

**INSIDE**

THE AFFIRMATIONS PROCESS: TEAMWORK FOSTERS PATIENT ADJUSTMENT AND REHABILITATION.....2

I WANT TO LIVE: SELF-PRESERVATION IS FIRST STEP IN PATIENT ADJUSTMENT.....3

I AM STILL ME: PRESERVING SELF-IDENTITY IS KEY TO OVERCOMING CHANGE ..4

I AM STILL VALUABLE: AFFIRMING SELF-WORTH FOSTERS PATIENT ADJUSTMENT.....5

I AM IN CONTROL: PATIENT SELF-EFFICACY LEADS TO ACTIVE SELF-MANAGEMENT.....6

*Adjusting to Life with Kidney Disease*

## Affirming the “Self” Amidst Challenge and Change

**C**hange. Throughout our lives, it is something to which we must all adapt. Most of us can recall our own anxious transition from dependent youngster to somewhat rebellious teen to mature adult. Even in adulthood, we continue adjusting to change—with marriage, after the birth of a child, or with the death of someone we love. Quite literally, change is life.

Perhaps nowhere is this truth more evident than for people with kidney disease. Not only must kidney patients adapt to the full variety of life events they encounter, they must do so with the added physical and emotional challenges of chronic illness and a complex, ongoing, and invasive treatment program.

Amidst all this change, it's not uncommon—or surprising—for patients to temporarily lose sight of who they are. Some may question: Who am I now? Am I still valuable? Will I ever feel in charge of my life again? Do I even want to live this new life with kidney disease?

For patients, recognizing and confronting these issues is a necessary step to successful adjustment, active self-management, and rehabilitation.

### CONFRONTING CHANGE

The recent Life Options *Long-term Dialysis Survivors Study* and last *Renal Rehabilitation Report* identified several changed circumstances patients must face as they adjust to life to kidney disease:<sup>1</sup>

- An uncertain future, including the risk of death
- Constraints on usual activities
- Dialysis treatment itself
- Repeated setbacks in health

When confronting these changed circumstances, patients' own values, qualities, and beliefs may be put to the test. To make a successful adjustment, patients must find ways to preserve these essential elements of “self”—they must work to hold on to important aspects of who they are and how they lived before kidney disease.

### OVERCOMING CHALLENGE

As humans, we all possess the ability to change—to convert bad circumstances into opportunities and to rebuild our lives around them. Many people with kidney disease have used this

*(continued on page 7)*

## Focus on Affirming the Self

**R**ecent research has proven something people with kidney disease already know: adjusting to life with kidney failure takes time and effort. The same research has also helped clarify the steps patients take in adapting to life on dialysis.

The first of these steps is coming to terms with changed life circumstances, including diet and fluid restrictions, dialysis treatment itself, potential medical and personal setbacks, and fear of an uncertain future. Difficult as these adjustments might be, they are not the only issues that people with kidney disease face.

This issue of the *Renal Rehabilitation Report* focuses on affirming the essential elements of “self” that are often threatened by kidney failure. By making such affirmations, many patients are able to effectively deal with the changes they face and rebuild their lives with confidence, courage, and determination.

Life Options' goal is to ensure that patients are aware of the potential for a long and full life with kidney failure—and to provide the support and information patients need to build such a life. To learn more, please contact the Life Options Rehabilitation Resource Center at (800) 468-7777. ♦

Life Options is supported by  
Amgen Renal Advances

**THE LIFE OPTIONS  
REHABILITATION  
ADVISORY COUNCIL**

Bryan Becker, MD, FACP  
Sally Burrows-Hudson, MSN, RN, CNN  
Mary Beth Callahan, ACSW/LMSW-ACP  
Jerry Fuller, MSW, LCSW  
Carol A. Keller, MPA  
Michael Klag, MD, MPH  
Derrick Latos, MD, FACP  
John Lewy, MD, FAAP  
Jill Lindberg, MD, FACP  
Donna Mapes, DNSc, RN  
Stephanie McIntyre, RD  
Frank Messana  
Anita Molzahn, PhD, RN  
Jo Reeder, PT, MCSP  
Wendy Funk Schrag, LMSW, ACSW  
Nancy Spaeth, RN  
Charlotte Thomas-Hawkins, PhD, RN, CNN

**EMERITUS MEMBERS**

Christopher Blagg, MD  
Kenneth Chen, MS  
Ann Compton, RN, MSN, CNN  
Karen Daniels, MM  
Peter DeOreo, MD  
Nancy Gallagher, BSN, RN, CNN  
Peter Howell, MEd, MPA  
Karren King, MSW, ACSW, LCSW  
Nancy Kutner, PhD  
Bruce Lublin  
Maureen McCarthy, MPH, RD, CS  
Anthony Messana, BSC  
Spero Moutsatsos, MS  
John Newmann, PhD, MPH  
Brian O'Moore  
Patricia Painter, PhD  
George Porter, MD  
Rosa Rivera-Mizzoni, MSW, LCSW  
John Sadler, MD  
Theodore Steinman, MD  
Sharon Stiles, BSN, RN, MS, CNN  
Beth Witten, MSW, ACSW, LSCSW

**NEWSLETTER EDITORS**

Roberta Braun Curtin, PhD, RN  
Nicole Thompson

Readers' comments and ideas are welcome. Contact:

Life Options Rehabilitation Program  
414 D'Onofrio Drive, Suite 200  
Madison, Wisconsin 53719  
TEL: (800) 468-7777  
FAX: (608) 833-8366  
E-mail: [lifeoptions@MEIresearch.org](mailto:lifeoptions@MEIresearch.org)  
[www.lifeoptions.org](http://www.lifeoptions.org)

*The Affirmations Process:*

**Teamwork Fosters Patient Adjustment and Rehabilitation**

**F**or people with kidney disease, rehabilitation is a lifelong process—never completed, often changing, and always challenging. Achieving a long and full life with kidney failure is a very real possibility. Along the way, however, patients must overcome many changes to their life circumstances and many challenges to their sense of “self.”

**AFFIRMING THE SELF**

To begin the journey to active self-management, which is the embodiment of rehabilitation, patients must affirm a “self” that is forever changed by chronic disease. They must choose to embrace life with kidney failure, come to know they are still valuable, and feel that their most essential self is unchanged, despite chronic illness.

By making these affirmations, patients can move from merely staying alive to feeling whole again—and they can commit to gaining control over a disease that will be part of their lives, for as long as they live. (For more information about affirmations, see *Affirming the “Self” Amidst Challenge and Change*, on page 1.)

**POSITIVE OUTCOMES**

Research has just begun to explore the specific role of affirmations of self in the overall process of adjusting to life with kidney disease. Still, the potential significance cannot be ignored.

For example, studies suggest that patients who come to terms with the changes in self and circumstance that accompany chronic illness are likely to become active self-managers of their lives and at least some aspects of their own care.<sup>1,2</sup> In addition, active participation in self-care activities has been shown to improve patients' health status and decrease doctors' visits, hospitalizations, and pain.<sup>2,3</sup>

In the end, it all boils down to this: adjusting to a changed self through affirmations promotes self-management, and patients who self-manage do better overall. That, in itself, is a strong case to support the importance of affirmations.

**A TEAM APPROACH**

While research has begun to shed light on the affirmations process, many questions remain. For example, do

all successful patients experience each affirmation? And, are affirmations accomplished forever, or do they require ongoing effort to maintain?

While the answers to these questions are not yet clear, we must at least assume that the affirmations are perhaps unique to each patient's circumstances and personality. If there is still so much to learn and the process is so individual, what exactly can care providers do to help? Plenty.

In the Life Options perspective, affirmations are best approached in the same way all aspects of rehabilitation should be approached—with patients and care providers acting as partners in care.

The first and foremost responsibility of all care providers is, of course, to ensure each patient receives the best medical care possible. However, beyond that, there are some things providers can do to assist patients in the process of affirming the self.

It is, of course, patients themselves who must adjust to a changed self and changed circumstances. However, patients' confidence and determination can be bolstered by support and teamwork from their providers. For specific strategies on how patients and providers can work to achieve this success in the affirmations process, see pages 3-6.

**A ROLE FOR EVERYONE**

For people with kidney failure, affirming a will to live, to retain unique personal qualities, to recognize their own value, and to regain a sense of control is a necessary part of overall adjustment—one that can and should be supported by every member of the healthcare team. ♦

**REFERENCES**

1. Curtin RB, Mapes D, Petillo M, Oberley E. Long-term dialysis survivors: A transformational experience. *Qual Health Res* [In Press.]
2. Curtin RB, Mapes D. Healthcare management of long-term dialysis survivors. *Nephrol Nurs J* 28(4):385-394, 2001
3. Lorig K, Sobel D, Stewart A, Brown B, Bandura A, Ritter P, Gonzalez V, Laurent D, Holman H. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization. *Med Care* 37(1): 5-14, 1999
4. Lorig K. Chronic disease self-management. *Am Behav Sci* 39(6):676-683, 1996

*I Want to Live:***Self-preservation is First Step in Patient Adjustment**

In the 19 years since she first began dialysis, Patty Stewart has experienced a lifetime of challenge and change. Through it all, the 51-year-old home hemodialysis patient has learned to live by a simple but profound credo: never give up.

Stewart describes her own kidney failure as “a sudden and cataclysmic event.” In 1982, complications from a severe infection damaged her kidneys beyond repair and forced her to begin dialysis. Stewart’s condition was so serious, in fact, she remained hospitalized for 53 weeks.

**LIFE CHANGES**

Dialysis had an immediate effect on Stewart’s life. Because of technology at the time, she, like many patients, simply did not feel well during treatment. “I absolutely dreaded dialysis days,” she recalls. “Being on the machine for 3 hours at a time was just devastating to me. At times, I wished I could jump right out of my own skin.”

Aside from the physical challenges she faced, Stewart worried about finding her place in society after spending more than a year in the hospital. “At the time, I felt damaged,” she explains. “My biggest fear was that I wouldn’t have friends, that I wouldn’t be loved, that nobody would ever want to date me,” she recalls.

Stewart’s struggles continued even after she left the hospital. Still weak and unable to care for herself, she moved in with her mother. “I was physically and emotionally drained,” she recalls. “I needed daily nursing care just to get by.”

**A TURNING POINT**

After several months, Stewart reached a turning point. “I realized I was only 32 years old and I had a lot of life ahead of me,” she says. “I knew I had a decision to make—and I decided I wanted to live.”

Stewart’s nurse manager was instrumental in helping her restore her sense of self, to feel normal again. “She saw a spark in me—a glimmer of the person I was,” Stewart recalls. “She encouraged the young male techs to come and talk to me. She helped me see I wasn’t repulsive to people my own age.”

Stewart believes recognizing the value in herself and her life helped her decide to go on and make the best of life with kidney failure. “Sometimes, you have to get down to the very basics to find the things you’re truly grateful for,” she says. “It might simply be the fact that you can see, that you

can hear, that you can breathe. The important thing is, you have to start by being grateful for *something* in your life.”

**TAKING THE GOOD AND THE BAD**

For Stewart, part of finding value and purpose in life has meant reaching out to others. In her case, it began when she worked to coordinate a cancer volunteer program. “I was working, I was helping others,” she says. “And that made me feel better about myself.”

Stewart has continued to do volunteer work, and she stays active in other ways, including exercise and travel with her husband. “If all you have is dialysis, your life can quickly appear less worth living,” she says. “You need to get out, to see people, to experience fresh air and sunlight.”

Stewart says it’s important to understand that even the most acclimated patients will have bad days. “We’re only human,” she says. “We have to give ourselves permission to ‘take a day off’ once in a while.”

Throughout every facet of her life—her volunteer work, her marriage, her hobbies—Stewart has found ways to maintain her sense of self and to make the most of life with kidney failure. “Even now, I have arthritis, my fingers are gnarled, I use a walker to steady myself—but I don’t feel I’m a different person,” she says. “I might be physically altered, but intellectually and emotionally, I am still me.” ♦

**“I realized I was only 32 years old and that I had a lot of life ahead of me. I knew I had a decision to make, and I decided I wanted to live.”**

**—Patty Stewart**

*I Want to Live:***Tips for Patient Self-preservation**

**T**o begin the process of adapting to chronic disease, patients must first decide their new life is worth living. Here are some tips for self-preservation:

**Recognize the value in yourself and your life.**

Make a list of all the things in your life for which you are grateful. Start small if you have to. Know that your life has value and promise.

**Live outside of dialysis.**

Begin each day by making a plan—to read a book, to call two people you haven’t talked to in a while, or to go to the store and get yourself a treat. Set aside some time to focus only on other important aspects of your life.

**Develop a network of support.**

As much as possible, surround yourself with family, friends, and other patients with whom you can share your feelings. Don’t expect them to fix things, but allow them to understand what you’re going through. ♦

*I Am Still Me:*

## Preserving Self-identity is Key to Overcoming Change

**"Your character, your morals, how you treat other people—those things, not your disease, determine how people react to you."**

**—Marylee Hansen**

**K**idney failure may change the circumstances of your life, but it doesn't have to change you as a person," says 47-year-old Marylee Hansen. And with more than 2 decades as a dialysis patient, Hansen speaks from experience.

### FACING CHANGE

At age 11, Hansen was diagnosed with Lupus—a disease that eventually caused her kidneys to fail when she was 25. Over the years, Hansen has faced many challenges, from adjusting to the restrictive renal diet to adapting her schedule around treatment.

"Kidney failure and dialysis impact everything you do," she explains. "Life becomes so compressed—you just don't have time for everything."

For Hansen, the role change was especially difficult. "As a woman, I was so used to taking care of other people," she says. "Now I was the one who needed help. Suddenly, the entire family schedule revolved around me, my appointments, and learning to live with dialysis. That was hard."

Hansen has also experienced a number of medical setbacks. "My friends consider it a good year if I don't end up in the hospital," she says. "I've had 21 operations, from transplant and gallbladder surgeries to hip replacement. It seems like it's always something."

### A SOLID START

How has Hansen been able to maintain her sense of self in the midst of all these challenges? Among other things, she credits a strong sense of self-awareness.

"I've always had a pretty clear picture of myself," she says. "I know who I am, I know my values, I know how to treat people, and I know how I want to be treated. That's what makes me 'me'—kidney disease or not."

For Hansen, the seeds of self-awareness were planted early on. "My parents always expected me to be able to take care of myself," she says. "That's the way they raised me."

This, she feels, has helped her minimize the effects of kidney disease on her daily life. "I think if you present yourself as disabled or in need of help, that's how you're likely to be treated," she says. "If you don't act helpless or different, people won't treat you differently."

### OVERCOMING CHALLENGE

Over the years, Hansen has used a variety of strategies to redefine her life with chronic illness. "Having kidney disease teaches you to set priorities," she says. "I had children before I began dialysis. For me, my kids have always been number one. I wanted them to have as normal an upbringing as possible."

So, even with dialysis, Hansen finished school, continued working, and stayed physically active. "I think I spent less time decorating and cleaning than I might have otherwise," she says. "I learned to overlook some of the details, because time is so precious."

As such, Hansen feels it's especially important to appreciate her time away from dialysis. "I've really come to enjoy just having an evening to myself—to simply sit down and read the paper or take the time to cook a nice meal."

This simple sense of gratitude has gone a long way in helping Hansen preserve her own self-identity. "I always had faith in the Lord, and that helped me feel secure," she says. "Even when I was really scraping by, I somehow felt blessed."

That philosophy has stayed with Hansen to this day. "I still experience challenge and change," she says. "Kidney failure hasn't stopped trying to run my life, so I haven't stopped trying to make sure it doesn't."

In the end, the results of Hansen's efforts speak for themselves. "I feel lucky," she says. "I've had a really good life on dialysis." ♦

*I Am Still Me:*

## Tips for Affirming Self-identity

In the process of adapting to chronic disease, it's important to find ways to preserve your own unique qualities and traits. Here are some ideas:

### Think positively.

Expect the most from yourself. Try not to become reliant on other people to do things you can realistically do yourself.

### Learn from others.

Talk to other patients who have been successful. Ask them what challenges they have faced. Find out what has worked—and what hasn't worked—in the process of overcoming those challenges.

### Set priorities.

Maximize your time away from dialysis. Decide what activities are most important to you, and write an action plan to keep doing them. ♦

*I Am Still Valuable:***Affirming Self-worth Fosters Patient Adjustment**

I don't think of myself as being sick," says 43-year-old hemodialysis patient Michael Apodaca. "I just have a few more obstacles to overcome than most people do." And overcome them he has.

When Apodaca was just 4 years old, he was diagnosed with a congenital condition that caused his kidneys to fail at age 35. After a failed transplant in 1997, Apodaca began hemodialysis, and he has remained on it ever since.

**CHALLENGES TO SELF**

Like most patients, Apodaca has had to confront many changes related to kidney failure and dialysis. Apodaca says, given his Hispanic heritage, the most difficult challenges were those that threatened his sense of self.

"In our culture, men have to be strong," he explains. "The whole idea of kidney failure and dialysis flies in the face of that belief. That makes adjustment very difficult. When you let part of your heritage go, you're also giving up part of who you are."

How did Apodaca overcome these challenges and find ways to hold on to his sense of self? To start, he credits his parents for instilling in him a strong sense of optimism, self-sufficiency, and self-worth.

"I'm thankful for the way my parents raised me," he says. "They never babied me, they never hid things from me. They just expected me to live like a normal kid."

**FINDING PURPOSE**

Apodaca says this approach has helped him throughout his adulthood as well. "There has never been a day that I've asked 'why me?'" he says. "Instead I ask, 'Why *not* me? How can I adjust to be more comfortable, to make my life more livable?'"

For Apodaca, part of successful adjustment has meant finding value and purpose in life, despite kidney failure. One way he has done this is by reaching out to help others—through volunteer work, in patient support groups, and as the dialysis advocate in his unit.

"I feel it's my duty to help other patients," he explains. "I see so many new patients struggling to adapt. But, once they see they can regain control, they can really begin to live life. That's my satisfaction—that's why I do it."

**GIVING AND RECEIVING**

As much as Apodaca has given, he feels he has gotten even more in return. "For me, the biggest thing has been the tremendous love and support I've received from my wife and my family," he says. "It has not only given me strength, it has given me incentive. After all, part of why we're all here is to make other people happy."

Ultimately, Apodaca feels the responsibility for affirming self-worth falls on his own shoulders. "If I feel bad, that affects other people," he says. "I do what I can to feel good about me, so other people can feel good about me too."

This philosophy has served him well in many ways. "I have a lot of friends, and they know who I am," he explains. "I'm not Michael Apodaca with kidney disease. I'm just plain old Michael Apodaca."

**A VALUABLE SELF**

Apodaca believes, whether it's through surrounding yourself with caring people or by going beyond yourself to help others, that maintaining a sense of self-worth is essential for adjusting to the changes of kidney disease and dialysis.

"You have to be able to wake up each day feeling you are a valuable and viable person," he says. "You have to believe you have something to give." ♦

**"You have to wake up each day feeling you are a valuable and viable person. You have to believe you have something to give."**

**—Michael Apodaca**

*I Am Still Valuable:***Tips for Affirming Self-worth**

**D**espite your changed life circumstances, it's important to recognize your own value, with or without kidney failure. Here are some ideas:

**Take stock.**

Think about those who have cared about you and those whose lives you have touched—your family and friends, even your pets. Know you've made a difference.

**Reach out to others.**

Share yourself and your abilities with others. If you like to cook, bake cookies for a friend. Organize a food drive at your church. Or, just ring your neighbor's doorbell and have a chat.

**Be good to yourself.**

Allow yourself to feel good about your accomplishments—big or small. Give yourself permission to have a bad day now and then, but come to understand what you need to do to get back on your feet again. ♦

*I Am In Control:*

## Patient Self-efficacy Leads to Active Self-management

**"Dialysis is just 15 hours a week. The rest of the time is yours. Don't let the disease beat you—don't let 15 hours a week control your life."**

**—Robert Washington**

**A** wise person once said, "It's not so much the burden you carry—it's the way in which you carry it." And so it is for Robert Washington. At age 46, Washington has lost both his legs and his kidney function to diabetes. But one thing he hasn't lost is his sense of control.

"It's up to me to determine how long I live on dialysis," he says. "My future is in my own hands."

This take-charge approach has not only helped Washington overcome great obstacles, it's helped him maintain many aspects of the life he enjoyed before kidney failure.

### MAINTAINING CONTROL

Washington was 39 years old when he began dialysis in 1994. Even then, he was determined not to let kidney failure rule his life. "Since I already had diabetes, kidney failure wasn't a big shock to me," he says. "If it would have been liver failure, transplant would have been my only hope. Instead, I felt fortunate—I knew I had options."

Understanding these options allowed Washington to continue work and other activities he enjoyed before kidney failure. "When I first started dialysis, my job required me to travel," he explains. "Hemodialysis would have made it very difficult for me to continue working, so I decided to try peritoneal dialysis instead."

Washington remained on peritoneal dialysis for 2 years, until he began experiencing complications from his second amputation. "I wasn't healing," he explains. "I wasn't hungry, and my nutrition was poor—I just wasn't doing well. It was one of the most challenging times in my life."

Despite these challenges, Washington found the strength to regain control—and he did so by looking inside himself. "I guess when you're always just a few days away from not being around, you tend to be more reflective," he explains. "I just came to realize I had a lot of things going for me. I had a good job, a good education, and a wonderful family. I had nieces and nephews I wanted to see grow up."

That's when Washington decided to make a change. "After consulting with my doctors, I decided to switch to hemodialysis," he says. "And that made all the difference. I felt much better on hemodialysis."

### INVOLVED AND IN CONTROL

Sometimes, adjusting to the ongoing, day-to-day effects of kidney failure can be as challenging as dealing with the major medical setbacks it can cause. Like most dialysis patients, for example, Washington has had to work hard to adjust to the restrictive renal diet. "I used to grab a banana and some orange juice on the way to work," he says. "I can't do that now that I'm on dialysis."

Washington has, however, found ways to maintain a sense of control by making careful, informed modifications now and then. "Sometimes, I cheat a bit on the cheese," he admits. "But, while I'm not always totally compliant, I *am* compliant enough not to hurt myself."

Washington finds ways to be in control in the dialysis unit as well. By choice, he dialyzes more than 4 hours each session, and he takes part in a variety of self-care activities. "I weigh myself, clean my graft, take my temperature, write down how much fluid I want to lose, and hold the sticks after my needles are pulled," he says. "I think it's important to do as much for myself as possible."

### INVOLVED AND IN CONTROL

Through all the challenges he has faced as a result of kidney failure and dialysis, Washington has been able to maintain a sense of control. He hopes other patients can find ways to do the same. "Dialysis is just 15 hours a week," he says. "The rest of the time is yours. Don't let the disease beat you—don't let 15 hours a week control your life." ♦

*I Am Still In Control:*

## Tips for Affirming Self-efficacy

**M**aintaining a sense of control over kidney disease and dialysis is a big part of successful adjustment. Here are some ideas for doing so:

### Understand your options.

From the beginning, find out what options are available. Alternative treatments or treatment shifts may help you schedule dialysis around work, school, or family responsibilities.

### Take charge.

Seek information from a variety of sources—your care team, other patients, the Internet. As much as possible, get involved with self-care activities and in decision-making about your own treatment.

### Maintain communication.

Don't be afraid to ask questions. If you feel something isn't working, ask your care team what can be done about it. ♦

*Adjusting to Life with Kidney Disease***Affirming the “Self” Amidst Challenge and Change** *(continued from page 1)*

ability to overcome the challenges of kidney failure and enjoy long and full lives.

For example, each patient in the *Long-term Dialysis Survivors Study* reported facing major life changes, from altered family and social roles to repeated medical setbacks. Some patients chose to deal with these challenges by re-examining and redefining their life goals and then setting new day-to-day priorities. Others looked to loved ones or their faith to help them through the tough times.

In the end, all found ways to adapt to the changes of kidney failure and dialysis—and to affirm their sense of “self” in the process.<sup>1</sup>

**AFFIRMING THE SELF**

The *Long-term Dialysis Survivors Study* identified four affirmations patients must make in adjusting to life with kidney failure and dialysis:<sup>1</sup>

- Self-preservation—I want to live
- Self-identity—I am still me
- Self-worth—I am still valuable
- Self-efficacy—I am in control

Just as every patient is unique, so too are the strategies each patient uses to fulfill these affirmations. Some suggestions as to what these strategies might be are described on pages 3-6.

**Self-preservation: I Want to Live**

We’re all born with the instinct of self-preservation, or survival. While the challenges of chronic disease may test this instinct, successful long-term patients find ways to sustain it.

This fact was demonstrated by participants in the *Long-term Dialysis Survivors Study*, all of whom recall making a conscious choice and effort to stay alive, despite the difficulties they encountered. “I’ve got to do my struggle, my war,” said one patient. “And if I don’t...then I’m giving up life, and I think it is a privilege to be alive.”

When people with kidney failure affirm their desire to live, they also agree to accept a life with all the day-to-day effects of kidney disease and dialysis. This is the first step in restructuring the self within the context of kidney disease.

**Self-identity: I Am Still Me**

Even after patients have come to embrace life with kidney failure, they may at times feel their self-identity is threatened.

For example, they may see themselves—or believe others see them—as defined by their illness. To overcome such challenges, patients must work to separate themselves from their kidney disease. In effect, they must come to believe that, even with kidney disease, “I am still me.”

Explained one patient, “You know...it happened to me... it’s a big part of my life—but it’s not me.” This patient was able to identify the essence of his “self” and to affirm its presence within him, despite his kidney failure.

For patients, affirming self-identity doesn’t mean denying the truth of kidney disease. Instead, it means accepting chronic illness and adapting to the implications it has on their lives.<sup>2,3</sup>

**Self-Worth: I Am Still Valuable**

Sometimes, the experience of illness can cause patients to question their own social and personal worth.<sup>4</sup> This is no different for people with kidney disease.

However, despite the constraints of kidney failure and dialysis, patients can indeed recognize and affirm their own value. Sometimes, this can be achieved through employment, volunteer work, or other fulfilling activities. Said one study participant, “I made the choice that I was too worthwhile to die. I was worth too much. I had too much more to give...”

Affirming self-worth requires patients to carefully examine their own thoughts and feelings about who they are—and to appreciate the value of this “self,” with or without kidney disease.

**Self-Efficacy: I Am in Control**

Studies have shown that a sense of control leads to better quality of life and improved rehabilitation outcomes in patients.<sup>5-7</sup> Yet, it’s no secret that kidney disease and dialysis can threaten patients’ sense of control over day-to-day events and even life itself.

Said one *Long-term Dialysis Survivors* patient, “I don’t even have control over what happens on the machine... that’s scary...”

So, how can patients reclaim a sense of control? To affirm their own self-efficacy and move forward with adjustment, patients must avoid retreating into their illness. They must not only accept the constraints of kidney disease and dialysis,

**Affirming self-worth requires patients to carefully examine their own thoughts and feelings about who they are—and to appreciate the value of this “self,” with or without kidney disease.**

*(continued on page 8)*

*Adjusting to Life with Kidney Disease*  
**Affirming the “Self” Amidst Challenge and Change** *(continued from page 7)*

they must also take positive action toward controlling the aspects of their care and treatment that can be controlled.

“I guess I just...realized that I did have control over my life,” said another *Long-term Dialysis Survivors* patient. “And it’s felt real good...not to feel like I am the subject of the doctor.”

**THE ROAD TO REHABILITATION**

The challenges of living with kidney disease and dialysis never end. However, as many patients have already shown, it is both possible *and* necessary to confront and overcome these challenges. Finding ways to affirm essential elements of “self” is the first step to doing just that.

To adjust to the changes of kidney failure and dialysis, patients must come to realize that life with kidney disease can be worth living, that their self-identity and self-worth can be

preserved, and that some degree of control is possible. Only then can patients move on to active self-management—taking charge of their disease and its consequences, and coming to enjoy long and fulfilling lives. ♦

**REFERENCES**

1. Curtin RB, Mapes D, Petillo M, Oberley E. Long-term dialysis survivors: A transformational experience. *Qual Health Res* [In Press.]
2. Goldman JB, Maclean HM. The significance of identity in the adjustment to diabetes among insulin users. *Diabetes Education* 24(6):741-748, 1998
3. Paterson B, Thorne S, Crawford J, Tarko M. Living with diabetes as a transformational experience. *Qual Health Res* 9(6):786-802, 1999
4. Fife BL, Wright ER. The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav* 41(1):50-67, 2000
5. Fuhrer MK, Rintala DH, Hart KA, et al. Relationship of life satisfaction to impairment, disability and handicap among persons with spinal cord injury living in the community. *Arch Phys Med Rehabil* 73:552-557, 1992
6. Cunningham AJ, Lockwood GA, Cunningham JA. A relationship between perceived self-efficacy and quality of life in cancer patients. *Patient Ed Couns* 17:71-78, 1991
7. Lewis FM. Experienced personal control and quality of life in late-stage cancer patients. *Nurs Res* 31:113-119, 1982



**RENAL REHABILITATION REPORT**

Life Options Rehabilitation Program  
 414 D’Onofrio Drive, Suite 200  
 Madison, Wisconsin 53719  
 (800) 468-7777

NONPROFIT ORG.  
 U.S. POSTAGE  
 PAID  
 MADISON, WI  
 PERMIT NO. 1188

*The Renal Rehabilitation Report is dedicated to identifying effective programs, projects, and people who are helping dialysis patients to live long and live well.*

*RRR is a quarterly publication of the Life Options program, which supports initiatives for renal rehabilitation in the vital areas of Encouragement, Education, Exercise, Employment, and Evaluation.*

Supported by Amgen Renal Advances

