





# Who Stole My Kidneys?

A book about saving kidneys  
and saving lives in America

By

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*It is not the intention of the author of this book to provide specific medical advice, but rather to provide users with information to better understand their health and diagnosis of kidney disease. Specific medical advice is not being provided, and the author urges you to consult with a qualified physician for diagnosis and answers to your personal questions.*



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# Introduction

This book was written for the 20 million Americans who have chronic kidney disease (CKD) and want to know more about it. The goal of this book is to provide the reader with information regarding the common causes of kidney disease, the different stages of kidney disease, and what we can do to save our kidneys.

Of the 20 million Americans who have chronic kidney disease (CKD), it is estimated that about 350,000 Americans have chronic renal failure or end stage renal disease (ESRD). Only about 2% of Americans with kidney disease will progress to chronic renal failure and require dialysis therapy or renal transplantation to maintain life.

Recent data suggests that Americans with CKD who do not develop renal failure have a very high mortality rate over a five-year period—ranging from about 20% for Americans with mild or moderate CKD to almost 50% in Americans with severe CKD. This means that over a five-year period, individuals with severe kidney disease have a one out of two chance of death.

Chronic kidney disease is a relatively unknown disease, and individuals who are at high risk of developing complications of CKD do not usually know the cause or treatment of this lethal condition. Individuals with CKD should believe that this condition is real no matter how they feel. For most Americans, CKD is a silent, lethal disease and can only be detected by blood tests and a follow-up appointment with your doctor.

Although kidney disease affects almost one out of every ten Americans, very few people know that obesity, high blood pressure, and diabetes mellitus are the major causes of kidney disease in America. Obesity, which has been called an epidemic, affects more than twenty-five percent of our

population. Unchecked, it could cause many Americans to develop kidney disease by the year 2010.

It now costs taxpayers about \$70,000 per patient, per year, to provide dialysis or transplant services for those individuals who have chronic renal failure. At the present rate of growth, over 500,000 Americans will have chronic renal failure by the year 2010. At that point in time, it is estimated that the cost to taxpayers will be over \$30 billion per year. With all of us working together, a twenty-five percent reduction in the number of patients developing kidney disease could save taxpayers more than \$7 billion by the year 2010. This is of particular interest now because there is a growing concern that Medicare (which pays for most of the cost in managing individuals with renal failure) may become bankrupt by the year 2020!

In this book, I used four imaginary characters (Mary Miracle, Dorothy Denial, Nellie Nephron, and Sam Survival) to exemplify how virtues or character strengths (Wisdom, Justice, Fortitude and Temperance) may determine the outcome of those who were unfortunate enough to have developed kidney disease.

For some patients, hope is all we have to motivate them through the many complications associated with a chronic illness like kidney disease and kidney failure. Sometimes fate allows a miracle to occur, and we see a patient with a very poor prognosis have an excellent outcome. Other patients are in denial and have been in denial about their disease most of their lives. If we are unable to help them help themselves then we are obligated to help them find peace with themselves and help them manage their chronic illness.

The proactive patients are a delight to care for. They challenge the health care team and in most cases have excellent outcomes. Finally, we encourage all patients to have a positive attitude. We help these patients accept the fact that they have a chronic illness and plan a course

of treatment which will maximize their quality of life and increase their chances for survival.

Having an illness, like chronic kidney disease, may involve facing new situations, complicated problems, challenges, and obstacles that sometimes could (or can) have no right or easy answers. At times, this uncertainty may cause pressure to fall on both the patient and the physician. When and if this occurs, the patient must try to remain calm and stay honest and proactive. In most cases, this illness is not going to go away, therefore, the patient must get all the information possible about this disease, be prepared to ask for help when needed, and try hard to accept being comfortable with being uncomfortable.



## Miracle Mary

"I want a second opinion," Mary said, when I asked her if she knew why she was here today for this visit.

As she spoke, Mary studied my face, looking for clues, trying to determine if I would listen to her and agree to care for her.

"I was recently treated at the medical center, but now I wish to be treated by a physician close to my home," she added.

I had agreed to care for Mary before I finished reviewing her chart. Sitting at my desk in the nephrology clinic, where I work, I had reviewed Mary's file prior to her appointment. A nephrologist is a physician who specializes in taking care of patients with kidney disease and high blood pressure. Our training involves four years of college, four years of medical school, and seven years of post-medical school training in the specialties of internal medicine and nephrology.

In despair, I reviewed Mary's medical records for some detail that might have been overlooked or incompletely investigated, hoping it might guide me to a rational and possibly effective treatment.

Mary has severe, uncontrolled blood pressure, and she is only fifty years of age—although she looks twenty years older. Tall in stature, she has long brown hair and a very petite body. The previous physician's diagnosis was uncontrolled hypertension with kidney failure.

I imagined how Mary had translated her diagnosis in private to her family in order to help them understand why her kidneys were failing and how she would need artificial kidney treatment. By the time Mary saw me, she

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had been started on dialysis. In the 1960s, a diagnosis of renal failure was similar to a diagnosis of cancer. Without a kidney transplant or dialysis, a patient with kidney failure would only live a few weeks. Death was eminent because the toxins and fluid normally removed by the healthy kidney accumulate in the body. Patients become comatose and die shortly thereafter from respiratory distress and cessation of a normal heartbeat.

“Before we go on,” I told Mary, “let’s start from the beginning. I want to hear the story directly from you and in detail, from the time you first developed problems with your blood pressure until the time you saw the nephrologist at the medical center. Then I will examine your vital organs, review your laboratory data, and we will think through this disease process together.”

In medical school, and through mentors in residency, I learned that there was a journey taken when a physician listened empathetically to a patient recount a history and when vital organ systems were evaluated in a systematic fashion. It was a journey of investigation that allowed me an opportunity to understand the origins and previous management of her disease. I planned to walk deliberately along the milestones of my new patient’s life, the family history of medical diseases, the nature of her occupation, the status of her personal relationships, and the history of her prior and current illnesses and treatments. Hopefully, for a brief but illuminating moment, I would become truly empathetic and integrated into her experience.

After imagining her past, I would be prepared to enter her present through the physical examination. I would measure her blood pressure and vital signs and then examine the blood vessels in the back of her eyes. Using a stethoscope, I would hear the character of her heartbeat, breath sounds from her lungs, and the sound of blood going to her kidneys. My hands would palpate the size of her heart and feel the size of her kidneys.

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Mary's father and mother had hypertension, but no one in her family ever developed kidney disease. She works as a legal assistant and is married with three grown children. She has had no major surgeries and has never smoked or used illicit drugs. She has no allergies and does not take over the counter medications or herbal products.

When I examined Mary, her blood pressure was elevated at 200/100 mmHg (normal blood pressure is 120/80 mmHg) and the back of her eyes were abnormal, showing signs that her blood pressure had been uncontrolled for many years. Her heart was also enlarged as a result of hypertrophy from trying to send blood to a body with elevated blood pressure. Her lungs were filled with fluid. There were no signs of abnormal blood flow to her kidneys. Her legs were swollen from excess fluid in her body.

When I reviewed her labs, I was amazed to find that her high blood pressure had completely destroyed her kidneys. When one has blood pressure that is uncontrolled, the kidney sees high pressure for many years. Despite regulatory changes, the kidney cannot handle the high pressure and shuts down.

"I tried to take care of myself," she said. "I did not know I had high blood pressure until I was in my early twenties. Many doctors tried to get my blood pressure under control without success. Now I am on five different medications, my blood pressure is still high, my kidneys have failed, and my lungs are filling up with fluid."

Mary was asking me to take care of her. She knew I cared, but would I be able to find a treatment that would help her beat the odds and live longer? Was there really any hope to be offered? I backtracked in my mind and looked for any opening, any opportunity to devise a therapy that might help her. I knew her only chance for long-term survival was a kidney transplant.

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As I sat back in my chair, I knew that high blood pressure had stolen Mary's kidney. I prayed it was not going to steal her life.

## II

### Dorothy Denial

"My doctor sent me here," Dorothy Denial said, when I asked her if she knew why she was here today for this visit.

I had reviewed her file before she arrived for her appointment. Dorothy had chronic renal failure from uncontrolled high blood pressure, uncontrolled diabetes mellitus, high cholesterol, obesity, and years of using pain medications that were toxic to her kidneys. This meant that her kidneys were no longer doing their job, and Dorothy would need dialysis or transplantation to stay alive. Dorothy was frightened and did not know that her condition was so serious.

"Let's start at the beginning," I said. "How old are you?"

"I am 54 years old," she said. "I have had diabetes for almost fifteen years. First, I used to treat my diabetes with oral medications, and now I use insulin. My sugars are always high. I have been admitted to the hospital several times for high blood sugars and one time spent the night in the intensive care unit so that doctors could better control my blood sugars."

"Have you had any other complications from the diabetes?" I inquired.

"Well, I see the eye doctor every three months because of bleeding in the back of my eyes. I think I am almost blind in my right eye. I also have difficulty feeling my feet, and they tingle and hurt when I try to go to sleep at night."

"Do you have a history of heart disease?"

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"I have had two heart attacks and bypass surgery. The doctors say I have very high cholesterol, but it is better now that I take medication to keep it under control."

"Do you smoke?"

"Yes, I do," she said. "Almost two packs per day. I have tried to quit many times, but each time I try to quit, something happens in my life and I start smoking again."

"Please tell me the names of the medications you are presently taking to treat your medical problems."

"I take some medications for my heart and blood pressure. I do not know the names of them, and I forgot to bring my bottles with me. I also take insulin twice a day."

"Do you take any over the counter medications?" I asked.

"Yes, I do," she said reluctantly. "I take a medication for pain. I think it is called ibuprofen. I take four or five a day for low back pain."

"Let's move on to the physical examination," I said, "and when we are finished, I will review your laboratory tests with you."

Very carefully, I measured her blood pressure and vital signs. Using a fundoscope, I looked behind her pupils to look for signs of diabetes and hypertension injury. My ears listened to her heartbeat, breath sounds from her lungs, and bowel sounds. Dorothy's blood pressure was 180/110 mmHg and the back of her eyes were abnormal, showing signs that her blood pressure and diabetes had been uncontrolled for many years. Her heart was also enlarged as a result of hypertrophy from trying to send blood to a body with elevated blood pressure. She had a large scar on her chest wall from heart bypass surgery. Her legs were thick and swollen from extra fluid in her body. Because of years of uncontrolled diabetes, the nerves in her legs were damaged. She had very little sensation in her feet.

When I reviewed Dorothy's labs, I was amazed to find that her high blood pressure and diabetes had destroyed her

kidneys. Her urine was filled with protein, a sign that the filter system in her kidneys was significantly damaged. An ultrasound of her kidneys showed that her kidneys were very small. Her chest x-ray showed that her heart was enlarged, and there was extra fluid in her lungs.

After I finished her evaluation, I sat down with Dorothy to summarize my findings. I explained to her that her kidneys were completely destroyed. To maintain life, we would need to start dialysis treatment soon. This meant admitting her into the hospital, establishing an access for removing blood from her body, and then starting dialysis therapy. To say the least, Dorothy was very discouraged.

She said to me, "Who stole my kidneys?"

I said, "Diabetes mellitus, high blood pressure, high cholesterol, obesity, and pain medications stole your kidneys."

"Can we get them back?" she asked.

"No," I replied, shaking my head, "but it is not the end of the world. We will help you get on dialysis as soon as possible and try to get you a renal transplantation."

After arranging for Dorothy to be seen by our renal team and to attend a class on different ways to treat kidney failure, I wondered whether, if we had seen her five years earlier, we could we have helped slow down the progression of her kidney disease. For most of her adult life, Dorothy had not taken care of herself. She was overweight and did not exercise. She smoked cigarettes. In addition, her history of multiple hospital admissions for uncontrolled diabetes mellitus suggested that she did not follow a diabetic diet and did not monitor her blood sugar levels closely. By the time the diabetes mellitus, hypertension, and tobacco had destroyed her kidneys, they had certainly destroyed many of the vessels that go to her brain, heart, and legs as well. Dorothy was a walking time bomb. I wondered if she would live until her next appointment.

### III

## Nellie Nephron

“Good morning, Ms. Nephron,” I said. “Would you like a seat?” She sat down in the chair in front of my desk. Nellie was a middle-aged African-American female with diabetes mellitus. She had recently read an article on the Internet about the benefit of seeing a nephrologist (or kidney doctor) if you were at high risk for developing kidney disease. Her kidney function was almost normal. I asked her if she knew why she was here today.

“I am here for advice,” she said. “I want to know what I can do to prevent kidney failure.”

I was glad she had come. These are the patients we love to see in our clinic. New data suggests that if we can get high-risk patients into a preventative kidney program, we can slow down the progression of kidney disease.

“There are no guarantees,” I said, “but if we work together, we can do everything that the literature suggests to extend the life of your kidneys.

“First, we will need to educate you about your kidneys. We want you to know where they are, what they do, and how you can do everything in your power to protect them from injury. Let us get you scheduled for kidney class and get some laboratory studies to see how your kidneys are doing.”

She agreed to attend kidney class and to see me after her laboratory studies had returned. After spending some time with this nice young lady, I knew no one was going to steal Nellie’s kidneys without her knowing about it.

## IV

### Sam Survival

Sam Survival was a forty-eight-year-old white male who came to me for consultation. He was a very pleasant gentleman who had a long family history of kidney disease.

“My mother and grandfather had polycystic kidney disease, and I am told I have the same condition,” he said, after I asked if he knew why he was here for his appointment.

Polycystic kidney disease, or PKD, is an inherited kidney disease. The polycystic kidney gene is a dominant gene that is located on chromosome 16 in our cells. Dominant means that if the gene is present, it will be expressed. Sam inherited the gene from his mother, who inherited the gene from her father. This gene causes multiple cysts (a closed pocket or pouch of tissue that can be filled with air or fluid) to form in each kidney, destroying the function of the kidney. The gene also affects other parts of the body, and this condition may also be associated with kidney stones, diverticuli (pouches in the colon), cysts in the liver and pancreas, and aneurysms of the blood vessels in the brain.

Polycystic kidney disease is much more common in adults. Symptoms do not occur until middle age. The condition affects one out of every thousand Americans. There is no known cure at this time. Mr. Survival was aware of his condition and had prepared for the moment he would need to see a kidney specialist.

“I developed high blood pressure about ten years ago, and my doctor put me on blood pressure medication,” he said. “I try to eat right and exercise daily. I am in good shape.”

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Indeed he was. A physical examination revealed that he was a muscular man at 6 feet in height. He was not overweight. His blood pressure was normal, and except for slightly enlarged kidneys, his exam was completely normal. I explained to Sam his condition and told him that we would need to perform some blood tests and a kidney ultrasound. He agreed to do these studies and see me in about two weeks. Sam was a legacy. Polycystic kidney disease was a genetic curse that had been stealing kidneys from his family for several generations. Sam knew who had stolen his kidneys and understood that they were not to be reclaimed. He did know how to take care of himself and how to deal with life when it throws you a curveball. Sam was self-aware and self-controlled. He knew that the time had come for him to face his legacy. Together we would do everything possible to increase his chance of survival, even though he was losing his kidneys.

## V

### Kidney Class

Sam, Nellie, Dorothy, and Mary arrived at the kidney class with about twelve other patients followed by the renal team. This class was a monthly introductory class for all patients entering our kidney program—a means of exposing patients to a number of topics related to the causes of kidney disease and its prevention.

Nellie was very attentive and was even seen taking notes. Dorothy was not very interested and fell asleep at least twice. Mary was not feeling well, and we actually had her go over to urgent care because she was short of breath.

The class was designed for people like Nellie Nephron, who are proactive. Dorothy and Mary were invited because they had never been to a kidney class. Sam was invited to help him assimilate into our program. Individuals who have renal failure, like Sam, Dorothy, and Mary, need additional education that includes classes on dialysis, transplantation, and end-of-life issues.

The first obvious question addressed in class is always, “What is kidney disease?”

We are born with two kidneys, located in the middle of the back on either side of the spine. Each kidney is about the size of your fist. Blood that needs to be cleaned enters the kidneys through the renal artery. After blood is cleaned, it returns to the body through the renal vein. Excess water and waste products are excreted into the urine. Urine is excreted from the kidney into a very thin tube called the ureter. Each kidney connects to a single ureter that takes the urine to the bladder, where urine is stored until we go to the bathroom. The urine is removed from the body through the urethra.

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In class, we explain that although kidney disease affects almost one out of every ten adult Americans, few Americans know the causes of kidney disease and even fewer know how to prevent chronic kidney disease.

Renal failure is the loss of the ability of the kidneys to adequately perform critical functions, such as excretion of wastes and water. Most kidney diseases destroy both kidneys simultaneously, and the damage can occur slowly, over many years. Gradual loss of kidney function is commonly referred to as chronic kidney disease or CKD. Persons with chronic kidney disease may go on to develop permanent kidney failure. The condition of total permanent kidney failure is called end-stage renal disease or ESRD. Persons with ESRD must undergo dialysis or transplantation to stay alive.

The most common causes of kidney failure are diabetes mellitus and high blood pressure. Less common causes of kidney failure include glomerulonephritis (inflammation of the kidneys), polycystic kidney disease (many cysts inside and outside the kidney), and obstruction of the tubes that send urine from the kidney to the bladder. Common causes of obstruction include kidney stones and cancer.

The diagnosis of kidney disease can be made using three simple tests. These include a spot check for protein or albumin in the urine (proteinuria), calculation of percent of normal kidney function, and ultrasound imaging of the kidneys. Patients with kidney disease usually have protein in the urine, lab tests showing a low percentage of kidney function, and small kidneys by ultrasound (less than 10 centimeters in length). For some patients, simple tests cannot make a diagnosis of kidney disease, and the caring physician may recommend a kidney biopsy to confirm the cause of kidney disease.

After kidney disease is diagnosed, the patient is usually referred to a kidney specialist or a nephrologist. The nephrologist will help manage complications of ESRD, which

may include uremia (accumulation of excess waste products in the body), anemia (low blood counts), and bone disease.

The signs and symptoms of a person with kidney failure may include increased or decreased urination, fatigue, itching, loss of appetite, unintentional weight loss, nausea and vomiting, swelling or numbness, drowsiness, difficulty concentrating, increased blood pressure, darkening of the skin, muscle cramps, headache, bleeding or bruising easily, and frequent hiccups.

When the kidneys no longer do their job, water and waste products accumulate in our body. If we are unable to eliminate water from our body, we start to swell. Swelling can occur first in the face around the eyes and eventually in our legs. This is called edema. Increased water in our body can eventually put pressure on our heart, and fluid can leak into our lungs. This results in shortness of breath and may raise our blood pressure.

Urea is a breakdown product of protein that is removed from the body by excretion into the urine. Urea is toxic to our body and needs to be removed on a daily basis. When urea accumulates in the body of someone with kidney failure, they may lose their appetite and complain of headaches and being tired all the time. In severe cases, they may get confused or even go into a coma. Before dialysis, patients would not live long with kidney failure. Today, we can treat renal failure by dialysis or transplantation.

Our kidneys perform many important functions. First, they remove excess fluid. When we drink fluids, our kidneys determine how much fluid we need in our body to stay healthy and what needs to be eliminated. Excess fluid is eliminated in the urine. The other vital function of the kidney is the elimination of salt. A high salt diet can raise our blood pressure and make us feel bloated from fluid retention. When we eat a salty meal, the kidneys control how much salt we need in our body and how much needs to be excreted in the urine. In kidney failure, our bodies cannot

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get rid of salt and our blood pressure will increase, even if we eat a low salt diet.

As stated above, the kidney removes toxins or waste products produced by the digestion of food and the rebuilding of our muscles, bones, and other vital organs. The waste products are eliminated from our body in our stool and urine. When toxins build up, we can become very ill.

The kidneys also produce two hormones that are important in keeping our bones strong and making sure we have enough red blood cells to circulate oxygen throughout our bodies. The kidneys produce the active form of Vitamin D. Vitamin D is generated in our skin by sun exposure. Vitamin D can also be absorbed from our intestinal tract from our diet. Vitamin D requires activation before it helps us absorb minerals that keep our bones strong. Activation of Vitamin D occurs first in the liver and then in the kidneys. When our liver or our kidneys fail, we cannot produce active Vitamin D, and our bones gradually start to break down.

The kidneys also make a hormone called erythropoietin or EPO. This hormone tells the bone marrow to make more red blood cells when our red blood cells get old and die. Without EPO, we become anemic and may feel tired and complain of no energy.

When we calculate kidney function, we get a number that represents the percent of our kidney function that is normal. Using this concept, we can divide kidney disease into different stages, such as mild kidney disease (60-89% of normal kidney function), moderate kidney disease (30-59% of normal kidney function), severe kidney disease (15-29% of normal kidney function), and kidney failure (less than 15% of normal kidney function).

An individual with kidney disease should know the percentage of their kidney function like they know their serum cholesterol level. It gives them and the caring physician a baseline value to develop a treatment plan. Obviously, there is more urgency to develop a treatment

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plan if the kidney function is 30% as opposed to 80%. In addition, your renal care management team may advise you on specific diet and medications that will be started as kidney function deteriorates to less than 30%. When kidney function goes below 20%, it is time to prepare mentally and physically for renal replacement therapy.

The focus of individuals with kidney function greater than 30% is taking their prescribed medications and following other recommendations that are designed to slow the loss of kidney function over the next few years. For example, if someone has 50% kidney function and does nothing to help their kidneys, they may lose 10% kidney function per year and may need dialysis in four years. However, if the same individual can develop a treatment plan that helps prevent kidney injury, they may lose only 5% of their kidney function per year and may not need dialysis for 8-10 years. If kidney function loss can be slowed down to 1% per year, the patient may never need dialysis!

The kidneys are vascular organs that receive blood from the heart. The blood vessels of the body can be compared to the plumbing system in your house. As the pipes in your house get clogged with dirt, hair, and rust, the flow of water through the pipes gets disrupted. This may result in a decrease in your water pressure or even a leak that requires re-piping. Diseases like diabetes mellitus, high blood pressure, high cholesterol, obesity, and injury from tobacco products affect our body's plumbing system, causing blood vessels to get clogged and injured. Over time, if these diseases are not treated, the blood vessels going to our vital organs (brain, heart, and kidneys) get occluded and damage the organ to which they are supplying blood.

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<b>Six Key Ways to Prevent Kidney Damage</b>
1. Control blood pressure
2. Control blood sugar if you have diabetes mellitus
3. Avoid obesity
4. Control blood cholesterol
5. Avoid kidney toxins
6. Stop smoking

Hypertension is a common health issue in the United States. It is estimated that 20% of the general population has hypertension and 65% of patients over 65 have hypertension. Hypertension is defined as a blood pressure greater than 140/90 mmHg. Optimal blood pressure is 120/80 mmHg. Lifestyle changes that decrease blood pressure include weight loss, low salt diet, exercise, and limiting alcohol intake. Despite knowing these facts, blood pressure in America is not well controlled.

Most patients with hypertension (95%) have essential or benign hypertension. Some individuals have what is called secondary hypertension. Common causes of secondary hypertension include non-steroidal anti-inflammatory medications, birth control pills, anti-histamine medication, kidney disease, thyroid disease, and tumors secreting hormones that raise the blood pressure.

The treatment of hypertension can be difficult in a patient who is resistant to standardized therapy. First line treatment for all patients is a low sodium diet, weight loss, and exercise. Low sodium diets appear to be particularly helpful in elderly and African-American individuals. Weight loss and exercise is helpful in almost all patients. Second line therapy is usually a diuretic (water pill). Diuretics help treat hypertension by helping our bodies excrete salt. Additional medications used to treat hypertension include beta-blockers

and calcium channel blockers. These medications prevent blood vessel constriction and allow blood vessels to relax, resulting in a lower blood pressure. The main side effects of beta-blockers include feeling tired and a slow heart rate. Common side effects for calcium channel blockers include constipation, leg swelling, headache, and a low heart rate.

Most people's blood pressure can be controlled with one blood pressure medication. Some individuals need two medications, which most often include water pills and an additional medication. Blood pressure can be controlled by teamwork. You should invest in a home blood pressure monitoring system that allows you to check your blood pressure daily and record the blood pressure measurement with mmHg. This data should be shared with your healthcare professional team at each visit. Monitor your blood pressure on a regular basis. Contact your health care professional if your blood pressure is consistently greater than 140/90 mmHg. By obtaining control of your blood pressure, you will significantly reduce your risk for developing kidney disease and heart failure and decrease your risk of having an early heart attack or stroke.

A low sodium diet is very important in controlling your blood pressure. Sodium intake causes our body to retain water. Increased sodium and water in our blood vessels elevates our blood pressure. By limiting our sodium intake or increasing the removal of salt (via water pills), we can lower our blood pressure. Sodium is present in almost all foods prepared at fast food restaurants. Hidden sources of salt are found in seasonings (garlic salt), pickled foods, canned vegetables and soups, packaged foods, and luncheon meats. Packaged foods contain information listing their sodium content. For individuals with high blood pressure, we ask them to try and limit their daily sodium intake to less than 2,000 milligrams or 2 grams per day. For reference, some soup products contain 800 to 1,000 milligrams of sodium per cup. Most individuals are surprised by how much salt they ingest every day.

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In America, the average individual may ingest over 8,000 milligrams of sodium daily. When you start a low sodium diet, do not get discouraged. For most people, they will notice that food just does not taste the same. This is because we have been eating high sodium diets for most of our lives. Over time, your body (and taste buds) will adjust. The benefit is that you may not have to take blood pressure medications, or if you are on blood pressure medications, you may not have to take as much medication as someone who does not follow a low sodium diet. Less medication means fewer side effects.

Individuals with diabetes mellitus are at risk for developing kidney disease. In diabetes mellitus, the body does not make enough insulin to keep blood sugar levels normal. Uncontrolled diabetes mellitus with constantly elevated blood sugars can result in blindness (diabetic retinopathy), loss of feeling in the legs (diabetic neuropathy), and kidney disease (diabetic nephropathy). For this reason, individuals with diabetes mellitus need to monitor and control blood sugars.

The metabolic syndrome characterized by obesity and elevated blood sugars can also lead to kidney disease. In these individuals, weight loss and following a diabetic diet are crucial to their long-term survival.

To control blood sugars, it is important to follow a diabetic diet, exercise regularly, and monitor blood sugars daily. A dietician can help you design a diet that is right for you. Blood sugar monitoring is usually done with a glucose-monitoring machine. These are available through your health care provider. Blood sugars should normally be less than 120 mg/dl. Blood sugar levels greater than 150 mg/dl are abnormal. Your health care provider may monitor your blood sugar control by performing a lab test called the HgbA1C level. This test lets you know how well your blood sugar has been controlled over the last few months. Normal HgbA1C levels are less than 6%. An individual with uncontrolled diabetes mellitus could have HgbA1C levels greater than 10%. For individuals who cannot control their blood sugars

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with diet, exercise, and weight loss, medications or insulin may be needed. Your health care professional will determine the medication regimen that is right for you.

If you have kidney disease, diabetes medications may need to be adjusted based on your kidney function tests. In general, insulin therapy is safe for individuals with kidney disease. Since the kidneys metabolize insulin, less insulin therapy may be needed to control blood sugar levels as kidney function deteriorates. Also, as kidney function deteriorates, your health care professional may want to change you from long acting medications that may accumulate in your body to short acting medications that are metabolized quickly. Long acting blood sugar lowering medications may severely lower blood sugar levels and cause you to go into a hypoglycemic or low blood sugar coma. As your kidney function deteriorates, discuss switching your diabetes medications regimen with your health care professional.

Most Americans now understand the importance of controlling blood cholesterol levels. Most Americans know their cholesterol level, and if it is elevated, they have been advised to lower their intake of high cholesterol foods and possibly take cholesterol-lowering medications. A low cholesterol diet involves limiting intake of foods that are high in cholesterol. This includes decreasing intake of red meats and eggs. Egg products that do not contain the yolk of the egg are good sources of protein and do not raise your blood cholesterol level. For individuals who are not able to control their blood cholesterol level with diet, they may want to seek consultation with their health care provider about starting therapy with cholesterol lowering agents.

There are many types of cholesterol lowering medications, and your health care provider will determine which one is right for you. Your target cholesterol goal to decrease risk of kidney disease progression is to lower your low-density lipoprotein, or LDL cholesterol, to less than 100 mg/dl.

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Many medications are toxic to the kidneys. Individuals with kidney disease or those at risk for developing kidney disease should be aware of all medications that may injure the kidneys. The most common cause of kidney injury by an over the counter medication is a group of medications called non-steroidal anti-inflammatory medications. These are commonly known as ibuprofen and naproxen. If you have kidney disease, these medications should be avoided at all costs. If you have pain and need pain medications, consider taking acetaminophen until you can discuss pain management with your health care professional.

Other medications that may injure the kidneys include contrast dye used for radiological studies, herbs, and antibiotics. Contrast dye is a direct kidney toxin. This dye is used during radiological procedures to look at blood flow to the heart, brain, liver, and kidneys. Large amounts of contrast dye can cause acute renal failure. Individuals with kidney disease, heart failure, and diabetes mellitus are at risk for this type of renal injury. If you have any of these conditions, please inform the radiology department staff that you may be at risk for contrast induced kidney injury. Other options include an MRI, which uses a contrast material that is not toxic to the kidneys.

Antibiotics can cause allergic reactions that may affect the kidneys. Similarly, some can cause scarring and irreversible kidney damage. If you have kidney disease, inform your health care professional about the need to adjust antibiotic dosing based on your kidney function. In general, all patients with kidney disease are advised to avoid herbal treatment until they have discussed possible side effects with their health care professional.

In addition to increasing awareness about medications that can hurt your kidneys, there are medications that can protect your kidneys. These medications are called kidney or renal protective medications, and they help preserve our kidney function by decreasing the pressure on our kidneys. Most renal protective

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medications are also used to treat high blood pressure. These medications work by preventing the formation and binding of substances that cause blood vessels in the kidney to constrict. As a result, blood pressure is lowered inside the kidneys, and the kidneys are protected. These medications have been shown to slow the progression of renal disease and extend the life of the kidneys. They may also delay the need to begin dialysis therapy. All patients with kidney disease and all patients with diabetes mellitus should be evaluated by their health care provider as candidates for this type of protective therapy.

Finally, all patients with kidney disease (and all individuals) should avoid tobacco products. Tobacco serves no useful purpose in life. Smoking cigarettes causes irreversible changes in lung cells and in the cells lining the blood vessels of our brain, heart, and kidneys. If you smoke, you lose. Just stop smoking.

<b>Advice for Patients with Kidney Disease:</b>
1. Know the stage or percent of your kidney function.
2. Keep a medication list with you at all times.
3. Follow your kidney diet.
4. Control your blood pressure, blood sugar, and cholesterol.
5. Inform health care professionals that you have chronic kidney disease.
6. Avoid renal toxins.
7. Avoid tobacco.

At the end of the class, Sam and Nellie had a many questions, which we answered. Dorothy Denial sneaked out the back door. Fortunately, Mary's shortness of breath did not

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require hospitalization. She was sent home on home oxygen with a follow-up scheduled at the dialysis unit.

## VI

### Choices Class

Because Sam, Dorothy, and Mary were diagnosed with kidney failure, they were referred to our Choices class. In this class, individuals with kidney failure are informed that when their kidneys fail, they will need renal replacement therapy to sustain life. When someone is diagnosed as having renal failure, their options or choices include starting dialysis (hemodialysis or peritoneal dialysis), transplantation, or no treatment.

In the United States, 90% of renal failure patients who have not had a kidney transplant are on **hemodialysis**. Hemodialysis cleans and filters your blood using a machine to temporarily rid your body of harmful wastes, extra salt, and extra water. Hemodialysis uses a special filter called a dialyzer that functions as an artificial kidney to clean your blood. During treatment, your blood travels through tubes into the dialyzer, which filters out wastes and extra water. Cleaned blood flows through another set of tubes back into your body. The dialyzer is connected to a machine that monitors blood flow and removes wastes from the blood.

Dialysis is usually needed three times a week to keep your blood free of toxins and excess fluid. Each treatment lasts from three to five hours. During dialysis treatment, you can read, write, sleep, talk, or watch television.

Before starting hemodialysis, you will need a physician to create an access to your blood stream. You may need to stay overnight in the hospital, but many patients have their access placed on an outpatient basis. This access provides an efficient way for blood to be carried from your body to the

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dialysis machine and back without causing discomfort. The three main types of access are a fistula, graft, or catheter.

To create a fistula, a surgeon connects an artery in your arm to a vein in your arm. The increased blood flow makes the vein grow larger and stronger so that it can be used for repeated needle insertions. This is the preferred type of access because this form of vascular access uses your own blood vessels and does not involve foreign body material. As a result, there are fewer infections or problems with clotting. This access may take several weeks or months to heal before it is ready for use.

A graft connects an artery to a vein by using a synthetic tube. Grafts develop faster than a fistula so it can be used soon after placement. Because they contain synthetic material, grafts are more likely to have problems with infection and clotting.

If your kidney disease has progressed quickly, you may not have time to get a permanent vascular access before you start dialysis treatments. You may need to use a catheter, a tube inserted into a vein in your neck, chest, or leg near the groin, as a temporary access. Some people use a catheter for long-term access as well. Catheters that will be needed for more than about three weeks are placed under the skin to increase comfort and reduce complications.

Hemodialysis is usually done in a dialysis center by trained professionals. In some parts of the country, it can be done at home with the help of a partner. If you decide to do home dialysis, you and your partner will receive special training.

Common problems with dialysis include infection, muscle cramps, low blood pressure, weakness, dizziness, or feeling sick to your stomach. You can avoid many side effects if you follow a proper diet, limit your liquid intake, and take your medications as directed. The diet for renal failure patients involves eating enough protein to avoid malnutrition and

watching your potassium, fluid, salt, and phosphorus intake.

Benefits of dialysis include going to a dialysis center for renal replacement therapy. At the dialysis center, you will be cared for by trained professionals and have an opportunity to socialize with other patients. Disadvantages of dialysis treatments include visits to the dialysis center three times per week, diet restrictions, and problems with vascular access (infections, clotting, multiple surgeries).

**Peritoneal dialysis** is another procedure that removes extra water, wastes, and chemicals from your body. This procedure uses the lining of your abdomen (called the peritoneal membrane) to filter your blood. Prior to starting peritoneal dialysis, a soft tube is inserted by a surgeon into your abdomen. After a few weeks of healing, a dialysis solution (which is a mixture of minerals and sugar dissolved in water) travels through the soft tube into your abdomen. Waste products, chemicals, and extra water from the tiny blood vessels in your peritoneal membrane are drawn into the dialysis solution. After several hours, the used solution is drained from your abdomen through the tube, taking the wastes products out of your body. Fresh fluid is then inserted and the whole process is repeated throughout the day. Potential complications of peritoneal dialysis include bowel obstruction, constipation, and infection.

The diet for individuals on peritoneal dialysis is similar to patients on hemodialysis. However, patients on peritoneal dialysis can eat more protein since protein is lost in the peritoneal fluid when it is removed from the body. Patients on peritoneal dialysis have more control over their fluids and have to monitor their calories closely to avoid high blood sugar levels. The solution used for peritoneal dialysis contains high concentrations of sugar that can be absorbed through the peritoneal membrane.

The main benefit of peritoneal dialysis is dialysis therapy at home. The diet is less strict, and no needle sticks are

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required. Traveling is easier. The problems associated with peritoneal dialysis include high risk of infection, weight gain, and the need for treatment seven days per week.

The third option for management of renal failure is **transplantation**. In this procedure, a surgeon places the new kidney inside your lower abdomen and connects the artery and vein of the new kidney to your artery and vein. The new kidney produces urine and cleans your blood similar to your native kidney.

Transplantation may not be for everyone. Some individuals have a condition that would make transplantation dangerous or unlikely to succeed. You may receive a kidney from a member of your family (living, related donor), a person who has recently died (deceased donor), or a very close friend (living, unrelated donor).

Before you can get a kidney transplant, you must fulfill three immunological requirements. First, both you and the donor must have compatible blood types. This is the most important matching factor. Second, the proteins on your cells must match up with the proteins on the cells of the donor kidney. Third, you must have a negative cross match test in which the cells from the individual who is donating the kidney is mixed with your blood. If these three tests show no significant incompatibilities, the transplantation can take place.

The benefits of a kidney transplant include fewer diet restrictions and no need for dialysis or needle sticks. Life expectancy is significantly improved. Problems with kidney transplant include an increased risk for cancer, infection, and medication side effects.

For many people, dialysis and transplantation are not good options and **no treatment** may be the best life path. If your quality of life is poor and you do not wish to extend your life with artificial kidney treatment, you can decide on no treatment. This difficult decision may be made after discussing your options with family members or friends. Even

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if you decide on no treatment, you can always decide to start getting treatment at a later date.

You have the right to refuse or withdraw from dialysis treatment at any time. Some patients will express in writing their wishes by naming a person to speak for them if they cannot talk (Durable Power of Attorney for Health Care) or by stating what treatments they would or would not want (Living Will). In addition to dialysis, patients can choose or refuse other life-sustaining treatments such as cardiopulmonary resuscitation, tube feedings, mechanical or artificial respiration, antibiotics, surgery, and blood transfusions.

## VII

# Transplantation

Mary Miracle was not doing well on hemodialysis. Despite close monitoring of the fluid that is removed during each dialysis treatment, Mary continued to have shortness of breath and uncontrolled hypertension. Because she was not doing well on dialysis, our renal team felt it was necessary to get her a renal transplant as soon as possible. She was scheduled for a special class to discuss the risks, benefits, and alternatives of kidney transplantation.

Transplantation is a relatively recent phenomenon. Many of the big developments in the area of kidney transplantation have taken place within the past 50 years. Researchers realized that without treatment, patients with kidney disease would die. The first human-to-human kidney transplant was performed in 1933. Because doctors did not understand the immune system at that time, the transplanted kidney only worked for about one hour.

In the early 1950s, cortisone-like medications were used to suppress the human immune system, resulting in some successful kidney transplants. In 1954, Joseph E. Murray and a team from Peter Bent Brigham Hospital in Boston performed the first truly successful kidney transplant from one twin to another. This was done without any immunosuppressive medication. Following this surgical success, more kidney transplants between identical twins were performed. However, to allow patients with end stage renal disease to receive a kidney from a non-related donor, new approaches were needed to prevent the body from rejecting the donor kidney.

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In the 1960s, better techniques for matching a donor kidney to a recipient's immune system were developed, and powerful immunosuppressive agents became available. Combining these techniques helped decrease the likelihood of renal transplant rejection.

After the discovery of the immunosuppressive agent cyclosporine in 1978, transplantation became widespread and successful. Cyclosporine inhibits white blood cells that are the specific mediators of organ rejection. Because these white blood cells (called lymphocytes) are not activated, the immune system is inhibited and kidneys are not rejected. Since the introduction of cyclosporine, the annual mortality rate for kidney transplant patients is less than 5%.

Renal transplant can be risky. Because patient's immune system is suppressed by medications used to prevent kidney transplant rejection, they are at high risk for infections. The side effects of cyclosporine and other medications used to suppress the immune system also include hypertension and malignancy.

Despite these risks, Mary was interested in kidney transplant. The waiting list for living, related donors (family or friends) is about one year while the wait for a cadaver donor is about ten years. Mary was referred to the university medical center for evaluation. She had several sisters interested in donating one of their kidneys; however, before we could get her a renal transplant, we needed to treat her high blood pressure.

## VIII

### Vascular Access

Dorothy had received education on kidney diseases and the different options for renal replacement therapy. She chose hemodialysis. We scheduled her for surgery to get a vascular access as soon as possible because she was already showing signs of uremia. She said, "I am losing my appetite and feeling very short of breath. Last night, I could hardly sleep."

On examination, her blood pressure was elevated, she was breathing faster than normal, and her lung examination revealed decreased breath sounds (she was drowning in her own body fluid). Her legs were swollen like tree trunks. She was in pulmonary edema. This condition occurs when the body is unable to get rid of excess fluid. Because Dorothy's kidneys were not working, she could not get rid of the excess salt and water she consumed on a daily basis. The fluid goes in but does not go out.

I explained the situation to Dorothy and advised that she go to the hospital for treatment. This would mean taking a ride over to the local emergency room and getting a chest x-ray. I told her, "If the findings are consistent with excess fluid in your lungs, we will need to start dialysis after a catheter is placed into one of your neck veins for access to your blood."

After I explained the situation to Dorothy, I answered her questions about dialysis. I reviewed the risks, benefits, and alternatives of kidney replacement therapy that we reviewed in class.

I asked Dorothy if she wanted to continue and she said, "Yes, I am not ready to die."

I think she felt so miserable that she just wanted to get her blood cleaned and fluid removed so she could feel better. She wanted a quick fix to her problems. As she had put it, she was not yet ready to die.

My nurse called for an ambulance, and we took Dorothy to the emergency room. I asked my nurse to hold my calls and drove to the hospital. In the emergency room, we gave Dorothy some oxygen and obtained lab work, an electrocardiogram of her heart, and a chest x-ray.

Her blood work showed that she was now in complete kidney failure. Her calculated kidney function was only 5%. An electrocardiogram of her heart showed no signs of a heart attack, but her heart size was very large. The heart becomes enlarged when it tries to pump blood to a body with elevated blood pressure and excess fluid. Initially, the heart muscle gets strong, but after years of pushing blood against high pressure, the enlarged heart muscle becomes weak, and the heart becomes a big, baggy sack. A chest x-ray confirmed that Dorothy was in heart failure, and her lungs were filled with water. Untreated, she would drown in her own fluid and go into respiratory failure in a matter of hours.

With some urgency, I arranged for Dorothy to have her dialysis treatment in the hospital. Since Dorothy did not have a vascular access for dialysis treatment, I called a surgeon to come see Dorothy immediately so we could get Dorothy ready for dialysis.

The surgeon greeted Dorothy and explained in detail what he was going to do. He went through the risks, benefits, and alternatives of placing a catheter to be used for dialysis into the internal jugular vein in her neck. Slightly frightened, Dorothy understood what was happening and signed the consent form.

Using sterile techniques to prevent infection, the area around the right side of her neck was cleaned and draped. The surgeon gave Dorothy some local anesthesia to numb the skin where the catheter would be inserted into her body.

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After waiting a few minutes for the skin to get numb, the surgeon placed a needle into Dorothy's neck to locate the internal jugular vein.

The internal jugular vein is one of three veins used for acute access to the blood system so we can perform dialysis. The other two veins are the subclavian vein located under the collar bone and the femoral vein located in the groin or upper thigh region of the lower extremity. For years we used to use the subclavian vein, but studies have shown that this vein would commonly form scar tissue and close up after being traumatized by an indwelling catheter. The femoral vein (located underneath the lower thigh muscle in your leg) is used only in emergencies when other veins are not accessible. Because of its location, the risk of infection is high and the catheter makes it difficult for patients to ambulate.

The internal jugular vein is now the vein of choice for dialysis access. Veins are blood vessels, which take blood from the body to the heart. Arteries are blood vessels that take blood from the heart to the body. Catheters are usually put into veins, not arteries. Veins are used for catheters since the pressure system is low and the risk of blood loss and vessel injury is low. Putting a catheter into an artery is risky because if the high-pressure artery is punctured, the patient could lose a lot of blood over a short period of time. Injury to a major artery can also affect blood flow to the part of the body distal to the injury. This can result in loss of an extremity or vital organ.

The internal jugular vein is located in the neck medial to the internal carotid artery. The surgeon places a needle into the vein, being very careful not to puncture the artery. Once the needle is successfully placed in the jugular vein, a guide wire is inserted and the catheter is slipped over the guide wire. The guide wire is removed, and the catheter is sewed into place.

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Dorothy tolerated the procedure well. A stat chest x-ray was obtained to make sure the catheter or guide wire had not punctured the lung or caused bleeding into the lung. After this was confirmed, Dorothy was ready for her first dialysis treatment.

## IX

### First Dialysis

Like most patients, Dorothy was scared about starting dialysis. The thought of blood leaving her body, going to a machine, and then returning blood back to the body just does not go over well with patients. Patients think the procedure is painful but in reality, most patients do not feel any discomfort.

Dorothy's dialysis nurse was very pleasant. I thanked the dialysis nurse for coming to the emergency room so quickly. She said, "You're lucky. I just finished dialyzing a patient in the intensive care unit. The timing was perfect."

Dialysis nurses are highly trained professionals. All dialysis nurses are registered nurses who have emergency room or intensive care unit experience before completing training in the area of dialysis. They are used to critical situations and remain calm even under the most stressful of circumstances.

The dialysis nurse knew that Dorothy would be feeling much better in about one hour after dialysis therapy was initiated. The nurse prepared the dialysis machine, hooked up the tubing that would circulate Dorothy's blood, connected the dialyzer to the blood circuit loop that would filter unwanted water and toxins from Dorothy's blood stream, and then connected the entire circuit to Dorothy's dialysis catheter. The very dramatic moment was barely noticed by Dorothy. She was breathing very hard now, and her overhead monitor showed that the oxygen in her blood was abnormally low.

An individual's oxygen saturation is obtained by placing a band-aid like monitor around one of the fingers. Normal

oxygenation is about 95-100%. In Dorothy's case, her oxygen saturation was only 75%. I knew if we did not take off fluid quickly, Dorothy would be in big trouble. Because Dorothy's blood pressure was high, we were able to take off about one liter of fluid from Dorothy's body in less than an hour. Like a new woman, Dorothy was sitting up in bed without respiratory distress. Her oxygen saturation had improved to 94%, and we could even see some of the swelling in her legs decrease during the dialysis procedure. In addition to removing fluid, the dialyzer also cleaned the blood of waste products called urea and removed excess electrolytes (potassium and phosphorus) that can damage the heart.

After two hours of dialysis treatment, Dorothy was much improved. Her appetite was returning, and for the first time in two days, she felt hungry.

Dialysis was completed, and Dorothy was admitted to the hospital for observation and dialysis treatment. In addition, the surgeon had already scheduled Dorothy to go to the operating room to have a fistula placed in her arm. I returned to my office knowing that Dorothy's condition had stabilized. Tomorrow would be a big day for Dorothy. That day, thanks to the care of a great hospital team, she was alive and out of danger, but her kidneys were now lost forever.

# X

## Nellie's Lab Work Review

Miss proactive, Nellie Nephron, never missed a scheduled appointment, class, or opportunity to learn more about kidney disease. Today, she wanted me to review and explain all the lab tests that we have our patients do before they see me in the clinic.

"I want to learn more," she said. "I really enjoyed the kidney class and felt it was very helpful. Why do you order so many lab tests on kidney patients? They must have taken 20 vials of blood from me in the outpatient laboratory. Do I get it back if they don't use it," she joked.

"No," I said. "We do a thirteen point inspection on your body just like the mechanic does an inspection on your car. Kidneys are truly amazing organs that keep our bodies in balance. Without a well functioning kidney, our electrolytes and hormones will get out of balance. The blood tests we do are designed to look at all these systems to make sure they are working properly." I smiled at her. "Are you ready to begin?"

She nodded, clearly anxious.

I handed her a sheet of paper with her lab results and comparison numbers to show the normal range for the different blood tests we'd performed on her blood. After she had time to look at the numbers, I began to explain the results.

Lab Test	Normal	Nellie's Labs
Percent kidney function	> 90 percent	53 percent
Creatinine	0.6 to 1.1 mg/dL	1.2 mg/dL
Potassium	3.5 - 5. meq/L	4.5 meq/L
Bicarbonate	21 - 31 meq/L	24 meq/L
Calcium	8.5 - 10.5 mg/dL	8.7 mg/dL
Phosphorus	2.7 - 4.5 mg/dL	3.6 mg/dL
PTH	60 - 180 pg/mL	62 pg/mL
Hemoglobin	12 - 16 g/dL	13 g/dL
Albumin	3.5 - 4.8 g/dL	4.0 g/dL
LDL cholesterol	< 100 mg/dL	141 mg/dL
HgbA1C	4.2 - 6.7%	7%
Hepatitis B antibody	Positive	Negative
Urine protein	Negative	Negative

"The first two tests show your percent kidney function and your serum creatinine," I told her. "The percent kidney function tells you what percent your kidney is functioning in the normal range. It is calculated using a computer program that takes into consideration your race, sex, and age. Even though your serum creatinine is slightly elevated, you only have 53% of your kidney function. It is a good thing you are proactive. By coming to kidney clinic early in the course of your disease, you may have prevented further injury to your kidneys."

"What is creatinine?" Nellie asked.

"Creatinine is a protein produced by muscle and released into the blood. Normal levels are 0.6 to 1.0 mg/dL. The amount of creatinine produced per day is relatively constant. The creatinine level in the serum is determined by the rate it is removed by the kidneys. As kidney function decreases, serum creatinine levels increase.

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“The next blood test is your serum potassium level. Potassium is a mineral or electrolyte that is involved in both electrical and cellular functions in the body. Potassium plays a role in keeping your heartbeat regular and your muscles working properly. It is the job of the kidneys to keep the right amount of potassium in your body. When kidneys no longer work well, it is difficult for the body to get rid of potassium. Patients with kidney disease are unable to excrete excess potassium into their urine. High levels of potassium in our blood can result in cardiac arrhythmias and sudden death. The recommended daily allowance for potassium is 2-3 grams per day for individuals with kidney disease. Your potassium level was normal,” I added, pointing to the numbers. “If your potassium had been elevated, then you would have to watch your intake of foods that are high in potassium. These include dairy products, starchy vegetables, leafy green vegetables, and fruits.”

She nodded.

“Bicarbonate in your blood tells us if your body is acid or alkaline. Patients with kidney disease are unable to excrete acid into their urine, resulting in a build up of acid in the blood. High levels of acid in our blood can result in cardiac arrhythmias and sudden death. When acid levels are high in our blood, we can neutralize acid by taking sodium bicarbonate pills. Your serum bicarbonate levels are normal, so you do not require extra bicarbonate.

“Next, we will talk about your serum calcium levels. Calcium is one of the most common minerals in the human body. Ninety-nine percent of the calcium in your body is found in your bones. About one percent is found in the blood and soft tissues of your body. Calcium levels in the blood and fluid surrounding the cells must be maintained within a very narrow range for normal functioning of the heart, brain, muscles, and bones. The normal kidney makes Vitamin D. In kidney disease, Vitamin D is not produced, and a deficiency of Vitamin D results in decreased absorption of calcium and

phosphorus from the gastrointestinal tract. As serum calcium levels fall, the body secretes a hormone called Parathyroid Hormone or PTH from the parathyroid gland located on either side of your thyroid glands in your neck.”

“Parathyroid hormone or PTH is the most important endocrine regulator of calcium and phosphorus concentration in body fluid. This hormone finds its major target cells in the bones and kidneys. The hormone’s main job is to increase serum calcium levels and decrease serum phosphorus levels. Vitamin D in the blood suppresses secretion of parathyroid hormone.

“Parathyroid hormone causes bone to release calcium and phosphorus into the blood. The hormone also increases production of Vitamin D and increases the kidney’s ability to get rid of phosphorus into the urine. Vitamin D is not produced in people with chronic kidney disease, so calcium and phosphorus are poorly absorbed in the gut. The kidney cannot excrete phosphorus so serum phosphorus levels rise. Parathyroid hormone levels rise to maintain normal calcium levels and decrease elevated phosphorus levels. As parathyroid hormone levels rise, bone breakdown occurs at an accelerated rate. Uncontrolled bone breakdown can result in weak bones and fractures

“Phosphorus is an essential mineral that is required by every cell in the body for normal functioning. The majority of the phosphorus in the body is found as phosphate. Approximately 85% of the body’s phosphorus is found in bone. Normal body phosphorus levels are required for energy production. Elevated calcium and phosphorus levels can cause calcification of tissues, leading to organ damage and heart disease.

“In kidney disease, it is important to keep parathyroid hormone levels and serum phosphorus levels in normal range. We can decrease parathyroid hormone levels by taking oral or intravenous Vitamin D. Eating a low phosphorus diet and taking phosphate binders with your meals normalizes

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phosphorus levels. Foods that are high in phosphorus, which should be limited if your phosphate levels are high, include dairy products such as milk, cheese, and yogurt; nuts and seeds; beans and peas; bran cereals and bran muffins; and colas and beer. Fortunately, Nellie, your calcium, phosphorus, and parathyroid hormone levels are normal. You can eat a normal phosphorus diet, and you do not need to take oral Vitamin D.”

She smiled and motioned for me to continue.

“Next, I want to talk to you about anemia. Anemia means having less than the normal number of red blood cells or less hemoglobin than normal in the blood. Anemia is usually detected or at least confirmed by a complete blood cell (CBC) count. In a CBC test, the different types of cells in the blood are counted and examined. Hemoglobin is a red pigment that gives the red color to red blood cells and to blood. Hemoglobin is the key chemical compound that combines with oxygen from the lungs and carries the oxygen from the lungs to cells throughout the body. Oxygen is essential for cells to produce energy. People with a low hemoglobin level have anemia. When there is a low hemoglobin level, there is often a low red blood cell count. When hemoglobin is low, oxygen transport through the body is subnormal. The person with anemia is under-oxygenated and may complain about feeling tired, having palpitations, and becoming short of breath.

“The normal kidney produces a hormone called erythropoietin or EPO. This hormone is secreted when hemoglobin levels start to decrease. When individuals get kidney disease, erythropoietin production is diminished. Patients with anemia related to chronic kidney disease can be treated with erythropoietin shots. Again, Nellie, you are lucky. You have no signs of anemia. Your hemoglobin levels are normal, and you will not need erythropoietin at this time.

“The next lab test reported is your serum albumin levels. Serum albumin is a protein in our blood that is made in the liver and is important for normal body function. Low serum albumin or low body protein stores is called malnutrition and can result in poor healing and decreased immunity, which can make us susceptible to infections. Low blood protein or low serum albumin levels are associated with a high mortality rate. Malnourished patients can increase blood protein levels by consuming foods that contain large amounts of high biological protein such as tofu, meat, and eggs. However, these foods may not be good for chronic kidney disease patients who have high blood cholesterol or high blood phosphorus levels. Protein supplements may be a good alternative. Some protein supplements—such as protein powders, protein drinks, or protein bars—are safe for individuals with kidney disease and others are not. Individuals with kidney disease should avoid protein supplements that contain large amounts of phosphorus, potassium, or cholesterol. Malnourished individuals should try to consume about 15 grams of protein per serving or about 45 grams of protein per day. Not all protein supplements are the same, so you need to talk to your dietician before taking over the counter supplements that may be harmful to your body. Fortunately, Nellie, your albumin levels are also normal.

“The next test to be evaluated include your cholesterol levels. This test on your sheet reports the levels of your LDL or low density lipoprotein. LDL cholesterol is called the “bad cholesterol” because it takes cholesterol from the liver and deposits cholesterol on the blood vessels in the heart. High levels of LDL cholesterol are associated with a high mortality rate secondary to coronary artery disease. Your LDL cholesterol levels were elevated, so we will start you on a low cholesterol diet, and if your cholesterol levels do not improve, we will give you medications that have been shown to reduce the blood levels of bad cholesterol.

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“The long term control of your diabetes can be determined by measuring the HgbA1C levels in your blood. High levels of HgbA1C mean your diabetes is poorly controlled. Low levels of HgbA1C means you do not have diabetes mellitus or that your diabetes mellitus is under good control. Your HgbA1C was slightly elevated. Are you following your diabetic diet?”

“Yes, I am,” she said. “I cheat once in a while, but most of the time I do pretty well.”

“Have you ever been on diabetic medication?”

“No,” she responded.

“When we are done reviewing your laboratory studies, we will talk about medications that will help you keep your diabetes under control.”

She nodded.

“The next test on your sheet tells me if you have been immunized to Hepatitis B. Hepatitis means inflammation of the liver and is usually secondary to a virus called Hepatitis B. Hepatitis B viral infections are usually caused by exposure to the blood of someone with Hepatitis B. Because kidney disease patients are at risk to receive a contaminated blood transfusion, they are advised to get Hepatitis B vaccination. The success of immunizing you with the Hepatitis B vaccine depends on where you are in the kidney disease spectrum. Before someone goes into renal failure, the chance of successful immunization, as determined by the formation of Hepatitis B antibodies in your blood, is about 90%. Once someone develops kidney failure, the success rate drops to 50%. Finally, if they get a kidney transplant, the success rate is a dismal 10%. This is why we want to immunize you now. Do you have any questions?”

“Will I get sick like I did after receiving my flu shot last year?” she asked.

“The Hepatitis B vaccination is a little different than the flu vaccine. The flu vaccine is designed to expose you to many different types of viruses. The Hepatitis B vaccine exposes you to one type of a dead virus. The immunization

does not usually produce a flu-like response. Most people do not complain of having a reaction after the Hepatitis B vaccine.

"Finally, we took a urine sample to determine if you are spilling protein in your urine. A normal kidney does not allow loss of protein in your urine. Kidney injury may present as protein in the urine. Fortunately, you do not have any protein in your urine. Your test was negative."

I put her test results aside.

"Now that we have finished reviewing your lab report, let us summarize our findings. Surprisingly, your kidney function is reduced to 53%. This is all right, as long as we do everything we can to prevent further injury to your kidneys. You will not need dialysis or transplantation unless your kidney function gets to be less than 15% of normal. Do you remember what we talked about in class about the four ways to prevent progression of kidney disease?"

"Yes, I do," she responded. "Control our blood pressure, control our blood sugar, control blood cholesterol, and avoid renal toxins."

"Very good," I said. "Now your lab tests showed that your HgbA1C and bad cholesterol levels were elevated. Your blood pressure has been under good control, and you are not taking any renal toxins like ibuprofen or naproxen?"

"No," she said.

"Good. We already talked about the plan for getting your cholesterol under control. Let's talk about getting your diabetes under control. At this time, you do not need insulin, but you will need an oral medication called a hypoglycemic agent. There are many types on the market, but the one we want you to take is called a short acting oral hypoglycemic agent. Unlike some of the other diabetes medication that can accumulate in the blood in patients with kidney disease, this medication is broken down quickly in your body and does not accumulate over time. Medications that accumulate can cause severely low blood sugars that can harm you. We will

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start this medication at a very low dose until we see how you respond and then increase the dosage until your blood sugars are under excellent control.

“While you are on this medication, I want you to watch your sugars closely. In addition, I want you to look into a daily exercise program. This will help you lose a little weight and make it easier to control your blood sugars.”

Nellie nodded her head in approval.

“Before we finish, there are two other issues I want to discuss with you. In class, we talked about kidney or renal protective medications. These medications have been shown to slow the progression of kidney disease—especially in patients with diabetes mellitus. It is very important that we start you on this type of medication. The main side effect is cough and a small possibility that your kidney function will worsen. To be extra careful, I want you to call me if you develop a cough, and I want you to return in one week after starting the kidney protective medication to repeat your serum creatinine level.”

Nellie wanted to stop for a second to clarify what I’d just said. “The kidney protective medication may *hurt* my kidneys?”

“Yes,” I responded. “The kidney protective medications work by lowering the pressure on the part of your kidney that filters your blood. For most patients, the decrease in pressure results in less work for the kidneys and prolongs the life of diabetic kidneys. Some patients need the increased pressure in their arteries to make sure the kidneys get enough blood to do their job. These patients have illnesses that you do not have, such as heart failure or bilateral renal artery stenosis. Patients with heart failure do not pump normal amounts of blood to the body with each heartbeat. As a result, the kidney does not get enough blood to maintain normal function. In these patients, the kidneys need pressure to maintain normal perfusion in a situation where they are not getting enough blood from the heart. The other condition at risk for

kidney injury is seen in individuals with bilateral renal artery stenosis. Renal artery stenosis means the blood vessels going to the kidneys are closing up. This usually occurs in patients with severe atherosclerosis or a bad plumbing system. The closing of the blood vessels prevents blood from getting to the kidneys. When blood pressure is lowered, less blood gets to the kidneys and they stop working. Therefore, when we prescribe kidney protective medication, we always re-check serum creatinine because we cannot predict with certainty which patients will be affected negatively.”

She nodded.

“Finally, I would like you to start taking a baby aspirin to reduce your risk of stroke and heart attack.”

Nellie agreed to these recommendations, and I asked her to review the side effects of all new medications with the pharmacist.

“Please call me if you have any questions,” I said. “I will see you in about two weeks. You can call my nurse in about ten days for your lab tests results. If there is any significant change in your serum creatinine, I will call you myself.”

## XI

### Sam's Lab Work Review

Sam Survival had returned from his initial consultation to review his lab work and to develop a treatment plan. He had been to Kidney Class and Choices Class. On his own, he had done some independent reading. In addition, unlike most of our patients followed in the Kidney Clinic, Sam had seen several members of his family develop renal failure and undergo dialysis therapy to sustain life. He had seen first hand the complications associated with chronic renal failure and was determined to do everything he could to be the best dialysis patient in our clinic. He came to our meeting prepared to assimilate all the information given to him. He'd even brought a notebook so he could take notes and keep copies of handouts and lab reports.

"Good morning, Sam. How are you feeling?"

"I am feeling good. I have no nausea, vomiting, or shortness of breath. My blood pressure is well controlled."

"Very good," I said. "I am afraid your lab work shows that you are in renal failure. Let me explain by going through each lab test so we can understand your condition and use this information to develop a treatment plan. Do you have any questions before we start?"

"No," he said, shaking his head.

"As you know, Sam, your lab tests tell us how your kidneys are doing and what effect loss of kidney function is having on your body's chemical balance." I handed Sam a sheet of paper with his lab results, similar to the one I gave to Nellie Nephron.

Lab Test	Normal	Sam's Labs
Percent kidney function	> 90 percent	11% percent
Creatinine	0.6 to 1.1 mg/dL	7 mg/dL
Potassium	3.5 - 5. meq/L	5.5 meq/L
Bicarbonate	21 - 31 meq/L	14 meq/L
Calcium	8.5 - 10.5 mg/dL	8.7 mg/dL
Phosphorus	2.7 - 4.5 mg/dL	6.5 mg/dL
PTH	60 - 180 pg/mL	302 pg/mL
Hemoglobin	12 - 16 g/dL	15 g/dL
Albumin	3.5 - 4.8 g/dL	4.6 g/dL
LDL cholesterol	< 100 mg/dL	102 mg/dL
HgbA1C	4.2 - 6.7%	5.5%
Hepatitis B antibody	Positive	Positive
Urine protein	Negative	Negative

I went through the opening explanation regarding his percent kidney function and his serum creatinine. "As you can see, your serum creatinine is elevated, and you only have 11% of your kidney function. This means that you are now in renal failure, and we will need to prepare you soon for dialysis therapy."

"Doc, when do you think we need to start treatment?"

"Probably in about three months. After going to Choices Class, did you decide what type of dialysis therapy was right for you?"

"Yes, I choose hemodialysis."

"The plan will be to have you see a vascular surgeon for placement of a fistula, and when the fistula is ready, we will schedule dialysis therapy."

Sam nodded in approval.

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Most of his questions had already been answered during the Choices Class and from experience watching many family members go through the dialysis process.

"The next blood test is your serum potassium level. Your potassium level is elevated. As you know, Sam, high levels of potassium in our blood can result in cardiac arrhythmias and sudden death. I want you to start watching the potassium content in you diet. Your goal is to ingest less than 2 grams per day of potassium. Certain foods are very high in potassium and will need to be avoided." I explained to him what those were.

"Your blood bicarbonate levels are very low. This means your body is very acidic. To neutralize the acid in your blood, I will give you sodium bicarbonate pills. You will take two pills between meals, and we will check your serum bicarbonate levels in about one month.

"Your serum calcium levels were normal. Because your diseased kidneys do not make Vitamin D and eliminate phosphorus, your Parathyroid Hormone (PTH) levels and serum phosphorus levels are elevated. Like we discussed in class, it is important to keep your phosphorus and PTH levels in normal range to prevent heart and bone disease."

"Doc, I understood the bone disease discussion from kidney class, but I am not quite sure why high phosphorus levels cause heart disease."

"Our bodies make bone by the binding of calcium to phosphorus. When circulating blood levels of calcium or phosphorus rise, they may form a bone like substance that deposits in the walls of arteries and veins. This calcification process can cause abnormalities in the electrical system of the heart and clogged arteries, resulting in a heart attack. Does that make sense?"

"Yes," Sam said.

"Eating a low phosphorus diet and taking phosphate binders with your meals will normalize your phosphorus

levels. High phosphorus foods that I would like you to avoid include the following:

<b>High Phosphorus Foods</b>
- Dairy products, such as milk, cheese, yogurt, and cream soup
- Some fruits and vegetables, such as asparagus, peas, mushrooms, and corn
- Dried beans and prunes
- Breads and cereals
- Bran muffins and bran cereals
- Pancakes and waffles
- Whole wheat bread and corn bread
- Chocolate and cocoa
- Pizza and beer
- Nuts and peanut butter, and
- Dark-colored carbonated beverages.

“In addition, I would like you to take some calcium carbonate pills, which will bind phosphate in your food and help you decrease the amount of phosphorus you absorb in your gastrointestinal tract. Finally, you will need to start taking Vitamin D pills to tell your Parathyroid Gland to stop making PTH.”

I could see that Sam was getting a little depressed. I had just told him he had renal failure. I had significantly increased the number of pills he takes every day and limited

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the intake of several foods he really enjoyed, like chocolate, pizza, and beer.

"Let's take a break," I said. "Tell me about your family."

"I have been married for fifteen years. I have two twin eleven-year-old boys. Both children were tested for the polycystic kidney disease gene, and they were negative. Looks like the curse stops with me. I work for the police department. My boss's mother had kidney disease, so he is very empathetic to my situation. He told me to take all the time I need to sort things out. In addition, he said he would adjust my work schedule to allow me to go to dialysis therapy."

"What do you do for fun?" I inquired.

"Well, I love to golf with my wife, and the kids are very much involved in baseball. My wife and I have coached their baseball teams since they were in T-ball. We often go to baseball games together."

"Sounds like a good life," I said.

"It is a wonderful life. I am not sure why I have been blessed with a good family, but I have been. I want to take good care of myself so I can see my kids grow up. My parents were great role models. Despite my mom's kidney condition, we had a very close family."

"That is a great story. I will help you get through this difficult time; however, it sounds like you already have a great support system."

He nodded.

"Sam, do you want to continue our lab review, or can I schedule another time to finish going over the lab work?"

After regrouping, Sam wanted to continue.

"Well, there is some good news. Your hemoglobin levels, serum albumin levels, and cholesterol levels are normal. Individuals with polycystic kidney disease usually do not get anemia. The polycystic kidneys often continue to make the hormone that keeps our blood strong. Your hemoglobin

levels are normal, and you do not need erythropoietin therapy at this time. If your hemoglobin levels ever drop, I will let you know, and we can talk more about how to replace erythropoietin while you are on dialysis. Because your appetite is good and your blood protein stores are normal, we do not need to start you on protein supplements or cholesterol lowering medications.

"Your lab tests do show that you have antibodies to Hepatitis B. Were you ever immunized to Hepatitis B?"

"Yes, we went through a vaccination program at work."

"Excellent." I looked over the test again. "The rest of your lab tests show that you do not have diabetes mellitus, and there is no protein in your urine.

"Before we finish, I want to talk to you about one more issue. As you know, high blood pressure is related to salt intake. I want you to watch your sodium intake. When kidney function decreases, sodium and water are not removed by the kidneys and will remain in the body. Excess sodium and fluid in your body can cause increased thirst, tissue swelling, high blood pressure, and heart failure. A low sodium diet is prescribed for patients with kidney disease. A low salt diet means that you limit your sodium intake to 2 grams or 2,000 milligrams per day. Most package inserts of food products contain information on the sodium content. I've made a list of some major sources of sodium for you to look over." I handed him a chart.

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<b>Amount</b>	<b>Food</b>	<b>Milligrams of Sodium</b>
One teaspoon	table salt	2,000
One slice	lunch meat	300
One	hot dog	500
One	bread slice	150
One teaspoon	butter	30
One cup	soup	900
One tablespoon	salad dressing	160
One large	dill pickle	1,430
One large slice	pizza	600
12 ounces	diet soda	75

Once he was done reviewing the chart, I asked, “Do you have any questions?”

Sam had absorbed all the information. He had known that the day would come when he would need dialysis. He was a well-balanced man and had positive energy that helped him be a good family man, good police officer and now a good patient. He had learned to become comfortable with the uncomfortable and was ready for his next challenge.

“I will survive,” he said. “Just point me in the right direction.”

I shook Sam’s hand and asked my nurse to schedule him an appointment in two weeks so we could arrange for consultation with a surgeon to place a fistula in his arm. I knew Sam would follow his diet and start taking the medications I had given him.

Before he left, I asked him to bring me a picture of the baseball team.

## XII

# Hypertension

As mentioned earlier, hypertension, or high blood pressure, is a common health issue in the United States. It is estimated that 20% of the general population have hypertension and 65% of patients over 65 have hypertension. Hypertension is defined as a blood pressure greater than 140/90 mmHg. Optimal blood pressure is 120/80 mmHg. Lifestyle changes that decrease blood pressure include weight loss, low salt diet, exercise, and limited alcohol intake. Despite knowing these facts, blood pressure is not well controlled, and millions of patients are presently taking blood pressure medications. Most patients with hypertension (95%) have hypertension of unknown etiology. Other individuals have what is called secondary hypertension.

Common causes of secondary hypertension include birth control pills, anti-histamine medication, kidney disease, thyroid disease, and tumors secreting hormones that raise the blood pressure. When I reviewed Mary's record, I was concerned that she may have a secondary cause of her hypertension because of her young age and the fact that her hypertension was very difficult to control. There was no family history of hypertension.

After discussing these issues with Mary, she asked me what we could do to treat her hypertension at this time. I explained that we would proceed down two paths simultaneously. First, we would have to find a medication combination to treat her blood pressure. Second, we would have to perform studies to rule out a secondary cause of her hypertension.

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The treatment of hypertension can be difficult in a patient who is resistant to standardized therapy. The first line of treatment for all patients is a low salt diet. This appears to be particularly helpful in elderly and black patients. The second line of therapy is usually a diuretic or water pill. These medications help treat hypertension by helping us excrete salt. Side effects include lower serum potassium levels and an elevation of serum glucose levels. Low serum potassium levels may irritate the heart or cause feelings of fatigue or weakness. Elevated serum blood sugar could predispose patients to diabetes mellitus. Mary had tried both these treatments without success.

The next step is initiation of medications that are considered renal protective. These medications work by preventing the formation and binding of substances like angiotensin II, which cause blood vessels to constrict and blood pressure to rise. Blood pressure is lowered and the kidney is protected. In large trials, these medications have been shown to slow the progression of renal disease, resulting in the associated phrase renal protective. Mary had also tried this type of medication with little success.

Additional medications used to treat hypertension include beta-blockers and calcium channel blockers. These medications prevent blood vessel constriction and allow blood vessels to relax, resulting in a lower blood pressure. Mary had tried all these types of medication without success. She experienced many side effects including fatigue, leg swelling, and cough. I discussed the side effects of the different medications used to treat hypertension; she heard most of this information before. We decided to use these medications in combination.

We actually started Mary on four different types of blood pressure medications. The regimen we used was a kidney or renal protective medication, an alpha beta-blocker, a calcium channel blocker, and a vasodilator. Despite this aggressive treatment, her blood pressure was still not well

controlled. She did not tolerate many medications. This suggested that she had secondary hypertension.

The workup for secondary hypertension requires a series of blood tests and radiological scans. Mary was not on birth control pills or any other over the counter medications. She did have kidney disease, but we felt her blood pressure was much higher than we could explain from kidney disease alone. Her thyroid hormone levels, urine cortisol levels, and urine aldosterone hormone levels were normal, and a CT scan of her abdomen did not show any adrenal gland masses or tumors. After discussing the case with Mary, we agreed to perform studies to determine if she had renal artery stenosis or over secretion of an enzyme called renin.

Renal artery stenosis is a narrowing or blockage of the artery that supplies blood to the kidney. The disease is caused by fibromuscular dysplasia (common in young females) or atherosclerosis (common in older men). In fibromuscular dysplasia, the artery is occluded by a congenital disease, which causes the renal artery wall to thicken. In atherosclerosis, plaques or cholesterol deposits occlude the artery. Renal artery stenosis causes hypertension by decreasing blood flow to the kidneys. The kidneys think that the blood pressure is low, so it makes a hormone called renin, which causes the blood pressure to increase.

The diagnosis of renal artery stenosis is made by an arteriogram. In this study, dye is injected into the renal artery and pictures are taken of the vessel. Blood samples are also taken from the blood vessels and measured for renin. If the vessel is closing, a specialist can open the artery with a small balloon. When the renal artery is opened, blood flow is returned to the kidney, and it no longer thinks the blood pressure is low. The kidneys stop making renin, and blood pressure returns to normal.

The risks and benefits of this procedure were explained to Mary. Her questions were answered, and consent was obtained.

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Mary underwent the angiogram of her renal artery at our local hospital. The procedure was painful, and she did not tolerate it well. However, the results were helpful in determining the cause of her high blood pressure. The results showed that Mary did not have renal artery stenosis, but she did have small kidneys that produced large amounts of renin.

The renin-angiotensin system plays an important role in regulating blood volume, arterial pressure, and cardiac and vascular function. While the pathways for the renin-angiotensin system have been found in a number of tissues, the most important site for renin release are the kidneys. Nervous system stimulation, renal artery hypotension, and decreased sodium delivery to the kidneys stimulate the release of renin. Renin is an enzyme that cuts a large protein called angiotensinogen into a smaller protein called angiotensin I. Cells on the walls of blood vessels, particularly in the lungs, contain another enzyme called angiotensin converting enzyme (ACE), which converts angiotensin I to angiotensin II. Angiotensin II has several important functions that include causing blood vessels to constrict and release of hormone that will raise blood pressure.

Mary's kidneys, for an unknown reason, were making more renin than usual. As a result, her body generated large amounts of angiotensin II, which increased her blood pressure by constricting her blood vessels and caused her body to hold onto salt and water. Since she had not responded to medications that block the action of renin like beta-blockers (block  $\beta_1$ -adrenoceptors) and ACE inhibitors (block angiotensin II formation), she was evaluated by two sets of medical teams to consider if she would benefit from having both of her kidneys removed. Removing her kidneys would eliminate the source of renin and hopefully decrease the production of renin.

After reviewing all the data, both teams agreed that the benefit of bilateral nephrectomy outweighed the risk of

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surgery and that she was a good candidate for this outdated procedure.

## XIII

### Three-month Check Up

Nellie Nephron started her new medications and experienced no significant side effects. Her kidney function did not worsen. After starting an exercise program and an oral hypoglycemic agent to control her blood sugars, her HgbA1C levels normalized. Her cholesterol levels did not improve with diet alone, and she was started on a cholesterol-lowering agent. Her LDL, or bad cholesterol level, was now 84 mg/dl—far below our target of 100 mg/dL. Amazingly, her serum creatinine test was reported at 0.8 mg/dL. I repeated the test to confirm the results. Her serum creatinine had returned to a normal level, and her calculated kidney function was over 70%.

I sat down with Nellie to give her the great news and to tell her how proud we were of her results. By being proactive, she had actually improved her diabetes and cholesterol levels. Certainly, this helped the plumbing system of her body. Her kidney protective medications probably reduced pressure in her kidneys, which allowed improved kidney blood flow and an improvement in overall kidney function.

I explained to Nellie that she had done a tremendous job. She had learned and assimilated the goals of our clinic. She was a star and would come to see us every six months for lab studies and blood pressure check ups. I asked her to call us if she had any questions. She was grateful, and before leaving the clinic, she gave us some homemade chocolate chip cookies. Giving my assistant a big hug, she said she would see us in three months.

“Thanks for giving me back my kidneys,” I heard her say as she walked out the door.

## XIV

### Dialysis Center

Unlike Nellie, Sam, Dorothy, and Mary's kidneys were never found. Bad genes, high blood pressure, and diabetes had stolen their kidneys. Facing reality is sometimes difficult. We build our attitude brick by brick over time. Some of us are optimistic and others are pessimistic. To beat a chronic illness, like kidney disease, we must teach ourselves not to take it personally. We must understand that we are not in control. Natural laws or principles are in control. We are the only ones who make ourselves feel negative. We have two choices, get up and go home or choose to not let others or chronic illnesses derail us. Inner strength does not come overnight but after years of daily conditioning.

Every morning, I start my day rounding in the dialysis unit. Our dialysis unit is a beautiful new facility. It is a place where trained professionals care for patients with chronic renal failure. The staff consists of a physician manager, a business manager, facilities manager, dietician, social worker, four registered nurses, two administrative assistants, and about eight dialysis technicians. The nurses and technicians start their day at about 3 AM and do not finish until about 8 PM. We have two teams, which take care of two groups of patients getting dialysis therapy. Because the work days are so long, one team works a Monday, Wednesday, and Friday schedule and the other team works a Tuesday, Thursday, and Saturday schedule. We have team meetings once per week and quality control meetings once per month.

In our dialysis center, we have 22 dialysis chairs and dialysis machines. We run three shifts per day to accommodate our patients who are on dialysis for four hours per treatment.

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Each day we can serve about 66 patients (three shifts per day and 22 patients per shift). To say the least, we are very busy, and our staff works very hard.

Sam, Dorothy, and Mary undergo dialysis treatment at our dialysis unit. Sam and Dorothy are on the Monday, Wednesday, and Friday rotation. Mary dialyzes on Tuesday, Thursday, and Saturday. Lab work is obtained and reviewed with each dialysis patient monthly. Most patients on dialysis get erythropoietin therapy (to prevent anemia) and Vitamin D therapy (to prevent bone disease) with each dialysis therapy.

Sam comes to his treatment on the early morning (5 AM to 9 AM) shift so he can get to work. His attitude is excellent. He never misses a treatment and can often be found doing work while he receives his treatment. He rarely complains. Since I last saw him in clinic, he was seen by a vascular surgeon and had a beautiful fistula placed in his left arm. The vascular access was placed in his left arm since Sam is right handed. The fistula does not impair his ability to write or perform his job as a police officer. After the fistula healed, he started dialysis in the dialysis unit. This is much easier on the staff and less risky for the patient. As we saw with Dorothy, if patients get into trouble with fluid overload before they start dialysis, emergency dialysis is required and can be life threatening if not performed in an adequate time frame.

Sam's transition to dialysis was smooth and without complication. He has done well on dialysis, takes his medications as prescribed, and rides a bike three or four times a week. He continues to coach his kids in baseball. He finally brought me a picture of his baseball team. It hangs on the bulletin board in my office

"Good morning, Sam" I said. "How was your weekend?"

"My weekend was great. We won our baseball game by a score of twelve runs to five runs. My son hit a grand-slam home run."

"How is work?"

"Very good. I am doing mostly desk work."

"Do you have any shortness of breath?"

"No," he replied.

"Great. Your lab work looks excellent. You have brought your phosphorus levels down to normal and your PTH levels have normalized with the intravenous Vitamin D therapy. You show no signs of anemia. Your bicarbonate levels increased with the sodium bicarbonate pills. You still are a little acidic, so I would like you to increase the number of sodium bicarbonate pills you take per day to six—three in the morning and three in the evening. Otherwise, you are doing splendid. Do you have any questions?"

"How do I go about finding information about getting a kidney transplant?"

"You would be an excellent candidate. I will schedule you for a transplantation class to go into more detail. Do you have any potential donors?"

"Not really," Sam said.

"Well, bring your wife to the class. We are also looking at spouses as potential donors for our kidney patients. If her blood type is right, she may be a candidate."

"Thanks, Doc"

"Okay, Sam, I will see you next week. Have a good day at work."

I did not worry about Sam. He was a great patient. The staff adored him, and he was always polite and considerate. I had never heard anyone say anything negative about Sam. He was well balanced.

Mary Miracle has had a rough course. She and dialysis did not mix well together. Despite our best efforts to maximize her dialysis therapy, she continues to deteriorate. Her blood pressure is never normal, despite five different medications—all at maximal doses. She is always short of breath. While being on dialysis, I have seen this young lady go from working full time to not being able to work at all.

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She is now on continuous oxygen therapy and unable to walk. Her family brings her to and from dialysis in a wheelchair. Her labs show that she is very anemic and malnourished.

Malnourished individuals have a very poor prognosis. The mortality rate for an average dialysis patient is about 20%. This means that one out of every five patients will die over the next year. The most common cause of death is heart disease. Patients, like Mary, who are also malnourished, have about a 50% annual mortality rate. This means she has one out of two chances of still being alive in one year.

The cause of malnourishment in this population is not clear. Obviously, if they are very sick they lose their appetite and ability to get access to food.

Mary's blood proteins are very low and other studies performed in the dialysis unit suggest that her protein intake is also very low. Our dietician works closely with Mary to improve her protein intake. Good protein sources for Mary include non-yolk eggs (very high in protein), protein bars, and protein powder shakes. She takes these nutritional supplements religiously, and I honestly believe that her fortitude and focus on good nutrition is the only thing keeping her alive. Our plan for Mary is to control her nutrition, finish her work up at the transplant center, and have her kidneys removed. I pray we have enough time to complete our workup before she has another set back.

Dorothy Denial is a difficult patient. After almost dying in my office, she was stabilized, transferred to the hospital, and dialyzed acutely via a catheter in her right internal jugular vein. Before leaving the hospital, a surgeon placed a fistula in her arm, which clotted one week after discharge. This means she had to have another surgery to take the clot out of her arm. After her second surgery, she developed a wound infection, which required two weeks of intravenous antibiotics. When the antibiotic treatment was completed, an ultrasound of her fistula showed poor development, and she returned to the surgeon last week for another surgical

consultation. "I hope she does not have another surgery," I said to myself, as we rounded on her in the dialysis unit.

Dorothy's labs are always a disaster. Despite multiple case conferences with her and her family, she continues to take poor care of herself. Her diabetes mellitus is poorly controlled, and her family members say she refuses to stick to her diet. "She rarely gets out of bed," her daughter said once at one of our family meetings. Dorothy was sent to a psychiatrist for evaluation. They diagnosed mild depression, and she was started on an anti-depressant. It did not seem to work. I tried to encourage her at weekly rounds, but all my efforts did not seem to change her behavior.

Most recently, she has been telling the staff that she only wants dialysis for two hours instead of the recommended four hours to maintain adequate dialysis to maintain life. I showed her data, which suggests that mortality rate goes up as we decrease the time we spend on dialysis. She tells me that data on other dialysis patients does not apply to her.

"I feel better on two hours of dialysis therapy, and I am not going to stay for four hours of therapy."

Dorothy also refuses to follow her fluid restricted diet. Chronic renal failure patients who do not make urine have a one liter per day fluid restriction. This means that each day, their fluid intake should not exceed 1,000 milliliters or about 20 ounces. We know when they drink more than this amount of fluid between dialysis because of the amount of weight they gain between dialysis treatments. A normal dialysis patient gains about three liters between treatments. Weight gains higher than three liters are problematic because this is the amount of water that has to be removed before the patient may get off the dialysis. Otherwise, the patient will gradually start to accumulate water and go into pulmonary edema. Because Dorothy is not compliant with fluid and usually never wants a full dialysis treatment, she is frequently admitted to the hospital for acute dialysis to remove excess fluid. When she is acutely ill, she agrees to

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more time on dialysis, but when she is feeling better, she goes back to her old treatment schedule.

In addition, despite multiple attempts to get Dorothy to stop smoking, she persists. The risk of tobacco use has been reviewed with her on multiple occasions. She is in denial.

After my staff and I watched Dorothy's destructive behavior for about two months, we scheduled yet another family conference. Before the conference started, I met with Dorothy in my office with one of my assistants. I reviewed the series of events that had happened to her over the last few weeks. I asked her why she would not let us help her.

She said, "Doc, I have had diabetes all my life. At first, I did not believe I had diabetes even though the doctors told me so. I was young and invincible. I never followed my diet and took insulin only when my sugars were so high they made me sick. I was admitted multiple times to the hospital for diabetic acidosis. Over the last ten years, diabetes stole my eyes (diabetic retinopathy), the sensation in my legs (diabetic neuropathy), and now they have stolen my kidneys (diabetic nephropathy). I have no quality of life. I go from bed to dialysis and back to bed. Every couple of weeks I get sent by ambulance to the hospital, where I am stuck with needles all day long. I am tired, Doc, and I do not want to continue dialysis therapy."

I could see tears coming from both of her eyes. For the first time since I had known Dorothy, she was being honest. She was telling me the truth.

"Dorothy," I said. "We all care about you. Your family loves you very much. I agree that your quality of life is poor. You do have other options. As we talked about in the Choices Class, you have a right to refuse therapy. You have the right to say I do not want dialysis and would like to die at home with my family."

She looked me straight in the eye as if to say thank you, then said, "This is what I want to do."

Over the next half-hour, I reviewed in detail with her the process of stopping dialysis therapy. I called her psychiatrist, who concurred and said that they had discussed this option at their last session. He agreed with me that Dorothy was not suicidal and not depressed to the point where she could not make a reasonable decision. After we finished talking to the psychiatrist, I asked Dorothy if it was all right to discuss the issue with her family. She agreed.

Dorothy and I then went into the conference room where Dorothy's family had been waiting for the last hour. They were a little tired but glad we had come into the room. Dorothy's daughter saw that Dorothy had been crying and asked her if everything was all right. Dorothy nodded.

Without me saying a word, Dorothy took control of the conversation. She reviewed with them the situation, her prognosis, and her wishes. Almost instantaneously, everyone in the room including myself started to cry. Tissues were handed out by the box. Dorothy's family exchanged hugs, and they were very supportive of Dorothy's decision. Dorothy's family left the room very grateful for the time we had spent with them and our efforts to care for her over the last few months. Before Dorothy left with her family, she came back and gave me a big hug. She whispered into my ear, "Diabetes did not steal my kidneys. I stole them. Please tell others about this story so they do not end up like me."

I gave Dorothy a hug back and shook my head in approval. She then walked slowly out of the clinic surrounded by a loving and understanding family.

After Dorothy left, I called the Hospice Team and explained to them Dorothy's decision. I reviewed with them my discussion with Dorothy and her family. After faxing a referral to the Hospice Team, I closed up my office and went home. When I got home, I told my wife and each of my kids how much I loved them.

I did not see Dorothy again until the funeral. The Hospice Team saw her the day after she left my office. Because of

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her poor condition, she passed away in less than 48 hours. She was surrounded by family members and was lying in her own bed when she expired. She died just the way she wanted to, and after what she'd whispered in my ear, I knew that she had died with peace in her heart.

## XV

### The Nephrectomy

Bilateral nephrectomy (or surgical removal of both kidneys) used to be a common procedure for management of hypertension before widespread use of anti-hypertensive medications. Since medical therapy has been so successful, need for surgical treatment of hypertension has declined dramatically.

In Mary's case, blood pressure medications had not been helpful due to an enzyme in her blood called renin, which was secreted by her kidneys in large amounts and may have been causing her resistant hypertension. Issues were discussed with Mary and her family. At Mary's request, she was then referred to the local university hospital for transplant evaluation.

One of Mary's sisters was identified as an excellent living related donor; however, prior to doing the surgery, the physicians at the university hospital agreed that Mary should have both of her kidneys removed. They argued that after the kidney transplant surgery, her blood pressure could elevate significantly from the medications used to prevent transplant rejection. She would be at very high risk for a stroke. Mary now had three sets of doctors who recommended bilateral nephrectomy.

Surgery was scheduled. After being admitted to our medical center, surgery was cancelled because of severe hypoxemia (low oxygen in her blood) on the operating table. A chest x-ray showed a very large pleural effusion (fluid surrounding her lungs). Mary was drowning in her own fluid, which was not being removed by well functioning kidneys. A pulmonary consult was obtained, and the patient was

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admitted to the intensive care unit. An echocardiogram showed pulmonary hypertension or very high pressure on the right side of her heart caused by the excess fluid in her lungs.

After discussing the case with the hospital team, the urologist was reluctant to do the surgery. They were preparing to discharge the patient. The family was very discouraged because they knew that she would not get her renal transplant. After discussing the case with the surgeon and the intensive care physicians, I was able to hold the discharge and buy some time so the pulmonary physician could perform a small miracle. Over the next few days, the pulmonologist removed fluid from Mary's lungs by placing a needle into the space between her chest wall and lung tissue (a procedure called thoracentesis). The hospital nephrologist, one of my partners, ordered daily dialysis to remove extra fluid circulating in Mary's blood vessels. The goal was to make Mary dry so her lungs could get adequate oxygen and Mary's body could make it through the surgery.

Over the next 48 hours, Mary's oxygenation improved, and a repeat echocardiogram showed no pulmonary hypertension. This was a decisive point. If she was diagnosed to have pulmonary hypertension, Mary would not be a candidate for any type of surgery, including transplantation. The fact that her pulmonary hypertension resolved with fluid removal suggested that the condition was not permanent. Mary was cleared for surgery and underwent open, bilateral nephrectomy without complication.

After her native kidneys were removed, her blood pressure was easier to control. She was discharged from the hospital and scheduled for her follow-up at the university medical center for elective kidney transplantation.

## XVI

### I Found a Kidney

Two weeks after her kidneys were removed, Mary underwent elective, living related kidney transplant without complication. Her kidney function returned to normal. Three months after her renal transplant, she returned to see me at the same renal clinic where I'd seen her almost two years previous. I could not believe the difference in her overall appearance. She looked completely different. No oxygen tank, no wheelchair, and no shortness of breath. Her skin color was normal. Her blood pressure was also normal—on no blood pressure medications. This young lady had been brought back to life by the expertise of many different physicians at different medical centers. A miracle had occurred in front of my eyes. Mary and her family were most grateful. They had been to hell and back.

Now she enjoyed beautiful spring day walks with her husband. She had a new grandchild and loved to hold her and make her smile. She was talking about going back to work.

After Mary and her husband left my office, I reflected on the journey I had been on with Mary over the last few months. A roller coaster of a ride had ended to see this beautiful young lady telling me of the precious moments she now spends with her family, moments that a year ago, I did not think she was ever going to experience.

We must give them hope, I thought. We must believe in them and listen to their deep inner thoughts and dreams. We must help them become comfortable with the uncomfortable by giving them love and support, for this is the true meaning of empathy.

## Conclusion

It would be very difficult for you to manage your kidney disease alone. As explained in this book, a team of health care providers specifically trained to care for individuals with CKD best perform successful management of CKD. This team includes a physician who specializes in kidney disease, a nurse case manager, dietician, and social worker.

Personal growth is a natural process. We are all at different stages of growth. The war on kidney disease is just beginning. To win the war, individuals with CKD and health care providers must work together to form a strategic plan to save kidneys and save lives. Much of this work is just beginning.

As a valuable member of this team, Americans with kidney disease must develop the self so that they can maximize the advice given to them from the rest of their health care team. We should guarantee victory through knowledge, persistent analysis, and defensive proactive preparation. We should not rely on good fortune for victory. Victory should be sought through strategic configuration of our resources. In battle, one engages with the orthodox and gains victory with the unorthodox. We should keep all our options open and seek new treatments that may keep us from getting kidney failure or dying. One who knows self and knows the enemy will not be endangered.

We should avoid comparisons between other individuals and ourselves with kidney disease. Compare yourself with your potential. Realize that there are no shortcuts to success, and to improve our health, we must start from where we are.

In this book, I provide you with information on how you can save your kidneys and your life. The important facts are summarized below:

1. **Be wise:** Focus on slowing down CKD progression.
2. **Be just:** Do the right thing and work closely with your health care team to develop a treatment plan that is best for you.
3. **Be strong:** Have courage to start on your road to a better and healthier life.
4. **Be humble:** Be self-aware and have self-control to avoid doing those things that may harm your kidneys.

## Resources

### **American Association of Kidney Patients**

3505 East Frontage Road

Suite 315

Tampa, FL 33607

Phone: 1-800-749-2257 or (813) 636-8100

Email: [info@aakp.org](mailto:info@aakp.org)

Internet: [www.aakp.org](http://www.aakp.org)

### **Life Options Rehabilitation Program**

c/o Education Institute Inc.

414 D'Onofrio Drive

Suite 200

Madison, WI 53711-1074

Phone: 1-800-468-7777 or (608) 232-2333

Email: [lifeoptions@medmed.com](mailto:lifeoptions@medmed.com)

Internet: [www.lifeoptions.org](http://www.lifeoptions.org)

[www.kidneyschool.org](http://www.kidneyschool.org)

### **National Kidney Foundation Inc.**

30 East 33rd Street

New York, NY 10016

Phone: 1-800-622-9010 or (212) 889-2210

Email: [info@kidney.org](mailto:info@kidney.org)

Internet: [www.kidney.org](http://www.kidney.org)

### **United Network for Organ Sharing**

1100 Boulders Parkway, Suite 500, P.O. Box 13770

Richmond, VA 23225-8770

Phone: 1-888-894-6361 to order single copies

(804) 330-8541 to order bulk copies

Internet: [www.unos.org](http://www.unos.org)

## Suggested Readings

1. Kidney Disease Quality Outcomes Initiative
  - <http://www.kidney.org/professionals/kdoqi/index.cfm>
  - K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. National Kidney Foundation - Am J Kidney Dis - 01-FEB-2002; 39(2 Suppl 1): S1-266
  - Clinical practice guideline on shared decision-making in the appropriate initiation of and withdrawal from dialysis. The Renal Physicians Association and the American Society of Nephrology. Galla JH - J Am Soc Nephrol - 01-JUL-2000; 11(7): 1340-2
  - NKF-K/DOQI Clinical Practice Guidelines for Hemodialysis Adequacy: update 2000. Am J Kidney Dis - 01-JAN-2001; 37(1 Suppl 1): S7-S64
  - NKF-K/DOQI Clinical Practice Guidelines for Peritoneal Dialysis Adequacy: update 2000. Am J Kidney Dis - 01-JAN-2001; 37(1 Suppl 1): S65-S136
  - NKF-K/DOQI Clinical Practice Guidelines for Vascular Access: update 2000. Am J Kidney Dis - 01-JAN-2001; 37(1 Suppl 1): S137-81
  - K/DOQI clinical practice guidelines for management of dyslipidemias in patients with kidney disease. Kidney Disease Outcomes Quality Initiative (K/DOQI) Group - Am J Kidney Dis - 01-APR-2003; 41(4 Suppl 3): I-IV, S1-91
  - The National Kidney Foundation K/DOQI clinical practice guidelines for dietary protein intake for chronic dialysis patients. Kopple JD National Kidney Foundation K/DOQI Work Group - Am J Kidney Dis - 01-OCT-2001; 38(4 Suppl 1): S68-73

2. United States Renal Data System (USRDS). USRDS 2001 Annual Data Report: Atlas of End-Stage Renal Diseases in the United States. Bethesda, Md: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2001.
3. Keith, D.S., Nichols, G.A., Gullion, C.M., Brown, J.B., Smith, DH. Longitudinal follow-up and outcomes among a population with chronic kidney disease in a large managed care organization. Archives of Internal Medicine. Volume 164(6) 22 March 2004 p 659-663
4. Chen, J., Muntner, P., Hamm, L.L., Jones, D., Batuman, V., Fonseca, V., Whelton, P.K., and He, J. The metabolic syndrome and chronic kidney disease in U.S. adults. Ann Intern Med. 2004;140:167-174.
5. Brenner & Rector's The Kidney, 7<sup>th</sup> ed. Copyright © 2004 Elsevier
6. Goldman: Cecil Textbook of Medicine, 21<sup>st</sup> ed. Copyright © 2000 W. B. Saunders Company





## About the Author

Philip Tuso, MD, is a board certified nephrologist who has received numerous awards and held many administrative positions before being appointed Physician Director of the Fresenius Medical Care Dialysis Unit in Lancaster California. Over the past year, Dr. Tuso has focused on efforts to develop a population care management program to help improve measurable outcomes for individuals with chronic kidney disease. He is the founder and president of a non-profit organization called the Foundation to Improve Renal Nutrition whose mission is to increase public awareness of kidney disease and raise funds to supply nutritional supplements to malnourished individuals with kidney failure.





