In CONTROL

A Medical Education Institute/Life Options Publication

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How to Use *In Control*

Each issue of *In Control* offers background, tips, and patient education material on one issue 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 if you want to reprint an article. Help your patients get "in control" of their kidney disease.

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NEWS & ISSUES

Getting Enough Dialysis

Efforts to improve quality of care and outcomes for dialysis patients often focus on adequacy—with good reason. Many studies have shown a relationship between delivered dialysis dose, hospitalizations, and patient survival.

Getting enough dialysis is so important that the NKF-DOQI™ Guidelines established *minimum* standards for adequacy in 1997 (Kt/V = 1.2 for hemodialysis; weekly Kt/V = 2.0 for CAPD, and 2.1 for CCPD). The ESRD Clinical Performance Measures (CPM) Project, conducted each year by CMS, uses those guidelines to track performance of dialysis clinics.

Despite all the interest in adequacy, more than 10% of hemodialysis patients and about one-third of PD patients in the U.S. are not reaching the minimum adequacy floors. Is there something more we can do to help our patients get the dialysis they need?

Missing Treatments

Although several factors (for example, the dialysis prescription and access choice) can affect the delivered dose of dialysis, patient behavior also plays an important role. Patients who shorten or skip their treatments are reducing their time on dialysis, and, by definition, the amount of dialysis they receive.

There is no question that shortening and skipping poses a significant problem. About 20% of patients shorten treatments and about 6% skip treatments (Gordon, *NNJ*, 4/03). Data from the Dialysis Outcomes and Practice Patterns Study (DOPPS) demonstrated that skipping *one treatment per month* is associated with a 30% greater risk of mortality and a 13% greater risk of hospitalization. Shortening treatments, even by 10 minutes a month, was also associated with increased risks.

There are other consequences of shortening or skipping treatments, as well. According the Mark Meier, Consumer Services Coordinator, ESRD Network 11, patients who skip or shorten treatments may be called "noncompliant," a label that puts them at risk for involuntary discharge from their clinics. "Twenty-five percent of all involuntary discharges are related solely to noncompliance," reported Meier, "and noncompliance is a factor in 50% of all discharges." Being labeled noncompliant can also reduce the likelihood of getting a transplant.

Patient Perspective

With so much at stake, why do patients miss or shorten their dialysis sessions? Meier thinks we can do a better job of getting the answer: *by asking.* "Patients are not just being difficult," notes Meier. "They have reasons for doing what they do. We need to ask to find out what they are."

Sometimes patients don't understand the consequences of cutting dialysis time. In those cases, more education may help. Sometimes life tasks, such as work or appointments, create scheduling conflicts. Sometimes patients simply decide that dialysis is not their most important priority. "We cannot make assumptions about patients who miss treatments," said Meier, "we need to understand what it is about the dialysis situation that makes it difficult for the patient to come in."

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Social Work Project Reduces Missed Treatments

Social worker Rita-An Kiely, MSW, and other staff at the Kidney Institute of Wisconsin cut the average number of dialysis treatments missed each month by half! Their project was simple and straightforward. Here's what they did.

Baseline Analysis

Like dialysis teams everywhere, the staff at the Kidney Institute worried about patients who missed treatments. Kiely and colleagues took action, however, after several patients who had missed treatments ended up in the emergency room—due to fluid overload and hyperkalemia.

From January through April, 2003, Kiely collected baseline data about missed treatments. Patient care staff were asked to notify the social worker of any missed treatments. Kiely reviewed "no show" data from routine monthly reports. The average number of patients who missed 1 or more treatments each month was 18 (out of 95). The average number of treatments missed each month was 31: about one per day!

Raising Awareness

Kiely began the effort to cut down on missed treatments by simply hanging a poster in the waiting room. "What's Your Time?" reminded patients about the importance of getting all their prescribed dialysis; it also showed how a few missed minutes can add up over weeks, months, and years. "The poster was a low-key educational effort that reached out to all patients," said Kiely. The poster remained in place for three weeks in April to raise awareness about the importance of getting every minute of dialysis.

Targeted Education

In May, Kiely set up meetings with patients who had missed treatments for non-medical reasons, focusing on an assessment of the barriers to treatment. "Transportation wasn't an issue," said Kiely. Rather, she found that most patients did not understand the impact of missing treatments. Surprisingly, she also found that problems with constipation and diarrhea were causing several patients to stay home. "We needed to do some education," said Kiely.

One-on-one counseling and education sessions were done in May. Kiely

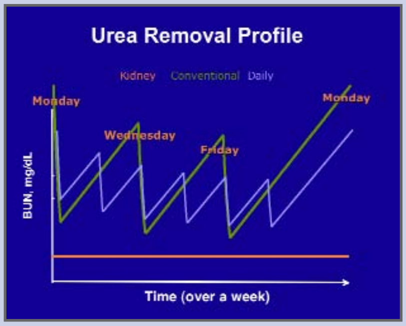
(continued on page S8)

More Hemodialysis, More Often

Standards set by the NKF-DOQI™ guidelines were never intended as goals. They are minimum standards of adequacy. Even though achieving these minimums for *all* patients remains a challenge, many dialysis providers are working to raise the standard of care. They want to move toward achieving optimal, not just adequate, dialysis for patients in the United States.

According to Dr. Carl Kjellstrand, optimal hemodialysis requires longer, slower, more frequent treatments. In a speech given in San Antonio at the International Society of Hemodialysis in 2004, he said a "preoccupation" with dose (Kt/V) has led many to assume that "as long as the result of the numerator, K x t, is maintained, all is well." He contended that this assumption is wrong. "A greater K cannot compensate for a short t," he said. "Short, ultrafast dialysis is not physiologic, and longer time is necessary to remove sodium, water, phosphate, and beta-2 microglobulin."

Dr. Kjellstrand and others are advocating for longer dialysis times and more frequent hemodialysis treatments to maintain homeostasis. The urea removal profile diagram provided by Dr. Todd Ing (below) illustrates how more frequent dialysis evens out urea levels and eliminates the very high BUN levels reached on non-dialysis days under conventional treatment regimens.



Currently, bureaucratic, payment, and scheduling obstacles make it difficult to provide longer, more frequent treatments. Home hemodialysis, using one of several modalities, may offer patients practical, new options for getting more dialysis, more often. For more information about home dialysis options, visit www.homedialysis.org.

Q & A:

Ask the Experts

An interview with Richard A. Sherman, MD
Professor of Medicine, Division of Nephrology
UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ

Q: In your experience, why do patients skip or shorten their dialysis treatments?

A: When patients shorten or skip a dialysis treatment, it is usually a question of priorities. Rarely (10% of the time) is there something that absolutely prevents a patient from getting to treatment or staying the entire time. Instead, patients shorten or skip because there is something else that is more important to them than getting that dialysis time.

As dialysis professionals who know that every minute of dialysis is important, missing treatment time seems unwise, but patients often see it differently. Quite a few patients do not really understand why they need dialysis, and what the dialysis treatments actually do for them. Many patients think that they need dialysis only to remove extra fluid. In those cases, it's easy to see why patients are inclined to shorten or skip a treatment if they don't feel they are having a problem with fluid at the time.

Q. What can professionals do to reduce skipped and shortened treatments?

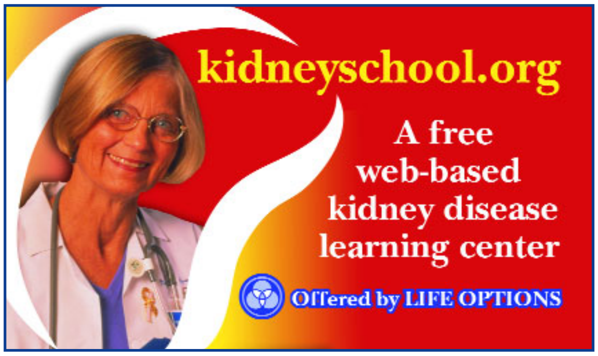
A: There are several things professionals can do:

Educate. We need to work harder to explain the purpose of dialysis. Emphasize the dose rather than taking off fluid. If patients know more about dialysis, it will be harder to rationalize missing or shortening treatments.

Make up *all* lost time. We need to send a consistent message about the importance of getting every minute of dialysis. That means we should be just as concerned about making up time that is missed due to *our* problems as we are about time missed due to *patient* issues. Being consistent helps to convey the message that the full treatment really is important.

Eliminate threats. Scare tactics simply don't work. If you try to scare a patient with threats about the dire consequences that will come from skipping or shortening a treatment (for example, heart attack, hospitalization, joint problems), and the patient does not experience those consequences, it diminishes your credibility. In practice, threats usually work against you by reinforcing patients' perceptions that they were right all along.

Stay positive. Replace negative comments and scolding with positive comments about what patients are doing *right*. Focus on the upside of patient behavior. It will encourage patients to be open and honest, and may help you learn more about the reasons behind noncompliant behaviors.



For more information about dialysis adequacy, visit Module 10 of Kidney School: *Getting Adequate Dialysis*, at www.kidneyschool.org.

Have your patients complete the module and bring you the certificate of completion—they'll learn about the importance of getting enough dialysis, and you'll feel confident that your patients are using a credible educational tool.

Asking About Missed Treatments

To get honest, accurate information from patients about missed or shortened treatments, wording and attitude are important. Blame, anger, and threats will not help; instead, they may create unnecessary conflicts.

The wording below was used in a study conducted by Gordon and colleagues, reported in the April, 2003 issue of *Nephrology Nursing Journal*. Patients were specifically asked these open-ended questions:

“Sometimes patients need to miss or shorten a dialysis treatment. When I reviewed your chart I noticed that in the last three months you have missed [enter number] dialysis treatment(s). Can you tell me why those treatments needed to be missed?”

“In the last three months [enter number] treatment(s) were shorter than expected. Can you tell me why those treatments needed to be shortened?”

According to Gordon, et al., “giving patients an opportunity to explain their perspectives about why they shortened or skipped dialysis enables investigators to avoid making potentially incorrect assumptions about reasons for shortening or skipping dialysis, which could occur if forced-response questionnaires had been used.”

Quiz Answers

1. True
2. False. Your doctor will prescribe a dose of dialysis to meet your needs.
3. True
4. True
5. True

Resources

- *Intensive Intervention With the Non-Compliant Patient* from the ESRD Network of Texas website at www.esrdnetwork.org/docs/intensiveweb.pdf
- *The Behavior Contract as a Positive Patient Experience*, Ramiro Valdez, PhD, ESRD Network Patient Services Coordinator, Network 6 at www.esrdnetwork.org/professional_difficult_pts.htm
- Reports and slide presentations on the increased risk of mortality and hospitalization as reported using data from the DOPPS studies at www.dopps.org
- Gordon EJ, Leon JB, Sehgal AR. Why are hemodialysis treatments shortened and skipped? Development of a taxonomy and relationship to patient subgroups. *Neph Nurs J* 30(2):209-217, 2003

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Social Work Project Reduces Missed Treatments

used two handouts, available on-line: “Are You Shortening Your Dialysis Time?” from www.ikidney.com and “Just the Facts: Getting Enough Dialysis” from www.lifeoptions.org. The renal dietitian also put together a poster, “Are Your Bowels Out of Whack?”

Follow-up

For each patient with a chronic pattern of missing treatments, Kiely prepared a “Missed Dialysis Time” documentation sheet. The sheet was used by the physician during the monthly clinic visit, and the message of getting enough dialysis was reinforced using a positive, educational focus.

Finally, the dietitian and primary nurse were also encouraged to provide education and counseling about missing treatments during their monthly patient meetings.

Positive Results

These simple interventions produced excellent results. The average number of patients who miss one or more treatments per month has dropped from 18 to 12. The average number of treatments missed each month has also dropped—from 31 to 16.

Results have been so positive that Kiely and her colleagues continue to track missed treatments. Reviewing “no show” reports and notifying the social worker are now routine. Physicians, too, have become accustomed to checking missed treatment reports, and now ask for these data before they make rounds.

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Patients In CONTROL

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Getting All the Dialysis You Need

When your kidneys fail, dialysis replaces some of the work your kidneys used to do. The treatments remove some fluid and wastes that build up in your blood. To feel your best, you need to get enough dialysis.

Your Prescription

How much dialysis you need depends on your height, weight, blood test results, and how much—if any—kidney function you still have. Your doctor will prescribe a dose of dialysis to meet *your* needs. There is no such thing as a "one size fits all" dialysis prescription.

- If you choose **hemodialysis**, your prescription will include a dialyzer (size and type), blood flow rates, and the amount of treatment time you need to achieve the desired "dose" of dialysis.
- If you choose **peritoneal dialysis** (PD), your prescription will include solution type and concentration, number of exchanges per day, and dwell times.

To get enough dialysis, you and your care team need to follow your prescription exactly. Your care team may adjust your prescription (especially in the first few months of treatment) to make sure you are getting enough, or "adequate," dialysis.

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Routine Testing

Your care team will do monthly blood tests to see if you are getting enough dialysis. There are two tests for tracking hemodialysis:

- **Urea Reduction Ratio** (URR). Urea is a waste product in your blood that is easy to measure using a test called *blood urea nitrogen*, or BUN. By looking at your BUN levels before and after a treatment, your care team can tell how much urea is being removed. This number is your *urea reduction ratio*, or URR. Your URR should be at least **65%**.
- **Kt/V** (kay T over V). This test uses a formula that includes dialyzer clearance (K); treatment time (t); and your body's fluid volume (V) to measure how well your treatments are removing urea. Your Kt/V should be at least **1.2**.

There is one test for measuring the adequacy of PD:

- **Weekly Kt/V**. This test measures how much urea is removed during one week of PD. Your weekly Kt/V should always be at least **2.0**.

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More Dialysis Keeps Athlete Running Longer

For many people on dialysis, getting the least amount of treatment is the "ideal" prescription. But for triathlete and dialysis patient Shad Ireland, longer dialysis treatment times, knowledge, and exercise are the keys to feeling great and keeping him active—active enough to set out to be the 1st dialysis patient to compete in any Ironman triathlon competition.

A Defiant Kid

Shad, 32, was diagnosed with staphylococcal kidney disease at age 11. Despite prednisone, he continued to get worse. A biopsy found type 1 membranoproliferative glomerulonephritis (MPGN). "They thought they could contain it for 10 years or so," recalls Shad, "But I started in-center dialysis 3 months later. They still don't know what caused the rapid onset."

Shad was a self-described "terrible kid" on dialysis. "I ate and drank what I wanted, I didn't listen to my care team—I was angry," he recalls. But the pediatric nephrologists at the University of Minnesota had a plan: for every kilo Shad gained between treatments he stayed on the machine for an extra hour. "I always had to be on for 6 hours or so since I gained 3–4 kilos each time!" he says. "Due to their aggressive treatment, I felt really good and I'm alive today."

Transplant Failure

In 1990, Shad received his first transplant, which rejected in 1993. "I was in a coma for 6 weeks and dropped from 150 to 75 pounds," says Shad. "After I woke up, I went to shave but my muscles atrophied and I fell down. I was so skinny that my bicep was the size of my middle finger and thumb put together."

This time would prove to be a life-changing experience. "I broke down and cried, and told myself that I would never be in this kind of shape again," he says. Determined to get fit, Shad spent 13 months recuperating on his mom's couch, then began exercising. "I could only do two pushups—now I do 250," he remembers. "I would feel bad after dialysis, and trying to exercise made me feel worse, but the key was to *stick with it* because eventually I felt much better."

In time, Shad received a second transplant, but "after 2 months, I demanded they take it out. The anti-rejection meds caused pseudotumors and pain," says Shad. "I have chosen not to take another transplant—I recommend it for others because I have seen them work well, but it just doesn't work for me."

More Is Better

Since his transplants, Shad has successfully continued in-center hemodialysis with an attitude of "more is better." "For me it's part of my life, like breathing—I need it," he says. "The *minimum* for me is always 4 hours. I have run 3 hours a few times, and I can feel the difference because I normally feel so healthy."

Shad also feels that knowledge is key to success on dialysis. "I feel that success starts with being an educated patient—it challenges staff to do better," he says. "I look at my lab values and want to know where I'm at—I always push for higher and better. My URR is in the 70s, but I'd like to see it in the 80s."

For medications, Shad takes only RenaGel®, Epogen®, Zemplar®, iron, and a multivitamin. He puzzles physicians with his 70/40 blood pressure, but credits longer dialysis, exercise, and vigilant care. "I follow a no salt-added-diet, which means that I avoid really salty foods, but if I want a piece of pizza I have it. I also pay close attention to phosphorus and potassium," he reports. "I drink whenever I'm thirsty but I don't gain weight between treatments because I sweat off a lot when I exercise. I really recommend exercise: whether you're 10 or 70, some level of physical fitness is important."

Exercise and Beyond

Exercising and taking care of himself have added importance for Shad since, on July 25th, 2004, he will compete in the Ironman® U.S.A. Triathlon—a race that consists of a 2.4 mile swim, 112 mile bicycle ride, *and* 26.2 mile run. "My goal is to complete the competition with a qualifying time that will enable me to compete in the world championship in Hawaii," says Shad. "If I had enough sponsors, I would race full-time in the worldwide circuit."

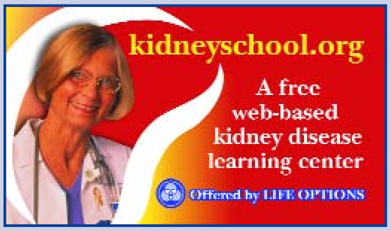
Shad is also busy finishing his college degree, and starts law school in 2005. "I believe any obstacle can be turned into an achievement," he explains. "I feel like I am what *could* be—people on dialysis don't have to be afraid; they can reach this level of health and wellness."

The Bottom Line

For Shad, raising awareness about the long-term effects of shortening treatment times is important. "I've been on dialysis for over 18 years, and most people don't make it that long," he explains. "Dialysis patients need to realize that shortening treatment has a cumulative effect—you're shortening your life."

In the future, Shad hopes to set up a dialysis machine in his home and dialyze 5 hours a day, every other day. "People equate dialysis with being tired, so they think shorter is better," says Shad. "The bottom line is that getting enough dialysis allows you to live longer."

For More Information on Getting Enough Dialysis...



For more information about getting enough dialysis, visit Module 10 of Kidney School: *Getting Adequate Dialysis*, at www.kidneyschool.org.

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Getting All the Dialysis You Need

Feeling Good

If you do not get enough dialysis, you may not feel well. Some symptoms you might feel include: feeling tired, ammonia taste in your mouth, poor appetite or nausea, weight loss, yellow skin color, itching, sleep problems, and swelling of your hands, feet, or face.

In the long run, not getting enough dialysis, raises your risk of hospital stays, heart disease, and even dying, from the effects of waste and fluid build-up in your system.

What You Can Do

Healthy kidneys work 24 hours a day, seven days a week. If you are doing in-center hemodialysis, you may only be getting 12–14 hours of treatment per week, so every minute counts! With PD, every exchange counts!

Be sure to get all the treatment your doctor prescribes. Over time, it makes a difference.

How you can be sure you get enough dialysis:

- Know your prescription and track your URR or Kt/V results.
- Report symptoms to your care team.
- Know your fluid limit and follow it.
- Report any changes to your “real” weight.
- Take care of your access or PD catheter and report any problems.
- Know your fluid goals for each treatment and check to be sure they are reached.
- Be on time for hemodialysis and stay until the end of your treatments.
- Stay late, if you can, to make up for any time that is lost during dialysis.
- Do all of your PD exchanges as prescribed.

Getting Enough Dialysis Quiz

Now that you’ve read about getting enough dialysis, let’s see how much you’ve learned! See if you can answer the questions below (the answers are on page S8):

1. When your kidneys fail, dialysis replaces *some* of the work your kidneys used to do. ☐ True ☐ False
2. Your dialysis technician will prescribe a dose of dialysis to meet your needs. ☐ True ☐ False
3. URR and Kt/V are two blood tests used to see if you are getting enough dialysis. ☐ True ☐ False
4. If you have an ammonia taste in your mouth, you may not be getting enough dialysis. ☐ True ☐ False
5. Not getting enough dialysis causes waste and fluid to build-up in your system. ☐ True ☐ False

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