

RENAL REHABILITATION REPORT

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LIFE OPTIONS NEPHROLOGIST OPINION STUDY

Examining Life Behind the Scenes of Dialysis

Over the past several years, the field of renal rehabilitation has grown and changed tremendously. A new vocabulary has emerged, rehabilitation programs have been developed and implemented, practice guidelines for clinical management have been defined, and several Exemplary Practices have been identified, acknowledged, and shared.

Each of these changes is notable. Together, they represent the beginning of a new era in dialysis—one that pairs optimal clinical care and rehabilitation to maximize the potential for patients to live long, productive, and satisfying lives. Both clinical care and rehabilitation can best be maximized when full partnership exists between patients and their care providers.

Rehabilitation Partners

In an effort to learn more about the dialysis experience and about keys to living long and well on dialysis, Life Options recently conducted a Patient Opinion Study. This investigation produced important findings about what people on dialysis believe and know about renal rehabilitation, their disease, and its treatment. (For more information about the Patient Opinion Study, see the January/February 1999 *Renal Rehabilitation Report*).

But patients are only one part of the dialysis care equation—healthcare providers play a vital role as well. One key member is the nephrologist, who has a direct impact on patients' overall treatment. As such, it is crucial

to know what nephrologists believe about renal rehabilitation, and about the keys and barriers to living long and well on dialysis.

To examine these issues, Life Options recently undertook a Nephrologist Opinion Study. (For information about methods and procedures used in the study, please see *About the Life Options Nephrologist Opinion Study*, below.) Because the Nephrologist Opinion Study interview sample was limited to 15 doctors, and because participants were not chosen randomly, findings from the study cannot be

generalized to all nephrologists. Nonetheless, the study did provide useful insights about how some nephrologists view renal rehabilitation and related issues.

For example, when asked about the meaning of "rehabilitation," respondents offered a number of descriptions. Many suggested that rehabilitation meant a return to predialysis activities. However, several maintained a very strong focus on employment as a defining element in rehabilitation. Most respondents

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About the Life Options Nephrologist Opinion Study

The purpose of the Life Options Nephrologist Opinion Study was to examine nephrologists' beliefs and opinions about renal rehabilitation. As part of the study, 15 nephrologists were interviewed by telephone.

The interview respondents had varied amounts of experience in nephrology, ranging from a few years to more than 30 years in practice. Three of the participants were pediatric nephrologists. Interview questions were open-ended, and addressed the following themes:

- The meaning of and possibility for "renal rehabilitation"
- Barriers to living long and well on dialysis
- Interventions and activities that can be started by nephrologists to increase the potential for their patients to live long and full lives
- Patients' roles in maximizing their own potential for a good life on dialysis
- The role of information, education, and communication in renal rehabilitation
- The most compelling aspects of nephrology

Although the interview sample size was small and participants were not randomly selected, the study provided important insights into the beliefs and practices of a select group of nephrologists. As such, it has important implications for rehabilitation, which are detailed in this issue of the *Renal Rehabilitation Report*. ♦

RENAL REHABILITATION REPORT

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LIFE OPTIONS NEPHROLOGIST OPINION STUDY Theme: What is Rehabilitation?

“Rehabilitated patients have come to terms with dialysis. They have worked it into their lives. They have learned how to get along with the disease, make the best of it, have active, productive lives around it.”

—Nephrologist Opinion Study participant

The Face of Renal Rehabilitation

Life Options has long believed in the concept of renal rehabilitation as a return to pre-ESRD levels of functioning. More than half of the respondents in the Nephrologist Opinion Study seem to share this belief.

Among nephrologists interviewed for the study, there was a fair amount of consensus about the meaning of the term “renal rehabilitation.” The notion that rehabilitated individuals look “normal” and have a reasonable quality of life was shared by 40% of respondents.

Six of the 15 nephrologists suggested that rehabilitation was linked with a return to work. In just a few cases, it was clear that respondents believed rehabilitation only meant a return to work.

Such a narrow view of rehabilitation might limit these nephrologists' receptiveness to rehabilitation programming and points to the need for education about the full range of renal rehabilitation activities in the “5 E's”: Encouragement, Education, Exercise, Employment, and Evaluation.

Potential for Rehabilitation

When asked about dialysis patients' potential for living long and well, there was little agreement among the study nephrologists. The expectation for a long and full life on dialysis seems to be somewhat different for children, as two of the three pediatric nephrol-

Analysis:

- Most nephrologists saw rehabilitation as a return to predialysis activities for people on dialysis.
- Eleven out of 15 nephrologists believed that living long and well was possible for people on dialysis; two of the three who did not were pediatric nephrologists.
- Six nephrologists equated rehabilitation with a return to work.
- Physician-defined keys to a long life included: excellent medical care, a low number of comorbid conditions, and strict adherence to the treatment plan.

Implications:

- Programs aimed at improving dialysis patients' quality of life and return to predialysis activities are still needed to reinforce the beliefs of those who are already convinced and to convince those who are still in doubt.
- Dialysis patients, care providers, families, and friends should keep spreading the word that a long and full life on dialysis is possible.
- Managing the symptoms of comorbid conditions and good clinical care are prerequisites to rehabilitation.

ogists interviewed said it would be difficult (though not impossible) for children on dialysis to enjoy long and productive lives.

Most of the nephrologists did agree that living long and well on dialysis depended largely on such factors as few or no comorbid conditions, excellent care, and patients' adherence to all aspects of the treatment plan. These findings seem to support the idea that quality clinical care and rehabilitation will maximize the potential for people on dialysis to live long, productive, and satisfying lives. ♦

LIFE OPTIONS NEPHROLOGIST OPINION STUDY

Theme: Barriers to Living Long and Well

The barriers [to rehabilitation] are family attitudes, family expectations, how much the family encourages [them] to be active. There are financial factors, family resources, lost time from work, some expenses for medication, transportation. There are medical factors that have to do with the timing of care. And there is self-motivation.”

—Nephrologist Opinion Study participant

Identifying Barriers

The Life Options Rehabilitation Program was founded on the belief that people on dialysis can live long and satisfying lives. For people on dialysis, reaching life goals depends, in part, on identifying and overcoming barriers to renal rehabilitation. Discussing such barriers was a primary focus of the Nephrologist Opinion Study.

When asked what barriers to rehabilitation exist for people on dialysis, nine of the study respondents cited comorbid conditions as a main obstacle, while four believed that the unavoidable symptoms of the disease and its treatment were serious hurdles. Nine nephrologists also viewed negative attitudes (those of patients, healthcare providers, family members, and support persons) as a barrier.

Analysis:

- Comorbid conditions were most often cited as the primary barrier to living long and well on dialysis.
- Negative patient, staff, and family attitudes were seen as a major barrier to rehabilitation.
- Nephrologists felt that lack of information is a barrier to rehabilitation for most people on dialysis.
- Most respondents felt that rehabilitation interventions could help overcome many of these barriers.

Implications:

- Information/education about tactics, techniques, and tips for managing the symptoms of comorbid conditions is vital.
- Strategies to improve patients’ and caregivers’ attitudes about the potential for rehabilitation are needed to fight negative outlooks and expectations.
- Education about the cause and effect relationship between patients’ own behaviors and possible negative outcomes is needed to help remove some of the barriers to rehabilitation.
- Information about resources, encouragement of family involvement, peer support programs, and other efforts to increase social support for patients are needed to promote rehabilitation.

Seven respondents felt that lack of education or information stood in the way of many patients’ ability to live long and live well. Five nephrologists pointed to patients’ general lack of support and/or resources, and five believed that patient noncompliance was a major barrier to a good life on dialysis.

Two respondents felt that lack of motivation detracted from patients’ opportunity for a full life, and four listed lack of activity as an ongoing problem. Four said the amount of time needed for dialysis was a major detractor from dialysis patients’ overall quality of life.

Interestingly, two of the three most often cited barriers identified by the nephrologists seem to be open to rehabilitation activities. Although little can be done to change the number and types of comorbid conditions patients have, negative attitudes may be changed by educational, motivational, and mental health rehabilitation interventions.

Further, just under half of the doctors saw patients’ lack of information as a barrier to the likelihood of living long and living well on dialysis. This lack of information can be addressed by rehabilitation activities focused on education. ♦

NEPHROLOGISTS’ VIEWS

The following comments have been excerpted from the Nephrologist Opinion Study interview transcripts.

“[People on dialysis] don’t have to be weak and disabled. If they do all they can, they could look like you and me...”

“My definition of rehabilitation is ‘somebody nobody knows is on dialysis.’”

“It is quite likely for [people on dialysis] to live long and well. It is related to their underlying disease, their age, comorbidities. It is also dependent on their own motivation. Good medical management is a factor.”

“One of the difficulties with regard to long life is that they hand over their own care—that is a reason for not doing well. Patients have to redirect their thoughts and activities beyond dialysis and treatments. Dialysis is not a terrible thing.”

“Whether or not patients do well has to do with the underlying disease. It also has to do with their attitudes—spiritual and emotional. There has to be a sense of helping themselves—‘I can do something about this.’ There is real difference in those who have a good attitude.”

“Those with fewer comorbid conditions and a better attitude—who don’t give up easily—do well. Sometimes they do get depressed, but they have to believe that they can meet the challenge.”

NEPHROLOGIST OPINION STUDY

LIFE OPTIONS NEPHROLOGIST OPINION STUDY

Theme: The Nephrologist's Role

Nephrologists...make [patients] as healthy as possible. After that, they answer the question 'what can I do?'

Encourage mental activity, encourage exercise, encourage general activity, encourage travel, instill a sense of wellness. The circumstance of dialysis breeds dependency, so we must give them a sense of independence."

—Nephrologist Opinion Study participant

The Clinical Care Connection

Nephrologists' commitment and support are vital to the success of any rehabilitation program. As such, doctors in the Nephrologist Opinion Study were asked about their own roles in the rehabilitation process.

The interviews made it clear that nephrologists are well aware of their responsibility to provide patients with good clinical care. Twelve of the 15 nephrologists interviewed specifically mentioned good medical management as an important part of their role in helping people on dialysis live long and well.

Eight nephrologists commented on the importance of education for patients, and one specified that such education must be provided in manageable pieces. Eight of the nephrologists felt that encouraging patients

Analysis:

- Providing excellent clinical care was cited by most nephrologists as their most important responsibility.
- Nephrologists felt they also played an important role in normalizing patients' lives, as well as providing patients with education and encouragement.
- Most nephrologists believed that empowering patients was a key role.

Implications:

- Providing nephrologists with information about the "5 E's" will foster their roles as partners in the full rehabilitation process.
- Programs and information that improve communication between dialysis patients and their doctors will likely be viewed as a valuable resource by both patients and nephrologists.
- Establishing true partnerships in care between nephrologists and dialysis patients is a very real possibility and a worthwhile goal.

was an important part of their role, and seven thought empowering patients was key.

Eight respondents believed that helping to keep other aspects of patients' lives as normal

as possible would help them to live long and live well. Six suggested that making the unit a good place to be, with competent and supportive staff, was a way to improve quality of life for their patients.

Five nephrologists talked about the importance of empathy with patients; three underscored the importance of having and clearly showing a positive attitude; and three emphasized the role of monitoring and encouraging patient adherence.

Other factors included providing vocational rehabilitation services, goal-setting with patients, resolving family issues, identifying individual and unique barriers to renal rehabilitation, addressing psychosocial issues, and early referral of predialysis patients to nephrologists' care.

The fact that nephrologists can see such activities as educating, encouraging, and empowering as potential role responsibilities is very heartening. This suggests that, when equipped with the appropriate tools and supports, nephrologists will be well-prepared to function as key actors in rehabilitation for people on dialysis. ♦

NEPHROLOGISTS' VIEWS

"Nephrologists first have to deal with the medical problems and the problems with diet. Patients have to have goals, have to want to do something. They need activities...that are important to them."

"Patients need...high quality care, adequate treatments. Patients need to know about the disease and its limitations. They need education. We do this well at the beginning, but continuing education helps patients stay well over time."

"We have to encourage [patients who] are well enough to go places and do things. They should not be tied to the machine...Dialysis is not taking away their goals or choices."

"Give [patients] a positive outlook—feedback that patients are rehabilitated, can work, and can be functional. Make sure staff is educated and supportive with managing patients. Provide an open environment so patients are free to discuss problems. Educate patients to be responsible for their own care to some degree."

"Take care of comorbidities and quality of life symptoms. Success depends on how involved staff is, explaining things to patients, providing good dialysis."

"The nephrologist can...give [patients] knowledge of how they can have a normal life. Help them to feel they're in control. Self-care is important—it gives patients a sense of living, not living to dialyze."

LIFE OPTIONS NEPHROLOGIST OPINION STUDY

Theme: The Patient's Role

“Patients must have internal locus of control—they must own their lives, own the disease, have control. Many patients have internal locus but can't access it. [We need to] tell them, 'you can do it,' and show them they are in control.”

—Nephrologist Opinion Study participant

Taking Charge of Life

For people on dialysis, knowledge and understanding is a key to self-management and self-advocacy. One focus of the Nephrologist Opinion Study was to examine physicians' beliefs about how patients can best attain these goals on the way to rehabilitation.

Nephrologists in the study were in relative agreement about what patients must do to help themselves to live long and live well on dialysis. Eleven of the 15 respondents felt patients' taking charge of their own lives was key to longevity.

Obtaining enough information about ESRD and its treatment was listed as a patient prerequisite by seven respondents. Six nephrologists pointed out the importance of regular exercise/activity for patients, while five suggested that setting and working toward individual goals was an important predictor of long-term survival.

Analysis:

- Nephrologists felt that it is in patients' best interest to take charge of their illness and treatment.
- Understanding the disease and treatment process can help patients find a sense of ownership and control.
- Other nephrologist-defined keys to living long and well include a positive attitude, physical activity, and following the treatment plan.

Implications:

- Programs to increase patients' involvement in their treatment are needed to establish patients' sense of control over their lives.
- Adequate information must be made available to dialysis patients. The more patients know about their own health status, the more empowered they will be.
- The important role of physical activity must be stressed, and ample education about how to exercise must be provided.
- Strategies to enhance patients' adherence to all aspects of prescribed treatments will increase the likelihood that they will live long and well.

Positive attitudes and ample coping skills were mentioned by six nephrologists as key factors if patients are going to live long and

productive lives on dialysis. Other suggestions included maximizing resources, self-advocating, getting sufficient social support from others, treating depression, and maintaining good nutritional status.

In the renal community, it is generally believed that adherence to the full treatment plan is an important issue for dialysis patients—one that has the potential to play a pivotal role in long-term health outcomes. It was not very surprising, then, that 10 out of the 15 nephrologists said overall treatment adherence was essential to patients' ability to live long and productive lives, and three respondents specified consistent adherence to the full schedule of dialysis treatments as essential to continued survival.

More than 70% of nephrologists in the study identified patients' involvement in their own care and/or their ability to take charge of their own disease and its treatment as important activities, likely to affect long-term survival. In light of these endorsements, the moment seems right for developing rehabilitation programs designed to empower dialysis patients to undertake activities of self-management and become partners in their own care. ♦

NEPHROLOGISTS' VIEWS

“Patients have the responsibility to take care, to follow prescribed treatments, to dialyze for the prescribed time. They need to know why the prescription was given. If patients understand, we can help them live a long time. [Even though] they are on dialysis, they still must go on living, and do whatever they were doing before.”

“Patients [need to] empower themselves—they should ask questions, get insights. That...enhances the patient-physician relationship.”

“The first thing that patients need is some sense of curiosity about what's happening to them. They should raise questions, raise ideas. Patients should set goals about compliance—they need to take charge of life on dialysis.”

“[Patients] need to understand the adequacy requirement, the equipment, the access, the payment system, in order to feel well and deal well with problems. They need to know more about what is going on in the unit. They must take an active rather than a passive role in their own care.”

“Patients have to have life goals outside of dialysis that make it all worthwhile. They have to be trained on their diet...They need to know how to quantify foods. Compliance should be a routine. They need an exercise program even before dialysis to gain strength. They need a good support system, interested families—the more knowledge they have, the better they do.”

NEPHROLOGIST OPINION STUDY

LIFE OPTIONS NEPHROLOGIST OPINION STUDY

Theme: Information, Education, and Role Modeling

If you give tools to patients, and patients are educated, then most nephrologists will go along with patient advocacy. The physician is the leader of the team, but he is not the whole team.”

—Nephrologist Opinion Study participant

The Road to Self-Advocacy

One purpose of the Nephrologist Opinion Study was to survey physicians about what information they feel patients need, and in what form. Twelve of 15 nephrologists in the study offered suggestions as to what specific topics might be covered and/or what specific methods might be used for patient education.

Suggestions included making sure information was straightforward; providing a patient instruction book for living long and living well on dialysis; making cause and effect clear in dialysis, so patients can know what to expect as a result of their own behaviors; listing common symptoms and ways of dealing with them; developing teaching notebooks in “looseleaf” form; providing reading materials for support people; developing written materials to augment common verbal instructions; and using videos as an alternative to print materials.

Analysis:

- Information was cited as the most important resource that can be provided to people on dialysis.
- Nephrologists feel patients need as much information as possible about their disease and its treatment.
- People on dialysis may benefit from successful patient role models.

Implications:

- There is an ongoing need for information on every topic related to renal disease and its treatment, and on all aspects of renal rehabilitation.
- Information presented in different venues, at varied times, throughout the course of a patient’s treatment is essential to overall adjustment and ultimate rehabilitation.
- Fellow renal patients are valuable resources who can serve as effective role models and as sources of information and inspiration to other people on dialysis.

Specific educational topics were also suggested by the interviewed nephrologists. For example, seven felt that more information about successfully rehabilitated dialysis patients

could prove very beneficial. Three suggested that information about “keeping ESRD in perspective” would be helpful, three felt there was not enough information currently available on exercise for dialysis patients, and two thought information on having reasonable expectations and setting realistic goals would be useful. Two other important topics suggested were the potential for group settings in which dialysis patients might share experiences, and knowledge and information about self-care options.

Eighty percent of the nephrologists agreed on the need for more information about renal rehabilitation. In addition, just fewer than half of the respondents thought that information would be more meaningful and thus more effective if it came from fellow (successful) dialysis patients. Role modeling was the primary educational intervention about which most of the respondents agreed.

The broad range of recommendations on this theme seems to emphasize the important role of education. It further suggests that many types of knowledge and information are required for people on dialysis to be rehabilitated across all areas of their daily functioning. ♦

NEPHROLOGISTS’ VIEWS

“Patients need concrete information...outlets for emotions and concerns. We need to know where they can go, and who they can talk to about problems.”

“Patients need to be educated about cause and effect in dialysis. They need to know that they can completely control their own symptoms on dialysis by their own behaviors. There is an urgency regarding education. We need adequate education about all the details of care.”

“We have to know about things to plug people into—things to keep us understanding what they’re going through. We have to get patients’ input. We must hear patients’ point of view.”

“Patients need to know that it is possible to do well. [We need to] find out what they want, and identify what stands in the way. Ask them, ‘What would have to happen for you to get a car, get a job, move out on your own?’ Self-advocacy is applicable to most patients. It is the only way to partner and to be genuinely committed in their care.”

“We should find out who people are...Give people whatever control they can possibly have. Sometimes, patients have two crummy choices, but even then they can choose what they want.”

“People can do well on dialysis...they should know they don’t have to be sick all the time.”

LIFE OPTIONS NEPHROLOGIST OPINION STUDY

Theme: Finding Fulfillment in Nephrology

“What I enjoy most is that I get to meet a lot of different people. I get to learn about people. I learn about their lives—I am reminded of what it is to be human.”

—Nephrologist Opinion Study participant

The Human Science

Being good at any given occupation depends, in part, on how much a person enjoys his or her work. One purpose of the Life Options Nephrologist Opinion Study was to find out what nephrologists feel is most compelling about caring for people on dialysis.

Nephrologists in the study were fairly consistent about what they found most compelling about the practice of nephrology. Four said they had chosen the specialty based on exposure to strong role models in the field.

Four nephrologists reported that they were challenged by the complex pathophysiology of renal disease, two cited variety in practice as nephrology’s initial appeal and/or attraction, five noted continuing interest in the skills and technology involved in renal care, and three described nephrology as being like “internal medicine with a narrower focus” or “more-

Analysis:

- Most nephrologists cited long-term relationships with patients as the most compelling part of nephrology.
- Nephrologists found their work to be satisfying and rewarding.

Implications:

- The potential for excellent physician-patient relationships should be maximized through encouragement of ongoing dialogue between renal patients and their nephrologists.
- It seems very likely that satisfied and fulfilled practitioners provide good clinical care and rehabilitation management. Thus, nephrologists’ reported job satisfaction is good news for patients and also might serve to motivate other new doctors to choose this specialty.

focused primary care.” Not surprisingly, two of the three pediatric nephrologists interviewed reported a particular interest in caring for children.

Eight nephrologists also expressed satisfaction with the challenge of giving renal care, six appreciated the chance to improve quality of life for ESRD patients, and four said it was a

wonderful accomplishment and contribution to be able to keep patients alive.

One of the most interesting and important results of this study had to do with patient-physician relationships. While popular culture often portrays the care of chronically ill patients as difficult, demanding, burdensome, and perhaps even depressing, this was certainly not the perception of the interviewed nephrologists.

Specifically, 10 of the 15 physicians interviewed said that the long-term relationships they were able to experience with their chronic renal patients were the most gratifying aspect of their practice. In general, the respondents reported choosing nephrology because of the opportunity it presented for “knowing patients over a long period of time,” “getting to know patients well, and seeing them often.”

Since people on dialysis have identified good relationships with their nephrologists as an important part of their rehabilitation, it would seem that efforts to improve communication between patients and nephrologists will enhance overall renal rehabilitation endeavors. ♦

NEPHROLOGISTS’ VIEWS

“The most compelling thing about the practice of nephrology is the patients—helping the patients to live. It is a test of skill and knowledge to maintain their lives. It is a fruitful field in terms of lives saved.”

“I enjoy chronic patients because you can have relationships—long-term relationships.”

“I wanted to make things right—to try to fix things. Dialysis, nephrology allows you to fix things.”

“I get to know my patients well, build a relationship, know and understand their histories.”

“I like to impact someone. I like long-term relationships. I can talk with patients and pay attention to them and enjoy the challenges and difficulties. I am touched by patients’ stories.”

“There is a close patient-doctor relationship. You see patients more frequently than any other subspecialty. Helping patients feel better once they start dialysis is very rewarding.”

“It is rewarding to care for very sick patients and to give them a chance for a good life.”

NEPHROLOGIST OPINION STUDY

LIFE OPTIONS NEPHROLOGIST OPINION STUDY

Examining Life Behind the Scenes of Dialysis

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expressed the belief that patients need information to increase their own longevity, and many felt that successful patient role models would also boost rehabilitation potential.

Most nephrologists in the study agreed that keys to living long and well on dialysis included: a low number of comorbid conditions, excellent medical care, regular physical activity, and a high level of patient compliance. Negative attitudes and lack of information were the most often cited barriers to rehabilitation. Fortunately, study participants expressed confidence that rehabilitation interventions could help overcome these barriers.

The Role of Nephrologists

When asked about their own roles in maximizing dialysis patients' potential for longevity, almost all of the nephrologists said that providing good medical care was their most important role. More than half also reported that normalizing patients' lives, and providing education and encouragement, were important physician roles.

Interestingly, nearly half of the study nephrologists stated that empowering patients was a key role for them. Further, most respondents agreed that patients must take charge of their illness and its treatment to increase their likelihood of living long and living well.

An Important Finding

One particularly important finding in the Nephrologist Opinion Study was that most of the nephrologists saw the opportunity for long-term relationships with patients as the most compelling aspect of treating renal patients. This is good news, given that improved physician-patient relationships were seen as a high priority by respondents in the Patient Opinion Study.

The challenge of managing the complexities of renal disease was a second compelling aspect of nephrology practice cited by most respondents. Overall, the physicians interviewed reported the practice of nephrology to be very satisfying.

Next Steps

Clearly, the beliefs, attitudes, and hopes that nephrologists hold about patients' clinical and rehabilitation management affect what they communicate, prescribe, and recommend. These "routine" role responsibilities are likely to have a major impact on patients' outcomes.

With this in mind, results from the Nephrologist Opinion Study will be used to develop new Life Options programs and materials. In addition, since many of the topics identified by study nephrologists parallel those in the Patient Opinion Study, future efforts will include developing ways to close the gap between patients' and nephrologists' perceptions of renal rehabilitation.

For More Information

If you would like more information about renal rehabilitation or about the Life Options Nephrologist Opinion Study, please contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777. ♦



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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