Life Options

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Nephrology News & Issues
Tomorrow's Answers Today

Celebrating a Decade of Change

Happy 10th Anniversary, Life Options!

> *"Life Options brings such an important dimension of thinking to the renal community...treatment is not a maintenance task...it is about 'life options.'"* —Life Options patient caller

FROM VISION TO REALITY

Ten years ago, a small group of people came together with an ambitious vision: to bring together individuals, ideas, and action to facilitate renal rehabilitation.

A decade later, this group, the Life Options Rehabilitation Advisory Council (LORAC), has made this vision a reality. Life Options has paved the way for a coordinated, integrated, and sustained rehabilitation initiative—and, in the process, has brought rehabilitation to the forefront of kidney patient care.

How has so much been accomplished in such a short amount of time? To answer this question, it is helpful to take a brief look back in history…

HISTORICAL PERSPECTIVE

In the early 1970s, advances in medicine and technology led to significant improvements in dialysis. Still, because of its cost, the life-saving treatment was limited to a small number of patients, chosen through a rigorous selection process.

At that time, the expectation was that, with dialysis, these patients would return to work—and to full, productive lives. Rehabilitation was a given.

Based on this premise, the government began providing Medicare coverage for dialysis in 1973. This change eliminated the need for selection committees and paved the way for exponential growth in the dialysis population.

As a result, many began dialysis who formerly would not have been selected. These patients were older, sicker, and had other medical conditions besides kidney failure. Over time, patient longevity and general health decreased.

COMBATING ANEMIA

Throughout this period, one of the most challenging aspects of kidney disease was severe, debilitating anemia. In 1989, the introduction of EPOGEN® (Epoetin alfa) helped reverse the downward spiral of anemia and created a chance for patients to return to more active and productive lives.

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Message from the LORAC Chair

In just 10 years, Life Options has changed the landscape of nephrology. Through a "research and response" approach, described in this issue, Life Options has made tremendous progress in sharing messages and practical tools to help improve rehabilitation outcomes for kidney patients.

Since 1993, Life Options has completed 16 research studies, published 15 peer-reviewed papers, and translated the results into 55 different research-based patient and professional educational materials which have been distributed to millions. Rehabilitation activities now occur in most dialysis centers.

In 10 years, Life Options has accomplished a great deal. And, each year that Life Options exists, we learn more about how to help patients continue to work, play, exercise, volunteer—to engage actively in all of their "Life Options." We are proud of what Life Options has done, and look forward to the next decade of helping kidney patients live long and live well. ◆

Bryan Becker, MD, FACP, is an Associate Professor of Medicine, Transplant Physician, and Chief, Section of Nephrology, at the University of Wisconsin, Madison. To obtain Life Options materials, visit the Life Options website at **www.lifeoptions.org** *or call (800) 468-7777.*

RENAL
REHABILITATION
REPORT

FOCUS ON 10 YEARS OF LIFE OPTIONS

Putting the Rehabilitation Wheels in Motion

Creating the Link Between Research and Education

Common sense has long dictated that rehabilitation is a "good thing." Historically, however, it has been difficult to measure the impact of specific rehabilitation interventions on patient outcomes.

As such, the renal community has struggled to answer such questions as, "How can we prove that rehabilitation really works?" And, "What are the best ways to implement it?"

Several years ago, Life Options set out to help answer these questions. In doing so, they endeavored to create a link between research and education through a unique strategy called "research and response."

THE FORMULA

Life Options' research and response approach was developed around a basic formula:

- Identify an unaddressed issue
- Generate research questions
- Conduct studies to answer the questions
- Formulate responses: initiatives, materials, and interventions

Through *research*, Life Options builds on the existing body of rehabilitation knowledge by conducting qualitative and quantitative studies on a variety of related topics.

In *response*, Life Options takes findings from each study and develops free, research-based educational materials, partnership opportunities, or additional studies. The following examples demonstrate Life Options research and response in action.

PATIENT OPINION STUDIES

From early work, Life Options knew that patients played a key role in their own rehabilitation. Still, little was known about what patients actually thought and felt, or what they feared and believed. The Patient Opinion Studies were designed to explore these issues. Among the many findings, the Patient Opinion Studies showed that:

- Patients want to know how long and well they can live
- Quality of life is compromised by fatigue and time constraints imposed by dialysis
- Patients want and need information
- With information, patients are very willing to advocate for themselves[1,2]

"With the Patient Opinion Studies, Life Options found that new patients have two essential questions: 'How long will I live?' and 'How well will I live?'" explains Dori Schatell, Life Options Director. "This underscored the importance of telling patients proactively and early on that a long and full life is possible."

According to Schatell, it also meant developing concrete, educational messages that would resonate with patients. Among them: a positive attitude (the possibility that you can have a good life), get answers, and take action (exercise, follow the treatment plan). Life Options translated these messages into the *Keys to a Long Life* educational materials.

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SUPPORT the LIFE OPTIONS REHABILITATION PROGRAM

Since 1993, Life Options has been making important contributions to kidney patient education and research. You can help ensure that our work continues, by making a tax-deductible donation to The Medical Education Institute to support the Life Options Rehabilitation Program. Any amount is welcome. You can offer your tax-deductible financial support to Life Options in one of two ways:

- Donate on-line: Click the "Support the Life Options Rehabilitation Program" button (above) on the Life Options website (*www.lifeoptions.org*) to donate through a Verisign™ Secure Site run by *Network for Good*, a resource for non-profit organizations.
- Send a check: Print out a donation form at the Life Options site listed above, fill it out completely, and mail it to the address provided on the form. We will mail you a receipt for tax purposes. ◆

Contact:
Life Options Rehabilitation Program
c/o Medical Education Institute, Inc.
414 D'Onofrio Drive, Suite 200
Madison, Wisconsin 53719
Tel: (800) 468-7777
Fax: (608) 833-8366
E-mail: lifeoptions@MEIresearch.org
www.lifeoptions.org
www.kidneyschool.org

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But despite this and other advances, patient outcomes did not improve. U.S. morbidity and mortality rates continued to exceed those of Europe or Japan.[1] Research in the late 1980s and early 1990s showed that patients were poorly informed about their disease, physically weak, and lacking access to vocational resources that could help them return to work.

The renal community asked, "What can be done to improve patient outcomes?" It appeared that a fundamental aspect of quality care was missing—and some believed that element was rehabilitation.

TIME FOR CHANGE

While renal rehabilitation had been a topic of interest and discussion, it had never been addressed nationally in a sustained, integrated fashion. It was with this purpose in mind that the Life Options program was developed.

In 1993, Amgen provided a grant to support the formation of the LORAC, a group of leading healthcare professionals, researchers, government representatives, private business persons, and patients.

EARLY WORK

The LORAC's mission was "to integrate resources that assist patients' return to active family and community lives." One of the group's first challenges was to provide definition—to answer the question, "What is rehabilitation?"

With this goal in mind, the LORAC identified the core principles of rehabilitation, which they termed the "5 E's"—Encouragement, Education, Exercise, Employment, and Evaluation. The 5 E's became the foundation for defining and operationalizing renal rehabilitation.

The LORAC's next charge was to detail the current state of rehabilitation and recommend improvements. They did so in a publication entitled *Renal Rehabilitation: Bridging the Barriers*.

MOVING FORWARD

In this early work, the LORAC uncovered a host of unaddressed issues. Among them: What are the keys to success on dialysis? What roles do patients and professionals play in managing kidney disease? How does exercise fit in?

The next challenge was to identify, prioritize, and address these issues. In taking on this monumental task, Life Options adopted a unique strategy. They set out to learn as much as they could from those who were "in the trenches" of kidney disease management—nephrologists, nurses, social workers, dietitians, and most importantly, patients themselves. It was out of this strategy that the Life Options "research and response" approach was born.

RESEARCH AND RESPONSE APPROACH

In *research* mode, Life Options began to undertake individual studies to examine specific aspects of rehabilitation. Each study was designed to explore the realities of life with kidney disease—and to build on what had been learned before (see the *Life Options Research Pyramid*, page S10).

In *response* mode, Life Options translated their research findings into practical applications, from patient advocacy initiatives to educational materials geared toward improving patient longevity and quality of life.

THE KIDNEY DISEASE CYCLE

Over several years of research and response, Life Options has learned much about successful adjustment to kidney disease. Top-line findings have been used to develop working models for approaching patient care and rehabilitation.

Most recently, Life Options has developed the Kidney Disease Cycle.[2,3] According to this model, whether at the kidney damage, dialysis, or transplant stage, people with kidney disease are really *one population*, moving from one stage to another throughout the course of their lives.

REHABILITATION IN ACTION

Because people with kidney disease have an illness that cannot be cured, they must work to regain control of their lives by learning to be partners and advocates in care—they must work to become rehabilitated.

What does this mean, in practical terms? To create an expectation of rehabilitation, it is vital that renal

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Putting the Rehabilitation Wheels in Motion

Creating the Link Between Research and Education

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PATIENT LONGEVITY STUDY

With the Patient Opinion Studies, Life Options learned more about patients' lived experiences. Still, many questions remained. Chief among these was, "Why are some patients able to live long and well for decades on dialysis, while so many others are not?" From this question, the Patient Longevity Study was born.

The Patient Longevity Study revealed that long-term dialysis survivors share a set of beliefs—or, affirmations—about maintaining a sense of control and a sense of self in their lives with kidney disease. These affirmations are: "I want to live," "I am still me," "I am still valuable," and "I am in control."[3] The study also identified eight self-management strategies common among long-term survivors:[4]

- Suggesting treatments
- Seeking information
- Using alternative therapies
- Self-care during dialysis
- Partnership in care
- Selectively reporting/managing symptoms
- Self-advocacy
- Impression management

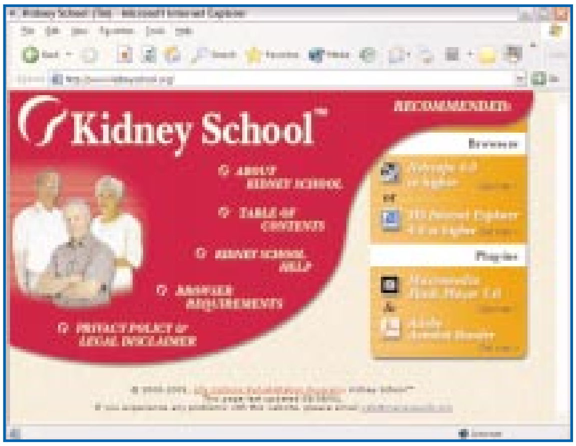
"The long-term survivors studied were active, comprehensive self-managers of their disease and its treatment," explains Schatell. "To self-manage at this level requires a high degree of knowledge."

ESRD SELF-MANAGEMENT STUDY

As a follow-up to the Patient Longevity Study, the quantitative, national random ESRD Self-management Study was undertaken to examine the relationships among dialysis knowledge, self-management, and functioning and well being (FWB)—a demonstrated predictor of morbidity and mortality.

This study found that knowledge about kidney disease and its treatment is positively associated with FWB. In addition, while some self-management efforts are positively related to FWB, others are negatively related.[5,6]

"What we found was exactly in line with the Longevity Study," says Schatell. "That is, functioning was associated with self-management—patients who knew more about kidney disease and who self-managed enjoyed higher physical and mental functioning."



KIDNEY SCHOOL

Once again, Life Options switched from research to response mode, and in doing so developed Kidney School™ (www.kidneyschool.org), a series of free, web-based, interactive learning modules, on topics ranging from treatment options and nutrition to understanding lab tests and getting adequate dialysis.

Kidney School is the culmination of 10 years of research about people with kidney disease. It was designed to help people understand and adjust to kidney disease and its treatment, make better health decisions, and live as fully as possible.

FROM RESEARCH TO EDUCATION

Life Options research has helped to shed light on patients' lived experiences, to underscore the important role of patient self-management, and to demonstrate that rehabilitation interventions can have an impact on patient outcomes.

In addition, by using completed research studies as building blocks, Life Options has been able to develop practical tools to help patients strive toward rehabilitation through partnership in care and active, comprehensive self-management. ◆

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FOCUS ON 10 YEARS OF LIFE OPTIONS

From Kidney Patient to Patient Advocate

Life in Kidney Disease Cycle Comes Full Circle

> **"After stabilizing on dialysis, I realized how wonderful it is to be alive—how wonderful it is to feel the sun on your face, to see the stars and the trees…"**
>
> **—John Newmann**

THE ART OF THE POSSIBLE

John Newmann has been called the "consummate patient advocate."[1] From all accounts, he could also be considered the consummate patient.

Over the past 3 decades, 61-year-old Newmann has experienced the full spectrum of kidney disease treatment—from in-center and home hemodialysis to peritoneal dialysis and transplant. And through it all, he has taken the lead role in directing his own care, becoming an advocate for himself and for other patients in the process.

DIAGNOSIS AND DIALYSIS

Newmann's introduction to kidney disease came when he was a senior in high school. After routine tests leading up to a hernia operation, doctors discovered that one of his kidneys was congenitally small, scarred, and had 10% function.

At that time, Newmann's prognosis was unclear. "They told me this could stabilize and I could live a normal life, it could get worse over several years, or I might just have a year or two," he explains. "The goal at that time was to prevent further scarring of my good kidney."

Newmann's diseased kidney was removed in 1960, after his freshman year in college. Over the next 11 years, the function in his other kidney gradually declined.

In 1971, as Newmann was writing his doctoral dissertation, he began to experience flu-like symptoms. Soon after, his remaining kidney failed, and he began in-center hemodialysis.

SETTING THE STAGE

At that time, Newmann was married, with two young daughters. He had a successful career with the Ford Foundation working on economic development programs in Asia, and he traveled extensively. Kidney failure could easily have been viewed as a major setback. Newmann recalls it differently.

"After stabilizing on dialysis, I realized how wonderful it is to be alive—how wonderful it is to feel the sun on your face, to see the stars and the trees," he says. "I became more sensitive to nature and to humankind."

Newmann credits a strong support network for helping him adopt a positive mindset right from the start. "I have

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Q&A

ASK THE EXPERTS: LIFE OPTIONS PAST, PRESENT, AND FUTURE

An Interview with Edith Oberley, MA

Ms. Oberley is founder of the Life Options Rehabilitation Program. She has been a home hemodialysis partner for more than 30 years and has worked in nephrology education since the 1970's. In addition to founding the Life Options program, she directed the original NKF K/DOQI™ development team and has worked in many other educational program areas.

Q *Where did the idea for Life Options originate?*

A From my perspective, Life Options is grounded in personal experience. I developed an interest in rehabilitation very early on, when my husband Terry experienced kidney failure.

As I watched and participated in Terry's treatment, I began to think of the areas—which we now call the "5 E's"—that are key to the restoration of a normal life.

Q *What circumstances precipitated the creation of Life Options?*

A In the early 90s, the advent of EPOGEN® provided an exciting opportunity to improve patient well being—and to approach rehabilitation in a more programmatic way. About this time, Amgen, inspired by Dr. Donna Mapes, indicated its interest in optimizing employment and other rehabilitation outcomes for people on dialysis. Amgen provided support to assemble a "think tank" to review the work that had been done in renal rehabilitation. This think tank, headed by Dr. John Sadler, became the LORAC.

Q *When your husband was just starting out on dialysis, did you feel you had meaningful life choices?*

A No. When we first started out, it seemed it as if there were no options—no life options. We had no education or encouragement, except through our home hemodialysis nurse. It seemed that we were boxed in.

We had just had our first child, Terry was in medical school, and we were desperate to talk to someone who was in a similar situation. I had read about a family in similar circumstances with dialysis. I wrote to them and got a letter back. In it, he described the accommodations he and his family had made and how they had come to terms with it all.

I shared the letter with Terry—and I read it over and over and over again. Knowing that just one other family could do it made all the difference for us. It created a little window in the box we were in.

As time went on, we began to think, "If one letter from one family could do this much for us, how much could be done for patients if success stories were widespread and readily available?"

very loving and supportive family and friends," he explains. "And, I was raised to always do my best and try new things. I knew I didn't want to live a mediocre life."

EARLY SELF-MANAGEMENT

Not about to let kidney failure stop him, Newmann set out to arm himself with education and self-advocacy. His take-charge approach to life with kidney disease began with his choice of treatment.

"I chose home hemodialysis because I wanted the control and the responsibility," he says. "I knew I wanted and had to work, and I wanted to spend as much time as I could with my family."

According to Newmann, early information also played an important role in this decision. "Several years earlier, I had met a college teacher who was on home hemodialysis," he says. "I knew if he could work and raise a family, I could do it, too."

STAYING ACTIVE

Newmann says the real lesson for him was learning to cope. "I came to realize what I really liked doing and what was now possible," he says. "I learned to let go of the things I couldn't do—and I spent my time enjoying the things I could."

Newmann continued with his travels, dialyzing in centers from South America to Southeast Asia. He also got involved with various renal organizations. "I began attending meetings to learn more about my own disease and how to manage it," he recalls.

For Newmann, that was the start of a long and stellar record of volunteer service—one that has included leadership posts in several organizations, including the American Association of Kidney Patients (AAKP), the Life Options Rehabilitation Advisory Council (LORAC), the United Network for Organ Sharing (UNOS), the National Kidney Foundation (NKF), and the American Kidney Fund (AKF).

PATIENT ADVOCACY

Before long, Newmann decided to put his interest and experience to work, literally. In 1979, he left his job in economics and accepted a fellowship to the School of Public Health at Harvard University. He went on to receive a second advanced degree—a masters degree in public health—and began his own health policy consulting business.

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Q *What were your initial expectations for Life Options, and have they been met?*

A From the start, the goal was very simple: we wanted to prevent other patients and families from having to go through what we went through—the black hole of no information. We wanted to help people understand the keys to success with dialysis and to have hope.

It's overwhelming to think about what has happened with the program—about the calls that come in, the materials that go out, and what people have to say about coming across this resource. The original goal of imparting hope and encouragement is being met, although we'd all like to see *all* patients ultimately gain access to the information.

Q *What is on the horizon for Life Options?*

A Through Life Options research, we've been able to examine the impact of rehabilitation programs—and to begin to assess the effect of rehabilitation interventions on outcomes. This quantifiable approach is one of the crucial contributions of Roberta Braun Curtin, PhD. She designed the research-and-response approach, adding an essential research dimension to what otherwise would have been purely an educational program. I think the challenge for Life Options and for the nephrology community is to integrate these interventions into their care plans and programs.

Q *What role will you play?*

A My role has always been to identify unmet needs in dialysis and to address those needs by assembling teams to develop programming on behalf of patients.

Once programs are up and running and assured of a bright future, it's important to find new leadership with someone who can extend the original mission. That's exactly what Dori Schatell (Program Director) is doing now with Life Options. She is one of the founders, so she knows the program very well. And she has really put her own stamp on it, which is exactly what should happen.

My role is that of a volunteer. I'll always be passionately devoted to rehabilitation, and I will always be "on call" to the Life Options team for anything they would like me to do. I will also continue to be involved in clinical issues and issues related to patient well being.

Q *What is the highlight of your work with Life Options?*

A One hightlight I remember is an e-mail I received from a patient—it was just a short e-mail that said "Thank you for your materials. Before I read them, I thought I would die very soon. Now, I understand that's not the case." That, for me, is a highlight. ◆

Celebrating a Decade of Change

Happy 10th Anniversary, Life Options!

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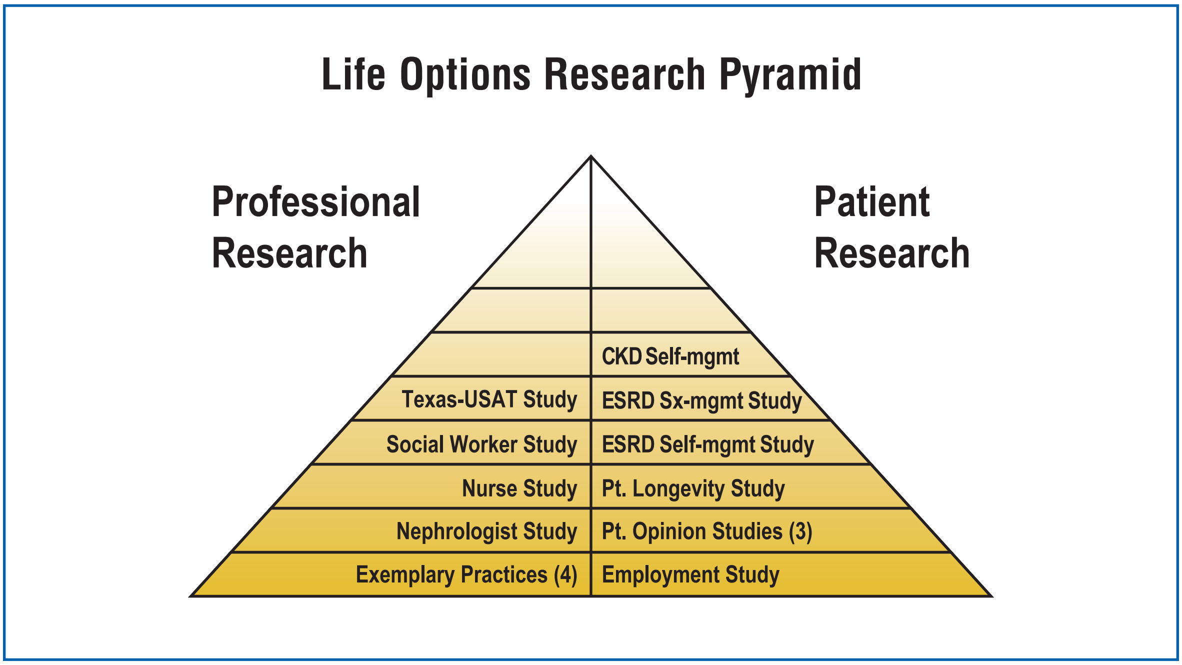

Life Options Research Pyramid

professionals believe rehabilitation is possible and that they reach patients early in the course of their illness.

One way to do this is to develop patient programs that provide hope, encouragement, and education about all aspects of kidney disease and its treatment. Such programs can help prepare patients to self-manage—to identify and report symptoms, work effectively with the healthcare team, recognize quality care, and advocate for themselves—at any given stage in the kidney disease cycle. This type of self-management is key to patients' survival and quality of life.[4-6] Research confirms it.

FOCUS ON THE FUTURE

Over the last decade, much progress has been made toward Life Options' original goal. Rehabilitation has grown from an amorphous, elusive concept to an important element of treatment programs and a major agenda item for renal organizations and policymakers alike. Still, many challenges remain. In the coming years, Life Options will continue to work hand-in-hand with other members of the renal community, with a focus on:

- Helping healthcare professionals promote rehabilitation and include rehabilitation activities as a routine part of care for people with kidney disease—not just a value-added service.
- Helping patients understand and exercise their rights and responsibilities to obtain the best care possible.
- Helping the renal community advocate with policy-makers to provide resources to support rehabilitation.

In addition, through ongoing research, Life Options will continue to strive toward a greater understanding of rehabilitation and the vital role it plays in helping people live long and live well with kidney disease. What a wonderful 10 years it has been. Happy 10th Anniversary, Life Options! Here's to the next 10 years… ◆

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From Kidney Patient to Patient Advocate

Life in Kidney Disease Cycle Comes Full Circle

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"I was able to combine my analytical and academic work with my personal experience," he says. "I've always wanted to do what I can to help other patients improve their quality of care and quality of life."

TRANSPLANT

In the mid 1980s, 15 years of hemodialysis began to take a toll on Newmann's body. He knew it was time to make a change. "Up until that time, I had avoided transplant," he says. "I was swimming, playing tennis, camping with my kids, traveling. But I started having nerve, bone, and muscle problems, so I decided to put my name on the transplant waiting list."

In 1987, Newmann received a cadaver kidney. The results, he says, were dramatic. "My energy improved, I could taste food again—I really felt terrific," he explains.

PERITONEAL DIALYSIS

Unfortunately, this improvement was relatively short-lived. Just over 2 years after receiving his transplant, Newmann's body began rejecting the transplanted kidney—a process he says was difficult, both physically and psychologically. "I had felt so well with the transplant," he says. "The rejection episodes were both scary and very depressing."

In 1991, after losing his transplant, Newmann began an experimental venture in treatment, combining CAPD with double high flux hemodialysis. He says that in terms of dialysis, it was the best of both worlds. "With PD, I enjoyed a more liberated diet," he says. "With hemodialysis, I had excellent clearances."

Newmann continued with the combination treatment for 18 months, until he developed peritonitis and had his catheter removed. He stayed on double high flux hemodialysis alone until he received his second transplant—a kidney donated by his youngest daughter—in November of 1993. He says, "It was a gift of love and life. I've felt very well ever since."

WORDS OF WISDOM

With so much experience behind him, what advice does Newmann offer to new kidney patients? "Managing your own care and keeping track of everything is tough," he says. "You need to learn as much as you can, from a variety of sources—other patients, the Internet, renal organizations."

Newmann says maintaining communication with the healthcare team is also important. "Write down questions before your appointments," Newmann offers. "If you don't understand the answers you get, be proactive. Start asking others, start reading. And, do what you can to stay as mentally, physically, and socially active as possible."

Finally, Newmann stresses the importance of keeping all options open. He encourages every patient to go to a transplant center to be evaluated. "People in transplant units specialize in transplants, and people in dialysis units specialize in dialysis," he explains. "You don't go to a plumber to have your electricity fixed."

LIVING LONG AND WELL

According to Newmann, throughout the kidney disease experience, no matter what treatment modality, patients continue to have "life options." Recognizing and seizing those options is the formula for enjoying a long and fulfilling life with kidney failure. ◆

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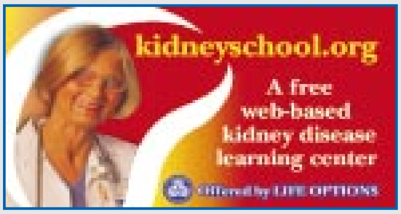

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