

RENAL REHABILITATION REPORT

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Taking Another Look at Exercise

The Life Options Rehabilitation Advisory Council (LORAC) believes that the importance of exercise for people on dialysis can never be overestimated. This issue of the *Renal Rehabilitation Report* offers possible reasons for dialysis patients' inactivity, talks about ways to measure activity baselines and progress toward goals, and explores barriers to exercise.

Most importantly, however, this issue expresses a very pointed message—that no matter what friends, families, or healthcare providers do or say to encourage exercise, it is patients themselves who must *accomplish* exercise activities.

For people on dialysis, self-management and partnership in care are required in all aspects of life. However, as this issue of the *Renal Rehabilitation Report* suggests, nowhere are they more crucial than with regard to exercise.

A new year approaches, and with it a new millennium. Life Options wishes you all the best in 2000—and you probably don't have to guess what New Year's resolution we hope will be at the top of the list for all of our readers this year!

For more information about exercise or renal rehabilitation, please contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777. ♦

MOVING TOWARD REHABILITATION: The Important Role of Exercise

For years, scientists and physicians have known that regular exercise can produce major health benefits. The link between exercise and good health is so strong that, in 1996, the U.S. Surgeon General issued a special report urging Americans to become more active.

“Physical activity is so directly related to preventing disease and premature death and maintaining a high quality of life,” states the report, “that we must accord it the same level of attention that we give other important health practices...such as sound nutrition...and the prevention of adverse health effects of tobacco.”¹

Link to Renal Rehabilitation

The relationship between exercise and good health is just as important for people on dialysis as it is for healthy individuals. In 1994, the Life Options Rehabilitation Advisory Council (LORAC) promoted this idea by identifying exercise as one of the “5 E's” (Encouragement, Education, Exercise, Employment, and Evaluation) of renal rehabilitation.²

More recently, dialysis patients in one study cited exercise as one of four “keys to a long life.”³ Indeed, exercise has been so closely linked to successful rehabilitation that many experts feel it should be part of the routine care of ESRD patients.⁴

Getting Started

If physical activity is so important, why aren't more people on dialysis encouraged to exercise?

There may be several reasons, but lack of physical ability plays a major role.

As a group, people on dialysis are far from fit. Many are so weak, they can do little beyond caring for themselves. For example, two-thirds of the patients in one study did not participate in *any* activities outside of dialysis.⁵ In another study, 40% of older adults on dialysis reported that they stayed in bed or in a chair most of the day.⁶

The weak condition of many people on dialysis has led some caregivers to conclude that dialysis patients are not capable of physical activity. Exercise physiologist Patricia Painter, PhD, believes otherwise. “The question we should be asking,” says Dr. Painter, “is ‘*Why* are these patients so weak and debilitated?’”

Reasons for Inactivity

Decreased strength and loss of physical ability in dialysis patients have a number of causes, including anemia, malnutrition, uremic muscle dysfunction, loss of muscle mass, and other comorbid conditions. However, inactivity itself can make the problem worse.

To illustrate this point, Dr. Painter has described a downward “cycle of deconditioning”⁷ (see graphic on page 6), in which disease leads to deconditioning, which leads to inactivity and a further decline in physical ability, which eventually leads to disability.

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TAKING CHARGE, CREATING CHANGE:

Exercise for Everyday Life on Dialysis



For Shari Gilford, exercise has been a life-changing endeavor. Just 2 years ago, the 34-year-old peritoneal dialysis patient was often too tired to make the bed, cook, or even stand for any length of time. "I had absolutely no strength," she says. "I felt like a washed-out dish rag."

But all of that has changed for Gilford, who credits encouragement, perseverance, and above all, exercise, for helping her return to a lifestyle she had once only dreamed of. "I am a totally different person now," she explains. "I have the energy to do almost everything that normal people do, and I feel great!"

Childhood Renal Failure

Gilford first experienced kidney failure at age 11, as a result of medullary cystic disease. Much of her childhood was spent dialyzing at the hospital, instead of playing at the park. "I was pretty inactive while I was growing up," she explains. "I had a doctor's excuse from gym class, and was even tutored at home for a while. I don't think the doctors even really knew about the benefits of exercise then."

For Gilford, this inactive lifestyle continued into adulthood. The effects of fatigue pervaded her daily life, affecting her concentration, her sleep, and even her relationships.

"I used to feel like I was in a fog all the time—like I hadn't slept," she says. "It was

hard to read a book, or concentrate on anything for any length of time. I could barely pray in the morning."

Introducing Exercise into Daily Life

About a year and a half ago, Gilford decided to see if exercise would make a difference. "My husband is very active," says Gilford. "So he just kept encouraging me—kept telling me that exercise would help me feel better."

It took some time, however, for Gilford to give exercise a try. "At first, I had all the excuses," she says. "I'd tell myself, 'I have anemia, low albumin, low blood count. Exercise might help an average person feel better, but it's not for me.'"

Her husband's encouragement eventually paid off, however, and Gilford began a regular exercise program for the first time in her life. She started by simply taking short walks. "I would walk to the post office, which is very close to my house. It was all downhill—and even that was difficult."

Soon, Gilford began using the exercise bike and lifting light weights twice a week at the same local fitness club that her mother belonged to. "I started out very slowly—nothing difficult," she says. "I just wanted to get my muscles moving."

Perseverance Pays Off

Results of Gilford's exercise efforts didn't come quickly or easily, however. "While I was glad to be up and moving, it was very difficult at times," she explains. "It was a good 4 or 5 months before I began to see any difference."

Still, Gilford stuck to her routine, consistently exercising twice a week. And it began to pay off. "I started to notice a big difference in my energy level," she recalls. "I felt stronger, I

was able to bike longer, and I even began to use the stair stepper.”

Nearly 2 years later, Gilford is going stronger than ever. She has worked her way up to an hour and 15 minutes of aerobic and strengthening exercises per session. “I make a point of pushing myself just a little bit more every day,” she says. “When I started, I was lucky to be able to lift 3 pounds. Now, I use 20-pound barbells for some exercises.”

Gilford has felt the impact of exercise in nearly all aspects of her daily life. “I fall asleep quickly and sleep through the night,” she remarks. “When I wake up in the morning, I feel refreshed and ready to go.”

The improvements in Gilford’s physical condition have also led to improvements in her overall quality of life. “Now, I can be who I need to be for myself and for the people around me,” she explains. “I can cook and clean and go hiking with my husband, and spend time with my friends. Most of the time, I don’t think they even think about the fact that I’m ill.”

A New Outlook

Gilford admits that, at times, exercise hasn’t been an easy addition to her life. Still, she hopes that other people on dialysis will give exercise a try and stick with it through the difficult times.

“A lot of people might think ‘I can’t do this—I’m just too tired,’” says Gilford. “But you have to start somewhere. Even if all you can do at first is walk around a block, just do *something* to get yourself moving.”

The results, she says, will be well worth the effort: “Exercise makes me feel alive. My life is no longer centered around dialysis. I’m *living* life now.”

Exercise and Activity

For some people on dialysis, all-out exercise is not an option, especially if they have secondary health problems or are just beginning a program of physical activity. Still, it is important for people on dialysis to *be active*. As dialysis patient Patty Stewart shows, there are many ways to do this—and they all begin with a single step.

“Every journey of a thousand miles starts with a single step,” agrees Stewart. And she would know. For the last 17 years, the 49-year-old hemodialysis patient has endured a variety of medical setbacks, from kidney failure and a 53-week stay in the hospital to numerous bouts with infection.

A tournament tennis player as a youth, Stewart was athletic and active prior to her kidney failure. That, she feels, has played a major part in helping her through her medical problems. “I attribute the fact that I survived it all to the fact that I had a good heart, good lungs, and a strong body from being athletic throughout my early life,” she says.

Life Changes

In 1982, obstructive uropathy from a severe infection caused Stewart’s kidneys to fail. After spending nearly 2 months in the hospital, she was put on dialysis. Due to complications from her infection, however, it was another 11 months before she was able to leave.

For a long time, returning to regular exercise was not an option for Stewart. Because of her prolonged hospital stay, she needed physical therapy just to get back to a level at which she could carry out activities of daily living. “I had trouble just lifting my arms over my head,” she recalls.

Even after Stewart’s health stabilized, the effects of kidney failure and inactivity plagued

her lifestyle. “It would take me an hour to work up enough energy just to walk across the room and turn on the TV,” she says.

Stewart remembers the exact moment that physical inability spurred her return to exercise. “It was in 1986—about 4 years after I got out of the hospital,” she recalls. “One day, I was sitting down in a chair, and I realized I couldn’t stand up without using my arms to push off. I remember saying to myself, ‘I’m really losing ground.’”

One Step Forward

Stewart went to her doctors and asked them to perform a physical assessment. Then she asked for permission to use the hospital’s rehabilitation gym. There, she began a program of 15-minute biking before each dialysis session.

Over the next 5 years, Stewart continued this routine, but not without her share of setbacks. “Just when I would start to feel like I was making progress, I would get another infection,” she explains. “I would lose the ground I had gained, and at times, even move backwards. It’s hard to find the mental strength to keep fighting just to stay on even ground.”

But, somehow, Stewart has found the strength, and she continues to make exercise a priority. “It’s not so much that I love doing it,” she says. “It’s more of a sense of urgency—I know that it will help me live longer.”

Stewart employs several methods to help her through the hard times. “Sometimes exercise is really a drag,” she admits. “But I look for creative ways to make it less boring.” She believes, for example, in rewarding herself for progress. “I recently added music to my exercise program. I love music, but I don’t get to listen to it very often. So, listening while I exercise is a treat.”

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PHYSICAL FUNCTIONING ASSESSMENT:

A Tool for Improving Quality of Life on Dialysis

Recent efforts in the field of renal rehabilitation research have shown strong evidence of the link between physical functioning, clinical outcomes, and quality of life in people on dialysis. As a result, assessment of physical functioning has become an increasingly important issue for dialysis professionals.

Although confusion does exist about how to define physical functioning, as well as how and why to measure it in clinical practice, assessing physical functioning does not have to be complicated or time-consuming. The potential benefits of improved patient outcomes and quality of life are worth the effort.

Defining Terms

Physical functioning is one of many terms used to describe a patient's ability or inability to perform certain physical actions or movements. Some of these terms are very precisely defined (peak oxygen uptake, for example); others are vague and non-specific.

To help clarify what is meant by physical functioning, physical actions have been classified into two categories: basic and complex.¹ Basic actions include such things as walking, bending, standing up, gripping, and lifting. Complex activities involve combinations of basic actions. For example, mowing the lawn is a complex activity because it involves the basic actions of walking and pushing.

Performing life activities requires that people on dialysis be able to carry out basic actions and combine them into complex activities. The ability to perform basic actions depends on several factors, including cardiorespiratory fitness, muscle function, and joint flexibility. Limited ability to perform basic movements can reduce the ability to maintain independence, fulfill essential roles (like homemaking or childcare), or enjoy recreational activities.

The relationship between physical functioning and quality of life can be seen in the "Quality of Life Pyramid," below. Physical functioning is the base of the pyramid. A person must have adequate levels of physical functioning to perform activities of daily living. Higher levels of functioning are required to take part in social, vocational, and recreational activities. Inability to meet the physical demands of one or more of these levels lowers quality of life.

Reasons for Assessment

Because physical functioning is a key building block of quality of life, measuring a patient's level of function is an important issue for the healthcare team. This assessment can provide valuable information about health status and may help clinicians make treatment decisions. Just as nutritional status, medications, and adequacy of dialysis are monitored, baseline assessment and subsequent re-assessment of physical functioning can be used to monitor a patient's clinical course.

Standardized assessments of physical functioning can also help clinicians identify patients who would benefit from physical therapy or other

activity/exercise interventions. Assessment may also aid in early detection of functional decline. Finally, changes in physical function over time may be a sign that there is a change in medical status not otherwise noted. For example, doctors who supervise exercise training for patients with cardiac disease often credit exercise with early detection of changes in medical status.

Measurement Methods

There are several ways to measure physical functioning. The first, and most rigorous, is laboratory testing. Laboratory tests can be used to objectively evaluate heart and lung function, muscle strength and endurance, and flexibility. These tests require costly, specialized equipment and highly skilled technicians to obtain accurate results.

For this reason, laboratory tests are used mainly for research. They are simply not practical in routine clinical settings. In addition, the intense level of activity required of test subjects often limits participation by patients with chronic illnesses like end-stage renal disease (ESRD).

*The Quality of Life Pyramid**



* Adapted with permission from: Painter P, Stewart AL, Carey S: Physical functioning: definitions, measurement, and expectations. *Adv Ren Replace Ther* 6:110-123, 1999

Physical performance testing was developed as a practical alternative to laboratory testing. It involves asking a patient to perform a specific movement or task, and assessing that performance in an objective manner (usually counting repetitions or timing the action).

Performance tests have been developed to assess balance, gait, flexibility, strength, and endurance. These tests have the benefit of being simple, inexpensive, time efficient, reproducible, and safe.¹ For all of these reasons, performance testing is well-suited to routine clinical monitoring of a patient's physical functioning. (For a detailed example of a performance-based test, see *Assessment in Action: The Sit-to-Stand Test*, at right.)

Self-Reporting

Over the past several years, self-report forms have often been used to assess outcomes in patients with ESRD.² These questionnaires most often focus on health-related quality of life, and usually require patients to assess their own level of physical functioning. The most commonly used questionnaires are the Kidney Disease Quality of Life (KDQOL), the Dartmouth COOP, the DUKE Health Profile, and the Medical Outcomes Study Short-Form-36 (MOS SF-36 or SF-36).

Self-report forms are easy to use—they can be completed by patients themselves or by staff members with little or no specialized training. In addition, they can be given repeatedly, and are particularly helpful in identifying changes over time.³ Perhaps most importantly, several studies have shown that self-reported physical functioning is closely linked with clinical outcomes, including nursing home placement, wellness, and survival.²

In light of these findings, complex and costly lab testing of physical functioning seems unnecessary. In many cases, self-reports can

provide enough information to identify problems and begin interventions.

Taking Steps To Improve Quality of Life

Assessment of physical functioning is the first step toward identifying physical problems that can affect a patient's ability to participate in activities that enhance quality of life. Physical functioning assessment can also direct the implementation of appropriate interventions. A focus on physical functioning, coupled

with efforts to optimize functioning, has the potential to help ESRD patients realize a better quality of life. ♦

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Assessment in Action: The Sit-to-Stand Test

Purpose

To measure leg strength in ambulatory patients

Materials Needed

A straight-backed chair (if the chair has arms, be sure the arms cannot move) and a stopwatch or timer

Staff Requirements

During the evaluation, a staff person is needed to time the patient and to stand by for safety

Technique

- Place the chair on a carpeted surface or against a wall so that it will not shift with the patient's movement.
- Have the patient sit down in the chair. Instruct the patient to stand up and sit down as many times as possible for one minute.
- Beginning on the word "go," count every time the patient stands as a repetition. If the patient cannot rise to a full stand, document the patient's position. Observe and document whether the patient begins to "push off" with the arms.
- The patient can stop or rest during the test, but keep the clock running. Record the results.

Interpretation

A healthy, sedentary, non-dialysis patient with no joint problems can easily stand up between 20 and 30 times in one minute. Fatigue from lack of strength or difficulty with the knees, hips, or ankles would reduce the number of repetitions. Compare the result to the patient's own results over time, or to an average of all the eligible patients in your facility.

Endurance is needed for sustained activities, such as walking, vacuuming, swimming, dance, aerobics, racquet sports, hiking, bicycling, and skating. Leg muscle strength is needed to climb stairs, use a regular toilet, get in and out of a car, or visit a movie, concert, or sports event without a wheelchair.

Note: The Sit-to-Stand Test is one of several performance-based methods used to assess physical functioning. For information on other methods, including the Lift and Reach Test and the Two- or Six-Minute Walk Test, please refer to the Exercise module of the publication *Building Quality of Life: A Practical Guide to Renal Rehabilitation*, which is available from the Life Options Rehabilitation Resource Center (RRC) at (800) 468-7777.

MOVING TOWARD REHABILITATION:

The Important Role of Exercise (continued from page 1)

Quality of Life

For people on dialysis, the loss of physical ability—from deconditioning or from other causes—has important implications for rehabilitation, quality of life, and even for survival. Physical limitations can keep dialysis patients from returning to work or taking part in social and recreational activities. Severe physical limits may also interfere with activities of daily living (ADLs), such as shopping, household tasks, and even personal care.

Loss of physical function at this level has been linked with such adverse outcomes as falls, extended hospital stays, nursing home placement, and increased mortality. Some researchers have even suggested that a patient's degree of debilitation may influence the course of the illness by affecting adherence to treatment, choice of treatment modality, and rehabilitation.⁸

It is not surprising that low physical functioning has been associated with poor quality of life. Explains Dr. Painter, "If patients are physically unable to perform activities of daily living, then most other activities will also not be possible, thus negatively affecting quality of life."⁹

The Benefits of Exercise and Activity

A growing body of evidence suggests that exercise can improve exercise capacity and/or physical functioning for people on dialysis. For example, Dr. Painter and others have shown that regular exercise can improve exercise capacity in ESRD patients.¹⁰

Similarly, results from the recently completed Renal Exercise Demonstration Project (P. Painter, unpublished data, April 1999) show that exercise interventions led to improvements in dialysis patients' physical performance, as well as in their self-reported physical functioning.

Experts believe that "even minimal increases in physical activity have the potential to make a major impact on patients' ability to perform ADLs...and possibly maintain independence."¹¹ When physical improvement is not possible, exercise may still be able to help maintain current levels of function by preventing deconditioning.

Specifically, exercise can reduce the risk of cardiovascular disease; improve endurance; and increase bone mass, joint flexibility, and muscle strength.¹ In addition, exercise may reduce anxiety and depression, and increase feelings of well-being.¹ Of special interest to people on dialysis, physical activity may even prevent or lessen the effects of diabetes mellitus and hypertension—two of the leading causes of ESRD.¹²

Managing Risks

The list of potential exercise benefits is compelling, but it must be weighed against the possible risks. For most people on dialysis, exercise carries less risk than does inactivity.

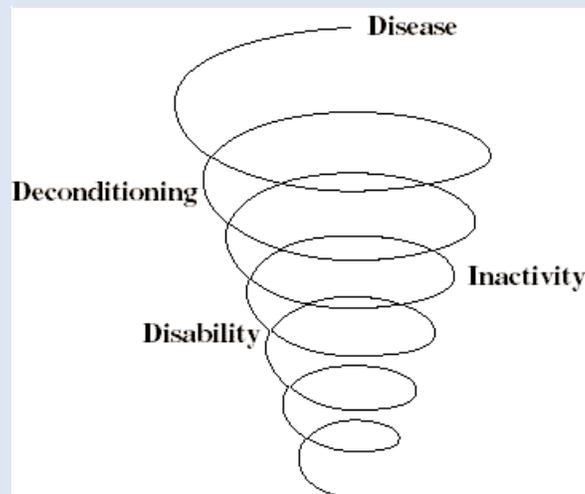
With proper caution, most dialysis patients can safely include exercise in their daily routine.

The most common risk of exercise is injury to the muscles and bones. Due to bone loss associated with chronic renal failure, this risk may be slightly higher for people on dialysis than for healthy individuals. However, adequate intake of calcium and vitamin D can reduce this risk, as can choosing non-weight-bearing or supported activities, such as swimming or cycling.

The most serious risk of increased physical activity is cardiac risk. Fear of cardiac consequences may prevent dialysis patients and caregivers from considering an exercise program.

It is important to remember, however, that such adverse effects are usually associated with intense exercise—at levels beyond the capacity of most dialysis patients. Careful screening of patients and selection of appropriate activities can greatly reduce the risks of exercise. Further, evidence shows that, over the

Cycle of Deconditioning*



* Adapted with permission from: *Am J Kidney Dis*, 24, Suppl 1 (July);S2-S9, 1994

long term, regular exercise actually *reduces* the risk of coronary heart disease and overall mortality.¹²

Staff Roles and Responsibilities

Because the potential benefits of physical activity are so significant, every effort should be made to reduce the barriers to exercise for people on dialysis. Many experts believe that dialysis facilities have a responsibility to do more than just reduce exercise barriers.

“We should be addressing the issue of physical functioning as part of routine patient care,” urges Dr. Painter. “If we hope to prevent deconditioning, we should do it sooner rather than later.” Here are some things dialysis staff can do:

- **Project a positive attitude.**

Dialysis staff have a major impact on dialysis patients and their families. As such, staff members “should stand out as a positive influence and facilitate and encourage participation in regular physical activity and life activities in whatever way possible.”⁴

- **Educate patients and families about the benefits of exercise.**

The lack of such information is often viewed by patients and families as a sign that exercise is not important or safe for people with chronic renal failure. In light of the Surgeon General’s report, Dr. Painter cautions dialysis staff that failure to promote the benefits of physical activity could be considered “negligent.”

- **Assess the physical functioning of every patient.** There are many ways to do this—sometimes it can be as simple as making a note in a patient’s chart. What is important, however, is to

“You have to start where you can, even if all you can do at first is walk around the block. It may be difficult for a while, but if you keep going, keep doing, keep pushing yourself to do a little bit more, you will persevere.”

—*Shari Gilford, dialysis patient*

include some evaluation of physical functioning as part of the routine treatment plan. (For more information on assessing physical functioning, see *Physical Functioning Assessment: A Tool for Improving Quality of Life on Dialysis*, pages 4-5.)

- **Direct patients toward specific physical activities.** This can mean

making a referral to physical therapy, or providing information about local exercise facilities and programs. It may even involve starting an exercise program at the dialysis facility. The comprehensive *Exercise for the Dialysis Patient* program, available from Life Options, offers many suggestions for various levels of staff involvement.

Patient Responsibility

Dialysis staff members play a major part in encouraging exercise. Ultimately, however, the responsibility for physical activity lies with each dialysis patient. “Other people can take you to dialysis,” says Dr. Painter. “They can feed you, they can give you your medications, but only *you* can exercise.”

Patients who want to take control of their health and well-being will accept the fact that they must also take the responsibility to be active. Many people on dialysis may need to start small. But the key is to start.

“You can’t just sit and think ‘I’m sick—I’m a dialysis patient. This is all there is to life,’” says PD patient Shari Gilford. “You have to start where you can, even if all you can do at first is walk around the block. It may be difficult for a while, but if you keep going, keep doing, keep pushing yourself to do a little bit more, you will persevere.” ♦

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FOCUS ON EXERCISE

TAKING CHARGE, CREATING CHANGE:

Exercise for Everyday Life on Dialysis (continued from page 3)

Sometimes even rewards are not enough. “I’m a human being,” she says. “Just like everyone else, there are times when I’m really good at it and times when I’m not so good at it. It takes a lot of effort to get yourself to exercise.”

In a good week, Stewart exercises every other day, dividing her time among a variety of activities, including the treadmill, leg lifts, and other strengthening exercises. Occasionally, she also goes for a ride on her “adult tricycle.” “I may look like a geek going down the street,” she jokes, “but I still do it!”

Day-to-Day Differences

While exercise has not been a cure-all for Stewart, it *has* made a difference in her daily life. “It’s the little things I notice,” she says. “I sleep better, I feel better after dialysis, and getting out of the couch is not the intense struggle it once was.”

She adds, “I used to have a hard time making it through the grocery store. Sometimes I

wouldn’t even stop unless I saw an open handicapped parking space. Now I pass right by those spaces so someone else can use them—I don’t mind walking.”

Everyone Can Exercise

Stewart firmly believes that exercise can benefit anyone, regardless of their health status. “I’m a good example,” she says. “I have bad joints, my bones are not good, I have some mobility problems. But I pick exercises that minimize the strain on those areas.”

According to Stewart, there are many ways to do this. “There is a woman on TV who does arm circles and other simple exercises while sitting in a chair,” she explains. “I actually do those myself.” And she believes that other people on dialysis can too.

“Even if you can’t walk, you can sit in a chair, you can lift your knees up, bend forward,” she says. “You have to start with something manageable—something that makes you say

‘no big deal,’—and increase in small but noticeable increments.”

Stewart also advises others to set goals that are fun, interesting, and worth achieving. “If you like to shop, why not park someplace and walk to Macy’s?” she offers.

In addition, Stewart says that it’s important to emphasize the positive, not the negative. “Even if you’ve only exercised twice this week, don’t be too hard on yourself,” she explains. “That’s twice more than nothing at all.”

Looking Forward

To see the impact exercise can make, all you have to do is take a look at Stewart—the woman who once had trouble getting out of her chair now looks forward to swimming and ocean kayaking in Hawaii with her husband.

“Exercise makes me feel like I am not losing ground,” she says. “It makes me feel more capable, more able, stronger.” And all this has happened one step at a time. ♦



RENAL REHABILITATION REPORT

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The Renal Rehabilitation Report is dedicated to identifying effective programs, projects, and people who are helping dialysis patients realize their fullest potential.

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