



Integration in Nephrology

Life Options Unveils New Kidney Disease Paradigm

Since 1993, the Life Options Rehabilitation Program has worked to help dialysis patients live long and live well. Now in its 10th year, Life Options is expanding its focus to encompass predialysis, or chronic kidney disease (CKD)—and offering a new paradigm for the kidney disease population in the process.

Life Options defines “rehabilitation” as a process in which patients, family members, and professionals work together to achieve the outcomes of optimal physical, social, emotional, and role functioning in the presence of a potentially disabling illness. Through research, Life Options has identified a number of strategies that promote rehabilitation, including:

- Helping patients believe that they will have a future and a good quality of life
- Providing patient education that supports active partnership in care and comprehensive self-management of kidney disease and its treatment

To advance rehabilitation, Life Options translates the results of its qualitative and quantitative studies into free, research-based education materials. Life Options research suggests that encouraging positive attitudes and creating an expectation of patient involvement in care is best done early.^{1,2} Reaching patients early in the course of their illness can improve the chance that they will adapt successfully to kidney disease.

CKD: A NEW APPROACH

In the past, Life Options conceived of kidney disease as a continuum that progressed from at-risk individuals to kidney disease and kidney failure.

But the notion of a continuum did not fully portray the complexity of kidney disease, nor did it address the fact that kidney disease is, by definition, a *chronic* illness. Further, treatment modality changes were not represented, and it was difficult to explain to patients all that life with

(continued on page S6)

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Message from the LORAC Chair

As a practicing nephrologist for 25 years, I have seen for myself the difference that rehabilitation can make in the lives of my patients with kidney disease and kidney failure. Empowering patients enables them to lead happy and “healthy” lives. The Life Options Rehabilitation Program, guided by the Life Options Rehabilitation Advisory Council (LORAC), develops research-based products and programs to help clinicians empower their patients.

This issue of the quarterly *Renal Rehabilitation Report (RRR)* introduces a new Life Options concept: integrating the full spectrum of kidney disease and its treatment. By looking at the common needs of CKD, dialysis, and transplant patients, we have an opportu-

nity to foster cross-specialty learning that can improve outcomes for all people with kidney disease.

This *RRR* also introduces the new Life Options web-based patient education curriculum: Kidney School™. Two years in development, Kidney School will help CKD and early dialysis patients learn to ask better questions, make better healthcare decisions, and improve the quality of their own lives.

Derrick Latos, MD, FACP, of Nephrology Associates, Wheeling, WV, is chair of the LORAC, and serves on the boards of directors for the Mid-Atlantic Renal Coalition (ESRD Network 5), and the Forum of ESRD Networks. Serving as the nephrology representative, he also is Vice-Chair of the ACP-ASIM Council of Subspecialty Societies. To obtain Life Options materials, visit the Life Options website at www.lifeoptions.org or call (800)468-7777. ♦

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www.KidneySchool.org

Life Options New Kidney School™ is Now On-line

How can we prepare kidney patients to stay as healthy as possible? By helping them to believe they can still have a good life if they partner effectively with their healthcare team—and providing the tools to help them learn what they need to know. Kidney School, a new Life Options web-based, interactive education curriculum in sixteen 20-minute modules (www.kidneyschool.org), is designed to help patients do just that.

INSPIRE, MOTIVATE, EMPOWER

The purpose of Kidney School is to inspire, motivate, and empower patients to take an active role in their healthcare—and improve their chances to live long and live well. Based on adult education principles and 9 years of Life Options research, each module has a pretest/posttest; patient-friendly content; pop-ups, photos, and patient quotes; an evaluation; and a certificate of completion. Animated graphics illustrate key concepts. A multidisciplinary panel of Life Options Rehabilitation Advisory Council (LORAC) members and patients and professionals from the renal community reviewed every module.

Support the Life Options Rehabilitation Program!

Life Options is administered by the Medical Education Institute, Inc. (MEI), a non-profit private foundation dedicated to helping people with chronic disease learn to manage and improve their health.

If you like the *Renal Rehabilitation Report*, and other Life Options materials, tell someone you know: your co-workers, friends on dialysis, chronic kidney disease patients, Amgen sales representatives, or others!

Thank you for your support!

A hallmark of Kidney School is its focus on attitude and behavior change to support self-management. Users provide information on their goals and challenges, and answer questions related to each topic. This information (kept confidential), is used to create a *Personalized Action Plan* for each module. Patients can print their plans and use them as step-by-step guides for goal-setting and action.

Adult learners (including kidney patients) assimilate information that is relevant to their lives—but people with kidney disease may not yet know what is relevant or why. For this reason, each Kidney School module begins with a rationale for why the topic is important, and what the patient can do.

GOING TO KIDNEY SCHOOL

Visiting Kidney School is a fun and easy way for patients to learn new information—or reinforce what their healthcare team is teaching them. With more knowledge, patients will be more effective partners in their own care.

Kidney School is on-line and available for free 24-hours a day. From the table of contents, patients can choose topics—in any order—from the completed modules. Additional modules will come on-line throughout 2002. Topics include treatment options, the healthcare team, following the treatment plan, coping, vascular access, anemia, lab tests, dialysis adequacy, and many others. Software requirements and downloads of up-to-date versions of key programs are available on the site. ♦

In Memoriam

The Life Options team is sad to report the death of Fred Russell, whose life and ideas inspired many, including readers of a recent story in the Renal Rehabilitation Report. Fred, who died in November 2001, was 57 years old and a dialysis patient since 1991. He will be remembered as one who loved to learn new things, was active in his Mormon faith, and believed in information and action for kidney patients. As his wife and dialysis partner Debbie says, "His example will stand forever before his three children, seven grandchildren, and many others...as one who endured well the trials placed before him."



No Computer? No Problem!

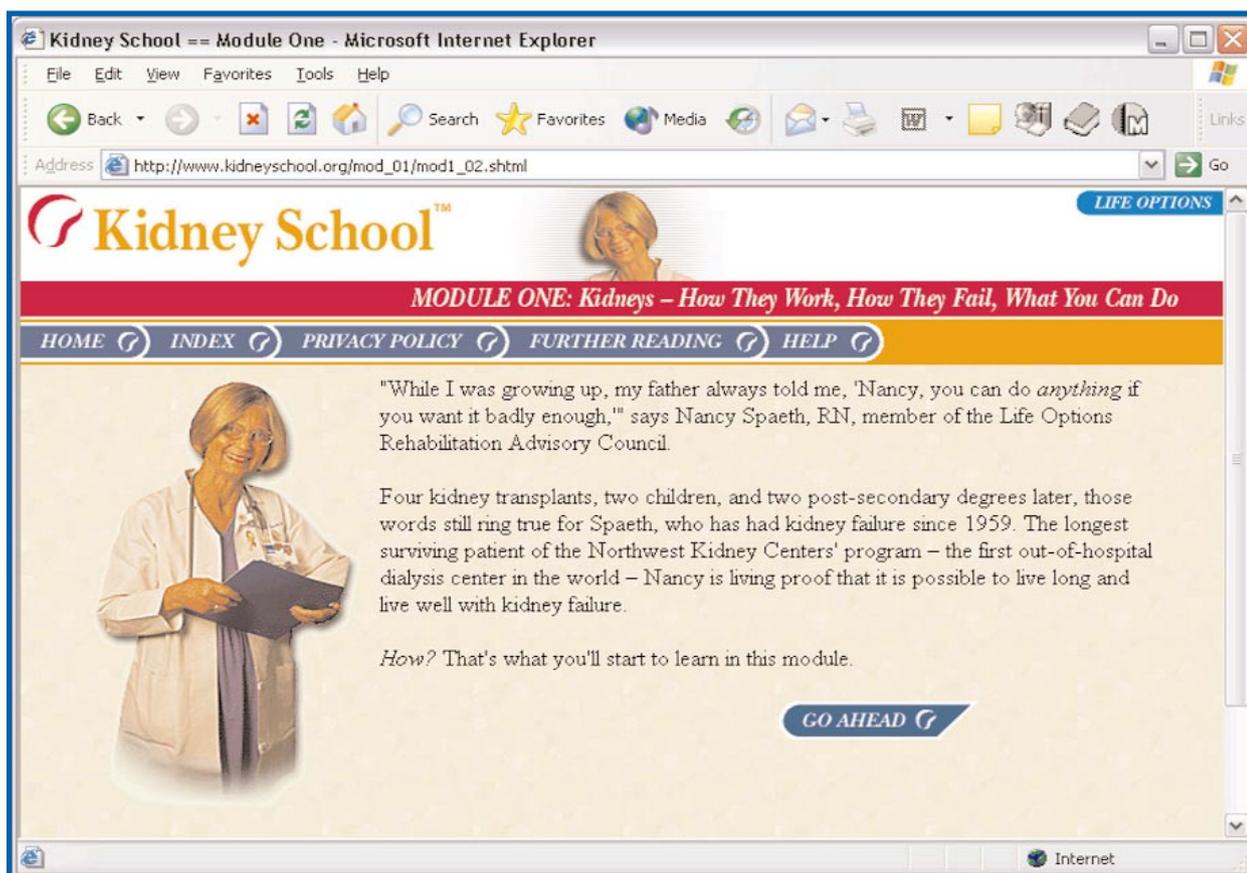
Visiting Kidney School™ at the Library

With resources from Kidney School to dialysis chat groups, the Internet is a valuable source of information for patients and family members. And, it isn't necessary to have a computer at home or even to know how to use one. Navigating the Internet is easier all the time.

Some dialysis units now offer Internet access in waiting rooms or chair-side. Life Options encourages dialysis units to make Internet-ready computers accessible to patients. If computers are not available to patients at dialysis, most public libraries offer free Internet access and have trained staff to help. While policies and procedures may vary from library to library, here are some questions to ask:

- Do you offer Internet access to the public?
- Is there a charge?
- Do I need to sign up ahead of time?
- Is there a time limit for Internet use?
- Can someone help me to get started?
- Can I print pages from sites I visit?
- Is there a charge for printing?

With this information and the Kidney School website (www.kidneyschool.org), patients can be on-line and surfing in no time. ♦



One CKD Patient's Journey From Kidney Transplant Back to Dialysis

"You need to do more than just trust your doctor. You need to find the information to make informed decisions about your life and your future."

—Jennifer Castillo

"This is your life," says 40-year-old dialysis veteran, Jennifer Castillo. "You need to do more than just trust your doctor. You need to find the information to make informed decisions about your life and your future."

As Castillo's experience shows, this is sound advice for people with chronic kidney disease (CKD), whether they're facing a new diagnosis or a failed transplant.

EARLY EXPERIENCE

Castillo began hemodialysis in 1979, when reflux caused her kidney failure. Just 18 years old, she was a model of self-management success from the start. "I read a lot and asked a lot of questions," she recalls. Castillo also joined the American Association of Kidney Patients (AAKP). "AAKP showed me that I could continue to go to school, that I could work—that I could have a normal life."

Castillo became actively involved in her own care, making informed decisions about her treatment. She began to set up her own dialysis machine and insert her

own needles. "I'm very proactive," she explains. "I don't wait around—if I can do something myself, I will." This approach has helped Castillo lead an active, full life with kidney disease for more than 20 years.

UNCHARTERED WATERS

Castillo had an early unsuccessful transplant, but decided to give transplant another try in 2000. This time, Castillo faced 13 months of acute and chronic rejection.

The experience took a devastating physical and mental toll. "I lived with a lot of pain," she says. Among her challenges, Castillo gained 46 pounds of fluid, struggled with high blood pressure, and could barely walk. "I finally begged to go back on dialysis," she explains. "I realized the job of the transplant team was to save the transplant. I think they would have kept trying to save it as long as I was willing to let them."

TAKING ACTION

Despite more than 2 decades on dialysis, Castillo found herself in a new situation, with few resources to guide her. "Everyone

Q&A

ASK THE EXPERTS: EXPLORING CHRONIC KIDNEY DISEASE

An Interview with Bryan Becker, MD, FACP
Assistant Professor of Medicine and ESRD Medical Director
University of Wisconsin—Madison

Q How important is it for physicians to introduce self-management to people with chronic kidney disease (CKD)?

A We have data to suggest that some therapies may help slow the progression of kidney disease. From early on, then, discussing self-management and what patients can do becomes very significant. As patients progress, self-management helps them to recognize important signs and symptoms.

Q What is the physician's role in education for people with CKD?

A The physician's initial challenge is conveying the reality of kidney disease to the patient. We need to take time to describe how the diagnosis is made, discuss what it means, and identify resources.

For some patients, our role may include helping them tap into organizations like the National Kidney Foundation (NKF). For patients with diabetes, it may mean developing a team approach between the

endocrine team and the nephrology team. For other patients, it may mean working with a social worker to address employment issues.

Q How would you describe the various stages of CKD?

A Stages of CKD are measured by a patient's creatinine clearance or GFR. When patients move from stage 1 to stage 2, evidenced by a decrease in their GFR, they may not have overt symptoms. If you dig deep, you may see some subtle changes in energy level or decreased ability to concentrate.

As a person moves into stages 3 and 4, you tend to see more non-specific symptoms—not feeling well, malaise, maybe some depression—that patients may attribute to, "I just don't feel well today." It's only when patients reach stage 4 that you begin to see more of the true biochemical abnormalities associated with kidney failure.

Q How do you approach education for patients in each of the stages of CKD?

A Most nephrologists usually see patients in stages 3 and 4. At that point, the primary messages become 1) you have this diagnosis,



encourages transplant,” she says. “Then, once it fails, there is nothing for rehabilitation, nothing to help you rebuild your life. I think they assume you already know all you need to know.”

To get back on her feet, Castillo returned to her self-management principles. She worked closely with her social worker and visited the dialysis unit on her off days to spend time with other patients who had lost transplants. “That helped a lot,” she says. “It was comforting to know that others were able to bounce back.”

Castillo also began an exercise class, reached out to friends, and read a book on bereavement. “I came to realize that no matter how much I knew, it didn’t matter—nothing could have made the kidney work for me.”

LESSONS LEARNED

Today, back on dialysis for nearly a year, Castillo continues the slow journey to recovery. She has lost the fluid she gained, her hair has grown back, and the stiffness and pain are getting better.

Though she was laid off and is unemployed for the first time in her life, she is looking forward to returning to work.

“I’m becoming more and more active,” she says. “My concentration is better, and my mental health is improving.”

Despite her failed transplants, Castillo continues to encourage new patients to consider all of their treatment options, including transplant. “I’ve had bad experiences with transplant,” she says. “But a lot of people do very well and keep their transplants for 10 or 20 years.” Castillo does caution that no treatment—including transplant—is a cure for kidney disease. “Transplant is just one treatment,” she explains. “Just like dialysis is.”

CKD SELF-MANAGEMENT

As Castillo has shown, it’s important for all CKD patients—whether newly diagnosed or dealing with a failing transplant—to learn about kidney disease, to self-manage their lives and health, and to be advocates for themselves.

“Every time you face something new, you have to be even more knowledgeable, you have to direct your care even more,” she says. “No matter what the challenge, the way to survive most effectively is to learn as much as you can.” ♦

and 2) let’s begin the education process. An important part of this is helping patients accept their diagnosis so they can move on.

Q *What can physicians do to dispel patients’ fears and instill hope for the future?*

A I think two things are very important: acknowledging the patient’s concerns, and finding resources—perhaps another patient—to talk to that person about what is likely to ensue and how to retain some autonomy.

Resources like Life Options’ Kidney School (www.kidneyschool.org) can provide patients with straight-up information and an independent confirmation of, “this is what I’m going to need to do in the future, and this is how I can best approach my own therapy.”

Q *How can physicians promote better communication with patients?*

A Today various pressures push our patient interactions into smaller timeframes. But it’s at the heart of what we do best if we can be

open and keep patients’ wishes in mind. I don’t sit in their chairs. I haven’t had kidney disease. But I do appreciate the strength it takes to have it, as well as the sacrifices to accommodate therapy into a lifestyle.

As physicians, if we are open and show respect for the fact that people in the unit are working hard, it builds a sense of trust. This doesn’t happen overnight. It happens in time, through brief and long interactions, some personal and some highly clinical. But what accrues is a unique bond between physicians who care for chronic illness and the patients who are afflicted with it. This trust helps improve communication.

Q *What benefits have you seen in CKD patients who come to self-manage?*

A I think the Life Options credo can be invoked by many individuals who adopt such an attitude. They truly are able to “live long and live well.” They are able to work, able to have an enjoyable family life, and able to integrate into their own existence a sense that, “this is part of me—but not all of me.” ♦

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(continued from page S1)

kidney disease might involve. It became clear that a continuum was not the best way to depict the course of kidney disease.

Instead, chronic kidney disease is more precisely viewed as a cycle. The schematic below was developed at the September 2001 meeting of the Life Options Rehabilitation Advisory Council (LORAC), the multidisciplinary expert panel that guides Life Options activities.

As depicted in the diagram, initial stages of CKD are likely to progress in a step-by-step manner. Once patients develop permanent kidney failure (end-stage renal disease), they remain in the cycle as long as they live. Their position in the cycle will likely change, but since there is no cure for kidney disease, they will be somewhere in that cycle for the rest of their lives.

IMPLICATIONS OF THE CYCLE

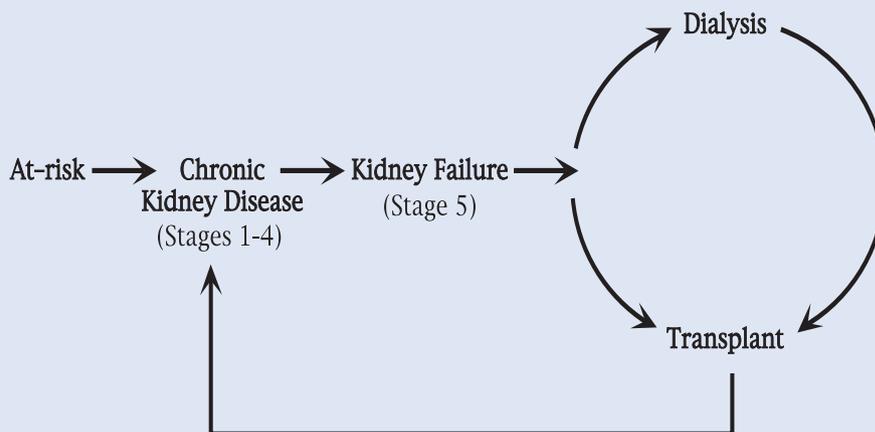
The Life Options Kidney Disease Cycle affirms that both dialysis and transplant are treatments—not cures—for kidney failure. The cycle also demonstrates that there are

two groups of people with CKD: patients who are first diagnosed with kidney disease, and patients who have a transplant failure. The former group has received considerable attention from the renal community recently. However, meeting the special needs of the many patients whose transplants are failing at any given time is a challenge that has gone largely unaddressed.

Life Options research has found that participation in self-management and greater knowledge of kidney disease and its treatment are associated with better functioning and well-being.^{3,4} Ideally, patient preparation for full partnership in care should begin at the earliest possible stage of CKD. This preparation must socialize patients into the partnership role and engender hope for a good life despite kidney disease.

Both patients and professionals need to fully appreciate the importance of preserving kidney function as long as possible. At the same time, patients need to understand that even if permanent kidney failure occurs, they will still

Life Options Kidney Disease Cycle



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have *life options*—work options, travel options, leisure options—many of the same options that were available to them before.

LIFE OPTIONS 2002 CKD PLANS

To further contribute to scientific knowledge pertaining to CKD in 2002, the Life Options program plans to explore self-management participation and educational needs of CKD patients. Two studies are underway. One study, in collaboration with Oxford Health Plans (a leading managed care organization in the New York metropolitan area) will assess CKD patients' self-management activities, employment status, and functioning and well-being. The other will test the ability of a CKD education intervention tailored to patients' needs to increase kidney knowledge levels and positively influence partnership in care.

Life Options will address CKD education in 2002 as well. Kidney School™, a web-based, interactive kidney patient education curriculum in 20-minute modules, is now available at www.kidneyschool.org. Additionally, a new "Kidney Disease Info" section of the Life Options website, www.lifeoptions.org, offers accurate, up-to-date information about risk factors for kidney disease, symptoms, lab test values, patient quotes, answers to frequently-asked questions, and action steps.

Taking a broader approach to include the full spectrum of kidney disease—from the early stages of CKD to dialysis and transplant—will permit new insights and new directions for managing CKD to emerge. Such an approach ensures that the rehabilitation needs of all kidney patients are addressed—a challenging and ongoing responsibility for the entire renal community. ♦

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How Does the Kidney Disease Cycle Work?

Integrating Patient Care

CKD. PD. Hemodialysis. Transplant. These aspects of kidney disease have traditionally been viewed separately by different groups of clinicians. But patients in all four groups share important commonalities: the need for hope, the need for information, the need to become involved partners in their own care and to adhere to prescribed treatment.

The Life Options Kidney Disease Cycle is a road map of the entire renal landscape. By focusing awareness on the big picture, the cycle can help practitioners in each specialty area take steps to improve long-term outcomes. Such increased integration and collaboration can help the renal community to better care for these patients throughout their lives.

Using the Cycle in Clinical Practice

When Stage 1-4 CKD is diagnosed, using the K/DOQI™ criteria*, it may be possible to slow progression with clinical management. If not, patients who live with kidney failure for many years are likely to use multiple treatment modalities. Informing them of this probability up front—and making it clear that this is a normal life event in kidney disease, not their personal failure—may ease transitions between modalities down the road. Informing patients of *all* treatment modalities, including home modalities, will allow them to maximize their quality of life.

The Kidney Disease Cycle can be used to show patients where they are in the course of kidney disease, and where they may travel in the future. Helping patients build realistic expectations, form positive attitudes, and take on an active role during the CKD interval will facilitate better adjustment to renal replacement therapy and improved adherence to treatment—whichever modalities they choose. ♦

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The Value of Active Involvement A CKD Patient Looks Ahead



People at every stage of chronic kidney disease (CKD) have an opportunity to influence their well-being in a positive way—first by learning all they can about their condition

and then by taking charge through self-management. Research supports this statement,¹ and so does practical experience. Julie, a recently-diagnosed CKD patient, illustrates information-seeking and self-management in action.

EARLY DIAGNOSIS

Julie, 38, learned of her potential kidney problems just over a year ago, during a routine physical. “My doctor noticed that my creatinine was a bit elevated,” she recalls. “At that point, I had no real symptoms, and he was careful not to tell me anything definite.”

Over the next several months, Julie’s creatinine levels continued to rise, and she was referred to a nephrologist. In October, an ultrasound helped diagnose her cause of kidney disease. “Being put on medication—an ACE inhibitor—was troubling because it made it very clear that this whole experience was real,” she explains. “But after learning more, I realized that knowing was a good thing.”

Julie’s doctor asked if she wanted a kidney biopsy, but said it would not likely change the course of her treatment. She decided not to have a biopsy right away. “It was nice to be involved in the decision,” she says. “But, at that time, I really needed more guidance.”

SEEKING INFORMATION

And so Julie began her quest for information. “My normal response to dealing with troubling situations is to do research,” she says. “I went on-line and found so much on the Internet,” she says.

Julie sought information from other sources as well. “I read the kidney section of *Gray’s Anatomy*,” she explains. “And I joined a kidney patient organization and a kidney disease e-mail group.” She also learned a lot from a family friend whose husband had been on dialysis for more than 15 years. “She told me it’s not the end of the world,” recalls Julie. “It was very helpful for me to hear what life on dialysis was like.”

TAKING ACTION

While her treatment was underway, Julie had reservations about her nephrologist. “He seemed to know what he was doing, but showed little interest in providing the thorough pre-ESRD care that I wanted,” she explains. Again, Julie took action. Searching on-line for a new nephrologist, she found the Yale nephrology website. “I had a good feeling about them from the start,” she says. “They had an established predialysis program, with an organized treatment plan for patients at each stage.”

Julie is happy with her new doctor. “My first appointment with him lasted 2 hours,” she reports. “I came with an organized list of questions, and he was very approving of that—he addressed every one of them.” Julie feels confident about the partnership she and her care team are developing. “There is still a lot to learn,” she says. “What we do know is that I’ve progressed from a mild stage to a moderate stage over the last year. I have 40 to 50% kidney function.”

To learn more about her condition, Julie’s nephrologist has scheduled a kidney biopsy for early 2002. “He said even though the course of therapy might not change, the biopsy can tell us a lot,” she notes. “We share the same philosophy—it’s better to know more than to know less.”

FUTURE IN FOCUS

When it comes to the future, Julie believes in focusing on the positive. “I realize I may eventually have to accept some limitations in my life,” she explains. “But today I’m focused on enjoying the health I have now.”

As Julie has shown, education can help people with CKD replace fear with hope and retain a sense of control by setting the foundation for self-management. “I’ve learned there are things you can do before you feel sick to help minimize complications later on,” she explains. “That’s why I’m driven to learn all I can. To the extent that I can do something to help myself, I will.” ♦

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