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Coming to Terms with a Chronic Illness

Overcoming the Changes of Kidney Failure and Dialysis

From the moment individuals become aware they are beginning to lose kidney function, life changes—both suddenly and forever. Schedules that may have been relatively free of day-to-day healthcare concerns must soon be adapted to include a changing diet, new medications, multiple medical appointments, and eventually a complex regimen of life-saving dialysis treatments. The impact of these changes may, at times, seem overwhelming.

Yet, despite the many challenges it brings, kidney disease does *not* mean imminent death. And it doesn't have to mean reduced quality of life. In fact, many successful long-term patients have shown that, with the right resources and mindset, it is possible to live long and live well with kidney disease.

SETTING THE STAGE

Make no mistake about it: adjusting to life with kidney disease is not easy, and it doesn't happen overnight. Participants in a 1999 Life Options Patient Opinion study¹ related that just "staying alive" with kidney failure requires a great deal of time and effort. Going beyond mere existence and learning to live

well—physically, mentally, and emotionally—requires an even bigger personal investment. To enjoy a long and full life, people with kidney disease must not only receive good clinical care, they must also commit to rehabilitation.

Rehabilitation has been described in a variety of ways. For people with end-stage renal disease (ESRD), it often means a return as much as possible to the life they experienced before dialysis. Such a return is a constant and evolving process—one that must begin with a change in the way we traditionally think about medical care.

TAKING A NEW APPROACH

Throughout our lives, we are taught to cope with illness by entrusting all aspects of our treatment to doctors or other care providers. In essence, we learn to put life on hold for the sake of recovery. With an acute, short-term illness, this approach is both necessary and appropriate.

However, for people with a chronic disease such as kidney failure, the case is different. Because there is no cure, complete recovery is not a realistic goal, but rehabilitation can be. To

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Focus on Coming to Terms

When kidney failure strikes, a patient's life changes—and it will never be the same again. While this statement may seem harsh and frightening, it also includes hope.

That's because, as Life Options often emphasizes, dialysis and transplantation allow people with kidney failure to go on living, in spite of their condition. And, when people with kidney failure become active self-managers—when they do what is necessary to take control of their illness—they can learn to adjust to the changes they encounter, and they can come to enjoy satisfying, full, and productive lives.

The last issue of the *Renal Rehabilitation Report* discussed the transformation that occurs as people with kidney failure work to cope with their condition and its treatment. This issue of the *RRR* focuses on one major part of this transformation—coming to terms with the permanent life changes caused by kidney failure.

Even with the many challenges they face, people with kidney failure *can* live long and well. Helping them turn that possibility into a reality is what Life Options is all about. For more information about self-management or renal rehabilitation, contact the Life Options Rehabilitation Resource Center (RRC) at (800) 468-7777. ♦

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Living Life to the Fullest

Dialysis Patient Travels the Road to Rehabilitation



At age 55, George Harper hasn't gone a day in his life without facing the realities of chronic illness.

"I am the sole survivor in a family with an undetermined, hereditary kidney disease," he explains. "Both my brothers died of kidney failure before I turned 15—and before dialysis and transplantation were widely available to treat it."

While Harper himself didn't begin to experience symptoms of kidney disease until a year before he began dialysis at age 34, he lived with the belief that his own fate had already been sealed. Not surprisingly, when dialysis was offered as a treatment for his condition, it was an option he readily embraced.

"For many people, the news that they will need dialysis is shocking—it comes suddenly and disrupts their entire lives," says Harper. "I grew up expecting to die, like my brothers. So, when I learned I could live a long time on dialysis, it was as if I had escaped my sentence of certain death from kidney disease."

PLANNING FOR THE FUTURE

While Harper's introduction to dialysis was different from most, the issues he faced as a result of kidney disease were not. For example, like most patients, Harper was uncertain about his future. "I was already married when I began dialysis," he says. "My wife, Irene, understood the potential outcome of my illness. At first, I was hesitant to buy a home, but she helped me understand that, together, we could make it work."

For Harper, there were other difficult decisions to make as well. "We decided not to have children," he says. "I worried about passing on the kidney disease—and about the likelihood that I might die while my kids were still young."

Even now, with more than 20 years of successful dialysis, Harper is often reminded of how precarious his own situation is. "People you know pass away on a regular basis," he explains. "It's difficult—you have to be strong to be on dialysis."

Harper has chosen to cope with this fact simply by doing the best he can, every day. "Before dialysis, I felt helpless to influence my fate," he recalls. "Since I've

been on dialysis, I've learned that I can do a lot to influence my quality of life and my medical outcomes."

DEALING WITH DIALYSIS

In fact, Harper feels that taking control of his own medical care has been the most important factor in his adjustment to kidney disease. For him, the process began when he chose home hemodialysis—a decision he believes was the springboard to his self-management success.

Harper says home hemodialysis has allowed him to maintain a more independent lifestyle. "From the start, I took full advantage of the freedom and control that home hemodialysis afforded me," he says. "I continued working as a high school counselor, I bought a sailboat, and I organized my reading, eating, phoning friends, and TV so I could make the most of my dialysis time."

This take-charge approach spilled over into his medical care as well. "I focused on getting control of my treatment," he explains. "I read about kidney disease and dialysis, subscribed to several journals, and attended many of the major renal conferences. I wanted to be sure I'd get the best treatment possible."

Harper says some of his best information came through networking with other patients and healthcare professionals. "The core of long-term survivors I met in the AAKP were instrumental in helping me start out in the right direction," he says. "And, by volunteering in the various renal organizations, I was able to meet some of the best and brightest nephrologists in the country. I learned a lot from them as well."

Through all this, Harper has come to understand—and to demand—what he needs in order to feel well. "I prefer a doctor who gives me all the facts and provides me with guidance and counsel, realizing that the ultimate choice is mine," he says. "Ideally, we'll agree on the course of treatment and move forward together."

GETTING ON WITH LIFE

From his choice of treatment to his decision to continue working, Harper has always looked for ways to minimize the impact of dialysis on his life. One of his most innovative strategies has also been one of the most effective. While Harper always understood he needed dialysis to "survive," he felt having the ability to travel would allow him to truly "live." So, he decided to find a way to do both.

After some research, Harper figured out a way to dialyze in his motor home. This made it possible for the Harpers to travel whenever—and wherever—they wanted. They soon found out that even this adventure would be a learning process. “On our first trip, the motor home kept stalling out,” Harper recalls. “We couldn’t go over 45 miles an hour.”

Finally, when smoke began billowing from the engine, the Harpers decided to pull off the road and leave the motor home behind. “We had to hitchhike 90 miles to my in-laws’ house,” Harper says. “Needless to say, the first trip was pretty harrowing.”

Eventually, the Harpers were able to perfect the process of “travel dialysis.” They have since ventured all across the United States and Canada. And, while the ride was a bit bumpy at first, it has led them closer to rehabilitation, allowing them the freedom to maintain a lifestyle they enjoy.

LIVING WITH LIMITATIONS

Harper admits that, even with all the successful adjustments he has made, life on dialysis is not without its constraints. For him, the renal diet is often the biggest challenge. “I used to eat out a lot,” he explains. “As I’ve gotten older, I’ve become even more compliant. I stick to certain restaurants, where I know I can get something without salt.”

The effects of such restrictions can reach far beyond issues of personal preference to affect social roles and activities as well. “The diet can be real restraining,” says Harper. “It can make you stick out like a sore thumb. And having to eat the same things over and over can get monotonous.”

But even this challenge, Harper says, can be overcome. “Some people think they have to have salt on an egg. But you *can* do without it,” he insists. “You will get used to it—and, in time, you’ll actually come to prefer it.”

Harper says the same can be said for adjusting to other aspects of kidney disease and dialysis. “It takes self-discipline,” he says. “You have to tell yourself this is what you want to do. In time, you see the benefits, and you become acclimated to the changes.” That doesn’t mean it’s always easy.

SETBACKS AND SOLUTIONS

Like most long-term dialysis patients, Harper has experienced more than his fair share of medical and personal setbacks, from vascular access problems to infections. One self-management strategy he has used to minimize such setbacks is to insert his own dialysis needles.

Perhaps one of Harper’s biggest challenges came in 1999, when changes within the structure of his dialysis provider threatened his ability to continue dialyzing in his motor home. For Harper, this could have been a devastating blow. “Being able to travel contributed greatly to my rehabilitation,” he explains. “I was determined not to give it up.”

And so he didn’t. Instead, he chose to face this challenge as he had chosen to face nearly every challenge before it—with spirit and determination. He did research, formed his own company, and got a Medicare provider number. “Now I get my own dialysis equipment and supplies,” he says. “And I’m still traveling in the motor home, as I have since 1982.”

Harper’s most recent test came earlier this year, when Dr. Peter Lundin, his long-time dialysis mentor and friend, passed away. “I had a chilly fear during my first dialysis after Peter died,” Harper admits. “Peter had always been there for me, and now he was gone. I wondered ‘can I really do this?’ But I made the decision to go on—to try to follow his example.”

COMING TO TERMS

Harper feels, when it comes to dealing with the effects of kidney disease, it is important for patients to understand they will have good days and bad days—and that’s normal. “Everybody has cycles,” Harper says. “There are times when you wonder if you can go on. But things always come around—things do get better again.”

While Harper knows he himself will likely face more obstacles, he has chosen to maintain an optimistic approach to life with kidney disease. “I don’t spend time worrying about things I can’t control,” he says. “I focus all my energy on how my own actions can help me achieve what I want in life. I feel I am responsible for my own happiness and well-being.”

Harper is living proof that this philosophy can work. “Even with hereditary kidney disease and dialysis,” he says, “I have achieved a happy and productive life.” ♦

George Harper has developed several resources for other patients interested in self-management. To learn how he balances travel and dialysis, see his article at www.globaldialysis.com/georgeharper.asp. To order his video, “Buttonhole Method of Needle Insertion Into AV Fistulas,” which explains one procedure for inserting dialysis needles, write to Dialysis Clinics, Inc., ATTN: Julie Helgerson, 3300 LeMone Industrial Blvd, Columbia, MO 65202. The cost of the video is \$50 for providers and \$15 for patients.

“I focus all my energy on how my own actions can help me achieve what I want in life. I feel I am responsible for my own happiness and well-being.”

—George Harper

*Step-by-step Self-management***The Process of Coming to Terms with Kidney Failure and Dialysis**

...adjusting to the many changes of kidney failure not only requires hard work, it requires information, self-motivation, and support.

We have all heard the advice before: to adjust to life with kidney disease, patients must accept the changes in self and circumstance that result from their condition and its treatment—as some dialysis outsiders might say, patients must “deal with it and move on.”

In theory, that might sound pretty simple. In reality, it is not. Most patients and providers will tell you that adjusting to the many changes of kidney failure not only requires hard work, it requires information, self-motivation, and support. And it begins with coming to terms.

UNDERSTANDING THE BASICS

What exactly does it mean to “come to terms” with a chronic illness such as kidney failure? Perhaps more importantly, how do patients learn to do it?

For people with kidney failure, coming to terms—or acknowledging and accepting permanent change—is the necessary first step in the process of adjusting to life with a chronic condition. Depending on the individual patient, this step can be completed in many different ways.

The changes connected with kidney failure affect patients at a very personal level. Such changes often involve the way patients feel about themselves and the manner in which they view their lives. For that reason, no two patients

will achieve their coming to terms in the same way. Developing a precise model for patients to follow is therefore very difficult. Some general guidelines are outlined in *Tips for Coming to Terms*, on page 7.

A CASE IN POINT

One way to better understand the concept of coming to terms is to examine how various patients have experienced it themselves. Take Howard, who was introduced in the last issue of the *Renal Rehabilitation Report*. Recently diagnosed with kidney failure, Howard was just beginning the process of adjusting to kidney disease. Even with dialysis, he often felt tired and sick, and he could no longer handle the long, physical hours required for his job as a construction supervisor.

In addition to the changes he saw in himself, there were many changes in Howard’s life circumstances as well. For example, he was uncertain about his prospects for the future, and that made him wary of planning ahead. He also had trouble sticking to the renal diet. And, with more than 12 hours of dialysis a week, he had little free time.

Kidney disease and dialysis seemed to control Howard’s life. Sometimes, he felt as if he was barely getting by. He often wondered how he could continue to face the challenges ahead—and whether he would ever enjoy life again.

Q&A**ASK THE EXPERTS: COMING TO TERMS****An Interview with Robert S. Lockridge, Jr., MD**

Dr. Lockridge is a nephrologist at Lynchburg Nephrology, Inc. (LNI), in Lynchburg, Virginia. In addition to offering the full range of traditional dialysis modalities, LNI currently serves 16 nightly home hemodialysis (NHD) patients—the largest number in the United States.

While, as a home treatment, NHD can be viewed as the ultimate in patient self-management, it also serves as a valuable reference point, helping to identify elements of self-management that can apply to all dialysis patients, no matter which treatment option they choose. For more information about NHD, visit the LNI website at www.lyncburgnephrology.com.

Q How would you describe patient “self-management,” as it relates to people on dialysis?

A Self-management is the idea that, for patients to achieve the best medical outcomes and the highest quality of life, they *can* and *should* take charge of their health by becoming actively involved and by making informed decisions about their own medical care and rehabilitation. That

can mean a lot of things, from deciding how long they will dialyze at each session, to choosing how closely they will follow the renal diet, to determining how to maintain employment or other activities they enjoy.

Being involved in this way helps patients to develop a sense of confidence and control, because they know *they* are responsible for being where they are—as well as where they should be—in terms of their healthcare.

Q For people on dialysis, are there any prerequisites to self-management?

A Traditional healthcare says that self-management is reserved for only the most motivated, active, and educated patients. But, I believe that if you make a true effort to offer patients a positive option—like self-management—that proves to be to their advantage and makes them feel better, most patients will embrace it.

Most often, when patients are able to truly understand and to see for themselves how self-management can positively affect their own lives, they *will* self-manage. In my own unit, some patients who have been the most

ACCEPTING CHANGE

One day during dialysis, Howard overheard two patients talking about an Internet support group they had just joined. It sounded interesting, so he decided to ask them about it. As they talked together, it became evident to Howard that both patients were doing quite well—they both had full-time jobs, and one of them had been on dialysis for over 15 years.

For Howard, the conversation marked a turning point. For the first time, he realized he wasn't alone—and that he could learn from people who had dealt with the same issues he was now facing. In the past, Howard had been given a lot of information about living with ESRD, but it had always seemed so abstract. For him, seeing living proof that such an adjustment was possible made a real difference.

MOVING FORWARD

While Howard's life had changed a lot since his diagnosis, he knew he still had much to be thankful for. He had a house and hobbies he could still enjoy. And, since he was able to reduce the heavy labor by sharing time between the office and building site, he was able to continue at a job he loved. Aside from all that, Howard realized that, for him, being a husband and a father was reason enough to have hope for the future. Accepting the changes in himself and his life allowed him to begin to move forward by focusing on the long-term.

Howard began to think about what *he* could do to help himself feel well. He decided to start by making a list of questions for his dialysis team. He wanted to ask his doctor about evening dialysis and other options that might help him more easily manage his busy schedule. He also wanted to ask the unit dietitian about ways he could safely modify the renal diet. Finally, Howard was tired of feeling dependent on other people, so he decided he would ask his nurse what he could do to begin tending to his own healthcare needs.

After a good deal of reading, talking, and learning, Howard came to understand that his lifelong adjustment to kidney disease was just beginning. He also understood that the road ahead would be both challenging *and* rewarding.

LIVING LONG AND WELL

For Howard, and for other people with ESRD, acknowledging and accepting the permanent changes of life with kidney disease is just one part of the overall adjustment process. Coming to terms is the first step toward self-management—a tool that can help patients regain control of their illness and their lives.

To follow Howard's continuing journey to self-management and personal restoration, watch for updates in future issues of the *Renal Rehabilitation Report*. ♦

Coming to terms is the first step toward self-management—a tool that can help patients regain control of their illness and their lives.

nonadherent on in-center hemodialysis have done exceptionally well on nightly home hemodialysis—not only because it makes them feel better, but because it allows them to be more in charge of their care.

Q *What advice would you give to patients about coming to terms with kidney disease and dialysis?*

A When I began as a nephrologist in 1978, we were running hard just to keep people alive—as a patient, you were doing well just to survive. Now, we can look more at issues of wellness and quality of life. As such, I have come to believe there are two approaches to living with dialysis. You can live to dialyze, or you can dialyze to live.

When patients live to dialyze, their whole life becomes based on and around dialysis. They often abandon their usual lifestyle and activities—along with hope for a fulfilling future. The mortality rate is high for people who take this approach. Patients who dialyze to live, on the other hand, have come to accept the changes of their condition. They have found ways to keep doing the things they want to do—they have learned to adapt to change. As a result, their chance for a long and full life is greatly improved.

Q *What differences have you seen in patients who have been able to come to terms and choose self-management?*

A Of course, in the self-management continuum, nightly home hemodialysis represents one extreme—patients are involved in their own treatment as much as is possible. On the other hand, it is unfortunately the case that, with some other treatments, patients can become mere passive recipients of care. However, no matter what the modality, I believe every patient can and should achieve some level of self-management.

As far as the differences between those who do and those who don't self-manage, I think the outcomes speak for themselves. Patients on NHHD have experienced increased blood pressure control, increased hematocrit levels, and decreased hospitalizations. They have also seen great improvements in terms of quality of life.

Patients on NHHD have taken an active role in their care, and they are more in control of their health and their lives. In short, these patients feel better—both physically and emotionally—and that enables them to live better over the long run. ♦

*Coming to Terms with a Chronic Illness***Overcoming the Changes of Kidney Failure and Dialysis** *(continued from page 1)*

...to have the best chance at rehabilitation, people with kidney disease must first decide they want to live. Once they have done this, they must also come to believe they are still valuable and in control.

return to a near normal life, people with a chronic illness must be willing to take responsibility for their own care. This can only happen if they are able to accept the changes caused by their condition as permanent and learn to adjust to a new life, with chronic disease.

ACCEPTING CHANGE

While it is difficult to cope with the changes of any chronic condition, adjusting to kidney failure can be especially challenging. For many patients, life with kidney failure is a constant struggle just to feel well. Normal routines are interrupted, often overtaken, by a complex and invasive treatment program—one that includes balancing an array of medications, juggling the huge time commitment of dialysis itself, and managing the social and role implications of a variety of lifestyle restrictions.

As if that weren't enough, people on dialysis must live with the constant reminder that a machine is keeping them alive—and that any number of life-threatening medical setbacks could turn their chronic condition acute. It is not surprising that, when faced with the prospects of kidney failure, many patients lose their sense of self. But, it doesn't have to be that way.

To reclaim their “self” and return to a life they enjoy, people with kidney failure must undergo a transformation. First, they must accept the fact that they are forever changed. Once they have “come to terms” with this reality, they can begin the process of learning to adjust. In a sense, they can seek a new life balance.

TAKING CHARGE

How can patients complete the transformation, from simply surviving to living well with kidney disease? To start, they can decide to take charge of their own healthcare—and take back their lives. In the most complete sense, a transformed patient is a comprehensive self-manager—someone who plays an active role in treatment while maintaining control over the signs, symptoms, and daily effects of kidney disease.²

While self-management is the ultimate goal, a few steps must precede it. First and foremost, to have the best chance at rehabilitation, people with kidney disease must decide they want to live. Once they have done this, they must also come to believe that, even though they are changed, they are still valuable and in control. As patients make these important

“affirmations,” they can begin work on adjusting to the full variety of life changes they will encounter.

ADJUSTING TO NEW CIRCUMSTANCES

A recent Life Options study³ identified four changed circumstances that people on dialysis commonly face on their way to rehabilitation:

- An uncertain future and the risk of death
- Constraints on such usual activities as eating, drinking, traveling, and exercising
- Dialysis treatment itself
- Repeated setbacks in health

These changed circumstances can affect many areas of life, including regular (and often comforting) habits, long-standing relationships, spiritual beliefs, plans for the future, and overall world views.⁴ For patients and family members alike, the impact of these changes can often be felt on a day-to-day basis. To facilitate the adjustment process, every person on dialysis, every family member and support person, and every healthcare provider must accept that these circumstances are the new normal—and that they can be faced.

**Circumstance #1:
The Fear of an Uncertain Future**

Most often, the first new circumstance patients confront is an uncertain future and the risk of death. The diagnosis of kidney failure often catches patients off guard, with little or no time to gather information. As a result, many new patients believe death is imminent.¹ Those who don't soon become aware of the high morbidity and mortality rates of dialysis patients around them.^{5,6}

Facing this reality is understandably scary. Coming to terms with it is critical. People with kidney failure must understand that, while the risk of death remains, they have great potential for a long and full life. The sooner they are able to acknowledge both the risk and the potential, the sooner they can begin to accept the information and support that will allow them to make the best decisions about their healthcare and rehabilitation.

While the relative instability of kidney disease is an ongoing challenge, many successful long-term patients have coped with this circumstance by becoming motivated to defy it. In addition, several studies have suggested that a patient's awareness of mortality may lead to greater self-awareness and introspection.^{7,8} “It is a conscious decision

and choice to do a lot of difficult things,” explains one patient. “I’m willing to invest hard work into my life so that I can have a higher quality of life.”¹

Circumstance #2: Constraints on Usual Activities

Once people with kidney failure realize they *can* live, they must also determine *how* to live. That’s because, while life on dialysis can indeed be very good, it is often very different from before. For example, kidney failure brings with it a host of constraints—on eating, drinking, travel, sports, and other activities. If adjustment isn’t made, these constraints can rob patients of their usual lifestyle.

How can patients learn to have an enjoyable life within these constraints? The answer is different for every patient. Some may use exercise to burn off sweat and slightly reduce fluid restrictions. Some may choose an evening dialysis shift or peritoneal dialysis so they may continue with their normal work schedule. Others may turn to their dietitian or a dialysis cookbook for creative diet solutions.

The bottom line for all people on dialysis is that they must acknowledge the limitations of kidney failure and find ways to live with them. “As far as family goes, you live within what you can and can’t do,” explains one patient. “You adapt. And that pretty much goes for everything else in life.”¹

Further, when patients feel they have some options—along with the freedom to choose activities they enjoy—their lives can seem more livable, they have less stress, and they can better maintain their sense of self.⁹

Being able to find some good in the illness experience can also help. Patients who see themselves in some way as changed for the better—closer to friends and family, for example—may adjust to constraints of kidney failure and find even more value in themselves.

Circumstance #3: Treatment Itself

For anyone joining the ranks of people on dialysis, the time and energy needed for treatment itself can be a major hurdle. The commitment is often the greatest for people on in-center hemodialysis—the average time required is 4 hours per treatment, 3 days a week, not including travel to and from the dialysis unit.

For these patients, fitting in a few “normal” activities, like employment, is often a big challenge. And, with the

strong emphasis our society places on independence, privacy, and autonomy, many people on dialysis may struggle with feelings of dependence.⁹

However, for optimal health, patients must find a way to adhere to the full treatment time without letting the thought of dialysis dominate their lives. Many long-term patients have been able to do this by viewing dialysis not as a burden, but as the medical miracle that allows them to live long and well.

For some, adjusting to the lifelong need for dialysis may be easier if they can approach each session as an opportunity to work on a project or hobby, to build relationships with fellow patients and healthcare workers, or even to start a regular program of exercise.

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People with kidney failure who see themselves in some way as changed for the better... may adjust to constraints and find even more value in themselves.

Tips to Help Patients Come to Terms

Coming to terms with kidney failure is a very individual process. However, patients can begin to cope by setting some common goals along the way:

Recognize yourself as a changed person.

Accept the fact that a complete definition of your “self” now includes kidney failure. That doesn’t mean you have to leave the other aspects of your “self” behind. You *can* hold on to the values, qualities, and beliefs you hold dear.

Acknowledge your changed circumstances.

Understand that life with kidney failure *will* be different. The changes you will experience are normal, and the challenges you face can be met. Always remember that you *do* have life options.

See the value in your changed self and changed life.

Believe that, while your life will be different, you have the power to make it full and satisfying. By managing their own medical care and rehabilitation, more people with kidney failure are living long and well.

Learn to adjust.

Identify the things that are most important to you and work to hold on to them. Don’t try to “reinvent the wheel”—talk to other patients who have found ways to cope. Ask your healthcare team what options and resources exist. Surround yourself with people who will support your efforts.

Take control of your health and your life.

Become an active self-manager. Learn as much as you can about kidney failure and options for treatment—search the Internet, consult your healthcare team, join a patient organization. Be a full partner in care by making informed decisions about your own treatment and rehabilitation. ♦

Coming to Terms with a Chronic Illness

Overcoming the Changes of Kidney Failure and Dialysis *(continued from page 7)*

Circumstance #4: Repeated Setbacks

Even when patients are transformed—accepting their disease, adjusting to their changed circumstances, and becoming informed self-managers—they will likely face repeated setbacks. Over the long-term, many patients will encounter access problems, bone disease, infections, hyperparathyroidism, cardiac arrhythmias, and one or more failed transplants.¹⁰

For an in-charge self-manager, such setbacks can be very deflating. During these times, it is often necessary for patients to transfer control of their healthcare back to the medical team until they are well enough to self-manage again. The back-and-forth of life, and especially of kidney disease, is a study in patience and determination that must be constantly replayed. Learning to cope with setbacks and discouragement is perhaps the most difficult part of working to restore the self.

HOPE FOR THE FUTURE

For people with kidney failure, each change—whether it be in self or circumstance—represents a challenge. And no experience will be the same. Some patients will struggle more with an uncertain future, some will find dialysis itself the most difficult, and others will have the most trouble adapting to the constraints and setbacks they are sure to encounter.

For these reasons, “coming to terms” with kidney failure is never finished. It is an ongoing process—a constant battle to fight, to stay in control of the illness, and to manage the

emotions of life with a chronic disease. Facing kidney failure with optimism and self-determination is a lot to ask of anyone. The message patients and families need to hear—and one every healthcare provider can help to deliver—is that it is possible to live long and live well with kidney disease.

More and more, long-term patients are showing that life with kidney disease can be longer, fuller, and more satisfying when they are able to come to terms with their changed self and changed circumstances—a step that paves the way not only to active self-management but to rehabilitation as well. ♦

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