

INSIDE

FINDING ANSWERS,
FINDING HOPE:
INFORMATION-SEEKING
LEADS TO PATIENT
EMPOWERMENT.....2

LIFE OPTIONS UPDATE:
RESOURCE CENTER
OFFERS REHABILITATION
INFORMATION3

FINDING ANSWERS ON-
LINE: INTERNET SERVES
AS NEW RESOURCE FOR
INFORMATION-SEEKERS...4

EDUCATIONAL
RESOURCES: RENAL
ORGANIZATIONS OFFER
INFORMATION AND
SUPPORT6

Taking the Lead in Renal Rehabilitation

Information-seeking Is Key to Patient Self-management

“I am going to have a normal life,” says 38-year-old renal patient Jennifer Castillo. “I’m going to demand it. I am determined, because you can do anything if you’re willing to work at it.” This attitude is key for people who want to forge a path to rehabilitation by becoming informed *and* involved in their own health management.

Life Options has long recognized the importance of active patient participation in the treatment and management of kidney disease. The very first Life Options publication, *Bridging the Barriers*, urged people on dialysis to partner with their care providers to optimize outcomes and maintain quality of life.

There is growing evidence to support this view. For example, research has shown that better outcomes, improved adherence, successful rehabilitation, greater satisfaction with care, and improved health-related quality of life are all linked to patient participation in care.^{1,2} And people on dialysis tend to agree. In one study, a majority of successful long-term dialysis patients agreed that taking an active role in dialysis care can improve attitudes and outcomes.³

KNOWLEDGE IS POWER

Today, the term “self-management” is often used to describe the active role that many patients have taken while pursuing their own rehabilitation. From self-care to self-advocacy, there are many ways in which patients can self-manage. But, no matter what level of involvement, success begins with information.

Information is key to helping people adapt to life with kidney failure. From the earliest stages, it helps answer important questions: What are my treatment options? Can I continue to work? Will I survive? Information also prepares patients for informed decision-making: I will choose home hemodialysis; I will keep my job; I will continue to live a full life.

In fact, studies have shown that education can reduce fear, increase hope, promote self-reliance, and improve the chances of successful rehabilitation.²

FORMING PARTNERSHIPS

Unfortunately, many people see education as a one-way effort—one in which dialysis staff are responsible for provid-

(continued on page 7)

Focus on Information- seeking

Life Options believes that people on dialysis can live better and longer if they are active partners in their own care—and active managers of their own health. Information is an important prerequisite to patient self-management.

As discussed in past issues of the *Renal Rehabilitation Report (RRR)*, adherence to the medical regimen is important, but more than just adherence is required for full partnership in care. Studies show that active patients ask questions, seek explanations, state preferences, offer opinions, and expect to be heard.

Treatment for renal disease is complex and may sometimes seem confusing. For patients, having the right information at the right time is key to understanding their own care needs so they can be involved in care decisions and processes.

This issue of the *RRR* is devoted to patient information-seeking. Empowering patients to obtain the knowledge they need to achieve the best life possible is one of Life Options’ primary goals. To learn more about information-seeking or renal rehabilitation, contact the Life Options Rehabilitation Resource Center (RRC) at (800) 468-7777. ♦

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Finding Answers, Finding Hope

Information-seeking Leads to Patient Empowerment



“When I’m in charge, my health improves,” says 38-year old renal patient Jennifer Castillo. This is something Castillo has learned from experience. In her 20 years on dialysis, she has seen it all, from in-center and home hemo to CAPD and a failed transplant. And through it all, information has been her guide.

DIAGNOSIS

Castillo first experienced kidney problems in 1973. “I was 13 years old,” she says. “I hadn’t had any real symptoms, but my grandmother noticed that my skin looked yellow.” Castillo went to the doctor, and tests revealed that she was experiencing retrogradient reflux—a condition that had severely damaged her kidneys.

Castillo was sent to Children’s Hospital of Pennsylvania, where she underwent corrective surgery 2 days later. Her kidney function was restored to 50%, and her condition was controlled with diet and medications until she started hemodialysis in 1979.

THE SEARCH FOR INFORMATION

From the beginning, Castillo sought information from a variety of sources. “At the time of my diagnosis, I wanted to be a doctor,” explains Castillo. “So I read a lot of medical books to learn about what was going on with me.”

Her doctor also played an important role. “Even though I was a teenager, he always made a point of talking directly to *me*,” she says. “He made me feel comfortable—and he taught me a lot.”

Castillo’s search for information didn’t end at her doctor’s office, however. She soon found ways to build on what she learned from her medical team. “I bought a lot of books,” she recalls. “For example, I got one about the renal diet, and then I started measuring what I ate.”

MAINTAINING ACTIVITY

Soon after Castillo started dialysis, she also joined the American Association of Kidney Patients (AAKP)—a decision that would change her life forever. “Everyone in my unit had pretty much given up,” she says. “But AAKP showed me that I could continue to go to school, that I could work—that I could have a normal life.”

So, despite her kidney problems, Castillo remained active. She went to college, completing a bachelor’s degree in English, and she held a variety of volunteer positions. She also made work a priority.

“Work is key for me,” she says. “I knew that I would get depressed if I stayed home. I didn’t want to ask, ‘Why me?’ Instead, I asked myself, ‘What do I have to do to lead a normal life? Where do I have to be in order to be healthy?’ And that became my mission.”

TAKING CHARGE

Castillo’s journey to rehabilitation was not trouble-free, however. When she began having problems related to treatment, she decided to take action. “I’m very proactive,” she explains. “I don’t wait around—if I can do something myself, I will.”

And so she did. Armed with the knowledge she had gathered, Castillo took charge of her own medical care. “I wasn’t getting the care I wanted,” she says. “So, I started self-care. I told the staff, ‘I’ll put my needles in and set up my machine. All you have to do is connect me.’”

Castillo also used this proactive approach later on, when recurrent peritonitis plagued her early experience with CAPD. “I told myself, ‘I can’t keep living like this. I’m going to fix it,’” she recalls.

Castillo decided to see a surgeon. “My life changed in the course of 3 minutes,” she recalls. “The surgeon recognized my problem right away.” Soon, Castillo had surgery to remove her catheter. Her peritonitis went away, and she returned to hemodialysis.

CREATING CHANGE

These experiences changed Castillo’s outlook. “From that day on, there was a shift in my mind,” she says. “I initiated treatments, I initiated change.”

In 1989, Castillo moved to San Francisco, where she continued her quest for information. “I walked to all of the area clinics, and I interviewed staff,” she says. “I asked them, ‘Where would *you* go if *you* were on dialysis?’”

HELPFUL RESOURCES

Castillo’s search didn’t end once she found a unit, however. “In 1994, I started going to the yearly AAKP conferences,” she explains. “That really opened my eyes. There you

are, with 300 to 400 people in front of you. They are the most active people—they are living life. It helps you see what your future can be.”

The Internet has also helped open the door to possibility. “The Internet is a great resource,” says Castillo. “It allows you to do research on-line. It’s amazing what’s out there.” Castillo keeps a binder of articles she has found, along with a list of doctors and patients she has met on-line and through AAKP. “It’s important to be connected,” she says. “You don’t have to be alone—there are a lot of people who know and understand what you’re going through.”

Serving on the Consumer Action Committee for Network 17 has also been a good way for Castillo to make connections. “I find that people there really ‘get it’—they share my perspective,” she says. “It’s also a good way keep up with the legislation and the current trends—to find out what’s going on and where to go for help when you need it.”

ASKING QUESTIONS, FINDING ANSWERS

With her own information-seeking in mind, Castillo offers the following advice to new patients. “Ask your doctor or social worker to put you in contact with an active, successful patient,” she says. “Then, ask to walk through an actual unit, so you know what to expect.”

Dialysis staff can help facilitate the learning process. “Ask new patients what information they think they can handle,” offers Castillo. “Let them determine what they’re ready to know. Then, ask them if they have a wish list—and help them to achieve it.”

A POSITIVE OUTLOOK

Castillo feels that knowledge has empowered her to strive toward her personal goals. “I have always thought with the ideal in mind—the ideal job, the ideal place to live,” she says. “Then I figured out how to get there. Whatever problems I encountered, I found a way to work them out, to make them manageable.”

This strategy has proven to be very successful for Castillo. She currently works from home full time as a senior sales consultant for a satellite Internet service. This past April, she received her second transplant. And, though she is no longer on dialysis, she sees information-seeking as a lifelong process. “I keep my eyes open,” she says. “And I keep learning.”

Castillo believes that other patients can do the same. “You decide your own destiny when you decide to take the path of ownership or the path of denial,” she says. “I’ve been able to find the information and support to live a normal life. And I own that every day.” ♦

“You don’t have to be alone—there are a lot of people who know and understand what you’re going through.”

—Jennifer Castillo



LIFE OPTIONS UPDATE

Resource Center Offers Rehabilitation Information

Education about life on dialysis is an ongoing and ever-changing process. People on dialysis face many questions, from the most basic to the very complex. What does my future hold? What treatment options do I have? Where do I go from here?

Dialysis professionals may have questions as well. How can I best encourage the education process? What strategies exist to foster learning?

One thing is certain—patients and professionals alike can benefit from resources that promote patient education and information-seeking.

To assist in this process, Life Options has developed a wide range of educational materials, from audiotapes and videos to booklets and fact sheets. These materials address an array of topics, from patient experience profiles to specific how-to tips and resources.

All of these materials are available free of charge through the Life Options Rehabilitation Resource Center (RRC). For more information, or to order educational materials, contact the RRC at (800)468-7777, e-mail lifoptions@medmed.com, or visit the Life Options website at www.lifeoptions.org. ♦

*Finding Answers On-line***Internet Serves as New Resource for Information-seekers**

People on dialysis can use the Web and e-mail to empower themselves by learning about their condition and treatment.

The Internet seems to be popping up everywhere these days. TV is filled with “dotcom” ads, and Web addresses appear on everything from billboards to food labels. People are trading stocks on the Web, and trading messages about hobbies with people they’ve never met. Schoolchildren use the Web for homework or games. The Internet seems to promise something for everyone—what does it offer for people on dialysis?

All of the above, and more. The Internet carries a wealth of information about ESRD and dialysis. Whether at a public library computer or on a home computer, people on dialysis can use the Web and e-mail to empower themselves by learning about their condition and treatment.

HEALTH INFORMATION

The Internet can provide background information and definitions, and can help raise new questions to ask the dialysis team. There are organizations to join and vacations to plan. The Internet can also be a meeting place, to share experiences and learn from other patients’ challenges and achievements.

Health information on the Internet has grown by leaps and bounds. One estimate in mid-1999 suggested that the number of healthcare Websites had reached 15,000.¹ Hundreds of those sites are related to kidney failure.

But don’t believe every Website you read. The useful, helpful Web pages exist side-by-side with money-making schemes, fake miracle cures, and just plain uninformed opinions. It takes a careful eye to sort the treasure from the trash.

TIPS FOR CAREFUL SURFING

This leads to the first rule of Web-surfing for health information: Always consult a healthcare professional! Before taking action or making any changes based on Web information, be sure to discuss it with your physician or nurse. Even the best on-line advice may not be right for your situation, and you won’t know for sure unless you ask.

In order to decide whether a healthcare Website is worth taking seriously, here are some points to consider.

- **Who is responsible for the Website?** A trustworthy site will give names, credentials, and contact information, preferably a phone number in addition to an e-mail address. Contact information indicates that the creators of a site are willing to stand behind what they’ve written.
- **What is the purpose of the Website?** Does the site contain verifiable facts, opinions, or advertisements? If the site is trying to sell something, that should be clearly stated. Look for a mission statement or statement of purpose.
- **Is the information current?** Health information can change quickly. Beware of sites that do not show when their material was updated, or that have not been updated in a long time.
- **Who is sponsoring the site?** Websites should be clear about who pays the bills.
- **Is your privacy secure?** Some sites will ask for personal information. Look for a privacy policy guaranteeing that the information will not be shared.

A good way to begin exploring reputable kidney failure Websites is to look for recommendations and reviews, either in print or on other Websites. Following are some good starting points for dialysis-related information on the Internet.

GENERAL ESRD INFORMATION

Several excellent patient-oriented sites have come on-line in the past year. Kidney Directions (*kidneydirections.com*),

Life Options on the Web

Life Options is on the Internet! Visit the Life Options Website at www.lifeoptions.org for a wealth of dialysis-related information, including:

Rehabilitation Resources and Information

General information about rehabilitation, on-line order forms for free Life Options materials, and printer-friendly versions of some materials to download immediately.

Showcase of Ideas

Practical solutions, strategies, and stories from renal patients and professionals around the country.

Links to Other Resources and Organizations

An extensive list of places to look for more information and support.

“5 E’s” Bibliography

A listing of recent, dialysis-related journal citations, which can be useful for education and research.

sponsored by Baxter Healthcare Corporation, offers information on such broad topics as “The Basics,” “Your Health,” and “Choices.” Visitors can choose to fill out a survey about themselves, or just click on “Site Map” to browse the site without giving personal information.

The *Kidney Patient Guide* (www.kidneypatient-guide.org.uk) also gives a well-organized introduction, from treatment to diet to emotions. Since the *Kidney Patient Guide* is based in Great Britain, some of the terms may be unfamiliar, but many aspects of kidney disease are the same anywhere in the world.

Other resources for general information include:

- *New Life, New Hope: A Book for Families and Friends of Renal Patients* (www.lifeoptions.org/nlnh/) on the Life Options Website, sponsored by Amgen Renal Advances. Although the book is aimed at families and friends, patients have found it useful as well.
- *The Early Renal Guidebook*, by Stephen Z. Fadem, MD (nephron.com/fkgframeset.htm), part of the sprawling but informative Nephron Information Center site. The *Guidebook* requires the free software program Macromedia® Flash™, which works together with your Internet browser.
- iKidney (ikidney.com), sponsored by R&D Laboratories.

All of these sites have pages that link to additional Websites, as a service to their visitors.

ORGANIZATIONS

Kidney patient organizations use the Web to make real-world connections between people. Their Websites can introduce people to the purpose and activities of the organizations, including such things as conferences, publications, and fundraising.

The American Association of Kidney Patients (AAKP) (www.aakp.org) is an organization for patients, while the National Kidney Foundation (NKF) (www.kidney.org) has both patient and professional councils. The American Kidney Fund (AKF) (www.akfinc.org) focuses on fundraising and patient aid programs for kidney patients. All three sites tell visitors about their organizations, but each one also has additional features.

PATIENT-TO-PATIENT MESSAGES

While the Web can connect people through organizations, people on dialysis can connect even more directly with others by posting a message on a mail list, a bulletin board, or a newsgroup. All three kinds of communication can be done using a web browser, and all three can put people in touch with others who share similar experiences.

People with kidney failure can form friendships on-line, encourage each other, and ask other people for opinions. These groups are usually very supportive, although disagreements may sometimes flare. Again, patients should be sure to consult with a dialysis professional before acting on any healthcare advice.

- The Dialysis Support mail list can be reached on the Web (www.egroups.com/list/dialysis_support/info.html) or by e-mail (to subscribe, send an e-mail message to dialysis_support-subscribe@eGroups.com). This is a busy patient support group, with an average of 30 to 40 messages a day.
- The Dialysis On-line! bulletin board (www.he.net/~brumley/renal/index.html) can only be reached on the Web. There are three sections of the site for people on dialysis and several for professionals.
- news:alt.support.kidney-failure is both the name and the address for a newsgroup. Most Web browsers can read this group if you type in the full address.

Links to all of these resources and many more can be found on the “Kidney Links” page at the Life Options Website (www.lifeoptions.org/links.html).

A PLACE TO START

From lifestyle changes to financial decisions and medical choices, there is a lot to know when it comes to living with renal failure. With support and encouragement—and with the proper information—people on dialysis can take steps toward managing their disease and their lives. For many patients and families, the Internet is a good place to search for the answers they need. ♦

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People with kidney failure can form friendships on-line, encourage each other, and ask other people for opinions.

*Educational Resources***Renal Organizations Offer Information and Support**

Over the years, several public service organizations have formed to serve the needs of patients and families living with ESRD. These groups provide a variety of educational and networking resources. Three, in particular, offer resources geared to patients and families.

AMERICAN ASSOCIATION OF KIDNEY PATIENTS (AAKP)

Founded more than 30 years ago, the AAKP is a national organization with local affiliates nationwide. AAKP's more than 8,000 members include patients and families, renal professionals, and friends. The group's stated purpose is to "help patients and their families cope with the emotional, physical and social impact of kidney failure, thereby enabling them to resume productive and satisfying lives." The AAKP provides a variety of educational materials and programs, including:

Educational Materials

- *aakpRENALIFE*. The official magazine of the AAKP, *RENALIFE* is published six times a year and covers a range of topics, including medical procedures, real life stories, and legislative updates.
- *AAKP Renal Flash*. A monthly electronic newsletter transmitted via e-mail.
- Many printed materials on such topics as understanding lab values, the Americans with Disabilities Act, anemia management, and treatment options.

Meetings

- A 4-day annual convention (Sept. 14-17, 2000 in Tampa, FL) offers opportunities to learn, exchange ideas, and share friendships.
- Meetings are also held by local chapters nationwide.

AMERICAN KIDNEY FUND (AKF)

The American Kidney Fund is dedicated to improving the daily lives of people with chronic kidney disease. The AKF's primary goal is to relieve the financial burden of chronic kidney failure through patient aid programs. AKF also offers:

Educational Materials

Numerous publications, some available in Spanish or large-print versions, on topics related to ESRD and its treatment.

AKF HELPLINE

A toll-free number for answers to questions about kidney disease and treatment.

NATIONAL KIDNEY FOUNDATION (NKF)

The NKF "seeks to prevent kidney and urinary tract disease, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation." The NKF is an excellent source of information for people on dialysis. Resources include:

Educational Materials

A variety of print materials and videos on topics from treatment choice and meal planning to sexuality and exercise:

- A six-part seminar called *People Like Us Live!* that uses patient volunteers to teach others about living with ESRD
- *Family Focus* quarterly newsletter with topics of interest to dialysis patients and their families
- A toll-free Information Hotline for questions or concerns—available weekdays

Meetings

- The annual meeting (Oct. 12-15, 2000 in Toronto, Ontario) and the Spring Clinicals (April 17-21, 2001 in Orlando, FL) include workshops and multidisciplinary sessions.
- Meetings are also held by local affiliates across the country.

Patient and Family Council

Dedicated to issues affecting people with kidney disease, this patient-based council has a major voice in public policy. Membership is free. ♦

Where to Contact Renal Organizations**American Association of Kidney Patients**

100 S. Ashley Drive, Suite 280 • Tampa, FL 83602
Information Hotline: (800) 749-2257
e-mail: aakpnat@aol.com • Website: www.aakp.org

American Kidney Fund

6220 Executive Boulevard, Suite 1010 • Rockville, MD 20852
AKF HELPLINE: (800) 638-8299
e-mail HELPLINE: helpline@akfinc.org • Website: www.akfinc.org

National Kidney Foundation

30 East 33rd Street • New York, NY 10157
(800) 622-9010
e-mail: info@kidney.org • Website: www.kidney.org

Taking the Lead in Renal Rehabilitation

Information-seeking Is Key to Patient Self-management (continued from page 1)

ing all the information patients need. While dialysis staff *do* play a major role in education—through needs assessment, program planning, presenting information, and evaluating how well it is received—the process is most effective when dialysis patients share the responsibility by actively seeking information.

For this to happen, people on dialysis must shed the “passive recipient of care” role. Castillo agrees. “This is *your* life,” she says. “You need to learn to do more than just trust your doctor. You need to find the information—whether it’s in journals, on the Internet, by asking questions, or by going to group meetings—to make informed decisions about your life and your future.”

ACTIVE LEARNING

Since most people do not become active information seekers overnight, this is where the real effort begins. Independent learning is built on a foundation of several basic beliefs, including: understanding the need for information, seeing the value of information, and accepting the responsibility to seek information.

Turning these beliefs into effective learning behaviors can take time and willingness to:

- **Accept and process the information provided.** In most dialysis units, patients receive a lot of information about kidney failure and its treatment. Actual learning begins when patients are ready and willing to read and understand the information given.
- **Ask questions.** Patients can often get more personalized information by asking experts on the dialysis team. To do this, patients may need to overcome fears about bothering the staff. On the other hand, staff can help by setting aside time for questions and by creating an atmosphere in which there are no “bad” questions.
- **Contact multiple sources.** As patients expand their knowledge, they begin to seek out new sources of information, including other patients, professionals outside their own unit, books, periodicals, national organizations, and the Internet. These sources can provide information to help patients and families learn to adjust to life with kidney failure.

- **Apply information.** Making informed decisions about treatments, medical care, and lifestyle is the ultimate goal of active learning. Information gives patients the power to act as self-managers—and as important members of the dialysis team.

PARTNERSHIPS

Dialysis staff can do a lot to foster active learning. One way that every member of the team can support active learning and independent action is by rewarding progress, no matter how small, toward these goals.

From the start, healthcare staff must accept *and* promote ways for people on dialysis to help themselves—from active information-seeking to any number or level of self-care activities, including tracking lab values, doing needle-sticks, or choosing home dialysis.

AN ONGOING PROCESS

For people on dialysis, learning about and adjusting to life with kidney failure is a continuous process. Therefore, there

(continued on page 8)

...education can reduce fear, increase hope, promote self-reliance, and improve the chance for successful rehabilitation.²

The Education Process

Information Needs Change Over Time

Although any time is a good time to seek information, most patients and dialysis educators agree that the need for information peaks at certain predictable times, including:

- **At diagnosis.** Patients want and need basic information about kidney failure, treatment options, what to expect, and how to cope. Although patients may feel overwhelmed at this time, studies show that “it may be better to err on the side of too much information than too little.”⁴
- **Start of dialysis.** In addition to training in the how-to of the dialysis process, patients need practical information on a number of topics, including diet, finances, and symptom management.
- **Established routine.** Once patients have adjusted to dialysis, the time may be right for more in-depth learning about a variety of topics, including self-care.
- **Ongoing needs.** Every interaction with a member of the dialysis staff presents an opportunity to reinforce basic concepts and offer new information.

*Taking the Lead in Renal Rehabilitation***Information-seeking Is Key to Patient Self-management** *(continued from page 7)*

are many reasons to encourage patients' ongoing search for knowledge. For example, information changes with advances in medical technology, research, methods, and approaches. Changes in a patient's condition or life circumstances may also cause new information needs to arise. And, patients may be more or less able to process new information at various times. What may seem like too much information at one time, may be just the right amount at another time.

Throughout the education process, success also depends on patient interest and readiness to receive information. For these reasons, dialysis educators must individualize education programs and permit patients to establish their own information needs and set their own pace for learning. In particular, patient education programs aimed at improving self-management must focus on what patients want to know, rather than what staff wants to tell them.⁴

KNOWING HOW TO SUCCEED

Many long-term dialysis patients have proven that successful rehabilitation is possible for people with kidney failure. These patients have made their own rehabilitation possible by becoming partners in their own care.

Such partnerships don't just happen. They are created by patients who seek out information and who insist on being actively involved in the treatment process. Armed with information, patients can become effective self-managers, and they can gain control over renal disease and its treatment. ♦

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**RENAL
REHABILITATION
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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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