Life Options

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*Finding Answers*

## Treating Information-seeking as a Second Job

From the moment of diagnosis, people with kidney disease confront a wide range of questions—about their condition, its treatment, and the effects each will have on their lives. What are my treatment options? Can I continue working? What will my quality of life be like? What is my kidney function? The list is virtually endless.

Finding answers to these questions through active information-seeking is a key to successfully adapting—and to living long and well with kidney disease.

### ATTITUDE, ANSWERS, ACTION

Life Options has long believed that information forms the foundation for rehabilitation. For people with kidney disease, the potential for living long and well rests with achieving the following goals:

- Developing a positive ATTITUDE that supports active involvement
- Getting ANSWERS that will help them self-manage effectively
- Taking ACTION on their own behalf

As discussed in the last issue of the *Renal Rehabilitation Report* (*RRR*), when patients recognize and embrace the potential for a good life, a positive attitude is likely to follow. The next step, moving from a positive attitude to getting answers, is an important part of taking charge of kidney disease.

### ACTIVE INFORMATION-SEEKING

Information-seeking is more than simply receiving educational materials from the dialysis unit or other sources. In its truest sense, effective information-seeking requires patients' active commitment to learning—and an intent to use the knowledge they gain. This is part of taking on the "job" of self-managing a chronic disease.

*(continued on page S8)*

## Message from the *New* LORAC Chair

It is with great enthusiasm that I accept the torch from Dr. Derrick Latos and begin my LORAC Chairmanship. Focusing our efforts on promoting patient self-management throughout the Kidney Disease Cycle is a critical challenge for the entire renal community. As a practicing physician, I have seen that patient functioning and well-being can be optimized and health and longevity improved. Encouragement from healthcare professionals, and commitment from patients and from those who care about them, are important tools for accomplishing this.

This issue of the *Renal Rehabilitation Report* (*RRR*) is the second in a series of three issues focusing on patients' roles in their own care. Taking action to seek accurate and relevant information is a vital part of the self-management process. Clinicians can help direct their patients to seek information that is specific and tailored to their needs.

This issue of the *RRR* also introduces a new Chain of Logic, a theoretical model that ties the whole concept of rehabilitation together—from process to outcomes.

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RENAL
REHABILITATION
REPORT

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### *Research Reveals Important Links*

# From Rehabilitation Process to Rehabilitation Outcomes

Every day, each of us engages in a host of activities that shape and define our lives. We take care of ourselves, take care of others, work within our homes, or outside of them—we run errands or tend to the yard. The specifics vary from person to person, but these activities form the routines of our daily lives.

In the healthcare setting, our ability to perform day-to-day physical activities is "physical functioning." Our ability to carry out mental, emotional, and psychological activities is "mental health functioning," or well-being.

It's easy to see why physical functioning and mental well-being are important. After all, our ability to carry out our desired physical and mental activities helps determine our quality of life.

But what do physical functioning and mental well-being have to do with rehabilitation? With information-seeking? With kidney disease in general? To answer these questions, it's helpful to start at the beginning, with the very basics of rehabilitation.

**In Memoriam**
Bruce Lublin 1946-2002

*Life Options lost an original LORAC member when Bruce Lublin died on July 16 at his home in Hartland, WI. Bruce exemplified what's possible with a positive attitude, active information-seeking, and patient self-management.*

*Living productively and enthusiastically for more than 30 years on home hemodialysis, Bruce became an expert on his machine and his own health. With his wife and dialysis partner Vicki, he learned so much about his disease and his machine that he often gave his doctors some ideas for treatment.*

*Besides serving Life Options, Bruce also was chair of the Patient Services Committee of the National Kidney Foundation of Wisconsin, a member of ESRD Network 11 Consumer and Medical Review Committees, and a much-valued national speaker.*

*Thank you, Bruce, for sharing your life and tenacious spirit. You taught us how to live the good life.*

## MAKING THE CONNECTIONS

Life Options defines "rehabilitation" as patients' ability to live long and productive lives with kidney disease. According to Life Options, rehabilitation is both a process and an outcome. The "process" includes key elements like development of positive attitudes, active information-seeking, and self-management activities, such as exercise. For the best outcomes, the responsibility for the rehabilitation process is shared between healthcare providers and patients.

Providers need positive expectations that patients can and will engage in the process—they must facilitate patients' involvement in every way possible. Patients, for their part, must accept the challenge, take advantage of available opportunities, cultivate a positive attitude, obtain the answers they need, and then take action on their own behalf.

## REHABILITATION OUTCOMES

The outcomes of rehabilitation have to do with how healthy or well a patient can stay and how long a patient can live, despite the presence of a chronic disease. It has long been known that certain clinical measures, like serum albumin levels and dialysis adequacy (Kt/V,)[1] affect the outcomes of hospitalization (morbidity) and death (mortality).

Recently, several studies have examined the relationship between functioning and well-being (FWB) and morbidity and mortality. These studies have shown that patient-reported measures of FWB can predict dialysis patient morbidity and mortality as effectively as some clinical measures.[1,2]

## TYING IT ALL TOGETHER

When we put all of these concepts together, we come up with a straightforward "chain of logic," or theoretical model (see *Chain of Logic* diagram, at right). We know that:

- To live productively, individuals must be able to function in their daily lives.

- To function well despite kidney disease, patients must embrace rehabilitation—they must work to maintain a positive attitude, seek information needed to self-manage, and then transform that attitude and information into action.

Finally, we know that such positive steps will improve the chances that people can live long, full, and productive lives with kidney disease.

## INFORMATION

This issue of the *Renal Rehabilitation Report* discusses active information-seeking as a part of the rehabilitation process necessary to achieve positive rehabilitation outcomes. Life Options research has shown that information and active, comprehensive self-management are linked with improved functioning and well-being.[3,4]

Previous research has already shown that FWB is related to the ultimate outcomes of decreased mortality and morbidity.[1,2] Future studies are being planned to see if interventions that improve FWB will, as predicted, reduce morbidity and mortality. If so, the path to improved patient outcomes will become even clearer.

## THE BOTTOM LINE

Research continues to reinforce the common sense notion that, with regard to kidney disease, knowledge is power. Helping patients find the information they need to become active partners in their care is important for preserving or improving functioning and well-being—and enhancing their ability to live long and well with kidney disease. ◆

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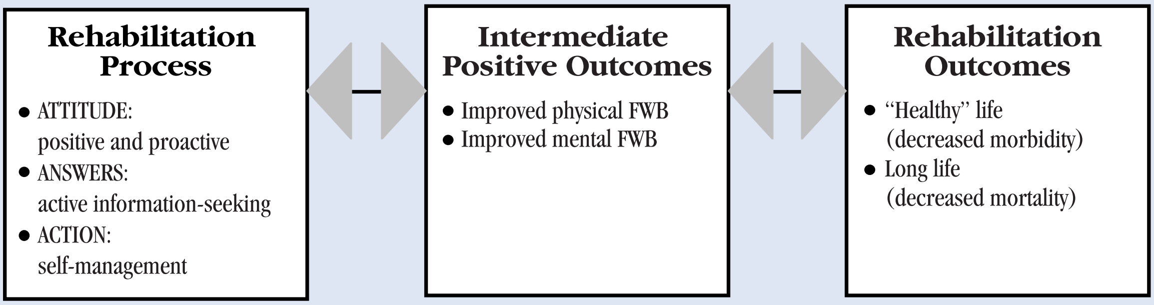
## Rehabilitation Process and Outcomes: Chain of Logic



**Rehabilitation Process**

- ATTITUDE: positive and proactive
- ANSWERS: active information-seeking
- ACTION: self-management

**Intermediate Positive Outcomes**

- Improved physical FWB
- Improved mental FWB

**Rehabilitation Outcomes**

- "Healthy" life (decreased morbidity)
- Long life (decreased mortality)

*30 Years of Learning*

# Dialysis Patient Shares a Lifetime of Seeking and Finding Answers

> **"Take advantage of all that's available to you. Do what you can to get involved and educate yourself about ESRD and dialysis."**
>
> **—Bruce Schultz**

Bruce Schultz has been on hemodialysis for more than 30 years, without interruption. In that time, the 44-year-old has learned a lot about how to live well with kidney disease.

"Dialysis can give you a longer lifespan, but it can't give you a life," he says. "That's something you have to do yourself." According to Bruce, living productively and happily with kidney disease means finding the information you need to become involved in your treatment and care.

### EARLY DIAGNOSIS

At 2 years old, doctors discovered that Bruce had a ureter defect that was destroying his kidneys. Bruce spent much of his childhood in and out of hospitals, undergoing several surgeries before his kidneys failed at age 13.

In those early days of dialysis, Bruce was one of a fortunate few to be selected for the life-saving treatment. "There were no dialysis centers in my area, so my dad and I went to Miami to train for home hemodialysis, and my mother got the house ready."

From the start, strong family support helped him maintain an active lifestyle. He finished high school on time, went to college, and earned a Master's Degree in Counseling Psychology. "I don't feel like I've missed a thing," he says. "I was just as active as any kid on the block."

### ADJUSTING TO DIALYSIS

For Bruce, the road to success was not without obstacles. "When I first started on dialysis, there were no support groups, no renal dietitians, no other people on dialysis close by," he explains. "All I had were my aluminum binders and a list of things not to eat."

There were other challenges as well. "As a teenager, I wasn't very compliant," he admits. "I didn't follow the diet and fluid restrictions, and I wasn't good about taking my binders."

The turning point came in his early 20s, after a long night out with his friends. "I think we hit every bar on the East Coast," Bruce recalls. "I didn't get home until 4:00 in the morning." His father immediately took charge.

## Q&A ASK THE EXPERTS: A PHYSICIAN'S VIEW ON INFORMATION-SEEKING

***An Interview with Stephen Z. Fadem, MD, FACP***
*Clinical Associate Professor, Baylor College of Medicine*
*and founder of* nephron.com
*Houston, Texas*

**Q** *How essential is it for patients to actively seek information?*

**A** Information-seeking is important because it empowers patients. It helps them feel more like part of a team, allows them to share in their treatment successes, and enables them to become involved in problem-solving related to their care.

In addition, by actively seeking information, patients can communicate on a much higher level with their physicians. Since these patients have already come to understand the basics of their disease and its treatment, their providers can focus on more essential information and begin their care at a more advanced level.

**Q** *What factors motivate patients to search for information?*

**A** It really depends on the individual. Often, when people become sick, it's instinctive for them to strive to be healthy again. Early on, they may be confused; they may feel as if the world is caving in. At this point, they need to sort things out and get organized. Many people begin looking for answers and support in search of hope and a plan for the future. This is a very good way to begin the process of adapting.

**Q** *Where can patients go to find information?*

**A** Today, there are many resources available to patients. Of course, the doctor's office, dialysis unit, and transplant center are all good places to start. The Internet is another excellent resource. In addition to providing information, many websites and e-mail groups can put patients in touch with others who have gone through the same ordeals and have done well. These patients can serve as great sources of inspiration and support.

For patients who don't have access to the Internet, calling or writing an organization is another option. Patients can request that information be sent to them. Organizational mailing lists are another choice. Patients can obtain outstanding resources from groups such as Life Options, AAKP, NKF, NIH, and dialysis chains or supply companies.

"He knew I was in trouble, so he put me on the machine right away," Bruce recalls. "It took another two treatments before I felt human again."

After he felt better, Bruce was met with an ultimatum. "My father told me he couldn't see continuing home dialysis if this was how I was going to handle myself," Bruce recalls. "I would have to get my treatments in-center if I continued being dangerously irresponsible."

"That little talk was not magic," says Bruce, "but I never again got drunk and drove, or overloaded myself with fluid like that." He learned how to take an active role in his own treatment, which gave him the confidence and improved attitude to deal with dialysis effectively.

## TAKING ACTION

Since then, Bruce's search for information has spanned decades. "I've learned a lot just by talking with my doctors, even now bringing a list of questions," he explains. "People on dialysis today don't have to make the same mistakes I did." He has also used the Internet, including the Dialysis Support e-mail list, to talk with other patients.

Over the years, Bruce has seen big improvements in dialysis and in the quality and quantity of kidney information. Information has helped him become involved in self-care, maintain a regular exercise program, and continue working. "I've had a lot of problems with hyperparathyroidism," he says. "So, right now, I'm learning about my options for transplant."

He hopes information will teach others about options. "Don't just sit back and let things happen," he advises. "Take advantage of all that's available to you. Do what you can to get involved and educate yourself about ESRD and dialysis."

For Bruce, the strategy is simple. "Develop good relationships with your healthcare team and learn to use resources like the Internet. Stick close to the diet and fluid restrictions, take your medications as prescribed, don't skip or shorten dialysis time, and exercise regularly and sensibly."

The benefits, he says, are well worth the effort. "Knowledge prevents kidney disease from looming so large in your life," Bruce says. "After you learn what you need to do, you can go on with the rest of your life." ◆

Finally, patient support groups are among the most valuable resources in a renal community. As patients develop teams, they can see firsthand the benefits of becoming well-informed and playing an active role in the management of their disease.

**Q** *How can physicians encourage patient information-seeking?*

**A** Physicians need to be aware of the existing information. The nephrology community at large needs to ensure that patients and staff have access to valid information. Nephrologists also have a role in educating primary care physicians, often the first line in dealing with patients who don't yet need dialysis and hopefully never will. By helping to educate these physicians, we can play an important role in delaying the progression of kidney disease.

Kidney disease worsens over time, but the earlier we treat patients the better. This requires a shift in the paradigm. Ideally, we will move from a scenario in which patients show up in the dialysis center or emergency room very sick with uremia to one where patients are evaluated early enough to begin dialysis with a functioning access, or can preempt dialysis entirely with a transplant.

**Q** *Are we making progress in encouraging patients to seek information?*

**A** I think we are in transition. Ten years ago, we were really just getting started. We didn't have a lot of the valid medical studies that we have today, and we didn't have the understanding of Internet technology that we do now. With this new information and technology, we are learning the best ways to communicate, and we are learning that it does not work the same for each patient. We still have a lot to learn. Ten years from now, what we currently consider state-of-the-art will likely be looked upon as primitive.

**Q** *What are your thoughts on approaching kidney disease as a "second job"?*

**A** That's one of the comparisons I make with my own patients who are about to start dialysis. Kidney disease is a major lifestyle change, and dealing with it really does become a full-time job. It's more difficult to work two jobs than one. Staying healthy is a very difficult extra job when one has a chronic disease, be it kidney failure, cancer, or heart disease. With chronic disease, the reward for this extra effort is often a better quality life, and a longer life. The alternative—well, there really isn't any alternative. ◆

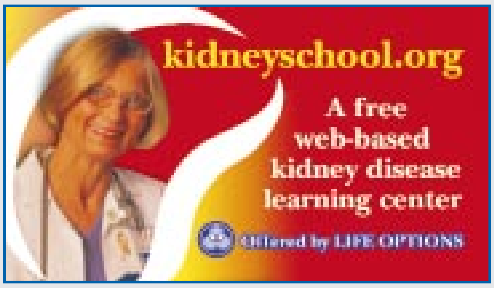
*Finding Answers*

# Treating Information-seeking as a Second Job

(continued from page S1)

In the context of kidney disease, information-seeking is a lifelong process. The reason is perhaps best explained with the help of the Life Options Kidney Disease Cycle.[1]

The Kidney Disease Cycle proposes that once individuals are diagnosed with kidney disease, they are kidney "patients" for as long as they live. Whether their disease remains at the earliest stage of chronic kidney disease (CKD), or progresses to kidney failure requiring transplant or dialysis, kidney disease is chronic—it has no cure.



## Tell Your Patients about Kidney School™!

Life Options has produced full-color Kidney School business cards that you can give out to your patients. The card, pictured above, features a brief description of Kidney School, the website address, and contact information.

To obtain cards, call Life Options at (800) 468-7777 or send your request along with a check (made payable to The Medical Education Institute) to:

Life Options Rehabilitation Program
c/o The Medical Education Institute
414 D'Onofrio Drive, Suite 200
Madison, WI 53719

The cost is $12 for 100 cards and $9.50 for each additional 100 ordered at the same time. Wisconsin residents please add 5.5% sales tax. ◆

Clearly, there are different sets of questions and different sets of knowledge required at each stage of kidney disease. But, information—and a lot of it—is required at each stage.

### CKD—EARLY INTERVENTION

Past issues of the *RRR* have addressed the information required at the later stages of kidney disease. However, since being informed plays a key role in patients' outcomes, there is no doubt information-seeking should begin at the earliest possible stage of CKD.

And there are good reasons for patients to engage in early information gathering. Early diagnosis and therapeutic interventions may help people with CKD slow—or perhaps even avoid—progression to kidney failure. These interventions include strict blood glucose control in diabetics and strict blood pressure control.[2]

Particularly in the early stages of CKD, kidney function may be improved or preserved. In addition, early in the disease course, treatment information can be gained at a more measured pace, and conditions such as anemia and bone disease can be monitored, so if patients do progress to dialysis or transplant, their health won't be already compromised.

In practical terms, information helps people begin the process of taking control. It enables them to recognize and report symptoms, ask informed questions, and begin to manage as many aspects of their care as possible. Information can help patients make the necessary adaptations so that their lives with kidney disease continue to resemble the lives they enjoyed before.

### CHALLENGES

There is no doubting the value of information. Finding appropriate information about early CKD, however, can be a challenge. Often, CKD is diagnosed before patients are under the care of a nephrologist.

## Tips for Patients: Finding the Information You Need

The job of seeking information about kidney disease can seem overwhelming—there is a lot to know, no matter what stage you're in. Fortunately, there are many ways to find what you need to take control and adjust successfully. Here are some places to start:

### Kidney organizations.

Several groups specializing in kidney disease offer free educational materials. Ask about local chapters, affiliates, and support groups—getting involved is a great way to network with kidney professionals and other patients.

- **American Association of Kidney Patients (AAKP)**
  *www.aakp.org* - (800) 749-2257
- **American Kidney Fund (AKF)**
  *www.akfinc.org* - (800) 638-8299
- **Life Options**
  *www.lifeoptions.org* and *www.kidneyschool.org*
  (800) 468-7777
- **National Kidney Foundation (NKF)**
  *www.kidney.org* - (800) 622-9010
- **The Polycystic Kidney Disease (PKD) Foundation**
  *www.pkdcure.org* - (800) 753-2873

### Your healthcare team.

Build a positive information-sharing relationship by talking openly with your doctor. List your questions before each visit, and don't be afraid to ask them. Nurses, social workers, dietitians, patient care technicians, and pharmacists can also help you locate valuable information.

### The library.

Your local library can help you locate a wide range of resources, from medical books to renal journals. Most libraries also offer free Internet access and trained staff to help you get on-line.

### The Internet.

Websites such as MEDLINEplus (*www.nlm.nih.gov/medlineplus*) and Nephron.com (*nephron.com*) offer a wide range of information about kidney disease and treatment. The Internet also has resources like the DialysisSupport mail list, an on-line support group you can subscribe to from the patient community section of the Life Options website.

It's important to remember—no matter what the source—always check with your doctor before making healthcare changes based on the information you find. ◆

Since the majority of CKD patients receive their care from a primary care physician or other non-nephrologist, there are no renal staff members to answer questions as they arise. In addition, people with early CKD don't have easy access to in-unit educational materials or to other kidney patients.

As such, the responsibility for gathering information falls largely on CKD patients themselves. This is no small task—there is a lot to know. Some strategies for getting started are included in *Tips for Patients: Finding the Information You Need*, above.

For people with kidney disease, actively seeking information to take action and become involved in their own care is a key to positive long-term outcomes. The challenges of doing so are well worth the rewards. Information forms the foundation for self-management, partnership in care, and, ultimately, a long and full life. ◆

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FOCUS ON ANSWERS

*From Early CKD to Dialysis*

# Patient Information-seeking Facilitates Adjustment

THE ART OF THE POSSIBLE

"When it comes to taking charge of life with kidney disease, one of the most important things you can do is to learn as much as possible about your condition and its treatment," says 44-year-old Amy Staples. "If you arm yourself with knowledge, you can more fully direct your life."

Amy has been on dialysis for less than 6 months, but she is no newcomer to chronic kidney disease (CKD). "When I was about 4 years old, my father was diagnosed with polycystic kidney disease," she explains. "Throughout my childhood, he was in and out of the hospital. With home hemodialysis, he was able to remain strong and active for several years. Kidney disease was a major part of our lives."

## INTRODUCTION TO CKD

Amy was 21 when she learned that she, too, had CKD. "I had reacted to a medication I was taking for a bladder infection," she recalls. "My urologist did several tests and found that I had inherited the polycystic kidney disease."

Over the next few years, she experienced relatively few symptoms. "I felt healthy," she says. "I lived a normal life. I got married when I was 25, and my husband and I decided to start a family. We have five children—twin 18-year-old daughters, Heather and Sara; two sons, Joseph, 15, and Darby, 14; and daughter Hannah, 11."

## THE SEARCH BEGINS

A chance meeting helped start Amy's search for information. "I was working at a big hospital in the medical records department," Amy recalls, "where I crossed paths with my urologist. He told me, 'You have kidney disease. You can't change that, but you can learn as much as possible, so you're prepared to cope with whatever comes.'"

For Amy, that advice was profound. "I wanted to be around for my family, for my kids," she explains. "So I decided to go to the medical library to see what I could find. I began reading everything I could get my hands on."

## STARTING DIALYSIS

Amy was 36 when she began noticing the distinct effects of her kidney disease. "I started having problems with multiple kidney stones and severe kidney infections that required hospitalization," she explains. "At one point, I lost about 50% of my kidney function in less than a year."

Over the next several years, her condition remained relatively stable. That all changed early in 2002. "I began feeling very tired, and I noticed that my urine output had really declined," she says. "I went to the doctor and found that my kidney function had fallen from 20% to 11% in less than 6 weeks. Two weeks later, I was beginning in-center hemodialysis."

Even though Amy had known for some time that she would eventually need dialysis, her initial reaction was shock. "My kidney function had been stable for so long," she says. "The reality hit me like a slap in the face."

## MOVING FORWARD

Despite the early challenges, Amy handled the transition in the best way she could—by making informed decisions about her treatment. It began with her choice of modality.

"I had learned that people on home hemodialysis live longer and aren't hospitalized as often, and that made things easy," she explains. "I'm still young, I have a family, and I want to live a lot more years, so home hemodialysis was ultimately the choice for me."

Even though her decision was easy, she has had to take a proactive approach on her path to home hemodialysis. "I had to change doctors three times to find one who would refer me to home hemodialysis," she says. "Sometimes, you have to be persistent to get what you want."

## MOVING ON

Even with all she has learned, Amy's quest for information hasn't ended. "I find a lot of information online," she explains. "The Internet has also pointed me to additional resources, from predialysis programs to other patients."

When it comes to information-seeking, her advice to others echoes the advice she herself received nearly 2 decades ago. "Arm yourself with knowledge, accept what is, and change what you can," she says.

It's a philosophy that has served Amy Staples well. "Dialysis really hasn't changed my life," she explains. "I feel I've thrived on dialysis, and I believe things will only get better."◆