RENAL REHABILITATION REPORT

VOLUME 7 • NUMBER 2 • MARCH/APRIL • 1999

A Closer Look at **Dialysis Self-Care**

he Life Options Rehabilitation Advisory Council (LORAC) believes that, through good clinical and rehabilitation management, people on dialysis can enjoy long and full lives. Keys to patients' renal rehabilitation success include ownership of their disease and full partnership in their care. Such ownership and partnership are achieved through self-advocacy, self-management, and self-care.

Self-advocacy includes patients' efforts to get the best care possible. Self-management entails self-advocacy and is additionally characterized by patients' efforts to gain a deeper understanding of their disease and its treatment and to have input into many aspects of their treatment plan. Self-care goes one step further, involving the actual performance of some aspects of care.

This Renal Rehabilitation Report explores modality choice as one possible part of the disease ownership and care partnership process. It details several of the current options for home dialysis and suggests some ideas for discussion between dialysis patients and providers.

Also in this issue, the LORAC introduces and invites entries for its new Showcase of Ideas recognition program.

If you would like more information about renal rehabilitation, self-care, or modality selection, please contact the Life Options Rehabilitation Resource Center (RRC) at (800) 468-7777. ◆

CHOOSING A DIALYSIS MODALITY:

Focus on Self-Care and Rehabilitation

While a variety of

treatment modalities

are available, matching

diagnosis of end-stage renal disease (ESRD) makes renal replacement therapy a necessity, but the inevitability of dialysis—or transplantation does not eliminate options. ESRD patients retain the power to have input into a number of choices about their lives. One of the most important is the choice of treatment modality.

Modality Choices

For those who are not candidates for kidney transplant or whose transplants fail, peritoneal dialysis and hemodialysis are modality

options. Hemodialysis therapies include in-center hemodialysis, home hemodialysis, and more recently, slow, nighttime hemodialysis. Peritoneal dialysis (PD) therapies include continuous ambulatory peritoneal dialysis (CAPD), continuous

cycling peritoneal dialysis (CCPD), and combinations of both.

While a variety of treatment modalities are available, matching the needs and preferences of the patient to the appropriate renal replacement therapy can be a challenge. Many factors, including the patient's medical condition, body size, mental alertness, ability to handle the treatments, lifestyle, and personal preferences¹ influence the choice of dialysis therapy. For these reasons, not all treatment options will be available to all patients. Further,

patients' needs and requirements may change over time, and their modality choice may also change in response. In fact, many patients experience more than one type of renal replacement therapy during the course of their lifetime with ESRD.

Current Modality Trends

According to the 1998 United States Renal Data System (USRDS) Annual Report, more than 80% of dialysis patients in the United States are treated with in-center hemodialysis, about 9% are treated with CAPD, and just

over 4% are treated with CCPD. Home hemodialysis patients represent just over 1% of the U.S. dialysis population.²

distribution of these modalities has been remarkably stable for the last decade,3 many

factors are leading some dialysis experts to anticipate an increase in the number of patients who choose to dialyze at home.4

New, user-friendly technologies and government review of reimbursement policies are likely to foster a shift to home dialysis. At the same time, efforts to improve quality of life through renal rehabilitation have already increased interest in self-care therapies like home hemodialysis and PD.

the needs and preferences of the patient While the percent can be a challenge.

(continued on page 7)

RENAL REHABILITATION REPORT

This publication is supported by Amgen Inc.

LIFE OPTIONS REHABILITATION ADVISORY COUNCIL MEMBERS

Karen Daniels, MM Nancy Gallagher, BSN, RN, CNN Peter Howell, MEd, MPA Karren King, MSW, ACSW, LCSW Michael Klag, MD, MPH Derrick Latos, MD, FACP John Lewy, MD Jill Lindberg, MD, FACP Donna Mapes, DNSc, RN Maureen McCarthy, MPH, RD, CS Frank Messana Anita Molzahn, PhD, RN Brian O'Moore Rosa Rivera-Mizzoni, MSW, LCSW Nancy Spaeth, RN Sharon Stiles, BSN, RN, MS, CNN

EMERITUS MEMBERS

Christopher Blagg, MD
Kenneth Chen, MS
Ann Compton, RN, MSN, CNN
Peter DeOreo, MD
Nancy Kutner, PhD
Bruce Lublin
Anthony Messana, BSC
Spero Moutsatsos, MS
John Newmann, PhD, MPH
Patricia Painter, PhD
George Porter, MD
John Sadler, MD
Michael Savin, PhD
Theodore Steinman, MD
Beth Witten, MSW, ACSW, ISCSW

NEWSLETTER EDITORS

Roberta Braun Curtin, PhD, RN Nicole Thompson

CONTRIBUTING WRITER
Paula Stec Alt

The Renal Rehabilitation Report is published bimonthly. Readers' comments and ideas are welcome. Contact the Life Options Rehabilitation Program, 603 Science Drive, Madison, Wisconsin 53711-1074
Tel: (800) 468-7777
E-mail: lifeoptions@medmed.com
Website: www.lifeoptions.org

HOME HEMODIALYSIS:

An Outcomes Advantage for Patients

"I wanted to keep

working full time, so

I chose to dialyze at

—Greg Cunningham

home."

reg Cunningham started home hemodialysis in 1977. "In those days, you couldn't get an in-center time slot that fit a job schedule," he says. "I wanted to keep working full time, so I chose to dialyze at home." While the ability to dialyze on his own time was what first sold Cunningham on home hemodialysis, he liked the modality enough to continue it for 17 years.

About Home Hemodialysis

The mechanics of home hemodialysis are basically the same as those of in-center hemodialysis. Home hemodialysis treatments are typically scheduled three times per week, and each treatment may last from 3 to 5 hours.

Even though home hemodialysis and in-center hemodialysis are similar technically, there is one important difference: among all dialysis modalities, home hemodialysis is associated with the best survival rates, quality of

life ratings, and potential for rehabilitation.¹

The Outcomes Equation

Research is needed to more fully understand why home hemodialysis patients enjoy such excellent outcomes. For instance, it is not certain whether patients who are doing well tend to choose self-care modalities such as home hemodialysis, or whether self-care modalities actually cause patients to do better. Nonetheless, factors such as patient autonomy and empowerment, higher dose of delivered dialysis, and various patient characteristics no doubt contribute to the positive outcomes.²

In spite of positive results, home hemodialysis is the least common dialysis modality in use in the United States. While there are some regional differences, the *United States Renal*

Data System (USRDS) 1998 Annual Report shows that of all people on dialysis, only 1.1% use home hemodialysis.³

A Complex Decision

Why is such a successful therapy so little used? There are several possible reasons. For one, the therapy may seem too difficult or complex for some patients. According to Dr. Zbylut Twardowski, a nephrologist at the University of Missouri School of Medicine, today's dialysis machines—the same ones used for in-center treatments—are "unnecessarily complicated" for home use.

In addition, the need for a partner who can help with treatments eliminates home

hemodialysis as an option for many people. Even Cunningham, an experienced home dialysis patient, returned to in-center treatment when his helper was no longer available.

Reimbursement Issues

Technical difficulties alone might not be enough to deter motivated patients, but federal reimbursement practices have also discouraged the use of home hemodialysis.

When Medicare began its end-stage renal disease (ESRD) program in 1973, reimbursement rates for in-center hemodialysis were higher than those for home hemodialysis. This imbalance led to a drastic decline in the use of home hemodialysis—from 40% of dialysis patients in the early 70s to less than 2% today.⁴

Even though Medicare now pays the same reimbursement rate for in-center and home hemodialysis, lack of reimbursement for the

cost of home dialysis aides has continued to work against home hemodialysis.

Despite such challenges, recent advances in home dialysis technology may soon overcome patient concerns about the difficulty of the procedure. Dr. Twardowski, for example, has generated a new "personal hemodialysis system" that is being developed by Aksys, Ltd. of Libertyville, IL.⁴ At the same time, the Health Care Financing Administration (HCFA) is looking into ways to improve patient outcomes and cost efficiency.

A More Enjoyable Routine

For Cunningham, home hemodialysis allowed a more enjoyable routine than in-center treatments. "Three days a week, I'd hook up to the machine when I got home from work," he explains. "The first hour of dialysis would go by quickly during dinner. Then, I'd watch TV, play with my son, or read."

In addition, Cunningham liked being able to go to sleep right after coming off dialysis. "If I felt washed out, I could sleep it off," he says.

Cunningham also cites other benefits of home hemodialysis, including the ability to make his own treatment schedule. "With home hemo, it's easy to make adjustments," he says. In addition, while home hemodialysis forced him to learn more about dialysis, Cunningham believes this knowledge has made him a better, more compliant patient.

Home hemodialysis does have some disadvantages. Cunningham acknowledges that the procedure is time-consuming for the dialysis partner. "Your helper must be there for the whole treatment," Cunningham explains. "So, two of you are tied down, not just one."

Home hemodialysis can also be intimidating. "The first three or four treatments are scary," Cunningham admits. "But if you stay calm and remember your training, you can work your way through any problems."

Words of Advice

Cunningham believes that people who are independent and want to be in control will

like home hemodialysis. "If you think you want to try it, talk to home patients," he says. "Go visit them while they're on dialysis." Cunningham also recommends seeking information from books and brochures.

For those who have made the decision to try home hemodialysis, Cunningham suggests paying very close attention during training. "If you learn as much as you can about the machine, and act independently during training, you'll be better prepared to be on your own," he says. •

References

- Oberley ET, Schatell DR. Home hemodialysis: Survival, quality of life, and rehabilitation. Adv Ren Replace Ther. 3(2):147-153, 1996
- 2. Oberley ET, Schatell DR. Home hemodialysis and patient outcomes. *Dial Transplant.* 24(10):551-556
- 3. United States Renal Data System 1998 Annual Report.
 National Institutes of Health, National Institute of
 Diabetes and Digestive and Kidney Diseases, Division of
 Kidney, Urologic, and Hematologic Diseases. Bethesda,
 MD, 1998 (p S52)
- Salzer, S. Experts say: There's no place like home for hemodialysis. Missouri Medical Review. Summer: 3-8, 1998



Call for Entries: The Life Options Showcase of Ideas

The Life Uptions Rehabilitation Program is now accepting entries for its new Showcase of Ideas recognition program. Here is how the program works...

Showcase for Renal Care Professionals/Organizations

If you are a renal professional and/or an organizational representative who has "tried and true" rehabilitation strategies or tips, Life Options would like to hear from you. Examples of innovative approaches and solutions may include (but are not limited to) the following:

- Strategies to improve patient/nephrologist communication
- Ideas to improve compliance with the care plan
- Tips for effective, efficient use of dialysis time
- Ways to motivate patients to exercise
- Approaches to help dialysis patients keep or find employment
- Strategies for implementing changes in rehabilitation activities, based on the Life Options Unit Self-Assessment Tool (USAT)

Showcase for Dialysis Patients

If you are on dialysis and have ideas and tips for self-management, Life Options would like to hear from you. Successful ideas—about keeping a positive attitude, getting answers, and taking action—may include:

- Ways to keep your spirits up and accomplish your goals while living with dialysis
- Tips on how to talk with doctors and other staff
- How you learned that you can live long and well on dialysis
- How you managed to hold or find a job after you started dialysis

For More Information

Entry forms for the Showcase of Ideas are posted on the Life Options website at *www.lifeoptions.org*, where results will be posted. For more details on the Showcase, visit the website or call the Renal Rehabilitation Center (RRC) at (800) 468-7777.

PERITONEAL DIALYSIS:

Offering Flexibility and Convenience for Patients

hen Dick Rosenstock was diagnosed with end-stage renal disease (ESRD) in 1995, he started researching his treatment options right away. Because he didn't want to put his life on hold while he waited for a transplant, he looked for a dialysis therapy that would fit his busy lifestyle.

"I work full time, and I travel on business," explains Rosenstock. "On top of that, I run a small computer software company out of my home." It was with this in mind that Rosenstock, in consultation with his nephrologist, chose peritoneal dialysis (PD).

About Peritoneal Dialysis

With PD, the peritoneal membrane (a thin layer of tissue that surrounds the body's internal organs) serves as a dialysis filter. Toxins and excess water are removed from the blood when they pass through the peritoneal membrane into dialysate fluid that has been placed into the abdominal cavity.

Patients on PD need a permanent abdominal catheter to carry the dialysate into and out of the body. Several times each day, PD patients drain the used dialysate and instill fresh fluid. Because the abdomen is always filled with dialysate, the process of dialysis occurs 24 hours a day.

Several variations of PD are available. The two most common are continuous ambulatory peritoneal dialysis (CAPD) and continuous cycling peritoneal dialysis (CCPD). These therapies differ only in when and how the fluid exchanges are made.

In CAPD, patients manually exchange their dialysate fluid, usually four times each day. Fluid from the last exchange of the day remains in the abdomen throughout the night. In CCPD, a machine called a cycler performs a series of fluid exchanges while the patient sleeps at night. Fluid remains in the

abdomen during the day, but no daytime exchanges may be needed.

According to the *United States Renal Data System (USRDS) 1998 Annual Data Report,*¹ 9.1% of dialysis patients in the U.S. use CAPD, and 4.2% use CCPD. Although in-center hemodialysis is still the treatment used by most dialysis patients, peritoneal dialysis is the most common home dialysis modality.

"I can travel unencumbered, I can work all day without interruptions, and I can be in charge of my own dialysis."

—Dick Rosenstock

Selecting Peritoneal Dialysis

Like Rosenstock, many patients have made PD their first choice for dialysis treatment. Compared with in-center hemodialysis, PD allows patients more control over scheduling treatments, it can be done in the comfort and familiar surroundings of home, and is generally perceived to be less disruptive to family and employment.³ The ability to enjoy a diet with fewer restrictions on foods and fluid is also a major advantage of PD.

Both CAPD and CCPD are often prescribed for patients with medical problems that prohibit the use of hemodialysis.² Two such problems include an inability to establish adequate vascular access for hemodialysis, and various cardiovascular conditions that may pose risks during hemodialysis treatments. On the other hand, certain medical conditions may compromise a patient's eligibility for PD.

A Personal Decision

For Rosenstock, the added independence and scheduling flexibility of CCPD played a big part in his choosing the modality. "The whole scenario appealed to me," he says. "I can travel unencumbered, I can work all day without interruptions, and I am in charge of my own dialysis."

The idea of round-the-clock dialysis also appealed to Rosenstock. "With PD, you're basically dialyzing all the time," he says. "I feel good all the time. I don't have the roller coaster ups and downs that I have heard about from some hemodialysis patients."

The more liberal PD diet was another factor in Rosenstock's final choice. "I watch my fluids, and I don't eat really high potassium foods, but my diet is really pretty normal," he says. In fact, the only drawback Rosenstock can find with CCPD is the nighttime immobility. "It's a little confining," he notes. "Once I'm hooked up at night, I can't go anywhere."

Everyday Life on PD

A typical day for Rosenstock begins at 6:30 am. "It takes me a half hour to get off the cycler, clean up, and reset for that night," he says. "It's just part of my routine, like brushing my teeth or shaving." After that, Rosenstock is off to work where he puts in a full day—usually from 8:00 am to 5:00 pm. "When I get home, my wife and I can go out or do what we want," he says.

In addition, the Rosenstocks have gone to Disney World and on a cruise without a break in the dialysis routine. "When I travel, I just take my cycler with me," he explains. "It fits into two cases. I can have my supplies shipped ahead so I can set up in my hotel or cabin for the night's treatments."

Secrets of Success

Although Rosenstock believes almost anyone can learn how to do PD. he thinks it takes a

certain personality to stick with the modality and succeed. "You've got to be a self-starter," he explains. "Nobody is there to tell me to do my dialysis. I could skip it if I want to, but I know I need it in order to feel good."

In addition, Rosenstock takes an active interest in every aspect of his medical care. "I take my blood pressure, my temperature, and my weight every day. I know my norms, and I don't hesitate to call if something is wrong."

Rosenstock also makes accommodations for his disease. "Of course, I have to make some adjustments," he says. During the busy season at work, for example, he arranges his workweek to have Wednesdays and Sundays off so he has a mid-week break to rebuild strength.

How to Learn More

Rosenstock's first information about dialysis choices came from a Missouri Kidney Foundation seminar for predialysis ESRD patients. "It was a great way for me to get the information I needed all at once," he says. "As a patient, you should also try to read everything you can get your hands on," says Rosenstock. "Patients should also talk to each other and to their dialysis team, as well as

utilizing organizational resources such as the National Kidney Foundation Patient Information Center," which can be reached at (800)622-9010." ◆

References

- United States Renal Data System 1998 Annual Report.
 National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Division of Kidney, Urologic, and Hematologic Diseases. Bethesda, MD 1998
- 2. NKF-DOQI Clinical Practice Guidelines for Peritoneal Dialysis Adequacy. New York, National Kidney Foundation, 1997
- Life Options Rehabilitation Advisory Council. Renal Rehabilitation: Bridging the Barriers. Madison, WI, Medical Education Institute, 1994

SLOW. NOCTURNAL HOME HEMODIALYSIS:

A New Option for Dialysis Self-Care

n the 10 years since her kidney failure, Joyce Cagle has tried several types of dialysis, including CAPD, CCPD, and in-center hemodialysis. Since October 1997, however, she has been doing long, slow hemodialysis treatments at home six nights a week, and is very happy with it. "I was skeptical at first," Cagle admits. "But, now I'm delighted. I feel 100% better."

A Modality Variation

Nocturnal home hemodialysis is a variation of standard hemodialysis. The principles of treatment are the same, but the parameters are different. For example, with nocturnal hemodialysis, the length of each treatment is longer (6 to 8 hours vs. 3 to 4 hours); the flow rates are slower; and treatments are more frequent (6 per week vs. 3 per week). Patients dialyze at night while they sleep, to fit in the long treatment sessions.

One of the main differences between in-center hemodialysis and nocturnal home hemodialysis is the need for a different type of vascular access. An arteriovenous (AV) fistula will not hold up well to the frequent needle sticks required for nocturnal home hemodialysis. In addition, an AV fistula does not provide enough security against an accidental disconnection.

For these reasons, vascular access for nocturnal hemodialysis relies on a permanent, in-dwelling jugular catheter. The catheter is carefully taped after each dialysis treatment, and remains completely hidden under normal clothing. A locking device designed for use with the catheter prevents accidental disconnection during treatments.

Improved Outcomes

Development of nocturnal hemodialysis was prompted by reports of excellent patient outcomes with long-duration daily hemodialysis. ¹ To date, trials with small numbers of nocturnal hemodialysis patients in Canada have been very promising, as well. ^{2,3} For example, patients in various Canadian studies have experienced a number of benefits, including the highest urea clearance rates of any dialysis modality, increased clearance of other toxins (especially the so-called "middle molecules"

like B2 microglobulin), improved blood pressure control, smaller fluctuations in fluid volume during treatments, and better control of serum phosphorus and potassium.³

Some experts believe that the longer, slower treatments more closely simulate the function of working kidneys. This "gentler" dialysis allows patients to enjoy more comfortable dialysis treatments with less cramping, fewer postdialysis symptoms, and more liberal guidelines for fluid and food intake.

Additional Findings

In addition to these benefits, the Canadian studies showed that nocturnal hemodialysis is also likely to eliminate a patient's need for blood pressure medications and phosphate binders. Study patients also reported that other symptoms like nausea, itching, and fatigue often decreased or disappeared, while appetite increased. At least one patient felt so good on nocturnal hemodialysis that he compared it to a successful kidney transplant.²

(continued on page 6)

SLOW. NOCTURNAL HOME HEMODIALYSIS:

A New Option for Dialysis Self-Care (continued from page 5)

Patients in the Canadian study adapted very well to nocturnal hemodialysis. After about one week of adjustment, patients said they were able to sleep soundly during their nightly dialysis sessions. Patients were closely monitored in the early trials, but few technical problems were reported.

Physicians were so confident that this modality was trouble-free, that current patients do not rely on any off-site monitoring. Alarms on the dialysis machine alert these home patients to potential problems, and they are trained to handle any emergency.

Most nocturnal dialysis patients perform their own treatments, without the help of a partner. According to Dr. Andreas Pierratos, one of the primary researchers in Canada, the modality offers "independence for people living alone." Dr. Pierratos adds that patients "...feel confident doing their own dialysis unassisted...."2

At the same time, the rehabilitation potential of nocturnal hemodialysis appears excellent; personal satisfaction, sense of well-being, and employment among study patients all increased.3 In light of these successes, many researchers hope to expand the availability of nocturnal home hemodialysis to more patients in Canada and the United States.

Feeling Well All the Time

The reports of nocturnal hemodialysis sounded so good that when Cagle was offered the opportunity to try it, she jumped at the chance. "I hadn't felt well on any type of dialysis," she explains. "So, what did I have to lose? Now, I feel well all the time."

While Cagle never quit her job during her first 8 years on dialysis, she often had to take sick leave. Since she's been on nocturnal hemodialysis, however, she hasn't had to take any days off. "I've got my life back!" she says. "My labs are better than they've ever been."

A Daily Routine

Six nights of the week, Cagle begins to set up her dialysis machine at about 9:00 pm. "It took me an hour at first, but now I can do it in 30 minutes," she says. She connects her catheter, double checks the locking device, sets the timers, and goes to sleep. "My husband doesn't need to help at all," she says.

> "I've got my life back! My labs are better than they've ever been."

-Joyce Cagle

Cagle prepared to do her own nocturnal home hemodialysis during 5 weeks of intensive training. "In the last week, they put me in a room with a phone and I had to do the treatments by myself, just like I now do at home," Cagle says. "If I needed help, I had to call."

Even with the extensive training, Cagle admits she was nervous the first few days at home. "It's human nature to watch the machine," she says. "Now I know it's safe and the alarm will wake me up if there's a problem." She also avoids daytime naps to make sure that she's tired at night and ready to sleep.

When Cagle disconnects in the morning, she rinses the used dialyzer and puts it into a special cooler. Once a week, she takes the cooler into her dialysis unit so they can reprocess the six dialyzers she's used during the week. At the same time, she picks up six reprocessed dialyzers to use in the days ahead. Cagle chooses to draw her own blood for lab tests once a month, and sees her doctor monthly as well.

Cagle has perfected her technique over a year and a half, but she thinks that almost anyone could learn to do it. "There's lots of repetition," she says. "It helps if you're an organized, methodical person. And if you're not, they'll train you until you are."

Pioneering a New Treatment

At present, few patients in the United States have the opportunity to use nocturnal hemodialysis. Those who do are truly pioneers. Social worker Jeanette Albert, MSW, believes the therapy is well-suited to independent, motivated patients like Cagle. "They have to be committed to doing the dialysis and know how to use resources," she says.

Cagle is lucky to be associated with the Lynchburg Dialysis Facility in Lynchburg, VA, one of a few units in the country that currently offers nocturnal home hemodialysis. Lynchburg is a for-profit, freestanding dialysis unit serving about 215 in-center hemodialysis patients. They currently have 30 home patients, including the nine on nocturnal hemodialysis.

Under current government policy, Lynchburg is reimbursed for only three of the six weekly dialysis treatments that each nocturnal hemodialysis patient performs. The center absorbs the additional costs so that patients who choose the modality do not have to pay the balance.

Lynchburg is, however, losing money and is petitioning the Health Care Financing Administration (HCFA) to allow reimbursement for four dialysis sessions per week. Such a change would make the nocturnal home hemodialysis program more financially feasible for facilities such as Lynchburg.

More Information

For more information about the nocturnal home hemodialysis program at Lynchburg Dialysis Facility, visit their website at www.lynchburgnephrology.com.

CHOOSING A DIALYSIS MODALITY:

Focus on Self-Care and Rehabilitation (continued from page 1)

Making the Case for Self-Care

There seem to be compelling reasons for patients and their care providers to seriously consider self-care dialysis options. When considering research on outcomes and modalities, it is important to remember that it has not been determined whether healthier patients tend to choose self-care modalities, or whether self-care modalities actually promote better outcomes. In either case, research has shown a relationship between modality choice and outcomes.⁵

For example, over the years, patients on home hemodialysis have had better survival rates than patients on other modalities. ⁶ Survival rates for CAPD patients have been slightly lower than for home hemodialysis patients and slightly higher than for in-center hemodialysis patients. ⁷

Further, authors of a 1990 study concluded that "among patients treated with dialysis,

those undergoing treatment at home had the highest quality of life." In another study, CAPD patients reported that they were "significantly more satisfied" on most measures of emotional well-being than patients treated with in-center hemodialysis.⁵

Finally, higher levels of employment are associated with self-care therapies. Although the reported numbers vary, patients using home hemodialysis or CAPD have higher rates of employment than patients on in-center hemodialysis.⁷

The Power to Decide

Positive renal rehabilitation outcomes might in fact be facilitated by the choice of self-care treatments. Part of the reason may be that many home patients simply get more dialysis, and they feel better because their blood chemistries are more nearly normal. Positive outcomes may also be credited to the independence and autonomy that go along with choosing self-care. Patients who take on self-care responsibilities must, by definition, become knowledgeable about their illness and dialysis treatment. Along with this knowledge comes the power to participate in decisions about medical treatments.

Education and training for self-care can help to restore a patient's independence and can provide a sense of confidence and control over ESRD and the lifestyle adjustments necessary to live with the disease. For example, active participation in dialysis therapy gives patients more flexibility. Treatment schedules can be adjusted to fit in work and social activities. In addition, many self-care patients value the chance to perform their dialysis in the comfortable, familiar surroundings of home.

Making a Commitment

The benefits of home dialysis do come with a heightened level of responsibility—a factor that can be intimidating to some patients.

(continued on page 8)

Self-Care Options for Patients and Professionals to Discuss

First Step Self-Care Options

- 1.a. Know name, purpose, dose, and frequency of medications taken
 - b. Tear tape strips to be used on access
 - c. Prepare station with personal items (i.e., blankets, books, craft materials, food and drink if unit permits, etc.)
 - d. Know type of access, check blood flow daily, protect access from blood draws/IVs/blood pressures (BPs), report symptoms (i.e., swelling, redness, loss of feeling)
- 2.a. Recite steps of an emergency disconnect from dialysis machine
 - b. Recite and participate in facility emergency procedures for fire, earthquake, weather, etc.
- 3.a. Put pressure on access site after needle removal
 - b. Perform skin prep on access
 - c. Know direction of flow in the access (arterial and venous side)
 - d. Be able to describe usual post-dialysis access dressing
 - e. Take and record temperature, blood pressure, and weight
- **4.**a. Verify dialyzer and ask if it has been correctly reprocessed, primed, and checked for disinfectant (if applicable)
 - b. Report symptoms during and off dialysis (i.e., swelling, shortness of breath, chest pain, dizziness, fever)
 - c. Know what symptoms to report during and off dialysis
 - d. Take and record BP
 - e. Explain basic principles of dialysis and how the machine works

Intermediate Self-Care Options

- **5.**a. Know what machine alarms mean
 - b. Know when fluid replacement is needed
 - c. Know steps to relieve common, non-life-threatening symptoms (i.e., low BP, cramping)
 - d. Know dry weight and how much fluid should be removed
- **6.**a. Know the rotational pattern for cannulating the access
 - b. Know where access shouldn't be cannulated
- 7.a. Know own normal venous and arterial pressure
 - b. Know desired and usual blood flow rates
 - c. Know if machine is set up correctly (correct dialysate flow, sodium modeling, heparin pump settings, TMP/UF rate)
 - d. Know normal lab values and how they compare (potassium, phosphorus, calcium, BUN, Hgb/Hct, albumin, Kt/V or URR, PTH; diabetics should know their HgbA1c)
 - e. Know medication purpose, dosage, and frequency during dialysis
- **8.**a. Set up and take down dialysis machine
- b. Insert hemodialysis needles with assistance

Advanced Self-Care Options

- **9.**a. Know how to troubleshoot dialysis machine (i.e., power or water failure, dialyzer leak, air in the lines, serious symptoms)
 - b. Insert hemodialysis needles unassisted

CHOOSING A MODALITY:

Focus on Self-Care and Rehabilitation (continued from page 7)

However, while it is true that the commitment, education, and circumstances required for successful home dialysis are not always present, some rehabilitation professionals believe that patient selection for home dialysis may be too stringent.⁶ With proper encouragement from dialysis staff, more patients might be willing and able to try home dialysis.

Full Partnership in Care

According to Dr. Jon Kabat-Zinn, associate professor of medicine at the University of Massachusetts Medical School, partnership in care is essential in nearly all forms of medical therapy—especially with chronic diseases such as ESRD. "In such cases," says Dr. Kabat-Zinn, "the quality of your life may greatly depend on your ability...to work at optimizing your own health within the bounds of what may be possible."9

Partnership in care can take many forms, all of which are worthwhile. As introduced in A Closer Look at Dialysis Self-Care (the shaded box on page 1), self-advocacy, selfmanagement, and self-care are composed of different but equally valuable activities. As such, even patients who cannot choose home dialysis can still actively participate in their own care.

Some issues patients might discuss with their care providers are included in *Self-Care* Options for Patients and Providers to Discuss, page 7, which was adapted from the Life Options publication Building Quality of Life: A Practical Guide to Renal Rehabilitation. 10

Partnership Leads to Rehabilitation Success

For people on dialysis, encouragement from medical staff and access to information are crucial at all levels of partnership in care. Still, it is the patient's responsibility to make this partnership a priority.

To achieve rehabilitation success, people on dialysis must make the commitment to take control of their own health. For those most determined to attain ownership of their disease and partnership in their care, home dialysis is an option that must be considered. •

References

- 1. Life Options Rehabilitation Advisory Council. New Life, New Hope: A Book for Families and Friends of Renal Patients. Madison, WI, Medical Media Associates, 1997
- 2. United States Renal Data System 1998 Annual Report. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Division of Kidney, Urologic, and Hematologic Diseases. Bethesda, MD, 1998 (p S52)
- 3. United States Renal Data System 1998 Annual Report. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Division of Kidney, Urologic, and Hematologic Diseases. Bethesda, MD, 1998 (p S53)
- $4.\ Salzer,\ S.\ Experts$ say: There's no place like home for hemodialysis. Missouri Med Review. Summer: 3-8, 1998
- 5. Simmons RG, Abress L. Quality of life issues for end-stage renal disease patients. Am J Kidney Dis. 15:201-208. 1990
- 6. Oberley ET, Schatell DR. Home hemodialysis and patient outcomes. Dial Transplant. 24(10):551-556
- 7. Oberley ET, Schatell DR. Home hemodialysis: Survival, quality of life, and rehabilitation. Adv Ren Replace Ther. 3(2):147-153, 1996
- 8. Evans RW, Manninen DL, Garrison LP et al. The quality of life of patients with end-stage renal disease. N Engl J Med. 312(9):553-559
- 9. Kabat-Zinn J. Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness. New York, NY, Bantam Doubleday Dell Publishing Group, 1991
- 10.Life Options Rehabilitation Advisory Council. Building Quality of Life: A Practical Guide to Renal Rehabilitation. Madison, WI, Medical Media Associates, 1997



RENAL REHABILITATION REPORT

Life Options Rehabilitation Program **603 Science Drive** Madison, Wisconsin 53711-1074 (800) 468-7777

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 bimonthly publication of the Life Options program, which supports initiatives for renal rehabilitation in the vital areas of Encouragement, Education, Exercise, Employment, and Evaluation.

NONPROFIT ORG. U.S. POSTAGE **PAID** MADISON, WI PERMIT NO.278