

In CONTROL

A Medical Education Institute/Life Options Publication

VOL. 3 | NO. 1

MARCH 2006

How to Use *In Control*

Each issue of *In Control* offers background, tips, and patient education material on one topic that is important to living well with kidney disease. The 2-in-1 format of *In Control* is designed to make it easy to find the information and share it with your patients.

For you, there are 4 pages of professional content (pages S1, S2, S7, and S8), along with practical tips for putting key concepts into practice.

For your patients, there are 4 pages (S3–S6) of easy-to-read information. There's also a quiz patients can use to test their knowledge.

We encourage you to make copies of *In Control*. Use it to supplement your own education materials, and call us at (800) 468-7777 if you want to reprint an article. Help your patients get “in control” of their kidney disease!

**In Control is supported
by Amgen Inc.**

AMGEN

and published in
cooperation with

NEPHROLOGY
NEWS & ISSUES

Matching Dialysis Modality to Patient Lifestyle

The primary goal of rehabilitation for people with kidney disease is to allow them to lead fulfilling lives that may include work, hobbies, travel, socializing with family and friends, and community and church events. Fitting these activities into a life that also includes dialysis takes some juggling, regardless of the choice of treatment. Choosing wisely can make a full and rewarding lifestyle much more possible for patients.

Dialysis technology has come a long way since this life-saving therapy was first performed on acutely ill patients in the 1940s. Today, there are more treatment modality and equipment options than ever before—including manual and automated peritoneal dialysis as well as short daily and long nocturnal hemodialysis (done at home or in-center). The opportunities to match dialysis modalities with patients' preferred lifestyles are greater than at any time in the past.

It is surprising and disappointing, therefore, that most of these options are, as yet, underutilized. Because patients have varying life event schedules, preferences, home situations, and help available, no one modality can meet everyone's rehabilitation needs. Yet, one modality predominates. Per USRDS data, more than 91% of Americans on dialysis do in-center hemodialysis.¹ These data suggest that efforts to individualize modality choice have been ineffective;

a one-size-fits-all dialysis approach has been applied to nearly all U.S. patients.

Increased Interest

Recently, the dialysis community has begun to focus more attention on modality options besides standard in-center hemodialysis. There are several very good reasons for this, including:

- **Quality of life.** Patient self-reports find differences in quality of life between those on hemodialysis (HD) and those on peritoneal dialysis (PD). In particular, Kutner et al.² found that PD patients scored higher on selected measures of quality of life, including effects of kidney disease, burden of kidney disease, and satisfaction with care. In another study, Wu et al.³ reported that health-related quality of life (HRQOL) scores differed between HD and PD patients. Some scores were higher for HD while other scores were higher for PD. These authors concluded that “in advising patients about modality choices, trade-offs should be discussed and individual preferences for specific aspects of HRQOL should be elicited.”
 - **Patient satisfaction.** Among the 656 patients who returned surveys for the CHOICE study, new patients receiving PD were much more likely than those receiving HD to rate their dialysis care as “excellent.”⁴ PD patients
- (continued on page S2)*

(continued from page S1)

Matching Dialysis Modality to Patient Lifestyle

were especially impressed with the “caring and concern of nurses” and the dialysis staff. The authors observed that, “when treatments provide equivalent survival benefits and clinical efficacy, patients’ views of their

treatment become more important in choosing among options.”

- **Employment.** Given the option, employed working-age patients are significantly more likely to choose “work-friendly”

treatment modalities, such as transplant or PD, that permit flexible scheduling and reduce the ups-and-downs in day-to-day symptomology.⁵ Patients who keep their jobs have better physical functioning, improved self-esteem, less depression, higher income that allows them to follow their treatment plan, and, in many cases, an employer group health plan—which improves the payer mix for their centers, as well.⁶

- **Patient preference.** Most nephrologists and dialysis care providers believe that patient choice *should* play a role in the selection of a treatment for kidney failure.⁷ Further, research has demonstrated that when patients know about all of the modality options, more of them are likely to choose PD.⁸ Schreiber et al found among 11,000 patients that predialysis modality education increased the percent of patients choosing home dialysis (PD) to 40%.⁹ *Who* makes the choice of modality is a vital question: a finding of the DMMS Wave 2 study was that patients who chose a treatment themselves had significantly lower mortality ($p < 0.0001$) and higher transplant rates ($p < 0.0001$) than patients whose doctors chose for them, or even those who partnered with their doctor in the decision.¹⁰

The Full Array of Dialysis Options: Seven Modalities

Standard In-center Hemodialysis. Patients travel to a dialysis center 3 times a week for treatments that last 3–5 hours, on a fixed schedule. Patients may or may not do some self-care tasks. Staff monitor the treatments.

Conventional Home Hemodialysis.[†] The patient and a partner train for 3–8 weeks* to do 3–5 hour treatments at home, three times/week or every other day—on their own schedule. Some plumbing/wiring may be needed in the home.

Short Daily Home Hemodialysis.[†] The patient and a partner train for 3–6 weeks* to do treatments at home. Most do 1.5–3 hour treatments 5–6 days a week, in the morning, at night—or whenever it is convenient to fit it in. Some plumbing/wiring may be needed.

Nocturnal Home Hemodialysis.[†] The patient and a partner train for 6–8 weeks.* Treatments are done at night while the patient sleeps (8 hours, 3–6 nights per week), leaving their days free. Extra taping secures the needles and lines, and bedwetting alarms are used to detect bleeding. Some centers monitor remotely via the Internet. Plumbing/wiring may be needed.

Nocturnal In-center Hemodialysis. Patients travel to the center 3 times a week or every other night, on a fixed schedule, to do dialysis while they sleep. Each session lasts about 8 hours. Staff monitors the treatment.

Continuous Ambulatory Peritoneal Dialysis (CAPD).[†] The patient does manual PD exchanges several times a day, 7 days a week. Training takes 1–2 weeks. CAPD can be done without a partner; a clean area and room for storage are needed.

Continuous Cycling Peritoneal Dialysis (CCPD)/Automated Peritoneal Dialysis (APD).[†] Patients use a cycler to do exchanges at night for 8–10 hours, while the patient sleeps. Some patients also do one or two manual exchanges during the day. CCPD may be done with or without a partner; a clean area and room for storage are needed.

*Length of training time depends on the machine used.

[†]Patients come to the center once a month for blood tests and check-ups. Dialysis staff are available by phone for trouble-shooting.

Barriers to change

With so much evidence on the side of offering patients a complete

(continued on page S4)

Q & A:

Ask the Experts

An interview with Anne Campbell, MSPH, CHES
Patient Education Coordinator, DCI, Columbia, Missouri

Q: You've been a patient educator for a long time. Is the modality decision-making process different today than it was years ago?

A: Absolutely! The whole model has changed. In the past, decisions were more likely to be made by healthcare providers. Today, there's been a shift toward more patient involvement in decisions. For the most part, I think the change is a good one. At the same time, I realize that making decisions is stressful—especially if you are ill. For some patients, the added responsibility is a burden, and there are some who want direct guidance. Still, in the end, I think that patients who do the learning and make an informed choice for themselves are better off.

Q: Once patients have learned the facts, how do you help them make a choice about dialysis modality?

A: After we've discussed all the treatment options in some detail, I like to ask my patients to "try on" the therapy that they think might work for them. I usually start by building on something I've learned about them. For example, to a working person with school-age children I might


say, "You seem really busy. How would your daily schedule need to change if you were going to dialysis 3 times a week? What would you have to do to make it work?" Asking patients to imagine what their life would be like with a particular therapy helps them to think about it in practical, personal terms. As they walk through the details, they begin to get a real picture of exactly what they would have to change; they begin to "own the therapy" and can make a more informed decision about whether it's a good fit for them.

Q: Are there limits to what education can do to help patients make a good choice?

A: Not all patients have a full range of choices. Even when they do, education can only help with the cognitive side of the decision. There's an emotional—even visceral—side to making a decision, too. I've had patients say to me, "Don't even talk to me about a catheter, I don't want a tube coming out of me." I've had others who rule out hemodialysis because they've known someone—usually a relative—who had trouble with hemo. Patients don't come to us with a blank slate; many have biases. Education may or may not influence a

patient's feelings, emotions, and biases. It's difficult to see patients eliminate therapies that could provide good medical results. In those situations, the best we educators can do is provide a framework for making a logical decision—even if our patients are not open to all the options.

Q: What is the biggest challenge you face in teaching patients about modality choices?

A: Lack of time. When a patient comes in needing to start dialysis next week, it's just not possible to follow an ideal dialysis education protocol. Ideally, you like to have several meetings with a new patient, to have the time to do a good assessment and get to know a little bit about the person. I prefer to teach about different modalities in different sessions because it makes understanding a lot easier. When you don't have enough time, everything is different. That's why early referrals are so important. If I have had to compress education predialysis, I often continue to work with that patient after they start their treatments to try to fill in their knowledge gaps. If appropriate, we might talk about the fact that changing modalities is an option. 

(continued from page S2)

Matching Dialysis Modality to Patient Lifestyle

array of treatment options—which would facilitate rehabilitation—why is the U.S. modality distribution so lopsided?

In practice, clinical considerations play only a minor role in treatment choices. Although U.S. nephrologists reported that “large” patient size restricted the use of PD, they did not consider other factors (diabetes, age, or sex) to favor the use of HD.¹¹ In fact, a group of leading nephrologists agreed that “most incident ESRD patients are suitable for either HD or PD.”⁸ Physician preference, often cited as the primary selection driver, may not be a major factor either. Practicing U.S. nephrologists claim that they would prefer to see 30%–40% of new patients start dialysis using PD.¹¹

One likely cause of the skewed U.S. modality distribution is lack of early referral to a nephrologist.¹¹ In the U.S., 47% of patients start dialysis within one month of their first visit to a nephrologist.¹¹ These patients almost always start treatment with in-center HD.

Another likely cause is patients’ lack of awareness that there *are* options besides in-center HD. The Dialysis Morbidity and Mortality Study (DMMS; Wave 2) found that only about one in four in-center HD patients reported having been told about PD or home HD.¹² Patients can’t ask for treatments that suit their lifestyles if they don’t know these other options exist.

Offering Options

Caregivers can do several things to improve the likelihood that people with chronic kidney disease will have access to a full range of treatment options:

1. Provide thorough, unbiased education about treatment options
2. Welcome patient participation in modality choice
3. Make a full menu of modalities available in more clinics

There are signs that the dialysis community is moving to improve the distribution of dialysis modalities, and more emphasis will be placed on individualizing modality selection. For example, the draft Statement of Work (3-year ESRD Network contract) included language that would encourage

the use of more selfcare therapies (no final draft at press time), and DaVita at Home has committed to making home dialysis available

to patients in certain U.S. regions, with growth expected. Efforts like these represent important steps toward making more treatment options available to more patients. ☺

References

1. U.S. Renal Data System. *USRDS 2005 Annual Data Report. Atlas of End-Stage Renal Disease in the United States*. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases: Bethesda, MD; 2005.
2. Kutner NG, Zhang R, Barnhart H, Collins AJ. Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant* 20:2159-2167, 2005.
3. Wu AW, Fink NE, Marsh-Manzi JVR et al. Changes in quality of life during hemodialysis and peritoneal dialysis treatment: Generic and disease specific measures. *J Am Soc Nephrol* 15:743-753, 2004.
4. Rubin HR, Fink NE, Plantinga LC et al. Patient rating of dialysis care with peritoneal dialysis vs hemodialysis. *JAMA* 291(6):697-703, 2004.
5. Witten B, Schatell DR, Becker BN. Relationship of ESRD working-age patient employment to treatment modality. *J Am Soc Nephrol* 15:633A, 2004.
6. CKD and job retention. *Nephrol News Issues* 2(2):S1, 2005.
7. Mehrotra R, Marsh D, Vonesh E, Peters V, Nissenson A. Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis. *Kidney Int* 68(1):378-90, 2005.
8. Mendelssohn DC, Blake PG, Burkart J, Golper T, Oreopoulos D. Dialysis modality distribution in the United States. (letter to ed) *Am J Kidney Dis* 37(6):1330, 2001.
9. Schreiber, et al. Preliminary findings from the national pre-ESRD education initiative. *Nephrol News Issues* 14(12):44-6, 2000.
10. Stack AG, Martin DR. Association of patient autonomy with increased transplantation and survival among new dialysis patients in the United States. *Am J Kidney Dis* 45(4):730-42, 2005.
11. Mendelssohn DC, Mullaney SR, Jung B, Blake PG, Mehta RL. What do American nephrologists think about dialysis modality selection? *Am J Kidney Dis* 37(1):22-29, 2001.
12. U.S. Renal Data System. *USRDS 1997 Annual Data Report. USRDS Dialysis Morbidity and Mortality (Wave 2)*. NIH, NIDDK: Bethesda, MD; 2005:p. 53.

Quiz Answers

1. True
2. False. CCPD is done with a machine called a cyclor.
3. True
4. True
5. True

In Control

Contact:

Life Options Rehabilitation Program
 c/o Medical Education Institute, Inc.
 414 D’Onofrio Drive, Ste. 200
 Madison, WI 53719
 Tel: (800) 468-7777
 Fax: (608) 833-8366
 E-mail: lifoptions@meiresearch.org

www.lifeoptions.org
www.kidneyschool.org

In *Patients* CONTROL

A Medical Education Institute/Life Options Publication

VOL. 3 | NO. 1
MARCH 2006

You Decide! Choosing a Treatment that Fits Your Life

Choosing a treatment for kidney failure may feel like the end of the world—but it's not. In fact, the right treatment option can help you keep your preferred lifestyle. Often, people (or doctors) make a quick choice that may not be the best fit. The key to making the right choice for you is:

- (a) Learn about *all* of your options
- (b) Look at *your* wants, needs, and limits

Your Treatment Options

You may have more treatment options for kidney failure than you think:

- **Transplant** – a new kidney from a donor (living or deceased) replaces your kidneys. It can take time to get a transplant. While you wait, you may need dialysis.
- **Peritoneal dialysis** – using the lining of the abdomen as a filter to clean the blood:

- ◆ **CCPD** – done while you sleep with a machine called a “cyclor”
- ◆ **CAPD** – done by you, without a machine, 4 times a day

- **Home hemodialysis** – you and a partner get training and do your treatments at home:

- ◆ **Short daily home hemodialysis** – done 5–7 times a week for 2–3 hours at a time
- ◆ **Conventional home hemodialysis** – done 3 times a week (or every other day)
- ◆ **Nocturnal home hemodialysis** – done 3–7 nights a week, while you sleep

- **In-center hemodialysis** – you travel to a center to get your treatments:

- ◆ **Conventional** – done 3 times a week for about 3-4 hours at a time
- ◆ **Nocturnal** – you sleep in the center 3 *nights* a week and keep your days free

When you choose a treatment, you don't have to stay on it forever. Many people change treatments, for reasons that may or may not be in their control.

Note that some options may not be offered at your center and/or may not work for you. Talk to your nephrologist and/or dialysis staff member if you want a certain treatment.

Take a Look at Your Life

Many factors go into choosing a treatment for kidney failure. You and your nephrologist

(continued on page P4)

In Control is supported
by Amgen Inc.

AMGEN

and published in
cooperation with

NEPHROLOGY
NEWS & ISSUES

Making the Right Treatment Choice for Me

Your treatment *can* fit your lifestyle. Read how four other people's choices suit their lives:

Debbie: In-center Hemodialysis (HD)

Debbie, 46, has been on in-center HD for almost a year, since her transplant of 17 years failed. "I thought about PD, but was urgently started on in-center HD when my transplant failed," she explains. "It seemed to me that in-center HD was easier to work around than doing a home therapy, because the home therapy would take more time."



In-center HD also seemed a better fit for Debbie's family life. "I work from 3:30 p.m. to midnight and my husband works nights," she explains, "so our time together is during the day. I didn't want to spend the whole morning doing dialysis at home." Debbie is on in-center HD 3 days a week from 11 a.m. until 2:30 p.m., and sleeps during her treatment. She then goes to work.

Debbie urges people to look closely at their lives. "Everyone's situation is different, so you really have to look at your lifestyle, work, etc., and see what would be a good fit," she explains. "For example, a retired person may find home dialysis easier than going to a center three times a week. The most important thing is to raise your head up and go on with what you have to do in life."

Kevin: Daily Home HD

Just 18 now, Kevin was born with a bladder problem that caused his kidneys to fail. Since he has had kidney failure for so long, Kevin has relied on different treatments to meet his needs at any given time.

At 5, Kevin received his first transplant. "I had that transplant for 10 years," explains Kevin. "When it failed, I tried PD but it didn't work because I had too much scarring from previous surgeries."

Kevin had a second transplant in 2003. "When it rejected, I began in-center dialysis," relays Kevin. "I talked with the team about home dialysis, and when the clinic started a home program they chose me to train."

Both Kevin and his care team thought daily home dialysis was a better fit for his life. Plus, Kevin feels much better since he dialyzes 6 days a week for 2 to 2.5 hours. "I'm a senior in high school now—I like to hang out with my friends, hunt, and fish," explains Kevin. "Home dialysis coordinates better with my day and lets me be more flexible and free."



Mary Ann: Continuous Cycling Peritoneal Dialysis (CCPD)

When Mary Ann's kidneys were failing 8 years ago, she considered her options. "Mostly, I chose PD because I worked," reports Mary Ann. CCPD left her days

free to work full-time. “I thought about in-center HD,” she says, “but the people looked so wiped out after their dialysis. Plus, I didn’t have the time to go in there 3 times a week. I’ve got work to do!”



Now retired, Mary Ann worked for 7 years on CCPD. “I hooked up to my cyclor for 8 hours every night and did one manual exchange at work.” Mary Ann got permission to use a small office for her mid-day exchange. “There really wasn’t much to it,” she says. “I just made sure things weren’t dusty, and I always washed my hands and masked.”

After 8 years on CCPD, Mary Ann feels good and finds her diet and fluid limits easy to manage. Best of all, she has the freedom to travel. “If you go on PD, you can do anything,” she says. She’s been on cruises, and done lots of U.S. travel. Mary Ann likes CCPD so well that she’s decided not to put her name on the transplant list. “What would be different?” she asks. “I’d still have to take medications. The only thing I wouldn’t have is boxes of dialysate crowding my living room,” she laughs.

John: Nocturnal Home HD

At 84, John may be the oldest person in the U.S. doing home dialysis. In late 2002, John was told his kidneys were failing. “He and his wife, Sarah, talked to his doctor about home dialysis, but then John had a setback. “I went into the hospital for a

heart attack and started dialysis there—much earlier than planned,” John reports.

John continued in-center HD, but “didn’t like it because the schedule messed up everything.” Sarah agrees. “The only time the center had was 5 p.m., so our dinner was interrupted and we didn’t get home until 10:30 or 11 p.m.” In addition, John didn’t feel very well. “I was cold all the time, very tired, and itching like mad,” he says.

John believes in “following how you feel,” and he didn’t feel well on in-center HD. So, he began training for nocturnal home HD. “We went to classes 5 days a week for 6 weeks,” remembers Sarah, “but it was worth it!” Now, 5 nights a week, John and Sarah take an hour to set up the machine before bed and 30 minutes to disconnect and clean in the morning. “You wake up feeling much better and ready to go,” relays John. “Plus, now I have time to mow four acres and garden!”

John feels great, doesn’t need blood pressure drugs, and can eat most things since he gets so much dialysis. He attributes feeling better to the longer time (8 hours) and slower blood flow and pump speed. “I would suggest nocturnal home HD to anyone,” says John. “I think how you feel when first diagnosed with kidney failure should guide how you choose a treatment, and for me [home dialysis] is the way to go!”



(continued from page P1)

Choosing a Treatment that Fits Your Lifestyle

will look at such factors as your health, your home, and any physical limits you may have. Be sure to look at your lifestyle factors, like work, an active family life, travel, and/or childcare needs, too. How will your treatment choice fit your life? You are the one who will need to make your treatment work for you.

Any option can create some changes in your life. But looking at what's most important to you will help you choose a treatment that will allow you to live long and well.

Online Help

You can learn more about the treatment options for kidney failure, and the pros and cons of each, on the Internet at:

- **Kidney School™**, www.kidneyschool.org is Life Options' free, on-line, kidney learning center. Module 2—*Treatment Options for Kidney Disease*, covers the types of treatments and the pros and cons of each.
- **Home Dialysis Central**, www.home.dialysis.org is a clearinghouse of information on home treatment options and centers that offer them.

If you don't have a computer at home, try the library. Or, ask a friend or relative to help you log on so you can use these valuable resources, and others. Deciding on a treatment is your choice, and it's one that you have a voice in—it's *your* life! ☺

Treatment and Lifestyle Quiz

Now that you've read about choosing a treatment for kidney failure, try to answer the statements below to see how much you've learned (answers are on page S8).

1. Travel and work are lifestyle factors to consider when choosing a treatment for kidney failure.
 True False
2. CAPD is done with a machine called a cyclor.
 True False
3. Short daily home hemodialysis is done 5–7 times a week. True False
4. With nocturnal in-center hemodialysis you sleep in the center 3 nights a week. True False
5. You don't have to stay on the same treatment forever. True False

In Control

Contact:

Life Options Rehabilitation Program
c/o Medical Education Institute, Inc.
414 D'Onofrio Drive, Ste. 200
Madison, WI 53719
Tel: (800) 468-7777
Fax: (608) 833-8366
E-mail: lifoptions@meiresearch.org

www.lifoptions.org
www.kidneyschool.org