kidney failure in the Black population is higher than rates for other groups, yet Black Americans with kidney failure (or end-stage renal disease) have lower access to kidney transplantation. These disparities continue to trend upward.

The high rates of diabetes and high blood pressure in the Black community accounts from some of these disparities. However, there are non-medical factors that also contribute, such as lack of access to insurance, medical care, and healthy foods, housing and other conditions historically liked to discrimination. Awareness of these disparities and the effects on CKD can empower you to take charge of your kidney health.

Compared to other ethnic groups, Black Americans are at increased risk of diabetes, high blood pressure, chronic kidney disease (CKD), and kidney failure.

Kidney disease, diabetes and high blood pressure are linked. Black adults have higher rates of diabetes and high blood pressure than White adults. Uncontrolled diabetes and high blood pressure are real risk factors for CKD. People who have uncontrolled diabetes and high blood pressure are more likely to develop CKD than people without these conditions. Each condition can lead to or worsen the other.

The Centers for Disease Control and Prevention looked at the percentage of US adults, aged 18 years or older with CKD and diagnosed diabetes who were prescribed blood pressure medications. The prescription of blood pressure medications is higher in Black adults with CKD and diagnosed diabetes (63%) than in White adults (37%) or Asian adults (32%). (The Centers for Disease Control and Prevention. Chronic Kidney Disease in the United States, 2021. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2021).

In addition, the United States Renal Data Service reports of the reported cases of end-stage renal disease in the US, approximately 39% have diabetes and 26% have high blood pressure.

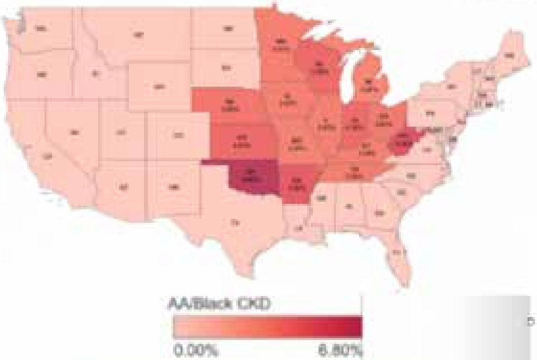
Rates of kidney disease in the Black population are higher than rates for other groups, and this trend is continuing.

In people who receive Medicare fee-for-service benefits, kidney disease is highest among Black Americans (33%). American Indians or Alaska Natives (28%) had the next highest rate of kidney disease, followed by Asian Americans or Pacific Islanders (26%).

If undiagnosed or untreated, kidney disease can get worse and lead to kidney failure (also called end-stage kidney disease). Black Americans make up 13% of the US population but account for 35% of the population with kidney failure.

Black Americans are about four times more likely than White Americans to develop kidney failure. The United States Renal Data Service reports kidney failure prevalence of 5,855 cases per million for Black Americans compared to 1,704 cases per million for White Americans.

See the rates of CKD among Blacks in your area, based on CMS and BRFSS data:



STAGES OF CHRONIC KIDNEY DISEASE		GFR*	% OF KIDNEY FUNCTION
Stage 1	[illegible]	[illegible]	[illegible]
Stage 2	[illegible]	[illegible]	[illegible]
Stage 3a	[illegible]	[illegible]	[illegible]
Stage 3b	[illegible]	[illegible]	[illegible]
Stage 4	[illegible]	[illegible]	[illegible]
Stage 5	[illegible]	[illegible]	[illegible]

This needs to be a high resoultion

Are You at Risk? Get Tested!

If you have diabetes or high blood pressure, you are at increased risk for CKD. Controlling these diseases can help prevent kidney disease or slow down its progression. Many other factors can put you or a family member at increased risk for CKD:

- Family history of CKD
- Age 65 and older
- Abnormal kidney structure
- Heart disease
- Smoking
- Obesity
- Disease that affect the kidneys, some are inherited

If you are at risk for kidney disease, get tested, even if you feel healthy today. Ask your doctor how often you should be tested. CKD is detected by getting simple blood and urine lab tests. One urine test used to detect protein in your urine is an albumin-to-creatinine ratio (ACR). Excessive protein in the urine is one of the earliest symptoms of kidney disease. A blood test that detects kidney disease is a creatinine test, which is used in a math formula to estimate your glomerular filtration rate (GFR). GFR estimates how much kidney function you have.

Support Groups for Kidney Transplant Patients

(Responsum for CKD)

Before joining a particular support group, ask the following questions:

- Is the group designed for people in a certain stage of the disease?
- Is it designed for a particular age group?
- Is there a mandatory participation, or can you observe until you are comfortable with sharing?

- When, where, and how often does the group meet?
- Is it peer-led or facilitator-led?
- If there is a facilitator, what is his/her training?
- Are meetings free? If not. What is the fee and for what is it paying?

Joining a support group will allow you to:

- Safely share your emotions
- Hear firsthand experiences of living with the disease and its treatment.
- Trade coping mechanisms
- Receive encouragement
- Feel connected, understood, and empowered.

Tips when joining a kidney disease support group

Joining a support group does not have to be a long-term commitment. Even if it is you do not have to stay.

- Some support groups meet once a month, while others meet once a week. After choosing a group see if it is a good fit. If you decide to try out several, jot down your impressions in a journal to separate. You may find that a particular group or format helps you more than others.
- Pay close attention to the group's protocols concerning sharing, confidentiality, and participant.
- Watch to see how effectively the facilitator (whether peer, lay or professional) guides the session disruptive group members. Negativity, and/or conflict.
- Beware of groups that:
    - Charge high fees (most support groups are free, though some may ask for a donation of a few snacks and operation costs.
    - Require you to buy products or services from members, facilitators, or host organizations.
    - Promise any outcomes from group participation, whether medical or otherwise.

Remember that support group therapy is neither therapy nor substitute for medical care. Let your doctor know if you decide to participate in a support group. Your doctor can also help is finding the right support group for you.

American Association of Kidney Patients *(https://aakp.org/center-for-patient-engagement groups/) The AAKP has a locator feature for independent support groups in 34 states, along with start your own support group.*

National Kidney Foundation: *(https://ww.kidney.org/patients/peers). The NKF offers a program you can call or fill out a form online, and you will be matched with a peer mentor. Your mentor will can support and share experiences and tips about disease management and treatments.*

Responsum for CKD: *(https://responsumhealth.com -chronic kidney disease) – a one-stop-shop for personalized patient information and resources on kidney disease.*

Renal Support Network: *(https://ww.rsnhope.org/rsn-programs/kidney-disease-resource) holds online support group (https://www.rsnhope.org.rsn-events/rsn-zoo) meetings that are nationally and internationally.*

DialysisFinder.com: *(https://dialysisfinder.com/) Davita Kidney Care's online locator can help find a center near you. Even if not on dialysis, a social worker or staff member at the center may be able to find a group.*

Online support groups

The Renal Patient Support Group (https://www.facebook.com/groups/RPSGroup/).

Kidney Patient Support Group *(https://facebook.com/kidneypatientgroup).*

Dialysis and Kidney Disease Support Page *(https:/www.facebook.com/Dialysisand kidney*

Preparing for Dialysis

There are two kinds of dialysis. In hemodialysis, blood is pumped out of your body to an artificial kidney machine and returned to your body by tubes that connect you to the machine. In peritoneal dialysis, the inside lining of your own belly acts as a natural filter.

Training and preparing for home dialysis treatment

If you have chosen to do home dialysis, your care team will collaborate closely with you to make sure you understand the treatment process and feel confident starting dialysis on your own. You will do your first dialysis treatments in the center with your home therapies nurse while you go through detailed, firsthand training. Once you are familiar with what home dialysis is like, your nurse will help you transition to doing dialysis at home. Remember, support is always just a phone call away–if you need help or have questions, you can call a nurse anytime day or night.

Five things to know about home dialysis training

1. Training for home dialysis is broken into sections, so you can go at your own pace. Training for home peritoneal dialysis takes about 2 weeks; training for home hemodialysis lasts 4-6 weeks.
2. You will learn to complete treatment safely–with or without a care partner. If you choose to have a care partner, you will bring your partner with you to training.
3. During training, you will prepare your home for treatment with the help of your care team. This includes learning how to organize and store home dialysis supplies.
4. When you come to training, you will bring all your medications in their bottles. You will also bring your glucometer, if applicable.
5. Plan, so you can be as comfortable as possible on training days. Wear loose clothing and bring a blanket, a book, and a healthy lunch or snack.

Peritoneal Dialysis: 2 Types, Your Choice

There are two types of peritoneal dialysis (PD): continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). Both types of PD have slightly different advantages, so it really comes down to your personal preference and schedule along with your nephrologist's recommendation.

You do treatments continuously, without a machine, 3 to 5 times each day in any clean environment–at home, at work or while traveling. That is why it is called "ambulatory." You are not attached to a machine of any kind. You can be on the move–wherever, whenever.

Peritoneal dialysis (PD) is a type of dialysis which uses the peritoneum in a person's abdomen as the membrane through which fluid and dissolved substances are exchanged with the blood.[1][2] It is used to remove excess fluid, correct electrolyte problems, and remove toxins in those with kidney failure.[3] Peritoneal dialysis has better outcomes than hemodialysis during the first couple of years.[4] Other benefits include greater flexibility and better tolerability in those with significant heart disease.[4]

Hemodialysis

Hemodialysis is ongoing dialysis (3 to 5 times a week) that cleans your blood, usually in a dialysis center. The hemodialysis access is in your arm. Peritoneal dialysis is ongoing dialysis (daily) that collects waste from the blood by washing the empty space in the abdomen (peritoneal cavity). It can be done from home.

If you are doing hemodialysis at home or in the center, you may experience side effects such as:

- Nausea or abdominal cramps
- Talk to your nurse if you are feeling uncomfortable. You may need adjustments to your machine settings, your medications, or your prescribed treatment.
- Fatigue
- You may feel tired when starting dialysis treatment. Over time, you will start to feel better.
- Low blood pressure

If you feel faint, warm, anxious, or sweaty, talk to your nurse. You may be experiencing low blood pressure during treatment.

Thriving on dialysis

Dialysis will help remove waste, toxins, and excess fluid from your body, and over time, you will start to notice the benefits—including improved mobility and flexibility, more energy, and being able to keep up with the activities you love. There are a few important steps you will need to take to feel your best and get the most out of your treatment.

How to feel your best while on dialysis

Eat well and manage your fluids–Because dialysis works to achieve chemical balance and remove excess fluid, it is important to eat well, limit sodium, and manage the amount of fluids you consume.

Take all medications as prescribed Working with a pharmacist who is specially trained in kidney disease can help ensure that all your medications are working together and right for someone on dialysis.

Protect yourself against infection–Avoiding infection of any kind will benefit your overall health. Talk to your nurse about proper access care and be sure to follow instructions on handwashing.

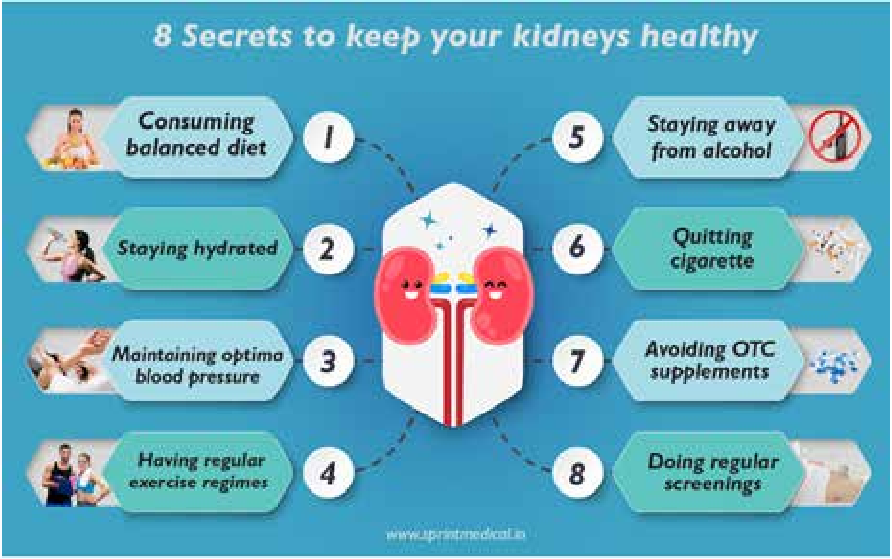
Build up your support network–It is important to have a strong network of family, friends, and care partners to encourage you as you start dialysis. Reach out to your loved ones and let them help you take the next steps in your treatment journey.

Three ways to get the most out of dialysis treatment

Taking an active role in your care can help you feel more in control and stay your healthiest, which can help you keep leading a full, satisfying life.

1. **Stay involved in your Care Plan** Your Care Plan is the blueprint for your kidney disease treatment. Your doctors and your care team will review your personalized Care Plan with you regularly to check in and make sure you are on track with treatment. This is a fantastic opportunity to speak up and stay engaged.
2. **Advocate for yourself** You are the most important person on your care team–and the most qualified to talk about how you are feeling. Reach out to your care team if you have questions, if you are not feeling well, or you have an issue and do not know how to solve it. We are always here to support you.
3. **Complete every minute of your treatment** Whether you are still getting used to dialysis or feel like an old pro, every minute of your prescribed dialysis treatment counts. Your treatment schedule is personalized to your body's exact needs. Completing each dialysis session as prescribed is important to your health.

How to Maintain Kidney Health



Whether you are at risk for CKD or not, living a healthy lifestyle can protect your kidneys and reduce your risk of developing other diseases. Start with these basic health strategies:

- Eat a balanced diet
- Keep fit and active
- Maintain blood glucose control
- Monitor your blood pressure
- Maintain a healthy weight
- Drink alcohol in moderation (or not at all)
- Maintain a healthy fluid intake
- Don’t smoke
- Don’t take over-the-counter medicine on a regular basis

Take the BE REAL Pledge

BE aware of the stigma that may exist…avoid the trap.

- Reject the notion that it is better to not know, than to know
- Early detection…ACT with a sense of urgency to slow progression
- Advocate for yourself and share your insights with loved ones
- Line of vision – work with your healthcare team to take control of your health… be an active player in making treatment decisions

Resources for Transplantation Information

National Kidney Foundation

Gift of Hope Organ and Tissue Donor Network

Mid-America Transplant

United Network for Organ Sharing (UNOS)

Association for Multicultural Affairs in Transplantation (AMAT)

Find your Local Organ Procurement Organization

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Black K.A.R.E. website

I think the back should have contact info for the organization or the website.

or a QR connecting youu to the online version of the books.

Maybe social media handles