

# **Emotional Issues Faced by CKD Patients**

## **By Mark Meier, MSW, LICSW**

As part of the human experience, we are all exposed to the challenges and rewards associated with having feelings. The emotions we experience throughout the course of any given day might range from good, to neutral, to downright miserable. As unwelcome as they may be, our feelings have the ability to unexpectedly enter our lives and catch us off-guard or unprepared for their impact. As a dialysis, transplant or chronic kidney disease (CKD) patient, it is likely you are experiencing a wide range of emotions related to your disease. Persons coping with kidney disease commonly cite feelings, such as anger, fear, depression, anxiety, confusion, frustration and helplessness.

Additionally, many individuals with chronic illnesses, such as CKD, choose to deny the impact of the disease on their lives and, in turn, make decisions based on this denial that only serves to harm them more, both physically and emotionally.

Despite these sometimes unsettling characteristics of our emotions described previously, it is important to remember that each of us has the ability to learn new coping skills and develop relationships with individuals who can provide support. Furthermore, if you take a moment and look around, you will discover many people living with CKD who are leading productive and fulfilling lives. As we move through this article, we will look at common feelings and thoughts raised by CKD patients and look at new ways of coping with these feelings.

### **Denial**

It is not uncommon or necessarily unhealthy to initially deny the challenges of a major illness, such as CKD. In fact, when you were informed of your illness, denial might have protected you from being so overwhelmed that you were unable to hear any information about your illness. Denial, in its healthy form, allows you to take in and process difficult news at a pace that is comfortable and manageable for you. Denial, in its unhealthy form, becomes problematic when you continue to refuse to recognize your illness, which might require you to modify certain aspects of your life, such as your work schedule, diet, family life, etc.

A patient on dialysis recently shared his story, which highlights how denial can work in your favor. Dan was told about six months prior to starting dialysis that his kidneys were beginning to fail. Dan recalled, "I was sitting in the doctor's office hearing words like uremia, dialysis, kidney transplant and vascular access. It

was as though I was being spoken to in a foreign language. It was not until I got home and let several weeks pass before I really started to understand what this news meant to me. In fact, for the first few months, I could not even think about visiting a dialysis clinic or allowing someone to do surgery on my arm for this thing call a fistula. But slowly, as time passed and I learned more about the disease, I started to visit clinics where I might go for dialysis, and I even had a fistula placed.”

Had Dan not taken the time to accept his CKD and continued to deny the inevitable, he may not have been able to pick a dialysis center or have a fistula placed until he found himself in an emergency room with little time or choice about where and how he would receive dialysis.

### **Anger**

Anger is one of those emotions that all of us experience from time to time. Like any emotion we experience, anger has an appropriate role to play in our emotional well-being. In addition, like denial, anger has positive and negative ways of being handled. For example, we might be angry about the unintended outcome of a project, at a clerk who treated us poorly in a store or perhaps at a neighbor for returning one of our possessions in poor shape. What these scenarios all have in common is that they have a readily identifiable source and they present an opportunity to resolve the anger. You could contact the neighbor and voice your concern about the damaged property, you could speak with a manager in the store about the clerk’s behavior or you could retry whatever aspect of the work project you were angry about.

The anger frequently discussed by people with kidney disease is different from this. This is not to say a CKD patient will not have days when they are angry with a neighbor, physician or clinic staff. Rather, the anger often talked about by CKD patients and others with chronic illness is more of a constant feeling of being angry, and this anger does not have a specific person or reason to go along with it. It is the feeling of being mad at the world or anyone who crosses your path that day. This anger is frequently associated with questioning “why me?” or “what did I do to deserve this?”

Ronnie described this anger very well. “When I first started dialysis, I knew I was being a nasty person. It did not make sense to me, but I was so mad at my family members who were up and about, who were laughing and joking and doing anything they wanted. I was nasty to the staff at the clinic, the bus driver and even my doctor. It took me awhile to realize it, but I was not mad at these people,

I was mad at the disease and what it was doing to me.” This description is not uncommon and certainly not unhealthy. It is very normal to experience this pervasive anger when you have been told that you have a disease that is going to change your life. When this anger can become unhealthy, is when you damage the relationships you have with others because of how you treat them or because of your anger, you alienate people who are there to support you and provide you with information that can help you cope with your illness.

A positive reaction to the anger you are experiencing about your CKD can be to funnel that anger into action against kidney disease. Many patients who are active in their dialysis clinics, patient organizations, participate in programs to mentor new patients or become involved in forming and leading support groups report a decrease in their angry feelings. By getting involved in this manner, you allow yourself to identify what it is you are angry at and it allows you to do something about your angry feelings.

### **Depression**

Depression is a very real and serious health issue receiving increased attention in the medical community and gaining greater awareness, understanding and acceptance in the general population. According to the National Alliance for the Mentally Ill (NAMI), major depression affects at least 9.9 million adults, about 5 percent of the United States population, in a given year. Additionally, there is a growing body of evidence, which suggests depression affects individuals with CKD at a higher rate than the general population. Some studies have shown rates of depression in the dialysis patients to be as high as 25-35%.

Like denial and anger, feeling sad is a normal part of life. Regardless of whether or not you have a chronic illness, there will be days you feel down about the death of a loved one, the loss of a job or some other life issue. As an individual living with CKD, you face additional burdens that may cause you to feel overwhelmed, such as having to go to dialysis on a day you do not feel up to it, wondering about when you might receive a transplant or facing the possible loss of a transplant.

But “clinical” depression is different than feeling sad, down, or overwhelmed. Similar to denial and anger, depression, if left unchecked or unattended to, can cause great difficulties. You should be aware of your depression when it starts to take over your day, does not pass in a few days and begins to affect your ability to sleep, eat or enjoy what were once pleasurable activities. You should also take notice if you begin to feel guilt about things that generally would not make you

feel guilty, begin to experience feelings of worthlessness or experience thoughts about suicide. These symptoms might indicate your depression is more severe than just having the “blues” or a bad day and warrants a discussion with your family, friends or healthcare team.

Denial, anger and depression are just a few emotional issues faced by CKD patients. Other feelings are happiness, satisfaction, hope, joy as well as countless other positive emotions. As you learn to live and cope with kidney disease, remember you do not have to go through the difficult times alone. Be willing to seek the support of your friends, family and healthcare team or patient organizations such as AAKP. Be open to the idea that difficult emotions are a normal part of life and cannot be avoided. These emotions can provide an opportunity to learn new ways of coping and help you grow as a person.

### **About the Author**

*Mark Meier is the Founder and Executive Director of Face It, a Minneapolis nonprofit focused on the needs of men dealing with depression. Mark is on staff in the University of Minnesota's Department of Family Medicine and Community Health and previously taught on Mood Disorders for a number of years in the Graduate School of Social Work at the University of Minnesota.*