

COPING, LIVING, AND THRIVING WITH KIDNEY DISEASE



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COPING, LIVING, AND THRIVING WITH KIDNEY DISEASE

WHAT IS KIDNEY DISEASE?

When someone has chronic kidney disease (CKD), their kidney function has slowed down. There are a variety of diseases or conditions that can lead to kidney disease. There are five stages of CKD. In Stage 1 there is little damage and by Stage 5 the kidneys have lost most of their function and there's a need for renal replacement therapy, such as dialysis or a kidney transplant to help take the place of your non-working kidneys. Changes in kidney function usually takes place over time.

However, being diagnosed with kidney disease, at any stage, can be challenging. Being diagnosed with kidney disease can leave you feeling overwhelmed and with more questions than answers. There are a lot of emotions and actions to think through. And many times, patients are also trying to juggle other responsibilities (such as family or work, or other chronic conditions such as diabetes, hypertension, heart disease, etc.) at the same time.

The Purpose of this Booklet is to empower individuals to take charge of their disease management by confronting negative feelings and providing strategies on how you and your team can thrive and become the warrior you want to be on this journey of kidney disease.

The booklet has been organized to assist patients with the following phases:

ACKNOWLEDGE: Begin the journey of accepting your diagnosis. Identify who is a part of your social support team. Recognize any negative feelings you may be having, so you and your team can overcome these negative feelings and build a more positive response.

ADDRESS: Identify short-term and long-term goals to begin problem solving.

RE-ASSESS: Determine what role each member of your team can have in helping you take charge of your health.

RE-PROGRAM: Revise your thinking and approach to your kidney health.

SOCIAL SUPPORT



Social support is crucial for every phase listed above. Having strong social support will help you learn to acknowledge, address, re-assess, and re-program your thoughts, attitude, and actions in taking charge of your kidney health.

A **social support team** is a network of people that you get information through and share information with. Social support can come in many different forms – from family, friends, colleagues, neighbors, and any other networks you may belong to (e.g., clubs, community groups, and religious organizations) as well as health care providers.

You might not find it easy to discuss your situation with people, to ask for help, or to depend on others. However, try to put yourself in their position, and think about how you would want to help your friend or colleague if they were experiencing a chronic illness. You may be surprised at people's kindness, generosity, and understanding.

You might prefer to speak to a few selected individuals privately, or it might be easier to have a trusted friend or family member share your status on your behalf. There is no right or wrong choice, as long as you have people in your corner to provide the support you need. The more support you have, the better chances you have of good outcomes for your physical and emotional health.

Your **team** can support you through this journey. Your team can help improve your knowledge of kidney disease and guide you through decisions that need to be made.

Growth is when you choose to address certain battles, stand still in the mist of the storm, and remain vigilant when you feel all hope is gone.

Throughout this booklet you will find statements in yellow boxes, like this one. These are ‘statements of affirmation.’ Try saying them to yourself or aloud, so that these words can belong to you and help you along your journey.

Individuals from different groups can form your team. These groups could be friends, family, health care staff, and people in the community. It may feel like you don't have anyone in one or more of these

groups that is on your team. Take some time to think about each of these groups – there might be someone in that group after all. And don't be afraid to search out new people to be a part of your team.

A **friend** can be anyone you feel comfortable to share your ups and downs with. A friend can be someone you have known for years and been through many life transitions with, or a person you may have just met but you feel connected to, someone who you feel like truly listens to you. Your friends just want to support you in your ups and downs; help them by sharing your journey.

Family can be related, or not. This can be your brother, sister, aunt, cousin, or someone very close that may not be related, but you consider them your family. There is a mutual care and love between you and your family members; you would sacrifice for them, and the feeling is mutual. Share with your family member, and allow them to support you being the warrior they know you are.

Health care staff can be a variety of healthcare professionals. They could be your kidney doctor, the pharmacist that fills your monthly prescriptions, or a nurse or technician at your dialysis unit. Don't hesitate to ask them questions. You may be surprised at how much they know and how much knowledge they are willing to share. If the staff member doesn't seem that knowledgeable about kidney disease, teach them what you know and bring them on this journey with you!

Community members are people you share something in common with, like living in the same neighborhood, working in the same building, or liking the same hobby. Community members could be work colleagues, members of your church, persons at your weekly card games, people you frequently see at your local American Legion, or people you see at your monthly book club. You are already sharing a part of a similar journey and have some things in common; continue sharing your journey with them!

ACTIVITY:

Who is on your team? Team members are those who can provide social support as well as practical support. Your team can come in many different shapes, sizes, and walks of life: lifelong friends, a helpful neighbor, a work colleague, or a nurse at your clinic. Take a few minutes to identify a few people in each of these groups that are on your team.

FRIENDS

FAMILY

HEALTH CARE

COMMUNITY

ACKNOWLEDGE

Acknowledge: Begin accepting your diagnosis and recognize any negative feelings you may be having so you and your team can overcome these negative feelings and begin building a more positive response. Remember, it's normal to experience a variety of emotions as you learn more about your kidney disease diagnosis.

You have a choice between engaging your social support team (as discussed) or exhibiting social withdrawal. We know that social support is essential to many situations in life, including navigating a chronic health condition. It may be difficult at first to learn to rely on people rather than going it alone or to open up about the challenges you're facing. With the help of social support, you are likely to have more success and an easier experience learning to accept your diagnosis and not letting your life be defined by your kidney disease.

Social Withdrawal can be caused by blaming or criticizing yourself for the situation or refusing to seek support from others when needed. Withdrawing can mean hiding the problem, not telling other people what you are experiencing, or thinking or feeling like you're "on an island" or don't have hope.

It can almost be too easy to feel alone and isolated when you get a diagnosis like kidney failure. Fortunately, **you are not alone**. Many people have been diagnosed with kidney disease or kidney failure or a similar chronic condition, and many more know someone close to them who has. Don't be afraid to share your story. You may be surprised to hear similar experiences as yours, how willing others are to support you on your journey, and might even learn someone close to you also has kidney disease and you didn't even know.

MORE THAN 1 IN 7



15% of U.S. adults are estimated to have chronic kidney disease, that is about 30 million people. (source: Centers for Disease Control and Prevention – CKD Initiative)

Thomas, age 47: "No one knew what I was going through. No one I knew had kidney disease, how could they even begin to understand what I was going through. Then one day I mentioned going to a vascular surgeon for a PD-access evaluation

to a golfing buddy. Turns out, his uncle had kidney failure and his dad gave the uncle a kidney! My buddy knew exactly what I was talking about. It felt good to

be understood and listened too. Kidney disease really does effect more people than you would ever know because no one talks about it!"

TALKING POINTS FOR YOUR TEAM

FRIENDS

Have your friends keep engaging you in their activities and keep asking you to hang out. You may not feel like doing anything right away, but tell them you still want to be involved and will join the group when you can.

FAMILY

It will be helpful for others to know what is going on, but you may not have the energy to tell everyone yourself. Ask a trusted family member to tell others about your kidney disease diagnosis. They may also start forming a strong support network that is there, whenever you are ready.

HEALTH CARE

The diagnosis of kidney disease can feel isolating. Ask the healthcare staff if they know of a support group, either in-person or online. Visit www.aakp.org/supportgroups to see if there's a support group in your local community. If not, AAKP has resources to help you take charge and start one.

COMMUNITY

If you don't want to ask for help yourself, a trusted colleague or fellow community member might be willing to seek help on your behalf. Do you ever think badly if someone posts a message or makes an announcement, seeking to support someone in a difficult situation? Of course not! It can also be done discreetly.

ACTIVITY:

Many people find it easier to say something in writing and from a distance so they can collect their thoughts, rather than in person or on the phone. It takes the pressure off, and you won't have to worry about how they respond to you in real time. Compose a written note, text, or email to a 'team member' you already identified in each of the following categories: friends, family, health care staff, and community members. In the note, practice what you will say to each of these significant persons to obtain help/support in dealing with your journey. For health care staff, make a list of questions, concerns, or anything you feel you may forget to discuss at an appointment. Next, send the notes!

You have a choice between wishful thinking and expressing your emotions. Wishful thinking might be tempting. It is hard to admit that life is different than what we expected, and it is natural to want to hold on tightly to what you used to believe or know. However, it is important to learn how to honestly recognize and express your emotions around kidney disease.

Example of a text to a friend:

Went to the doctor today and learned that my kidneys aren't functioning like they should. My doctor is really helpful but says I need to change my diet. Can you help me find new recipes?

Example of a written note to a community member:

Thank you for all your thoughts and prayers. I've been going through some health issues and appreciate the extra support. I am not ready to talk about it, just yet, but I am glad to know you are there when I am ready. Thank you.

Wishful Thinking is about believing or making decisions based on what you want to happen, not the reality of the situation. People who think wishfully may be having a hard time accepting the situation or reframing it so that it is manageable. Some people diagnosed with kidney failure will ‘hope things will get better’ and may not fully understand what is happening to their health.

Wishful thinking might not be harmful in the short term. For many people, wishful thinking may help you overcome the initial shock of the diagnosis. However, it is not a permanent solution. Sticking with this way of thinking could cause you to lose sight of what is truly important in your life and could create larger health problems by delaying decisions and treatment.

Melissa, age 65: “I was in disbelief when the doctor said my kidneys were failing. I told him I would eat more salads and less red meat to help improve my kidney function. I didn’t really listen to him when he said that my kidney function wasn’t coming back or maybe I thought I’d be that miracle person in which it would. It wasn’t until my pastor told me his mom died of kidney disease because she kept thinking it would come back and didn’t take the necessary steps to understand, learn and take control of her disease...that shocked me into facing this problem.”



TALKING POINTS FOR YOUR TEAM

FRIENDS

Have your friends sit with you and figure out what your priorities in life are. Then have your friends help you figure out what questions you need to ask or things you need to do to make sure you achieve those goals and maintain your quality of life.

HEALTH CARE

Listen when the doctor tells you about your health and how your kidney function is changing. Take what they are saying seriously. If they tell you to make a follow-up appointment, or get a consultation for a surgery, or complete specific screenings, do what they say and don't waste time – because life is too precious.

Be prepared to ask the right questions. **AAKP's Pocket Guide to Managing Kidney Disease** is a convenient brochure that provides suggested questions to ask your doctor at every stage of kidney disease, to help keep you on track and guide the conversation.

FAMILY

Your family can help you face reality and the full weight of a kidney disease diagnosis. Ask a family member to go with you to each doctor visit so they can hear the information and help you remember what is happening and what you should be focusing on. Remember, kidney disease can impact the entire family and there may also be questions from a caregiver's perspective that your family may want to know and you may not have thought of.

COMMUNITY

Connect with other people who are dealing with a chronic condition – it doesn't have to be kidney disease. Learn what challenges they had to overcome and how they overcame those challenges. Learn from other people's experiences. You may be surprised how similar the journeys can be.

Expressing Emotion is when you release and communicate your feelings. Some people choose to use humor to cope or share their emotions when grieving a diagnosis. If you are feeling scared about your kidney disease diagnosis, figure out what about it is scary or worrying you the most, and talk with someone in your social support team including your health care team to overcome this fear. Others may become frustrated or very sad trying to decide how this diagnosis can or will impact their life. It is important to rely on your health care team and other individuals close to you to acknowledge your feelings and learn to move beyond them. This is very important so that you can focus on what's really important: understanding and managing your condition, choosing the right treatment option for you, and maintaining your quality of life.

It is important to be honest with yourself and your feelings, while also not allowing them to control your life. Social support is critical

I will pursue my journey in spite of fear.

here. Rather than keeping your feelings to yourself, it is important to find an outlet for your feelings so that you are not overwhelmed by them. Many people find comfort in talking to trusted friends, family members, neighbors, coworkers, or other significant people in their communities. Sometimes you may need an activity as an outlet, such as taking a walk, sewing, golfing, painting, etc.



Darren, age 34: "The process to getting a kidney transplant was not easy for me and involved a lot of waiting and anxiety. I like to crack jokes when I am in the waiting room to help ease the stress and pass the time. I also talk with my sister about my high and low emotions in the process. She helps me focus on the positive."

TALKING POINTS FOR YOUR TEAM

FRIENDS

It is ok if you feel overwhelmed and out of control. Tell your friends this and ask them to be patient with you. They care about you and won't be angry with you, and may even offer their help.

FAMILY

Be mad. Be frustrated and scared. Be overwhelmed. And tell your family about these feelings. Don't hide your feelings from the ones who care about you. They will help you through these emotions and begin problem solving and re-programming to ensure you will thrive on this new journey.

HEALTH CARE

Don't hide your feelings from health care staff. They may be able to identify tips or resources to help you through the negative feelings and begin taking charge of your kidney health. Like your family, your health care team wants the best for you and wants to see you continue to live your best life despite kidney disease.

COMMUNITY

Connect with other people who are dealing with a chronic condition – it doesn't have to be kidney disease. Learn what challenges they had to overcome and how they overcame those challenges. Learn from other people's experiences. You may be surprised how similar the journeys can be.

ACTIVITY:

Journaling - get out your thoughts and emotions either on paper or on a computer/device. Don't worry about making it coherent – just write/type whatever you are thinking and feeling in the moment. Often, you might not realize what you are feeling until you try to put it into words. Many people find journaling to be useful. It can make you feel better to 'empty' your minds. It could also help you gain perspective.

ADDRESS

Address: Identify short-term and long-term goals to begin problem solving

You have a choice between (A) avoiding the problems of your CKD diagnosis or (B) trying to solve the problems of your CKD diagnosis. Problem avoidance is similar to wishful thinking – you are not really admitting the truth of the situation and what needs to happen. When you are problem solving, you are actively working to figure things out. Social support is vital during this process.

Problem Avoidance is denying the situation and avoiding thoughts or actions related to the condition. Some people have a hard time acknowledging the reality of kidney failure; you may view kidney failure as temporary or not serious. And so you may feel like shrugging off the need for positive coping strategies or lifestyle changes because ‘no real problem exists’.

Time is precious. If your doctor is already talking to you about kidney failure and discussing either dialysis or a kidney transplant, then there is literally no time to waste. Now is the time to ‘put one foot in front of the other’ and start making the

appointments that your doctor is recommending. Start meeting with the other health care professionals your doctor is recommending. Even if you don’t completely think you need to. Better to meet with everyone and gather information sooner, than needing it later and not having time to gather it.



Gary, age 69: “I kept telling my doctor I feel fine. I don’t need to think about dialysis because I feel fine, my kidneys are fine,’ and then I wound up in the ER with a tube in my neck on emergency dialysis after I passed out at my son’s house. Avoiding the problem only made it worse. I should have listened to my doctor and talked with my family about all of this before I was on the floor and them having to call 911.”

TALKING POINTS FOR YOUR TEAM

FRIENDS

Get your friends to help you understand how your health is changing. Have your friends help explore online resources (listed below) that can communicate what a diagnosis of kidney disease means to you and your lifestyle.

HEALTH CARE

Tell your doctor that you need them to hold you accountable to keep appointments and follow their advice. But show the health care staff that you care as much about your health as they do – keep your appointments, take notes, and try and follow their advice.

FAMILY

Have your family hold you accountable and show you ‘tough love’. Give your family a detailed report each time you visit your doctor so it helps you remember and your family understand what is happening and the changes taking place. This is important if you have any dietary changes you need to abide by. Allowing your family to know what those are and how they can help, will ultimately make things easier on you when at family dinners, parties and events.

COMMUNITY

Understand that your peers and community care about you. When you are ready to talk, they will be there to listen and support you. They will help you find ways to stay involved with your regular activities and hobbies.

ACTIVITY:

Pick three of the following resources to investigate, explore, and/or participate in. Spend time learning about your condition and also interacting with other people who have experience in this area, and who may be able to provide support, advice, and guidance. Share them with your team and have them get more informed too!

Resource List:

- American Association of Kidney Patients: www.aakp.org
- Renal Support Network: www.rsnhope.org
- National Kidney Foundation: www.kidney.org
- American Kidney Fund: www.kidneyfund.org
- The iChoose Kidney risk calculator: A tool that educates patients about the risk of available treatment options for kidney disease.
www.ichoosekidney.emory.edu
- My Dialysis Choice: A tool that helps individuals with kidney disease choose the right treatment option for them. www.mydialysischoice.org

Problem Solving is about forming and acting on strategies to reduce their stress by changing the stressful situation. The strategies might involve changing your behavior or how you think about the situation. Problem solving involves being proactive with your health, following the advice of medical providers, asking questions when you don't understand or are concerned about what you are hearing, preventing potential setbacks from occurring, and making health decisions in a timely manner.

Some people find it helpful to make lists to help remember key steps to take and questions to ask. Many try to plan ahead to avoid possible challenges in the future. While others might look for as much information as possible, to become educated on their condition and their options.

Leticia, age 42: "Since I got diagnosed with kidney disease, my diet has changed, and I am taking pills I never heard of. But I listen to my doctor and I work closely with the pharmacist to make sure I understand what I'm taking, why I'm taking it and am following 'doctor's orders' as best as I can. If I have a question or don't understand something, I ask and make sure I write down the answers so I can remember."



TALKING POINTS FOR YOUR TEAM

FRIENDS

Plan a ‘kidney friendly’ potluck! Get recipe recommendations from your nephrology dietitian or through online resources (www.aakp.org/recipes) and send them to your friends. Have each friend pick a different recipe and then get together to share in a tasty meal!

FAMILY

Engage a family member to help you make a list of questions you need to ask at your next doctor’s appointment, or maybe of things you can buy (such as a weekly pill box) to help get and keep things organized.

HEALTH CARE

Work with your kidney doctor and nurse to identify who is on your health care team and the role each person plays, so you know who to go to for specific questions.

COMMUNITY

“I need to talk with my boss and coworkers about my diagnosis... but I need to let them know my work schedule may change.” I don’t need to tell them every detail, but I need to let them know my work schedule may change. Visit www.kidneyworks.org for more employment resources.

ACTIVITY:

What challenges are you facing or questions do you have, right now?

Are you trying to find new recipes that are more 'kidney healthy'? Trying to manage changes in your medication schedule? Or trying to determine which type of treatment option is best for you? List 4 to 6 challenges or questions that are weighing on you.

RE-ASSESS

Re-Assess: You've acknowledged your current situation and have begun thinking about how to answer specific questions and overcome challenges. You have also identified key members of your team that can help you on this journey. Let's get going! This section will help you figure out how each member of your team can help you take charge of your health.



Problem Solving with Social Support

Support: Problem solving can feel overwhelming at times. Sometimes it can be hard to decide which question to tackle first, especially when one question seems to lead to more questions. But you are not answering these questions all by yourself. One person can't know everything about everything!

You have your social support team with you. Your team can help you answer these questions. They are ready to help you navigate your biggest challenges; they may offer a different perspective that can lead to an even better answer than if you tried to do this by yourself.

Bruce, age 55: "I met a few other patients at the clinic I go to for dialysis and we decided we would get together once a month for lunch. We talk about everything. We talk about our friends, our kids and grandkids, everyday problems, and our kidney health. We talk about how we are managing our kidney disease and, together as a group, we brainstorm about facing any hurdles one of us might be facing."

Every action begins with a thought.
Positive thoughts encourage positive actions,
and positive actions manifest positive outcomes.

ACTIVITY, PART A:

Get your team involved! In the previous activity, you listed 4-6 questions or challenges you are facing, right now. How can your team help come up with answers or solutions? Think about each of your team members... what task or question can each team member help you with? When and where can you talk to them about it?

FRIENDS <hr/> <hr/> <hr/>	FAMILY <hr/> <hr/> <hr/>
HEALTH CARE <hr/> <hr/> <hr/>	COMMUNITY <hr/> <hr/> <hr/>

ACTIVITY, PART B:

For each question or challenge you have listed above, now list one or two specific actions that you and your team can work on together. This can include medical actions, social actions, behavior changes, and work/community actions. It would be useful to identify people that can help you in each of these actions.

FRIENDS <hr/> <hr/> <hr/>	FAMILY <hr/> <hr/> <hr/>
HEALTH CARE <hr/> <hr/> <hr/>	COMMUNITY <hr/> <hr/> <hr/>

RE-PROGRAM

Re-Program: Revise your thinking and approach to your kidney health. You are on this journey, but **you are not alone.** You have a strong team of people united to help you thrive!

Cognitive Restructuring

This is a mental strategy which means to re-program how you tackle a problem. It can help people cope with stressful situations by changing their outlook of a situation and find the positive aspects. For example, you can use your diagnosis of kidney disease to become more mindful about your overall health and life.

Life is full of changes and challenges. It doesn't help you mentally, emotionally or socially to dwell on the negative. Instead, focus on what you can do that will positively impact you, your health and your life. You may also find it helpful to accept the 'new normal' while creating new hobbies and moving forward with a productive life.

Life is not always pretty, but it can be a beautiful mess.

Cognitive Restructuring is easier with Social Support and when you Express your Emotions

Throughout this journey, don't forget to lean on the people who are there to support you. Tell them how you are feeling. It is important to rely on your health care team and other individuals close to you to acknowledge your feelings and help you move beyond them.

Jordan, age 18: "I was mad. I was really mad when I heard about my diagnosis. I thought it was so unfair, I'm too young and I wasn't nice to many people in my life. But my health care team was always kind to me. They would welcome me with a smile and say, 'You know, Jordan, we are going to get through this.' They never gave up. They helped me figure out what was important to me and how I can manage my kidney disease to be sure I reach my goals and not let it define my future. Through them not giving up on me, I made the decision to not give up on me."

TALKING POINTS FOR YOUR TEAM

FRIENDS

Talk with your friends about some of the challenges you are facing and the lifestyle changes you are making to thrive, manage your kidney disease, and maintain your quality of life. Ask them to help plan activities that fit into your new lifestyle so you can still enjoy spending time together.

FAMILY

Talk with your family members about what you can collectively do as a family unit to support you in successfully managing your kidney disease. Discuss if they may be at risk for kidney disease too; early screening is important for possibly stalling or slowing the progression of kidney disease.

HEALTH CARE

Talk with your health care team about what your priorities in life are for the next 3-months, what about the next 12-months? What about the next 12-months? Work with the health care staff to ensure you remain healthy so you can achieve your goals!

COMMUNITY

Consider seeking out people with kidney disease or other chronic illnesses in your network or join trusted groups on social media. They could help you manage your condition and may even become new friends.

ACTIVITY: (PART A)

Words of Affirmation! Changing what you say and how you say it can go a long way in helping you re-program how you approach your kidney disease. Below are a few different types of affirmative statements to help you proclaim your positive approach to managing your kidney disease.

Fill in the blanks:

Example: I am not alone

1. I am _____
2. I am _____
3. I am _____
4. I am _____
5. I am _____

Example: I can share my journey with others

1. I can _____
2. I can _____
3. I can _____
4. I can _____
5. I can _____

Example: I will work closely with my pharmacist to make sure my medication routine stays up to date

1. I will _____
2. I will _____
3. I will _____
4. I will _____
5. I will _____

ACTIVITY: (PART B)

Brainstorm ways you can remain involved in your typical social, family, and community activities that also allow you to prioritize your health.

FINAL ACTIVITY

**Now what? What are your next steps? What are your short-term goals?
What do you want to complete or accomplish in the next 3 months?**

GOALS:

1. _____

2. _____

3. _____

HOW CAN YOUR TEAM MEMBERS HELP YOU WITH THESE GOALS?

FRIENDS

FAMILY

HEALTH CARE

COMMUNITY

CONCLUSION

Remember, you are not alone. One in seven U.S. adults has some form of chronic kidney disease, so chances are, you may already know one or more people in a very similar situation. Also, kidney disease can progress at varying rates over time; just because you are diagnosed with reduced kidney function doesn't necessarily mean your kidneys will fail and you will require dialysis or a kidney transplant. Talk to your healthcare team and learn all you can on what you can do to delay or slow the progression. If you do progress to complete kidney failure, be prepared. Start having a discussion with your support team about what treatment is best for you to make sure you can continue to live your life and thrive in it. You will experience many different emotions on your journey through kidney disease; that is completely normal. It's ok to be angry, but don't live in that space. Use the tools outlined throughout this booklet to help you implement a game plan. Rise above kidney disease. Kidney disease will not define you or what you hope to achieve in your life. You will.

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