

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 at (800) 468-7777 if you want to reprint an article. Help your patients get “in control” of their kidney disease.

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NEPHROLOGY
NEWS & ISSUES*

Fatigue in CKD

Persistent fatigue can be one of the most debilitating symptoms of chronic kidney disease. Yet fatigue often goes unreported and untreated, especially in (stage 3–4) patients who have not begun dialysis. As a result, as many as 2/3 of CKD patients reach end-stage renal disease in a weakened state, and are at increased risk for serious complications.^{1,2}

The Need to Monitor

In practice, clinicians who monitor fatigue often do so as part of a diagnostic workup for anemia. This focus on anemia is understandable, since anemia is the most common cause of fatigue in CKD. And anemia has been associated with a host of problems, including heart disease, loss of mental function, and weakened immune response. In fact, NKF-DOQI™ guidelines* recommend an anemia workup in any CKD patient with a GFR < 60 (stage 3, 4, or 5).

Making fatigue assessment part of a workup for anemia can add useful information about the patient's symptoms. But there is another reason to monitor fatigue in patients with CKD. Quite simply, the fatigue *itself* is a concern.

The experience of fatigue can, and does, have a dramatic effect on the lives of CKD patients. For example, it is not uncommon for CKD patients to quit their jobs due to fatigue...before they ever start dialysis. In one small study, 8 of 9 CKD patients who quit their jobs cited severe fatigue and loss of

energy as the reason.³ Unfortunately, leaving a job may result in lifelong economic hardship and/or the loss of health insurance coverage.

Chronic fatigue can also reduce patients' quality of life. Results of a poll from Harris Interactive demonstrated the significant effects of fatigue, including less ability to exercise and participate in social activities. Some patients claimed fatigue “prevented them from having a normal life.”⁴

The impact of fatigue on every aspect of patients' lives warrants careful, consistent monitoring. Unfortunately, patients frequently do not report fatigue. As a result, dialysis professionals need to take a more proactive approach to assess this common symptom.

Assessing Fatigue

Dialysis clinicians cannot rely on patient self-reporting to help them make a diagnosis of fatigue. Many patients are reluctant to report fatigue—even if it is severe—for fear of being considered unmotivated or weak. Too, the development and gradual worsening of fatigue over time may cause patients to “adjust” to lower energy levels, so they fail to recognize the magnitude of their impairment. Nevertheless, the subjective nature of fatigue requires that information come from patients' symptom reports. How can clinicians best encourage and interpret patient reports of fatigue?

Ask first. Don't assume the patient will offer information about fatigue, or that you can make a diagnosis

(continued on page S4)

*Assessment of fatigue is not part of the NKF-DOQI algorithm for diagnosis and treatment of anemia.

The Role of Deconditioning in Fatigue

“There’s an important component of fatigue that is largely unrecognized in CKD patients,” claims Dr. Brent Miller, assistant professor of medicine at Washington University in St. Louis. It’s deconditioning. “In spite of the fact that [Dr.] Trish Painter and others have been writing about the effects of deconditioning in dialysis patients for decades, the same phenomenon is just not on the radar screen in CKD,” says Miller. “And we need to address it if we want to help our patients return to active lifestyles.”

Hidden Problem

What is deconditioning? It is the muscle atrophy and related weakness

that result from a prolonged period of inactivity. “It’s insidious and gradual,” says Miller, “and it definitely starts in CKD.”

Deconditioning can make patients so weak that they are not able to do much physical activity. Their inactivity, in turn, allows more deconditioning, setting off a downward spiral that can result in serious disability.

So, why doesn’t deconditioning get more attention? “There are so many things that must come first in CKD,” says Miller. “Clinicians must identify and treat the medical causes of fatigue, like anemia, electrolyte imbalance, hypertension,

acidosis, etc., and that takes time.” Next, physicians need to rule out any side effects of medication, as well as uremia. “The effects of deconditioning are hidden by so many other things,” says Miller, “we often don’t get around to correcting muscle weakness.”

Action Plan

Miller and his colleagues at the CKD clinic of Washington University in St. Louis would like to see a greater emphasis on preventing deconditioning in CKD patients. “We’re taking the first ‘baby steps,’” says Miller, “by just identifying the need.”

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Using a Fatigue Rating Scale

Recognizing and assessing fatigue are needed to provide treatment. For CKD patients, fatigue assessment is often informal, but there are several well-developed fatigue rating scales available. Fatigue scales attempt to measure either:

- Intensity of fatigue (perceived)
- Functional limits caused by fatigue (perceived)

Although there is no “gold standard” assessment tool, because fatigue is subjective and difficult to define, the following fatigue scales may be useful.

Brief Fatigue Inventory – 6 questions scored using a scale of 0–10, with 0 being “no fatigue” and 10 being “as bad as you can imagine.” Although the test was originally developed for use in cancer patients, this tool measures the impact of fatigue on activities of daily living. It was developed by the University of Texas, M.D. Anderson Cancer Center. For more information and permission to use the survey, go to the M.D. Anderson website at www.mdanderson.org.

Fatigue Severity Scale – 9 items scored using a numerical scale of 1–7. Patients rate how each of the 9 statements applies to their fatigue during the past week; higher scores mean the statement is more accurate. This scale has been used to differentiate between clinical depression and fatigue and was developed for use in patients with multiple

sclerosis and other conditions associated with chronic fatigue. (Krupp LB, et al. *Arch Neurol* 46:1121-3, 1989).

Multidimensional Assessment of Fatigue (MAF) Scale – 16 items scored using a numerical scale of 1–10; 2 items have multiple-choice responses. The MAF scale is designed for use in patients with chronic illness, and attempts to assess the impact of fatigue on activities of daily living. Translations are available in several languages. The MAF is copyrighted by Basia Belza, PhD, RN, University of Washington–Seattle. To obtain permission to use the MAF, complete the permission form on the website at www.son.washington.edu/research/maf/.

The scales listed here represent just a sample of the many fatigue assessment scales available. The decision to use a formal fatigue scale must be based on practical considerations in the individual clinical setting. Recognizing the *need* to assess fatigue is the critical factor.

Recently, work has been done on a comprehensive assessment tool that attempts to identify dialysis patients at risk for poor outcomes. The 16-item tool, called the *Risk for Outcomes Adverse to Dialysis (ROAD)* includes a question about fatigue. Preliminary testing indicates that the ROAD may help clinicians identify hemodialysis patients who are at risk for hospitalization and poor quality of life. (Lamb, et al. *Neph Nurs J* 31:267-282, 2004.)

Q & A:

Ask the Experts

An interview with Charlotte Szromba, MSN, CNN, APRN, BC
Nurse Practitioner, Section of Nephrology, University of Chicago, Chicago, IL

Charlotte Szromba is a nurse practitioner at the University of Chicago Nephrology/Transplant Outpatient Clinic. The target population served in this clinic are patients with chronic kidney disease stages 2–4. Charlotte has a case load of patients and manages the anemia treatment program at the clinic. She has 20 years of experience in nephrology nursing.

Q: In your experience, how well do CKD patients self-report their symptoms, especially fatigue?

A: Patient self-reporting of fatigue is quite variable. In some cases, fatigue is the primary presenting symptom—the reason a patient seeks medical help. These patients recognize that their fatigue is a problem and are very ready to talk about it. At the other end of the spectrum are patients who don't mention fatigue at all. They don't think it is "serious," because they don't realize it can be a sign of a medical problem. They tend to worry about other, more specific symptoms, and don't think fatigue is a cause for concern. In fact, many think fatigue is just a normal part of getting older and don't want to appear to be complaining about it. We know as health care providers that fatigue can impact quality of life, preventing patients from doing things they want to do, or having energy to interact with family and friends.

Q: What do you do in your clinic to evaluate patients for fatigue?

A: As a specialty clinic, we include evaluation of fatigue in

the initial patient assessment. Every patient is asked about his or her energy level. I have found that I can get a good sense of whether fatigue is a problem by asking: "Are you able to do everything you want to do?" This works much better than asking, "How's your energy level?"

I listen carefully to patient responses. If they report restricted activity, or starting things they can't finish, I consider fatigue. If they say, "I can't do anything," and report that they don't even *try*, I inquire about depression, too. I simply ask, "I'm wondering if you're feeling depressed." You'd be surprised at how readily patients will admit to depression; just asking opens the door. Finally, I always ask about sleep patterns. Daytime sleepiness is often a sign of fatigue and may also indicate progression of their kidney disease.

At follow-up, I continue to ask about activity levels. We see stage 2 patients every 6 months. By stage 4, we are seeing patients monthly. If patients are receiving treatment for anemia, I look for them to report that they feel less tired and are able to do more of their regular activities about 6–8 weeks after starting treatment.

Q: Do you use any formal fatigue assessment tools?

A: There are many different tools for assessing fatigue, physical and social functioning, but we do not use specific tools at this time. However, if patients are experiencing fatigue I may ask that they keep a daily log to help me evaluate the impact of fatigue in their lives. It may seem like a lot of paperwork, but it can help patients remember better and be more specific when they come in for their visits.

Several tests are also available to evaluate or rule out depression. Most recently, we have used the SF-36 to get a baseline measure of functioning and well-being, then we re-do the test at the 3–4 month follow-up visit. Other valuable tools recommended in the K/DOQI Clinical Practice Guidelines on chronic kidney disease include the Dartmouth COOP Functional Health Assessment Chart, the Duke Health Profile, and the Kidney Disease Quality of Life Tool, which is specific to kidney disease. By carefully listening to our patients and asking questions, we can help them manage their fatigue and improve their quality of life. 🗣️

Fatigue in CKD (continued from page S1)

from observations or lab reports. Severe fatigue can exist even if lab values are “normal”; only patients can tell you how they are really feeling.

Be specific. Different patients will use different words to talk about fatigue, including tired, weak, lack of energy, or exhausted. The varied vocabulary makes it difficult to interpret patient reports. Instead, ask about how the fatigue is affecting specific activities of daily living.

Educate. Patients need to understand that severe fatigue is *not* “normal,” and that there are treatment options for fatigue. Knowing help is available may encourage more honest reports.

Try tools. Consider using a formal assessment tool to measure and evaluate fatigue. There are several available. (See sidebar on page S2 for examples.)

Rule out depression. The symptoms of depression may mimic the symptoms of severe fatigue. Consider a psychological evaluation to rule out depression.

The effects of fatigue on CKD patients can be devastating. Clinicians who are prepared to work with their CKD patients to diagnose and assess fatigue can help them maintain their quality of life. 🗣️

References

1. Obrador GT, Ruthazer R, Arora P, et al. Prevalence of and factors associated with suboptimal care before initiation of dialysis in the United States. *J Am Soc Nephrol* 10:1793-1800, 1999
2. From DOPPS study reports and slide presentations at www.dopps.org
3. Schatell D, Ellstrom-Calder A, Alt PS, et al. Survey of CKD patients reveals significant gaps in knowledge about kidney disease—Part 1. *Nephrol News Issues* 17:5:23-6, 2003
4. Harris Interactive Poll. New survey provides insight into CKD, exhaustion, anemia. *Nephrol News Issues* 17:2:29-31, 2003

Quiz Answers

1. True
2. True
3. False. It is important to be very detailed and specific about your symptoms.
4. True
5. True

(continued from page S2)

The Role of Deconditioning in Fatigue

Next steps include:

- Asking every CKD patient about fatigue
- Educating patients and families about the problem of fatigue
- Convincing patients that fatigue is *not* acceptable
- Providing good clinical care for all medical problems
- Promoting increased activity

“We do a good job of getting our transplant patients moving,” says Miller. “We even give them pedometers when they leave the hospital.” Now, it’s time to focus on CKD.

Challenges

Miller admits it is difficult to get CKD patients to exercise. “For one thing, you only see CKD patients once every 3 months,”

Miller notes. “And you don’t have the same level of support—the PTs, technicians, etc.—that you’d have in a dialysis unit.” Finally, Miller finds that the patients themselves are slow to get motivated. “Only about 15%–20% of our patients buy into the need for exercise,” says Miller. “So many patients just take for granted that fatigue goes hand in hand with kidney disease.”

Still, Miller hopes that one day soon promoting activity for CKD patients to prevent deconditioning will “become as important as anemia management.” Right now, no one really takes it seriously, he says, including the government or insurers. But Miller hopes that will change.

“In today’s world, anemia should be identified and treated right away. We recognize the need to treat anemia pre-dialysis, and it is no longer acceptable to have a patient starting dialysis with a hematocrit of 20.” Similarly, Miller doesn’t think it should be acceptable to allow CKD patients to become sedentary and deconditioned. 🗣️

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Reporting and Managing Fatigue

Many people complain of feeling worn out or having less energy and think it's due to being out of shape, not getting enough sleep, or being stressed. All of these may be true, but fatigue can also be a symptom of a more serious problem—early chronic kidney disease.

Why and How to Report Fatigue

Fatigue can come on slowly and you might not know it is a “symptom” worth telling your doctor about. But fatigue in CKD is most often caused by *anemia*, a shortage of oxygen-carrying red blood cells. Anemia—and fatigue—can and should be treated early to help you feel better and to prevent heart problems down the road.

To report your fatigue, it is key to know how to describe exactly what you feel. For example, saying “I feel tired” does not tell your doctor as much as if you say, “I am too tired to walk down the driveway and pick up my newspaper.” Being very

specific and offering detail can help your doctor see that your fatigue is severe enough to limit your daily activities.

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Anemia 101

In healthy people, the kidneys make a hormone called *erythropoietin* (EPO) that helps your body make red blood cells. Anemia begins early in kidney disease, when the kidneys are still working at about 45%, and tends to get worse as the kidneys lose function and produce less EPO.

Besides feeling very tired, other symptoms of anemia can include:

- Feeling cold all the time
- Shortness of breath/chest pain
- Pale skin, gums, and fingernail beds
- Trouble concentrating
- Dizziness/lightheadedness
- Headaches

The most important reason to report your symptoms and get early treatment is that anemia can cause heart damage called *left ventricular hypertrophy* (the heart muscle grows too big, trying to get more oxygen through your body). LVH is the leading cause of death in people with kidney failure. By the time the kidneys fail, nearly 75% of people already have some degree of LVH.

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Reporting Fatigue Allows Early Treatment

Fatigue is one of the most common—but often least reported—symptoms of early chronic kidney disease; a symptom that 2-year CKD patient Julie knows all too well. Concerned by her long-term lack of energy, Julie saw her doctor, who found her kidney disease and treated her fatigue.

Not Feeling Like Herself

For a few years, 41-year-old Julie had noticed that she was always tired after work. “I just thought ‘gosh, I’m so tired all the time,’” she recalls. “I thought it was related to my age or weight gain.” It wasn’t for a while that she went to get a full physical.

“I started to notice that some things with my general health were ‘off’—in addition to being tired, I had shoulder and back soreness and a swollen lymph node in my armpit,” says Julie. “Something just seemed to be wrong and I thought I should bring it up to my doctor.”

Julie saw her family doctor, who ran lab tests. “The tests found that I had mild anemia,” recalls Julie. “My doctor said I should start taking iron pills to help with the fatigue.” But besides anemia, tests showed that Julie’s creatinine level was too high—a sign of kidney disease. Seven months of tracking her creatinine levels ended in a kidney ultrasound that showed scarring. Julie was referred to a nephrologist.

Chronic Kidney Disease

The nephrologists did a biopsy, which revealed that Julie had interstitial nephritis. He believed Julie’s kidney disease may have been a result of undiagnosed Sjögren’s syndrome—an autoimmune disease in which white blood cells attack moisture-producing glands. “I had the classic symptom of very dry and red eyes, as well as fatigue, but not enough other symptoms to diagnose me,” explains Julie.

At first shocked by her kidney disease, Julie tried to learn as much as she could, for herself and for her family. “My teen-aged daughter needed to know that I wasn’t going to vanish from her life any time soon,” says Julie. “So, without painting too rosy of a picture, I told her about my disease and let her ask questions.”

Treating Anemia

Lab tests done during her nephrologist visit showed that Julie’s hemoglobin level was still too low, so he prescribed EPO. “I’m glad EPO exists because not so long ago people with anemia needed to have blood transfusions—and I feel like I’ve been spared the downside of kidney disease,” says Julie. “I never went through severe fatigue, because my anemia was caught early enough.”

Julie never linked her fatigue and lack of energy to anemia. “I felt that the disease

process in my body and the higher amount of waste in my blood could be causing my fatigue,” explains Julie. She knew that iron pills were often used to treat mild anemia, but didn’t know there were prescription drugs that could help with fatigue.

Staying Active

Julie’s energy level and sleep needs still vary, but she has kept working 4 days a week as a mechanical engineer, keeping her life as active and normal as it can be. “I have so many nephrologist visits that it’s good to have one day off a week to fit those in,” she notes. “It also helps to be able to sleep late, since I’ve found that I need more sleep now that I have kidney disease.”

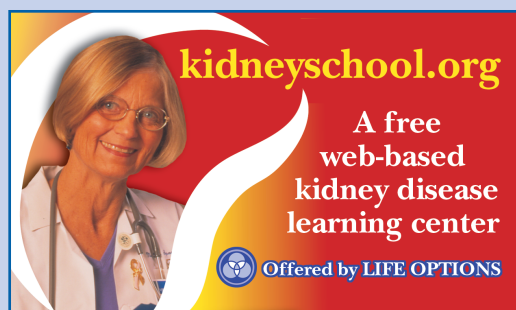
With changing levels of energy from day-to-day, Julie takes it easy and sleeps more when she needs to, but also keeps up with her exercise. “Staying active is key to good health or you get in a cycle of not doing anything,” she says. “I walk and sometimes go to the gym, but I also let myself sit down and put my feet up if I need to.”

Tips and Lessons

Julie’s kidneys are now working at 15% and she expects to start dialysis in a year or so, but she feels pretty good, saying, “I know that I need to take it easier and that I can’t push myself for weeks at a time, but I can do most everything.”

Julie tracks her hemoglobin and hematocrit levels with her nephrologist, who changes her EPO and iron doses as needed.

“Pay attention to how you’re feeling and don’t ignore it,” advises Julie. “Even if you think it could be nothing, report your symptoms!” Julie did, and it has led her to early treatment for fatigue and time to prepare for dialysis. “You need to stay involved in your care and learn as much as you can about yourself and your disease,” says Julie. “As you learn more and talk to others with kidney disease it doesn’t seem so scary.”



For More Information...

For more information about managing fatigue and reporting symptoms, visit: Kidney School Module 6: *Anemia and Kidney Disease*, Kidney School Module 7: *Understanding Kidney Lab Tests*, and Kidney School Module 12: *Staying Active with Kidney Disease*, at www.kidneyschool.org.

Reporting and Managing Fatigue *(continued from page P1)*

Your doctor will do blood tests to see if you have anemia. These tests include:

- **Hemoglobin** (Hgb or Hb) – measures the amount of oxygen in your red blood cells.
- **Hematocrit** (Hct, or “crit”) – measures the percent of your blood that is made up of red blood cells.

The good news is that anemia can be treated. If you have anemia, your doctor may prescribe EPO to help your body make red blood cells. This treatment will help give you more energy, a better appetite, and greater endurance. Your doctor may also prescribe iron supplements if your iron levels are too low.

Results

Studies show that if you have to start dialysis, you’ll do much better if your fatigue and anemia are under control.

Reporting and managing fatigue and other symptoms will help you maintain your health and lifestyle.

With early treatment of fatigue, you can keep doing the things you did before you had kidney disease—work, volunteer, exercise. Staying active and involved are key to living long and well with *any* chronic health problem. 🧠

For More Information...

- Visit Life Options’ Kidney School Module 6: *Anemia and Kidney Disease* at www.kidneyschool.org.
- Take the Continuum Health Partners’ *Fatigue Assessment* at www.wehealny.org/healthinfo/index.html. This fatigue test is a tool to find the level of your fatigue. After submitting the survey, general fatigue information, tips, and resources are offered.
- Order *The Iron Story* from the American Association of Kidney Patients (AAKP) at (800) 749-2257.
- See the National Kidney Foundation’s *Getting the Most from Your Treatment Series: What You Need to Know about Anemia* at www.kidney.org/general/atoz/.

Fatigue Quiz

Now that you’ve read about managing and reporting fatigue, let’s see how much you’ve learned! See if you can answer the questions below (the answers are on page S8).

1. Fatigue is one symptom of early chronic kidney disease. ☐ True ☐ False
2. Treating fatigue early will help you feel better down the road. ☐ True ☐ False
3. “I feel tired” is a good way to describe your fatigue. ☐ True ☐ False
4. By the time the kidneys fail, most people already have some heart damage. ☐ True ☐ False
5. EPO is prescribed to help your body make red blood cells. ☐ True ☐ False

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