## Life Options



THE RRR IS PUBLISHED

IN COOPERATION WITH

ephrolog

# enal Rehabilitation Report

VOL. 10, NO. 4

WWW.LIFEOPTIONS.ORG

WINTER 2002

Recipe for Successful Rehabilitation

## Taking Action through Self-management and Rehabilitation

t's a fact. People with kidney disease do better—physically and emotionally—when they take an active role in their own treatment.

It has long been known, for example, that self-care is associated with improved mental health, quality of life, <sup>1,2</sup> and successful rehabilitation.<sup>3</sup> More recently, a Life Options study has shown a link between self-management and improved functioning and well-being in people on hemodialysis.<sup>4</sup>

#### ATTITUDE, ANSWERS, AND ACTION

When it comes to adjusting to life with kidney disease, however, taking action is just one part of the equation. In fact, Life Options believes the potential for patients to live long and well rests with achieving the following goals:

- Developing a positive ATTITUDE that supports active involvement
- Getting ANSWERS that will guide self-management efforts, and
- Taking ACTION on their own behalf

#### "5 E'S" AND SELF-MANAGEMENT

In the Life Options view, the ultimate goal is for patients to become their own experts—to learn to recognize and report symptoms, ask informed questions, and begin to manage as many aspects of their care as possible.

This type of self-management is most effective when patients partner with their healthcare team in five key areas: Encouragement, Education, Exercise, Employment, and Evaluation. The long-recognized Life Options' "5 E's," play a powerful role in patients' ability to live long and well with kidney disease.

#### **ENCOURAGEMENT**

When it comes to self-management, encouragement can be viewed as the foundation "E." And the reason is clear. Research shows that newly-diagnosed patients share two nearly universal questions: "How long will I live?" And, "how well will I live?"<sup>5</sup>

Encouraging patients early on—by showing them that a long and full life is possible with kidney disease—can

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Message from the LORAC Chair his issue of the *RRR* focuses on the theme of **taking action**, which can mean many different things to patients. Following the treatment plan, traveling, staying physically active through exercise, and working or volunteering in the community are vital aspects of self-management that can help improve patients' quality of life, and even survival.

Healthcare professionals play a key role in helping patients to take action on their own behalf, by creating an expectation that patients will take on self-care tasks, guiding them to information sources, suggesting travel resources, referring them to physical therapists for strengthening exercises—and these are just a start.

Life Options believes that keeping a positive **Attitude**, getting **Answers**, and taking **Action** will help patients to stay actively engaged in life, so they can live long and live well with kidney disease—and have as many "life options" as possible.

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# RENAL REHABILITATION REPORT



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#### FOCUS ON ACTION

### Working Toward a Common Goal

## A Team Approach to Rehabilitation

or people with kidney disease, taking an active role in treatment is a key to living long and living well. Taking action is best approached as a shared effort between patients and providers.

To start, healthcare providers must themselves take action: first, by helping patients understand that a long and full life is possible. Providers must also create opportunities for education and expectations for patient self-management and partnership in care. Patients must take action as well—by using the knowledge they gain and taking advantage of the opportunities provided.

#### HYPOTHETICAL CASE IN POINT

Consider Lori, a real estate agent, wife, and mother of two. Balancing her busy schedule had always been a challenge, but one she enjoys. Over a period of several months, however, she begins to feel increasingly tired. When Lori finds it difficult to keep going, she makes an appointment to see her doctor. After several tests, it is determined that Lori's kidneys are failing, and she will soon need dialysis.

Lori's diagnosis takes her by surprise. She isn't sure what to expect—but she fears the worst. She has countless questions and very few answers. How will she cope with the complex regimen of dietary restrictions, medications, and dialysis treatments? Will she be able to go back to work? How will she take care of her children? Will she survive?

#### REVISITING THE "5 E'S"

For Lori—and others—adjusting to life with kidney failure begins with adopting a positive attitude and seeking the answers needed to take action through self-management. And the healthcare team plays a major role, by supporting activities in five key areas:

- Encouragement. From the start, Lori's health-care team assures her that, with the proper care and her own self-management, a long and good life is possible. They introduce her to a "dialysis mentor"—a woman in her unit who had been on dialysis for nearly 10 years. For Lori, hope soon buoys a positive attitude.
- Education. Lori's healthcare team uses the Life Options Patient Interest Checklists (available

at www.lifeoptions.org) to identify her areas of interest and concern. With this information, they tailor Lori's education through classes, written materials, videos, and on-line resources like Kidney School<sup>TM</sup> (www.kidneyschool.org).

Encouraged by her healthcare team and fellow patients, Lori makes a list of questions before each doctor's appointment, joins a support group, and goes on-line to search for information. Soon, armed with knowledge and confidence, Lori prepares to take action. She carefully watches her food and fluid intake, weighs herself before and after dialysis, and begins tracking her lab results.

- Exercise. Lori's healthcare team encourages her to stay active and gives her several resources, including an exercise log and a sample walking schedule. With her doctor's approval, Lori begins an exercise program. She starts by simply walking around the block near her home—about 10 minutes every other day. Gradually, she works her way up to 30 minutes of daily exercise, alternating between walking and riding an exercise bike.
- Employment. Lori soon begins to feel stronger and less fatigued. She decides she is ready to go back to work, at least part time. Still, she isn't sure how working will affect her medical coverage—or her dialysis schedule. Again, Lori takes action by making appointments with her social worker and a vocational rehabilitation counselor to discuss her employment options.
- Evaluation. Lori is on her way to successful adjustment. To help her stay on course, her care team schedules routine care plan meetings so, together, they can track Lori's progress.

#### TYING IT ALL TOGETHER

As Lori's example shows, when it comes to treating kidney disease, taking action is a team effort. Partnership in care—in the areas of Encouragement, Education, Exercise, Employment, and Evaluation—is important for helping patients live long, full, and productive lives with kidney disease. And that is what rehabilitation is all about.



Central New York Dialysis Center

## In-unit Internet Access Helps Patients Take Action



At Central New York Dialysis Center (CNYDC) in Syracuse, providing in-unit Internet access is just one strategy for helping patients take action toward self-management. It's part of an overall philosophy that has served patients well.

"Making computers available to patients is part of our comprehensive education program," says unit social worker Missy Domachowske, MSW. "It encourages patients to get involved in their care by actively searching for information. It also gives them something positive to do during dialysis."

#### **ABOUT THE CNYDC**

CNYDC is an independent, physician-owned facility, which opened in December of 2000. The center currently serves a diverse population of more than 150 patients, with a staff of 2 dietitians, 2 social workers, and a team of nurses, dialysis technicians, and nephrologists.

Each of the center's 30 hemodialysis stations comes equipped with Internet access, and laptop computers are available for patient check-out during dialysis. "The computers are on wheeled carts, which fit right over—or next to—the dialysis chairs," explains Domachowske. "Patients can sign them out as they come in for their treatment."

For CNYDC, providing patients with Internet-ready computers is not a new idea. "Even before we opened, it was something the nephrologists—Drs. Scheer, Tolchin, Frymoyer, Green, Gupta, Reinhart, and Kopecky—knew they wanted to do," says Domachowske. "They've worked hard to provide an environment that fosters professionalism, respect, and camaraderie among patients and staff alike."

#### **ABOUT THE PROGRAM**

At CNYDC, patients are encouraged to make use of the computers right from the start. "Most new patients are very eager to learn as much as they can about their treatment options," explains Domachowske. "The computers are a great way to help them do just that. That's why we introduce the computers as part of our orientation programs for new dialysis patients—and predialysis patients."

To encourage Internet searches, CNYDC staff members bookmark useful websites, such as kidneyschool.org. If patients need help, bedside nurses are there to assist.

According to Domachowske, about 15% of CNYDC's patients use computers during each dialysis session. "When patients do their surfing in-center, they're able to discuss information they find with nurses or dietitians right away," she says. "That's a huge benefit."

#### FOCUS ON EDUCATION

Aside from providing computers with Internet access, CNYDC promotes patient action in many other ways. "We have a patient education team, made up of nurses, dietitians, and social workers," she says. "The group meets regularly to choose a patient education 'topic of the month.' We then decide what information to present and how to present it. Week by week, over the course of the month, we build on the information patients receive on that topic."

To encourage employment and other activities, the center stays open 6 days a week and offers nighttime dialysis shifts. Staff members hold regular care plan meetings and invite patients to be involved.

"We encourage patients to make their own follow-up appointments, arrange their own transportation, and pick up their own prescriptions," says Domachowske. "We try to increase their sense of independence by reducing their dependence on us. We try to help them see that kidney failure is not their whole life."

#### PROMOTING ACTION

In the process of taking action toward rehabilitation, patients need as much information as possible. As CNYDC has shown, in-center Internet access is just one tool that can help lead patients toward self-management and rehabilitation.

"It's all about education and empowerment," says Domachowske. "Kidney disease can take control of your life. As a patient, you have people telling you what foods to eat, what medications to take, when to dialyze. Using the computer really helps patients regain a sense of control—it boosts their self-esteem. And, to me, that's the greatest benefit of all."

Does your unit have computers for patient use? Life Options is interested in finding innovative ways to promote patient self-management. If your clinic provides Internet access—or other unique tools to encourage patient action—please call the Life Options Rehabilitation Resource Center at (800) 468-7777, or e-mail us at lifeoptions@MEIresearch.org.

#### The Art of the Possible

## Taking Action, Making a Difference on Dialysis

"I can travel,
I can keep a
dog. I just live
my life. There
are worse things
than kidney
disease."

-Bill Peckham

Bill Peckham's philosophy on life with kidney disease is simple and to-the-point.

"People's expectations should be higher," he says. "
If you aim low, you'll hit low. I always assumed I could
work and travel on dialysis—and I will continue to do so
until something shows me otherwise."

At age 39, Peckham has been able to live a full and productive life with kidney disease. He feels that maintaining a positive attitude, finding answers, and—above all—taking action, have made all the difference.

#### DIAGNOSIS, TRANSPLANT, AND DIALYSIS

Peckham was first diagnosed with kidney disease in 1985, shortly after he graduated from college. He was 22 years old. "One day, I woke up with swollen ankles," he recalls. "It was my first indication that something was wrong."

When the swelling reached his knees, Peckham went to the hospital, where tests revealed that his kidneys were failing. Over the next 3 years, he was forced to play a waiting

game. "That was a difficult time," he says. "I had to wait until I was sick enough to have a transplant. I felt like my life was on hold."

Finally, in July of 1988, Peckham underwent surgery to receive a kidney donated by his brother. After an initial period of success, the transplant began to fail.

Doctors found that Peckham had focal segmental glomerulosclerosis (FSGS), a condition that would likely cause future transplants to fail as well. For Peckham, dialysis was inevitable.

#### **EDUCATION AND ENCOURAGEMENT**

In 1990, after 2 years with a failing transplant, Peckham did indeed begin dialysis. "I started out in the Northwest Kidney Centers' education unit, where I received individual instruction," he says. "Unfortunately, I wasn't a good student in the beginning," he says. "I was angry, and I didn't want to talk about kidney failure."

But the dialysis staff were persistent. "They kept encouraging me to take responsibility—to draw my own

## Q&A

#### <u> ASK THE EXPERTS: TAKING ACTION THROUGH EXERCISE</u>

#### An Interview with Patricia Painter, PhD

Adjunct Associate Professor, Department of Physiological Nursing University of California—San Francisco

How important is exercise to patient self-management?

A Exercise can benefit patients on many levels. Research in other populations suggests that inactivity is an independent risk factor for heart disease. Exercise can also modify other risk factors, such as hypertension and abnormal cholesterol—and people on dialysis experience both.

Physical activity promotes overall quality of life by improving patients' ability to perform daily activities, such as walking, climbing stairs, and carrying groceries. It may also reduce hostility, anxiety, and depression. Because patients can do exercise for themselves, they may feel more in control.

Overall, when dialysis patients are physically active, they feel less fatigued, they have more energy, and they are stronger. They feel better and are physically able to do more of the things they need to do.

How can dialysis professionals encourage patients to take "action" through exercise?

A Dialysis professionals have a huge responsibility, because they are the ones who inform patients about what can and cannot be done. Patients often come in not feeling well—they are fatigued, they don't have information. The normal response is to do nothing.

It is essential for professionals to encourage each new patient to maintain physical activity—or, for patients who aren't physically active, to start walking, to ride an exercise bike, or to find another way to be active.

How can patients incorporate exercise into their lives?

A First, patients need to find out what they can do. If walking is something they can do comfortably and safely—even around their home—they can just go out and walk. If it's 5 minutes, that's a start.

If they are very weak, they may want to ask their doctor for a physical therapy referral to help them build enough strength to walk. For most patients, it's just a matter of making a commitment to do something. Move more, walk up stairs, lift things. Patients shouldn't avoid physical activity. But, they should start slowly, and progress gradually.



syringes, to set up the machine, to weigh myself and take my own temperature," Peckham recalls. "At first, I thought 'you're out of your mind!'"

Eventually, however, the encouragement paid off. Peckham took control and even began placing his own needles. "I'm grateful they asked more than once—that they kept coming back," he says.

#### TURNING THINGS AROUND

For Peckham, the real turning point came in 1994, after he had spent nearly 2 years in what he calls a "hoping it would rain" mood. "One day, I just decided to make a change," he says. "I set three goals for the year: to play 50 rounds of golf, to spend 30 nights camping, and to spend at least 2 hours outdoors each day."

That decision—to get out, be active, and exercise—changed Peckham's life. "Even though I wasn't working, I started setting my alarm clock and began scheduling things," he says. "Soon, I began eating more and sleeping better. Before I knew it, the downward spiral had turned into an upward spiral."

#### STAYING ACTIVE

Today, Peckham works nearly full time as a union Tradeshow Specialist (Seattle Carpenters Local 131), producing floor plans and graphics for an event production company, and he continues to exercise regularly. One of his favorite hobbies is travel—a lifelong passion. The frequency of his travels has actually increased since he began dialysis.

"The turnaround year was 1994," Peckham recalls. "One day, I took out a *National Geographic* map of the United States and I just started calling units, started mapping a course. Before I knew it, my dog and I were touring the United States. We hit 22 states and Mexico. I had 15 treatments in 11 different units."

And Peckham hasn't looked back since. "I've gone to Europe every year for the last 7 years. In 1999 I managed to travel for 3 months, going all the way around the world," he says. "In all, I've visited more than two dozen countries on four continents since starting dialysis."

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What are the newest findings about exercise and chronic kidney disease (CKD)?

A There isn't a lot of information on predialysis exercise. There is one study that shows that predialysis patients who exercise regularly have lower blood pressure and maintain their levels of physical functioning, instead of deteriorating, which is the normal pattern.

The renal exercise demonstration project shows that people on dialysis, at even the very lowest levels of functioning, can make dramatic improvements in their strength, ability to walk, and quality of life—with minimal intervention.

It's important for the dialysis community to understand that patients will do regular physical activity, if they're given information and encouraged to do so.

What exercise successes have you seen in your own experience?

A There is a broad spectrum. We've worked with people who couldn't walk until a dialysis bike program helped them gain the strength to do so. Those types of things happen a lot. On the other end, we know

of a dialysis patient who rode a bike across the United States. He is the classic example of what's possible with regular physical activity.

The important thing is, people can do more than they're doing. If they're feeling tired and lacking in energy—and there's really no medical reason—they can overcome their fatigue by exercise that is initiated slowly and progresses gradually in both duration and effort.

Are there some basic rules people should follow, regardless of the exercise program they use?

A I don't really view prescribing exercise any differently in dialysis patients than in the general population. What's important is that people find something that's convenient and comfortable—something they like doing. And, of course, patients should first check with their doctors about their exercise plans.

A lot of people say they're too busy to exercise. It's important to tell patients that they can't afford *not* to schedule exercise into their lives. Just as they go to dialysis 3 days a week, they have to set aside some time to walk or exercise. Otherwise, they will begin to deteriorate. •



#### Recipe for Successful Rehabilitation

## Taking Action through Self-management and Rehabilitation (continued from page S1)

help them understand and accept their role in maintaining their health. In turn, this encouragement allows patients to begin seeking and absorbing the information they need to become experts in their own care.

#### **EDUCATION**

Of course, education also plays a major role in self-management. After all, the more informed patients are about kidney disease and its treatment, the more equipped they are to recognize which symptoms to report, which questions to ask, and which aspects of care to manage. Research supports the theory that patient education fuels action.

For example, Lorig has demonstrated that education leads to positive behavior changes and improved health outcomes in people with chronic disease. 6 In addition, informed patients have fewer symptoms, 7 and are more confident in their ability to manage the symptoms they do have.

#### **EXERCISE**

For people with kidney disease, the decline of physical functioning has important implications for rehabilitation, quality of life, and even survival. Physical limitations can keep patients from returning to work, taking part in social and recreational activities, or even performing activities of daily living.

Exercise can combat the muscle wasting associated with kidney failure.<sup>8</sup> In fact, exercise has been shown to improve physical performance and self-reported physical functioning, even for patients with the lowest levels of functioning.9

Regular physical activity has also been shown to reduce depression, improve social adjustment, and contribute to patients' feelings of independence, control, and self-esteem.<sup>10</sup> For these reasons, exercise is key to helping patients take an active role—both in daily life and in their own care.

#### **EMPLOYMENT**

Vocational rehabilitation is associated with medical, psychological, and social adaptation in people with kidney disease. Compared to non-working patients, patients who are vocationally active also report higher self-esteem and improved quality of life.<sup>11</sup>

It seems that active engagement in life—through employment, school, volunteer work, or other meaningful activities—can be viewed as the essence of self-management and rehabilitation.

#### **EVALUATION**

From the rehabilitation perspective, evaluation can help identify patients' needs, monitor the effectiveness of healthcare interventions, and improve the quality of care.

As part of self-management, patients can become involved in evaluation by measuring their own progress toward rehabilitation. For example, they can set goals for exercise and record their improvements over time. They can also track their lab values or keep a journal on how they feel from day to day.

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ince 1993, Life Options has been making important contributions to kidney patient education and research. You can help ensure that our work continues, by making a tax-deductible donation to The Medical Education Institute to support the Life Options Rehabilitation Program. Any amount is welcome. You can offer your tax-deductible financial support to Life Options in one of two ways:

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## Taking Action, Making a Difference on Dialysis

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#### MAKING A DIFFERENCE

Peckham, who is now on home hemodialysis, dialyzing 6 days a week, continues to stay active as President of the Northwest Kidney Centers (NKC) patient association. He volunteers on several NKC boards and committees, and has lobbied on behalf of dialysis patients at his state capital in Olympia, WA, and in Washington D.C. In 2002, he added five countries—Luxembourg and four Caribbean Island nations—to his lifelong list of countries visited (now over 35). His goal of visiting 50 countries seems well within reach.

While Peckham's life may seem extraordinary to some, he insists he simply takes things one day at a time—and does what he can to stay active.
"I've learned what's important to me," he explains.



Bill, right, atop the Sydney Harbor Bridge in Sydney, Australia, with his brother Charley.

"I can travel, I can keep a dog. I just live my life. There are worse things than kidney disease." •

#### Recipe for Successful Rehabilitation

## Taking Action through Self-management and Rehabilitation

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For patients and professionals alike, measuring progress toward goals is also an important part of the care process. Without such evaluation, there is no way to gauge success—or to set goals for improvement.

#### **PUTTING IT ALL TOGETHER**

When it comes to adjusting to life with kidney disease, patients must strive to maintain a positive attitude, find the answers to guide their self-management, and then take action on their own behalf.

Partnering with the care team in the "5 E's" areas of Encouragement, Education, Exercise, Employment, and Evaluation is the essence of self-management—and self-management is the key to rehabilitation and a long, full life with kidney disease. •

#### **REFERENCES**

 Devins GM, Binik YM, Hutchinson TA, Hollomby DJ, Barre PE, Guttmann RD. The emotional impact of end-stage renal disease: Importance of patients' perceptions of intrusiveness and control. *Int J Psychiatry Med* 13:327-343, 1983

- Meers C, Singer MA, Toffelmire EB, Hopman W, McMurray M, Morton AR, MacKenzie TA. Self-delivery of hemodialysis care: A therapy in itself. Am J Kidney Dis 27:844-847, 1994
- Korniewicz D, O'Brien ME. Evaluation of a hemodialysis patient education and support program. ANNA J21:33-39, 1994
- Bultman DC, Curtin RB, Schatell D, Beard K, Becker B, Klag M. Self-management activities of in-center hemodialysis patients. *J Am Soc Nephrol* 12 (Program and Abstracts Issue):194A, 2001
- Juhnke J, Curtin RB. New study identifies ESRD patient education needs. Nephrol News Issues 14(6):38-39, 2000
- Lorig K, Seleznick M, Lubeck D, Ung E, Chastain RL, Holman HR. The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. Arthritis Rheum 32:91-95, 1989
- 7. Treasure J, Schmidt U, Troop N, Tiller J, Todd G, Keilen M, Dodge E. First step in managing bulimia nervosa: Controlled trial of therapeutic manual. *BMJ* 308:686-689,
- 8. National Kidney Foundation. Kidney Disease Outcomes Quality Initiative (K/DOQI): Part 2—Background. *Am J Kidney Dis* 39(2):S32-S36, 2002
- Painter P, Carlson L, Carey S, Paul SM, Myll J. Low-functioning hemodialysis patients improve with exercise training. Am J Kidney Dis 36(3):600-608, 2000
- Painter P. Exercise gives ESRD patients strength and self-esteem. Neprhol News Issues 9:26-27, 1994
- Wolcott DL, Nissenson AR, Landswerk J. Quality of life in chronic dialysis patients: Factors unrelated to dialysis modality. Gen Hosp Psych 10:267-277, 1988