

Living with Kidney Disease

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(Adapted from a chapter in a program called PEAK [People Educated and Aware about Kidney Disease] given at Beth Israel-Deaconess Hospital in 2001. The chapter is intended for new or prospective patients. Other chapters will appear in future RenalGrams.)

Is this chapter for you?

If you have found yourself faced with any of the following thoughts or feelings, then this chapter is for you

- o Maybe this is just a dream and I'll wake up.
- o Why me?
- o I don't feel that bad. There's no problem with my kidneys.
- o What is my life going to be like?
- o Am I going to be at the mercy of my circumstances?
- o How will my family and friends react?
- o Can I live with this disease?
- o What do I do now?

There is no single formula for coping with the significant changes associated with your kidney disease. Taking stock of your own strengths and resources and mobilizing them at this stressful time is the beginning of a process that is ongoing.

No one knows you better than yourself, and it is self-understanding that will provide you the basis for the choices and challenges ahead.

Fear and worry

You are reading this chapter because your doctor has told you that there are warning signs that your kidneys are not working as they should. It is natural to feel

a range of emotions about this news.

Fear, shock, anger, sadness and despair can hit hard when you learn of a problem with your kidneys. You may find that you don't feel like yourself because of the change in your mood. It is important to pay attention to your moods and seek out ways to cope that work for you.

Sometimes people will try to protect themselves from the pain of realizing that there is a problem. It is human to try to create a distance between oneself and the reality of a new health problem. Signs can include:

- o Putting off or not showing up for a medical appointment
- o Justifying symptoms experienced as something else
- o Minimizing symptoms
- o Feeling like a stranger in your own body
- o Disbelief of lab results and what they show
- o Displacing fears and other feelings onto people around us

Even if this news is something you can believe, the process of accepting the change in your life is not immediate or easy.

You may feel overwhelmed and preoccupied with thoughts about the future and the unknown ways the change in your kidneys may affect your life. It is essential to allow yourself whatever feelings come up. This is something new and you are facing uncertainty.

While these reactions are natural, if they stay with you and interfere with your life, they can immobilize you. Your own personal strengths, the support of others and the living proof that thousands of people who have kidney disease are leading full lives right now are the path to your coming to terms with this change in your life. Taking part in this program is the first step on the path.

Keeping what is important in my life

Priorities, goals, loved ones and enjoyed activities give meaning to our lives. Kidney disease cannot change that. The greatest assurance that kidney disease does not become a controlling force in life is attitude. Everyone copes differently with stressful situations.

Give some thought right now to the things most important in your life.

Active coping is taking a look at how you adapt to uncertainty. You already possess the skills you have learned over the course of your life. Those qualities can work now to influence how you face this change in your life. For those already living with kidney disease there are many internal resources that help meet the challenge each day:

curiosity love

humor determination

spirituality hope

Even traits that might at first seem to be a disadvantage may turn out to be your greatest strengths. The energy you have in these qualities can transform into productive ways to manage your life.

stubbornness anger

frankness

Reminding yourself what is vital in your life and sharing it with people close to you can be a reassuring way to take stock. Let the people involved in your health care know what these things are and you can enlist them to support what is important to YOU.

Living a full life

You may find yourself thinking about your own survival. Since the kidneys perform a life-sustaining function, it makes sense that you are more aware of your existence.

However, kidney disease is treatable and people are living and finding ways to thrive. From the dietary shifts, exercise and medications that may help delay the need for dialysis or transplant, to those people who learn about and adapt to some type of treatment, the adjustment is possible.

There are compromises you will need to make but *caring for your body is a means to living* and not a replacement for it. You may not be used to focusing on yourself to keep your health a top priority. Even though your kidneys are not working as they used to, there are things you can do to minimize the impact it has on your life.

An unexpected discovery for many people with kidney disease is the perspective they gain on what is most important in life.

Staying independent

Even while your lifestyle may change you will have the same needs you always have—including:

- feeling useful

- affection

- social contact

People with kidney disease learn to navigate between how the mind and body respond to changes in the kidneys and the realities of life. Flexibility and communication make this easier.

Learning about kidney disease and its effects can help you adapt and also put others around you at ease. **Sharing what you learn** about kidney disease can relieve stress about the unknown. If you know your own situation then you can determine the ways you want to respond.

For instance, roles within a family can shift to recognize times when you may not feel able to do certain tasks at home. There can be physically strenuous work that another family member can help with while you take on some other household duty.

You may want to **talk to others who have kidney disease**. Ask your doctor or

social worker to help connect you. Look into organizations that can provide support such as the National Kidney Foundation, the American Association of Kidney Patients and the Kidney Transplant/Dialysis Association. Reach out to the people here with you today. It is possible you share similar concerns.

If you **take the lead** to learn what you can, it will be easier to balance the uncertainties with the things you can control.

How people live with this disease

People with kidney disease are invested in their health and also focus on other things that matter...



You have your own interests and priorities and there will be people to help you with practical solutions to maintain them and give emotional support along the way. Your natural supports such as family and friends and your healthcare team both play vital roles.

What I can endure

You know where you have already been in life and what has helped you cope in the past. Turn to these strengths and the people and resources around you.

Some ideas to keep in mind as you take the next steps:

- o Trust your instincts
- o Listen to your body and your feelings
- o Allow yourself to be imperfect
- o Ask for help
- o Keep what is important in your life
- o Express what you feel
- o Learn what you can
- o Remember who you are
- o Question your healthcare team and use them
- o Communicate

This is a journey and although you probably feel like an unwilling traveler, with time you can make the trip your own. It may be very different from what you imagined your life to be at this stage but there is value in your experience.

You are the only person who can keep meaning in your life. As you focus more on your kidneys and what you can do physically to mediate the impact of kidney failure do not forget to take care of yourself emotionally.