

INSIDE

SELF-MANAGEMENT IN ACTION: LONG-TIME DIALYSIS PATIENT OFFERS UNIQUE PERSPECTIVE ...2

APPROACHING A NEW YEAR WITH CONTINUED RESOLVE: NEW RESEARCH FORMS FOUNDATION FOR LIFE OPTIONS 20016

SELF AND CIRCUMSTANCE: ADJUSTING TO LIFE WITH A CHRONIC DISEASE7

Self-care, Self-management, and Rehabilitation

Laying the Groundwork for ESRD Patient Transformation

From a very young age, children are conditioned to master self-care activities—to brush their teeth, to walk, to verbalize their needs. As children grow and develop, so too does the complexity of the self-care skills they acquire. For each child, the hope is to reach full autonomy so that, in adulthood, they may independently carry out the routines of daily life—from eating well and staying active to going to work and balancing the checkbook.

In the healthy state, self-care is a perfectly natural condition—one that is neither questioned nor debated. Achieving full, independent self-care is the goal for those who are able—and achieving as much independence as possible within personal limits is the goal for *everyone*.

SELF-CARE AND ESRD

This ideal changes, however, with the onset of an illness such as end-stage renal disease (ESRD). After an ESRD diagnosis, many patients find themselves in a state of shock, forced to deal with a new, often unexpected, and dramatic life change. As ESRD and its treatment quickly begin to intrude into all

aspects of daily life, many patients turn their health and their self-care over to medical professionals.

With renal replacement therapy, however, people with ESRD have an opportunity to take back their lives. They can learn to overcome many of the challenges posed by their condition, restore hope for the future, and make the choice to adhere to a treatment regimen that will help to improve their overall quality of life. In short, they can learn to manage life with kidney disease—they can be rehabilitated, i.e., restored to a full and productive life.

Still, despite numerous treatment advances that have been made, a large number of kidney patients never reach full rehabilitation. Why is this the case? There are a variety of reasons, some of which may be linked with the traditional model of healthcare delivery.

THE ACUTE CARE MODEL

For much of medical history, acute disease was the primary challenge of healthcare. The modern healthcare system was, in fact, developed specifically to address acute conditions. Within

(continued on page 4)

Focus on Patient Transformation

Life Options believes that rehabilitation is the key to a full and productive life for kidney patients. Over the years, our understanding of rehabilitation and how to best achieve it has been studied and clarified. It is clear that care providers, family, and friends play a crucial role in teaching, supporting, and providing care. In the end, however, it is patients who must take the necessary steps to rehabilitation.

It is patients who must accept the changes that are part of life with a chronic disease. Patients must become partners in their own care. They must ask questions—find out what they need to know and then learn about

it. They must determine what they must do, as well as what must be done for them. They must maintain hope for the future and belief in their ability to persevere, even in the face of repeated setbacks. This may sound like a lot to ask. And it is. But patients continue to show that it can be done—that the possibility for a long, fulfilling life on dialysis is real and within reach.

This issue of the *Renal Rehabilitation Report* explores the process of transformation that occurs as patients work to cope with chronic disease. For more information, contact the Life Options Rehabilitation Resource Center (RRC) at (800) 468-7777. ♦

Self-management in action

Long-time Dialysis Patient Offers Unique Perspective



As a Performance Improvement Coordinator for the Department of Veterans Affairs, Carol Keller works full time to improve healthcare services for patients. She doesn't take her duties lightly. "Performance improvement isn't just my job—it's my life," says the 40-year-old from Omaha, NE. "I live and work to do better." Keller's commitment to quality care is two-fold, since she is a healthcare professional *and* a healthcare consumer.

In fact, Keller has been a kidney patient for much of her life. When she was just 15 years old, a congenital condition caused her kidneys to fail, and she began hemodialysis. Twenty-five years, two transplants, and a lifetime of experience later, she has skillfully adapted her life around ESRD and its treatment.

In addition to working at a job she loves, Keller also enjoys traveling and staying active through exercise, volunteerism, and social activities. "I am able to do what I want, to have the life I want," she says. "I have not only survived—I have thrived on dialysis."

Doing so, Keller says, required her to assess her own situation within the limits of her disease and treatment, to determine what she wanted her life to be, and then to set goals to achieve that life. Her career path is just one example of this. "I knew that I didn't have every career option available to me," Keller explains. "I needed insurance benefits and leave time, in case I received another transplant. I also sought a career in which people would be understanding of my condition."

Keller feels that making this type of successful adjustment—from what her life may have been without chronic disease to her new life with ESRD—has had a lot to do with her own self-management efforts, from maintaining a positive attitude, to becoming informed and actively involved in all aspects of her treatment.

SELF-MANAGEMENT FROM THE START

For Keller, the roots of self-management were planted early. "From a very young age, I was influenced by the dialysis pioneers—those who began dialysis before Medicare covered the cost of treatments," Keller explains. "They showed me how fortunate I am. Dialysis has

always been a privilege for me, and I have tried to make the most of it."

With this philosophy, along with encouragement from her care team, family, and friends, Keller was able to take an active role in her own treatment and rehabilitation from the start. "My initial team of nephrologists and nurses were very supportive," she says. "They encouraged me to learn as much as I could, to have as normal a life as I could."

For Keller, this meant not only educating herself to make informed decisions about her care, but also attending high school, being involved in volunteer activities, and working part time. "A lot of people slept or watched TV while they dialyzed," she says. "I wanted to do something else with my life by using this time and opportunity wisely."

Keller not only finished high school, she received a full scholarship to college and ultimately earned a master's degree in public administration in health services. "I never stopped living," she says. "I have tried to not let the symptoms interfere."

THE MOVE TO HOME HEMODIALYSIS

This proactive approach to life with ESRD has continued throughout Keller's time on dialysis. For example, when travel and other job duties made it difficult for Keller to maintain a regular, daytime dialysis schedule, she took things into her own hands. "I wanted more control over my own care," she explains. "At the time, the local units had only one evening shift, and none of them offered home hemodialysis. So I decided to find one that did."

The unit Keller found was 2 hours away, in Sioux City, Iowa. "For 3 months, I drove to Sioux City three times a week for home hemodialysis training," she recalls. "I received my dialysis treatments and education at the same time—I learned to set up and monitor the machine, cannulate my access one-handed, and deal with emergencies."

According to Keller, all of the hard work was well worth the effort. At home, with her mother's support and assistance, things have never been better. "Home hemodialysis has been the biggest change in my life," she says. "I can control the environment—I am responsible for the whole treatment. Having that control and flexibility makes a huge difference."

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) 833-8033
FAX: (608) 833-8366
E-mail: lifeoptions@MEIresearch.org
www.lifeoptions.org

Home hemodialysis has also made her work schedule, social life, and treatment easier to manage. “I can dialyze more hours over the weekend, when my schedule isn’t so busy,” she says. “And, I am able to maintain a full-time, responsible job. I have not had to miss work because of my treatment schedule in the 4 years since I began home dialysis.”

In addition, Keller is able to dialyze about 20 hours a week at home, as compared to the 12 hours she would normally receive at a dialysis center. “Because I dialyze so much, I have no prescribed fluid or dietary restrictions, though I do believe in moderation,” she says. “I take very few medications. I am a relatively healthy person.”

PARTNERSHIPS IN CARE

While home hemodialysis can be considered the ultimate form of patient self-management, Keller knows how important it is to keep in close contact with her dialysis team. “Once a month, I meet with my doctor, nurse, dietitian, and social worker to review my medical status and treatment plan,” she says.

According to Keller, this type of teamwork is a necessary part of successful self-management for any patient. She explains, “We need to change the belief that patients must be dependent on healthcare providers and the healthcare system—that patients must adopt the sick role.”

Keller says dialysis staff play a crucial role in making this happen. “Patients need education and information in order to make informed decisions,” she says. “Staff must take the time to ensure that patients truly understand the information they are being given—how it impacts them, and how it relates to their own situation. And, they must be willing to support patients’ efforts to take responsibility for their own care.”

ACTIVE INVOLVEMENT

Keller admits that the most important action is one that must be taken by patients themselves. “You must take the first step,” she says. “You must break the cycle of dependence, and take your own life back.”

Doing so means that patients must take stock of their own situation and decide where they want to go from there. “You need to ask yourself ‘how am I feeling?’” says Keller. “If you are not well enough to perform your daily activities, you need to ask for help.”

The healthcare team is often an important resource. “Don’t be afraid to make an appointment if your dialysis

team members are not available during your treatment time. You need to understand that this is your right—as much as it is your responsibility.”

Keller suggests that patients can make the most of talking with a provider by being prepared. Making a written list of questions and concerns ahead of time is one idea. “I still do that,” she says. “I make sure my doctor doesn’t leave the room until I have made it through my entire list.”

Once informed, patients can take the next step toward full self-management by becoming involved in self-care activities, from simply weighing in at each dialysis session, to taking their own blood pressures. Keller believes the positive effects of such involvement will spill over into other aspects of patients’ treatment and lives. “If you feel better, you will do whatever it takes to continue to feel well,” she says. “That means making sure you get enough dialysis, adhering to your diet, even starting an exercise program.”

In fact, Keller says, feeling better gives patients the chance to fully embrace rehabilitation. “Instead of sleeping or watching TV during dialysis, bring something to do,” she offers. “Start working toward your dream, whatever it may be. Ask yourself what you want your life to be, and then make it happen. It’s up to you. It’s in your hands to make things better.”

OVERCOMING SETBACKS

Keller acknowledges that, while self-management has the potential to transform patients’ lives, it isn’t always an easy process. “You will have some limitations, and you will experience setbacks,” she admits. “But you need to stay focused on what you want to do. And you need to surround yourself with a good support system—people with a positive attitude who can help when you are having a bad day.”

As much as possible, maintaining a sense of control and independence is also important. “For example, I had two infections this fall,” Keller explains. “Instead of going to the hospital, I had my home health agency deliver the IV medication to my home, and I administered my own treatment.”

THE QUALITY OF LIFE CONNECTION

Keller hopes that other patients will make the decision, as she has, to explore the benefits of self-management. “I have an excellent quality of life,” she says. “I have chosen to play the lead role on my healthcare team—the burden of responsibility is on me. I have a life that is of my own creation. I am truly blessed.” ♦

“We need to change the belief that patients must be dependent on healthcare providers and the healthcare system—that patients must adopt the sick role.”

—Carol Keller

*Self-care, Self-management, and Rehabilitation***Laying the Groundwork for ESRD Patient Transformation** *(continued from page 1)*

“Many patients don’t realize they have options—that they can manage their healthcare schedule around their life schedule—that, within themselves, they have the ability to do whatever they want to do.”

—Carol Keller

this system, healthcare providers and healthcare consumers alike viewed patients as passive recipients of care. It was understood that patients could and should do nothing for themselves except to follow directions from their care team and to concentrate on getting well.

Since most acute patients were too ill to make decisions or to act on their own behalf, many turned their complete care over to healthcare providers and the healthcare system. Health management was often just one part of the equation—in many cases, all aspects of patients’ lives, including their jobs, their families, and other role responsibilities were suspended in the interest of complete recovery.

This system did and, in fact, does continue to work well—in acute cases. However, because of healthcare advances overall, people are now living longer, and chronic disease has emerged as a new and very different challenge for the healthcare system. As in the case of ESRD, effectively dealing with chronic disease may require a dramatically different approach.

PATIENT TRANSFORMATION

The defining factor of chronic disease is that it doesn’t go away. As such, suspending life in the interest of recovery, as in the case of acute illness, is not a realistic goal. Rather, for those with a chronic condition, life must go on—with, and in spite of, their disease.

Life Options Rehabilitation Advisory Council member Carol Keller agrees. “I see a lot of patients who lose so much of themselves,” says Keller, herself a long-term dialysis patient. “Many patients don’t realize they have options—that they can manage their healthcare schedule around their life schedule—that, within themselves, they have the ability to do whatever they want to do.”

This is where the concept of “transformation” comes into play. Serious chronic illness catapults patients into a whole new life arena. All of the old familiar roles and ways of behaving and of doing things are challenged, even threatened, by the onset of chronic illness.

The diagnosis of ESRD changes individuals from persons without the ongoing complexities of chronic disease to persons with a permanent and relatively serious illness. To reclaim their lives, patients must undergo an evolution from one way of being to another. The first step is for patients to begin to see and accept themselves somewhat differently than before,

while still recognizing their own continuing value and their ability to effectively manage their care.

Patients must also acknowledge and accept the constraints ESRD places in their lives, in terms of time required for treatment, dietary restrictions, diminished energy, and reduced employment opportunities. The realistic assessment of and ultimate acceptance of life after ESRD—with all of the simultaneous limitations and possibilities—is the first step to taking back life—to being truly restored.

“Don’t ever settle for being less than you can be,” Keller advises other patients. “There are resources available to help you do well.”

THE ROLE OF SELF-MANAGEMENT

When it comes to taking charge of life with chronic disease, self-management is a very effective tool. In many ways, self management represents a new way of thinking—one in which patients acknowledge disease in their lives and then accept the role of partners with the healthcare team for the care that is required. Self-managers learn to take responsibility for as much of their care as possible, from simply being aware of what their care should entail to actually performing some self-care activities.

In general terms, self-management involves patients’ positive efforts to oversee and participate in their own health care to optimize health, prevent complications, control systems, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyles.

There is a good deal of evidence to support the idea of patient self-management. For example, research in chronic disease has shown that poor health outcomes often result when patients become dependent on the healthcare system and act as passive recipients of care.¹ Further, when patients take steps to actively self-manage their disease and its treatment, they are more likely to experience improved health-related quality of life.²

ACTIVE SELF-MANAGEMENT

Through self-management, patients seek to optimize their quality of care and their quality of life.³ Self-managers are strongly motivated to take positive action in their own best interests, to make decisions for themselves, to negotiate with healthcare professionals, and to take responsibility for various aspects of their own care and treatment.⁴

For people on dialysis, this means gaining and applying much of the information they need to carry out a regimen of complex medications, stringent fluid and dietary restrictions, intrusive dialysis sessions, and regular physical activity—all of which may be complicated by a variety of co-existing medical conditions.

Once patients assume full responsibility for the many aspects of their own care, they can begin to manage the effects of disease and treatment on their day-to-day lives. Depending on the individuals' circumstances, abilities, and resources, this can include family roles and responsibilities, social events, and financial and career activities. For specific ideas on incorporating self-management into daily life, see *Self-management Tips for Patients*, at right.

PROGRESS AND PERSEVERANCE

When it comes to self-management, it is important to remember that coping with chronic disease is an ongoing process, and people will be more or less able to self-manage at various points in their illness experience. This is especially true for ESRD patients, since even with proper medical care, they may experience setbacks and complications over the course of their lifetimes.

During acute periods, it is normal for people on dialysis to recognize that they are temporarily “sick” and set aside their usual responsibilities so they can fully concentrate on getting well. As soon as patients are back on their feet, however, they are wise to return to self-management to the greatest degree possible.

Sometimes, in the aftermath of an acute episode, healthcare providers may find it difficult to transfer responsibilities back to patients, even when patients are well enough to take them on. A cooperative relationship must ultimately be reached, in which care responsibilities pass smoothly back and forth between patients and providers as the patients' condition dictates.

“Patients and providers alike must be willing to make a paradigm shift,” explains Keller. “Whenever possible, patients should have control of their lives. With help and support from dialysis staff members, patients should become as informed and as involved in their own healthcare as they can.”

BUILDING ON THE FOUNDATION

Encouraging patient self-management in the healthcare setting will help patients become full partners in care and

become active, comprehensive self-managers of all aspects of their lives. By successfully self-managing the healthcare system and healthcare resources, people on dialysis can maximize the quality of care they receive and the quality of life they experience. And *that* is what rehabilitation is all about. ♦

REFERENCES

1. Singleton JK: Nurses' perspectives of encouraging clients' care-of-self in a short-term rehabilitation unit within a long-term care facility. *Rehab Nurs* 25(1):23-30, 35, 2000
2. Meers C, Singer M, Toffelmire EB, Hopman W, McMurray M, Mortan AR, MacKenzie TA: Self-delivery of hemodialysis care: A therapy in itself. *Am J Kidney Dis* 27(6):844-847, 1996
3. Steel DJ, Blackwell B, Gutmann MC, Jackson TC: The activated patient: Dogma, dream, or desideratum? *Patient Educ Couns* 10(1):3-23, 1987
4. Walsh-Burke K, Marcusen C: Self-advocacy training for cancer survivors. The Cancer Survivor Toolbox. *Cancer Pract* 7(6):297-301, 1999

Stepping Toward Transformation Self-management Tips for Patients

Comprehensive self-management may seem a big, if not daunting task for patients to undertake. However, breaking the process down into various stages, such as those outlined below, can help patients incorporate self-management strategies into daily life:

Start with the right outlook and support.

Believe that it can be done, and have hope for the future. Don't give up! Surround yourself with a good support network of family, friends, and understanding care providers. Your unit social worker is a good place to start.

Gather information, and form healthcare partnerships.

Ask questions—of your doctors, your nurse, your dietitian, and anyone who can help you determine your educational needs. Then seek the information you need—from your care team, the library, other patients, or the Internet. Work to become full partners with your caregivers.

Become as involved as possible.

Use the information you have gathered to become as involved as possible in your own care. Ask your caregivers to help you understand what you need to do to achieve your goals. Get involved in self-care activities. Set your own pace, and progress to more responsibility as you are able.

Manage your own rehabilitation.

Take responsibility for as many aspects of life with chronic disease as you can—including reducing illness symptoms, managing your treatment, and working to achieve your rehabilitation goals.

*Approaching a New Year with Continued Resolve***New Research Forms Foundation for Life Options 2001**

Since 1993, the Life Options Rehabilitation Program has been committed to helping people with kidney disease reach their fullest potential. Over the years, Life Options has shown that innovative research can lead to practical programs for people on dialysis. In 2001, Life Options plans to continue its efforts to carry out new research, helping to form the basis for programs that promote positive outcomes for patients.

In the coming year, Life Options research will continue to explore the topic of patient self-management—a focus which began with the recently-completed Patient Longevity Study. Based on interviews with 18 long-term dialysis survivors, the Longevity Study suggests that living long and living well on dialysis may depend on patients' adapting to their "new life" with chronic disease by actively self-managing ESRD,

its treatment, and their lives. Complete findings from the Longevity Study are to be published soon.

BUILDING ON THE LONGEVITY STUDY

Two current Life Options studies aim to further examine findings from the Longevity Study. A quantitative Self-Management Study is currently being conducted among a national, random sample of 18 facilities, with more than 400 dialysis patients. The study will test specific self-management strategies identified by patients in the Longevity Study.

In addition, a qualitative Affirmations Study is being conducted with 40 randomly-selected dialysis patients. Study participants are being interviewed about their strategies for adapting to life on dialysis. The goal is to examine the themes of self-preservation, self-identity, self-worth, and self-efficacy—affirmations identified in the Longevity Study.

OTHER NEW RESEARCH

A study to test the Life Options *Unit Self-Assessment Tool for Renal Rehabilitation (USAT)* is also nearing completion. In a unique research partnership, Life Options, ESRD Network 14, and CNSW of North Texas combined to study rehabilitation in 169 Texas facilities. The goal is to examine the relationships between rehabilitation and various patient outcomes. Study results will be presented at upcoming national renal organization meetings.

A new study in 2001 will look at self-management across the spectrum of kidney disease—from chronic renal insufficiency to dialysis. This quantitative study of more than 800 patients will test the degree to which self-management tactics among people on dialysis are also present in predialysis patients. It will also identify the range of symptoms in ESRD and explore the impact of those symptoms on patients' functioning, self-management, and quality of life.

LOOKING AHEAD

As Life Options looks ahead to 2001, the focus on patient self-management is clear, and the goal is steadfast and true—to provide research-driven programs that will help people on dialysis reach full rehabilitation. ♦

*Research and Education***Life Options Programs for 2001**

In 2001, Life Options will continue its tradition of developing educational programs from its research. Among the new and continuing Life Options programs for the upcoming year are:

- A pilot module for the new Life Options *Kidney School™* program will premiere on the Life Options web site. *Kidney School* is a self-paced, interactive web curriculum to help people with kidney disease learn self-management skills to improve long-term outcomes. *Kidney School* will provide information on such topics as anemia, vascular access, and treatment modalities. Self-tests at the end of each module will be part of the learning process.
- The Rehabilitation Resource Center (RRC) will continue to provide free educational materials and technical support for patients and professionals. For more information, call (800) 468-7777, or e-mail lifeoptions@MEIresearch.org.
- The Life Options web site, located at www.lifeoptions.org, will be updated and expanded, including printer-friendly versions of publications such as the *Renal Rehabilitation Report (RRR)*.
- The *RRR*, as well as various journal articles for patients and professionals, will feature research information, practical ideas, and patient education pieces.
- The Life Options Rehabilitation Advisory Council (LORAC)—a group of patients, nephrologists, nurses, dietitians, social workers, researchers, and educators—will continue to meet twice a year, identifying ways to offer patients and families more life options for kidney disease.

Self and Circumstance

Adjusting to Life with a Chronic Disease

In the “normal” world of healthy adults, life is fairly predictable, even with the constant change of today’s busy world. If asked about themselves, most people could create a word picture of their “self”—their good and bad points, their capabilities and shortcomings, the contributions they make and where they fail, how they react when certain things happen, and why their life is worth living.

Most of these same healthy adults could also describe the world in which they live—the “circumstances” of their lives. This might include what personal, social, and material resources they use to deal with life’s challenges, what they need to do to succeed in life, how much free time they have around their responsibilities, what their goals are, what they expect the future to bring, and what their life expectancy might be.

CHANGING SELF AND CIRCUMSTANCE

The fact that people understand themselves so well is really no surprise. After all, they have lived with and known themselves—both mind and body—for many years. Over time, people have seen themselves react to different situations and circumstances. They might wish for different, more glamorous and exciting lives, but at least they know generally who they are and what to expect on a day-to-day basis.

The world of predictable “self” and “circumstance” may come crashing to a halt, however, for people who are diagnosed with a chronic medical condition, such as end-stage renal disease (ESRD). For many of these individuals—and for their family and friends—such a diagnosis often arrives as suddenly and as powerfully as an earthquake. While they may not know what to expect, they may fear the worst—that they may not survive at all, or that their lives may never be the same again. And that is often only the beginning.

OVERCOMING CHALLENGES

Indeed, for patients and families, chronic disease can pose many challenges. With chronic kidney failure, people are quite suddenly faced with a changed self and life circumstances that include a complex and often invasive treatment regimen, different family and social roles and activities, financial and work-related stress, and altered self-image. Many of these are permanent, and can forever change patients’ lives.

Other factors may also prove challenging. For example, in many cases, when a person is diagnosed with a chronic

disease, family and friends are called upon to help by performing functions and duties never before required—from tasks as simple as taking out the garbage and preparing special meals, to duties as detailed as re-arranging household finances and partnering in home hemodialysis. These loved ones may or may not be equal to the task.

To the kidney patient, or any chronic disease patient, life may seem bleak indeed. They may feel they are “stuck with” a new self and new circumstances—a self they don’t want, and new circumstances that they don’t like.

A CASE IN POINT

Consider Howard, supervisor of a small carpentry firm. He not only ran the company, but he also performed much of the labor. He loved the creative energies of building, and he didn’t mind the long hours. Over a period of several months, however, he began to feel increasingly tired. When he found it hard to keep going, he made a visit to his family doctor. After many tests, a diagnosis was made—Howard’s kidneys were failing rapidly, and he would soon need dialysis.

Over the next year, Howard’s new “self” and new “circumstances” emerged, and they were not to his liking. His new self was frightening. He wasn’t sure anymore what his physical strengths were, but he did know that he couldn’t handle the long hours of carpentry. With more than 12 hours of dialysis a week, he had little free time. He often felt as if he couldn’t control anything in his life, and he felt useless to his family.

Howard’s changed life circumstances were even more disturbing. For one thing, he had no idea how long he would live. With such uncertainty in his life, he felt he couldn’t plan anything. In addition, dialysis sessions and medications seemed to control his life, and he felt totally dependent on his doctor, nurse, and social worker.

Understandably, all of this began to take its toll on Howard’s family as well. Because Howard was bewildered by his new self and circumstances, his wife and children were afraid to talk with him about how his condition was impacting them. Howard’s new world was at once scary and unpredictable, affecting every aspect of his life and theirs.

THE JOURNEY BEGINS

With seemingly overwhelming obstacles, is there anything that Howard and other kidney patients can do to face life with

(continued on page 8)

The world of predictable “self” and “circumstance” may come crashing to a halt...for people who are diagnosed with a chronic medical condition...

*Self and Circumstance***Adjusting to Life with a Chronic Disease** *(continued from page 7)*

a chronic disease? Have other patients adjusted successfully to ESRD? And, are there patients and families who actually enjoy their lives?

The answer is “yes” to all three questions. In the next several issues of the *Renal Rehabilitation Report*, the process of adjusting to ESRD will be examined in detail, and Howard’s own journey will be chronicled as one example of how patients experience transformation from life as a healthy individual to life with a chronic disease.

LIVING LONG AND WELL

Although it is not an easy road, patients like Howard can begin this process by coming to know and accept the new “self” and the new “circumstances” that accompany their illness and its treatment. For people on dialysis, the key to successful adjustment may lie in self-management—a tool that many long-term dialysis patients have used in their own

journey to rehabilitation. For more information on self-management, and how to incorporate self-management strategies into daily life, see *Laying the Groundwork for ESRD Patient Transformation*, page 1.

Taking the first step toward self-management—and, therefore, to rehabilitation—means being willing to reassess life through the new lenses of chronic illness. Chronically ill patients must redefine their new selves—and then manage their new and special circumstances. After that, with successful self-management, patients can work toward transformation into a more desirable life condition—one in which a sense of balance or has been restored.^{1,2} ♦

REFERENCES

1. Moch SD: Health within illness: Conceptual evolution and practice possibilities. *Adv Nurs Sci* 11(4):23-31, 1989
2. Paterson B, Thorne S, Crawford J, Tarko M: Living with diabetes as a transformational experience. *Qual Health Res* 9(6):786-802, 1999

**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 realize their fullest potential.

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.