



Turning Scary Emotions Into Hope for a Wonderful Life

by Lori Hartwell



Many people with chronic kidney disease (CKD) ride an emotional roller coaster. When we are first diagnosed with a chronic illness, our emotions flare up as we try to answer questions that are often unanswerable, such as “Why me?”

Our emotions typically are triggered because of a fear of the unknown and how living with CKD will affect our lives and those that we love. People often become extremely emotional during times of emotional stress, and we can be happy one minute and tearful the next. If this sounds like you, the first thing to realize is that you are not alone! Research has shown that most people go through many emotional stages when they are first diagnosed with an illness. In my case, I have had CKD since I was a small child, and my lifelong journey has been heralded by many changes in both the status of my disease as well as how I deal with it emotionally.

I have always believed that a disease is too demanding if you don't have hope, and that hope is a key to living a happy, long, and productive life with CKD. Hope is seen in the everyday examples provided by the hundreds of thousands of individuals who live a wonderful life despite having a chronic illness such as CKD. These people (I count myself among their ranks) are not defined by their disease—they define themselves and live full and wonderful lives.

That being said, emotions are common when living with a chronic

disease—and emotional upheavals should be recognized and treated like any other comorbidity. Emotional pain is often more difficult to deal with than physical pain. Since physical pain is easy to recognize, we are more likely to bring it to the attention of our healthcare team. Emotional pain, on the other hand, is often difficult for us to self-recognize, and may be more difficult to deal with.

One of the most powerful emotions humans experience is fear.

“Although I always strive to be eternally hopeful, I experience the same emotions as everyone else”.



Fear is an emotional reaction to danger. Fear triggers a basic survival mechanism that is often referred to as the fright, fight, or flight response. This response is thought to be a natural protection against physical dangers. When we are fearful, our thinking can become distorted and we see everything as a possible danger. We are stuck in survival mode, and do not think rationally—it is often difficult or impossible to make clear choices and recognize the consequences of those choices.

In modern society, a prolonged “fright, fight, or flight” response can be triggered by the stress of everyday living and ongoing emotional strife. When you learn your kidneys are failing and you will need dialysis or a transplant to survive, a million

potentially fearful images and thoughts pop up in your mind. Will I live? Will it hurt? Will I lose who I am? Will I be a burden? Will I have the will to survive?

The key to dealing with these emotions is to recognize that you are still in control of your own life, and that the hope of living a full and wonderful life is exemplified by thousands of role models. The signs of hope are all around us—you just need to recognize them when you see them (several examples are listed in the accompanying table).

While hope is very powerful, it is also vital that we all recognize that we may need some additional medical help to deal with our emotions. Depression, for example, is a commonly recognized

clinical condition in individuals with chronic illnesses. The table on page 3 lists some of the potential symptoms of depression, and it is important that you (and your loved ones) know about these symptoms. Decision-making is altered if you are depressed, and it is important that you do not make potentially life-changing decisions unless you are emotionally sound. The good news is that depression can (and should) be treated! Although many of us try to deal with our emotions on our own, it is important that you immediately notify your healthcare team if you are experiencing any symptoms of depression.

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weKAN Live & Give is a publication of the Renal Support Network, a patient-run nonprofit organization whose mission is to identify and meet the non-medical needs of those affected by chronic kidney disease.

weKAN Patient Activists serve to mobilize, educate, motivate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another. Together we can make a difference.

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have lived with my kidney transplant for almost 20 years, and am well aware of the accompanying emotional rollercoaster. However, for the past couple of years my kidney has been pattering along, and my medical team has told me that it may not last much longer. I have had to start thinking about my options. At first—even with all of my experience—I was in denial and did not want to recognize how my labs slowly started changing and the additional medications I needed to control my blood pressure, anemia, and PTH levels. It is like the game I played as a young girl—if you are under the covers, the monster can't see you and if he can't see you he can't get you.

But then I sat back and started to think about my wonderful lifelong journey. Sure I have CKD, but it has not defined me. I have lived a wonderful life on dialysis before, and I know I can do it again. I have had thousands of mentors, and continue to be amazed and proud of the examples being set by others with CKD.

And so, although I may soon be reinitiating dialysis, I have a great hope for the future. I have started the planning process to ensure that I am ready for dialysis, and reached out to others who provide a shining example of how to dialyze to live—not live to dialyze.

I encourage all of you to look for mentors who can help you in your emotional journey, while simultaneously mentoring those that can benefit from your experience. That is why I created the Renal Support Network and why the organization will continue to prosper—we all need to connect with others who understand what we are going through as we progress through the different stages of our journey. The inspiring examples of our peers with CKD have proven to me that if you turn on the lights and talk about the monster, he often disappears or isn't as big and bad as you may have thought!

Chronically Yours,

Lori Hartwell

*President & Founder
of the Renal Support Network*

Signs and Symptoms of Hope and Depression

HOPE	Depression (www.mayoclinic.com)
Looking forward to a new day	Loss of interest in normal daily activities
Feeling joyful	Feeling sad or down
Feeling positive	Feeling hopeless
Finding it easy to smile and laugh	Crying spells for no apparent reason
Sleeping through the night	Problems Sleeping
Being able to finish projects	Trouble focusing or concentrating
Feeling comfortable with one's decisions	Difficulty making decisions
Having a healthy appetite	Unintentional weight gain or loss
Being accepting and patient	Irritability
Being able to remain calm	Restlessness
Feeling content	Being easily annoyed
Feeling energetic, ready to go	Feeling fatigued or weak
Feeling appreciated	Feeling worthless
Having a healthy interest in sex	Loss of interest in sex
Excited about being alive	Thoughts of suicide or suicidal behavior

Fear less, hope more; whine less, breathe more; talk less, say more; hate less, love more; and all good things are yours.

~Swedish Proverb