

## 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!

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## In-center Self-Care: New Interest in an Old Idea

Dialysis centers across the U.S. are struggling to improve outcomes in the context of nearly flat reimbursement—and rising costs. Some experts believe that expanding the availability of in-center self-care might offer a solution to both challenges. Research and clinical experience suggest that in-center self-care units can, indeed, improve patient outcomes and reduce staffing costs.

### What Is In-center Self-Care?

According to long-time self-care practitioner Dr. Susan Bray, “self-care hemodialysis is a mechanism of granting empowerment and control to patients who have entered Stage 5 chronic kidney disease, or end-stage renal disease (ESRD), and are beginning dialysis.”<sup>1</sup> In practice, self-care means that patients share responsibility with the clinic staff for running their dialysis treatments.

Exactly how much responsibility a patient takes depends on the individual, but many self-care patients do it all—they set up their machines, program their ultrafiltration goals, check their dialyzers, record their weight and blood pressure, put in their own needles, administer their own medications, run and monitor the treatment, and prepare the station for the next patient.

### Good for Patients

Dr. Bray has promoted in-center self-care since the early 1980's, in

part because she has seen excellent results at Mt. Airy Self-Care Dialysis (formerly known as Chestnut Hill Dialysis Center, which she helped start). She reports that self-care patients at the inner city Philadelphia center have lower mortality rates (just 2% per year), a higher than normal transplantation rate, fewer hospitalizations, and “better quality of life.”<sup>1</sup>

Self-care patients have also had a good success rate when working with the Department of Vocational Rehabilitation to get into training programs and/or college. Dr. Edward Jones, current medical director at Mt. Airy confirms these comments (see page S2).

Experienced dialysis nurse Ann Compton estimated that about 38% (41 of 109) of patients in one of her outpatient dialysis clinics would be capable of performing in-center self-care.<sup>2</sup> Drs. Bray and Jones both report that the *desire to do self-care* is the most important criterion.<sup>1</sup>

### Why It Works

Research provides some insight into why in-center self-care patients may enjoy better outcomes. For example, a Life Options study<sup>3</sup> demonstrated that “self-care during hemodialysis was positively associated with physical functioning,” noting that higher levels of physical functioning predict lower hospitalization and mortality.

*(continued on page S4)*

# Self-care Improves Outcomes and Outlook

When Dr. Edward Jones, Medical Director of the Mt. Airy Self-Care Dialysis Facility in Philadelphia, compares the 50 in-center self-care patients in his clinic with the patients who are dialyzed in a traditional, staff-assisted facility, he sees major differences. “The self-care patients definitely have better outcomes and better attitudes about taking care of themselves,” he observed.

## Less Morbidity and Mortality

Based on data he has collected, Jones concludes that his in-center self-care patients experience significantly less morbidity and mortality. Specifically, compared with national averages for all hemodialysis patients, Jones’ in-center patients had:

- 66% fewer days in the hospital (4/1000 dialysis days vs. 12/1000)
- Half the mortality (9-10% vs. 22%)

Jones reports that serum albumin and serum phosphorus levels are better in the self-care group than in the staff-dialyzed group, too.

“There is some selection bias in the population,” Jones admitted, “because the self-care patients tend to be younger (on average 10 years younger).” He also conceded that the people who choose self-care might be more motivated to take care of themselves. “It is difficult to do a controlled study, so I haven’t published my data,” he added, “but it’s clear to me that in-center self-care is an excellent modality.”

## More Patient Empowerment

“Self-care gives patients the responsibility for their own health,” commented Jones. He finds that these patients understand their disease process, dialysis, and what they need to do in terms of watching diet and fluids. “If they do end up in the hospital, 90% can rattle off their meds and doses,” he added.

Self-care patients at Mt. Airy Dialysis set up their own machines (Fresenius 2008K); rinse their dialyzers, and administer their own EPO, iron, and vitamin D analogs. Many place their own needles. They track and log their blood pressure during treatments, and clean the chair and strip the machine when they’re through. “They do it all,” said Jones, “and our staff has been trained to encourage them.”

## Promoting Self-Care

Classes for predialysis patients always include a presentation of all available modalities, including in-center self-care. “If a patient seems interested, we push self-care a little and encourage them to give it a try,” noted Jones. “Anybody can do it if they want to, and most who start, stay with it. Very few have quit,” he added, “and the self-care unit is constantly full.”

Every staff member at Mt. Airy is committed to helping patients take care of themselves. Patients who choose self-care begin learning how to operate their machines on day one. Even patients in the regular unit (sometimes referred to as ‘modified self-care’) are encouraged to do some things,

for example, tearing their own tapes or taking their own blood pressures.

## Keys to Success

With 50 self-care patients and 20 years of experience, Mt. Airy Self-Care Dialysis might be one of the largest—and oldest—in-center self-care units in the country. What’s behind their success? “Your staff absolutely has to be on board with self-care,” advised Dr. Jones. He credits his staff, including training nurse LaRhonda James, RN and technician Van Price, for setting the right tone. Physical separation from patients who are being dialyzed in a staff-assisted center is also key. “You cannot mix the two groups of patients in the same room,” he noted, “or some self-care patients will begin to ask ‘Why do I have to do this myself?’”

## Win-win Situation

In-center self-care programs can be beneficial for the dialysis clinic as well as the patients. Jones noted that the staffing ratio in a self-care program is reduced, with two techs and one nurse for every 10 self-care patients.

“There are some financial benefits, too,” added Jones. For example, patients who are being trained for self-care can receive Medicare benefits from day one; they do not have to wait for 90 days. In addition, the dialysis clinic is reimbursed for training costs, and physicians, too, are paid from the first day of dialysis.

“Lately, there is more interest in in-center self-care than there has been for years,” said Jones. “The benefits for patients and providers certainly warrant a good look.”

# Q & A: Ask the Expert

An interview with Lynda K. Ball, RN, BSN, CNN  
Quality Improvement Director, Northwest Renal Network, Seattle, WA

*Ball is a national speaker and instructor in vascular access, and has been in nephrology nursing for 23 years. Helping patients learn to put in their own needles can open the door to self-care options. Ball offers her perspective on how and why to teach this important skill.*

## Q: Is it difficult to self-cannulate?

**A:** Learning to self-cannulate takes practice. There is a national policy and procedure on self-cannulation,<sup>1</sup> as well as a checklist for self-cannulation.<sup>2</sup> Your facility will also have a policy and procedure on self-cannulation. Patients will be taught to assess the access, look for signs of infection, and check to make sure the access is patent.

A few tips to pass on to patients learning to self-cannulate: Make sure your surroundings are quiet and calm to allow you to focus; ask questions about anything you don't understand; use practice arms to get the feel of the needle, how to hold it, and to choose the correct angle of insertion for the needle; and learn how to use a tourniquet if you have an AV fistula.

## Q: Are there advantages to patient self-cannulation?

**A:** Absolutely. A survey in the Southeastern United States found that more than 20 patients with AV fistulas more than 20 years old believed they lasted as long as they did because there was one cannulator. Patients can feel their vessel and direct the needles into just the right position. Nurse and patient Catherine Lewis writes about her experience, saying self-cannulation can build

self-confidence, decrease the pain of needle insertion, lessen fear and anxiety, empower patients to actively participate in the care and maintenance of their access,<sup>3</sup> and may provide alternative hemodialysis (HD) options.

## Q: What do you mean by alternative HD options?

**A:** Home hemodialysis. The fear some patients have about dialysis at home is not being successful inserting the needles or having other cannulation complications. When they learn to insert their own needles, it decreases the risk of those complications. Successful cannulation means good waste removal that will make patients feel better. Some home programs require patients learn to self-cannulate to perform dialysis at home.

## Q: What do renal experts say about self-cannulation?

**A:** The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI™) Clinical Practice Guidelines and Clinical Practice Recommendations<sup>4</sup> has new guidelines (2006) on self-cannulation: "Patients who are capable and whose access is suitably positioned should be encouraged to self-cannulate. The preferred cannulation technique is the buttonhole."

The Centers for Medicare & Medicaid Services (CMS) Fistula First Project developed 11 Change Concepts to assist facilities to increase the number of patients with AV fistulas. Change Concept #8, Cannulation Training, states that facilities should offer the option of self-cannulation to patients who are interested and able.

The American Nephrology Nurses Association's position statement on vascular access for hemodialysis states: "Education in self-cannulation should be offered to patients judged to have the ability and the access placement that enable them to do so."<sup>5</sup>

## References

1. Northwest Renal Network. Sample self-cannulation of vascular access procedure. Available at: <http://www.nwrenalnetwork.org/fist1st/SampleSelfCannulationProcedure.pdf>. Accessed August 2007.
2. Intermountain ESRD Network. Training checklist for self-cannulation. Available at: <http://www.esrdnet15.org/QI/c8f.pdf>. Accessed August 2007.
3. Lewis C. Let's empower patients with the choice of self-cannulation! *Neph Nurs J* 32(2):225, 2005.
4. National Kidney Foundation. KDOQI clinical practice guidelines and clinical practice recommendations for vascular access for 2006 updates: Hemodialysis adequacy, peritoneal dialysis adequacy, and vascular access. *Am J Kidney Dis* 48:S1-S322, 2006 (suppl 1).
5. American Nephrology Nurses Association. Position statement: vascular access for hemodialysis. Available at: <http://www.anna-nurse.org>. Accessed August 2007.

(continued from page S1)

## In-center Self-Care: New Interest in an Old Idea

Two studies by S.L. Tsay, PhD, RN have found that empowering patients—which includes teaching them to engage in self-care behavior—produces better clinical results, including better control of interdialytic weight gain,<sup>4</sup> decreased levels of depression,<sup>5</sup> and improved ability to take control of their ESRD.<sup>5</sup>

### Bridge to Home

Recently, there has been a great deal of interest in the numerous benefits—both clinical and emotional—associated with home dialysis modalities. While some of these benefits derive from increased frequency and length of dialysis treatments, others may derive from the self-care aspects of home treatment, and these can be provided in-center as well.

For patients who are afraid to attempt home dialysis, in-center self-care may create a bridge and an opportunity to transition to home after a period of confidence-building adjustment. For those who don't have a helper or who live in an unmodifiable rental, in-center self-care has the potential to offer better outcomes than standard, in-center treatment.<sup>2</sup>


### Benefits for Dialysis Clinics

Patients are not the only ones who benefit when a clinic offers in-center self-care. There are some real benefits for the staff as well. According to Compton, staff:patient ratios can be increased, resulting in ongoing reductions in staffing costs.<sup>2</sup> In addition, nurses may enjoy the “calm, pleasant work environment” offered by a self-care program.<sup>2</sup>

There are financial benefits to in-center self-care, too. “A dialysis facility can be reimbursed for self-care hemodialysis training just like it can be reimbursed for home hemodialysis training,” said Beth Witten, MSW. “The allowed charge is \$20 per training session (with a maximum of 25 sessions for hemodialysis) in addition to the composite rate. And, the nephrologist can also bill \$500 when a patient completes self-care training.”<sup>6</sup> (For more details about reimbursement, check the resources.)

### The Right Time?

“Offering patients the opportunity to become health care

partners by implementing self-care programs is a win-win,” claims Compton. Perhaps this is the right time to consider a program at your center. 

### References

1. Bray SH. Returning control to ESRD patients through self-care in-center hemodialysis. Available at: [http://www.ikidney.com/article\\_print.php?id=20070207125202](http://www.ikidney.com/article_print.php?id=20070207125202). Accessed May 2007.
2. Compton A. What common practices in dialysis units can be altered to improve patient care? *Semin Dial* 17(1):18-19, 2004.
3. Curtin RB, Sitter DC, Schatell D, Chewning BA. Self-management, knowledge, and functioning and well-being of patients on hemodialysis. *Neph Nurs J* 31(4):378-387, 2004.
4. Tsay SL. Self-efficacy training for patients with end-stage renal disease. *J Adv Nurs* 43(4):370-375, 2003.
5. Tsay SL, Hung LO. Empowerment of patients with end-stage renal disease: a randomized controlled trial. *Int J Nurs Studies* 41:59-65, 2004.
6. Personal communication. July 16, 2007.

### Resources

- Section 60 and 60.1 of the Medicare Benefit Policy Manual on ESRD. Defines training for hemodialysis, including training time, and mentions self-care. Available at: <http://www.cms.hhs.gov/manuals/Downloads/bp102c11.pdf>.
- Section 50.8 of the Claims Processing Manual on ESRD. Describes training and retraining, including providing codes to use. Section 150 of the Claims Processing Manual on ESRD. Describes physician reimbursement for each home or self-care training patient. Available at: <http://www.cms.hhs.gov/manuals/downloads/clm104c08.pdf>.
- Home Dialysis Central. Includes information about certification for home dialysis and some links about training. Available at: <http://www.homedialysis.org/pros/start/certification/>.
- *Building Quality of Life: A Practical Guide to Renal Rehabilitation*. Suggests steps to self-care to help staff start to promote patient participation in care. Available at: <http://www.lifeoptions.org>.

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## Quiz Answers

1. True
2. True
3. True
4. True
5. True

# In **Patients** **CONTROL**

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## In Control with In-center Self-Care

Knowing how dialysis works—how much water to remove, how to run the machine, how to put in your needles—can help you feel safer and more in charge of your life. And, you don't even have to leave your clinic to gain these benefits. In this issue of *In Control*, we'll tell you all about in-center self-care.

### What Is In-center Self-Care?

With in-center self-care, the staff teach you how to do much of your own treatment, and they are on hand to help you. Training goes on during your regular treatments and can take from a few weeks to a few months. You can learn at your own pace.

When you do self-care, you may learn how to:

- Gather the supplies you'll need
- Weigh yourself pre- and post-treatment
- Decide your fluid removal goal and set your machine
- Check the machine alarms to be sure they work
- Assess your access site

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- Take your temperature, pulse, and blood pressure
- Put in your own needles
- Monitor your treatment
- Chart your treatment data

Why would you want to do these tasks when your care team will do them for you? Because knowledge is power. When you know how to do your own care, you can feel more confident when you travel, avoid mistakes, and gain self-esteem from learning new skills.

### Self-cannulation

You don't *have* to put in your own needles (self-cannulation) to do in-center self-care, but it's a great thing to do if you can. Whether you'll be able to do this may depend on your access type and location, but most often it depends on your own comfort level. (Some centers believe they need self-care certification to let patients put in their own needles. This is not true).

You are the only person in the world who can feel both the needle *and* your access. This means you are quite likely to be your own best cannulator. People who

*(continued on page P4)*

## Choosing In-center Self-Care Hemodialysis

### Kineda

Thirty-one-year-old Kineda learned that she had lupus seven years ago. “A year and a half later I got really sick—nauseous, swollen, and short of breath,” recalls Kineda. “I was told I had kidney failure and was in the hospital for a month.”

A few days before Kineda was discharged, a nephrologist talked to her about dialysis options. “He pushed me to try in-center self-care, saying I’d learn how to set everything up myself with the help of staff,” recalls Kineda. “To be honest, I wasn’t really interested in knowing anything at that point, but I said ‘Yeah, whatever.’”

### Starting Self-Care

Kineda walked into the center on her first day of dialysis, watched people in the self-care unit, and thought to herself: “I’ve got to be in it to win it.”

“My first day was easy,” reports Kineda. “I was told what I’d need to know, showed where things were, talked to about procedures, and so on. They made me feel comfortable.” In two weeks time, Kineda felt pretty familiar with everything. “That’s when the nurse asked me to set up the machine on my own and I said ‘*what?!*’ But they helped me and it went just fine.”

Kineda has made some mistakes, but says it’s all part of the learning process. “It took me about two months to be very comfortable, but I think I’m a slow learner,” says Kineda. “I did go online to learn about dialysis and asked my social worker questions, but I’ve

learned more by doing it myself than by someone telling me about it.”

### Putting in My Own Needles

Kineda’s nurse had asked many times about when she’d try to put in her own needles, but it took two years to get up the courage to try. “I was sick in the hospital for a few days and needed to do dialysis there,” recalls Kineda. “They had a problem cannulating my small veins and tried three or four times—I didn’t appreciate that!” On her first day back at her center, Kineda told the nurse, “okay, I’m going to learn how to stick myself.”

It took Kineda another month and a half to get used to the feeling of where the needle should be. “I am glad I learned. Now, when I travel, I do my own needle sticks and I don’t have to worry about who’s going to stick me.”

### Why I Like Self-Care

Kineda likes self-care because she feels in control. “You are immediately aware if something isn’t right,” she explains, “and you don’t have to wait for anyone to help you.”

There are days where nothing seems to go right, reports Kineda, but it’s worth the self-care process. “I like being my own boss and feeling like I have a purpose,” she says. “I also feel like I have a better rapport with my doctor because there are two of us involved and I know firsthand what is going on with me.”

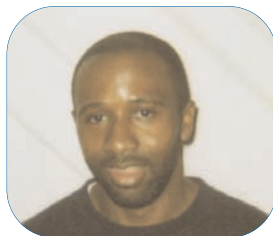
### Living Well

Dialysis has not held Kineda back in any way. “I still work part-time at a hospital and freelance as a fashion designer,” she

explains. Kineda enjoys spending time with family and friends, is involved in her church, exercises at least twice a week, and travels. “I try to live life as fully as I can. For me, it’s as much about quality as it is about quantity.”

## Maurice

In 2004, 33-year-old Maurice went to the doctor with terrible back pain. “I was told my creatinine was too high and they started to monitor me, but every visit the number went up,” he explains. “The doctors don’t really know what caused my kidneys to fail.”



“In 2005, when my nephrologist said I’d start dialysis, I thought they’d do everything,” explains Maurice. “But the doctor said because I was a young, strong man I would be a good candidate for the self-care unit.”

## Accepting Life on Dialysis

The first day of dialysis started off badly for Maurice. “I couldn’t accept that this was real when I saw all of the machines,” he recalls. “But the staff gave me a lot of support, and by the end of the first treatment it felt like home.”

It would be another month before Maurice accepted his new life on dialysis. “Initially, I had a kidney donor and thought I’d have a transplant in a month or two,” explains Maurice. “Then the transplant didn’t come through, so I had to accept it—dialysis is part of my life and it comes first before anything.”

## Self-Care

Maurice has learned how to hook up the machine, weigh himself, take his temperature and blood pressure, gather his supplies, rinse

his blood back, troubleshoot, and pull his needles out. “I can’t put in my own needles, yet,” explains Maurice, “it’s a mind thing.”


There are 10 people in Maurice’s unit and he says it’s a supportive group. “If a new person comes in and the tech or nurse is busy, we help one another fix problems correctly.”

For Maurice, the self-care center is not about age or being “able” to do it: “you have to *want* to do it,” he says. “I really feel every patient should learn how to do self-care dialysis because dialysis

is a part of your life,” he explains. “It forces you to be more disciplined in abiding by your diet, fluid rules, and medications because you are so involved in the process that you know the effects.”

## Words of Wisdom

Maurice feels happy about his decision to do in-center self-care. “I feel more confident, know more about dialysis, and I’m more connected with the machine and the experience I’m going through,” he says. “It’s given me control that I wouldn’t have if I were relying on staff—it’s my life not theirs.”

And while Maurice has tough days, he keeps a positive attitude. “I try to live a normal life, day by day,” says Maurice. He stays active and strong by exercising, walking, and spending time with family and friends. “A lot of people don’t know I’m on dialysis because I live life to the fullest,” says Maurice. “Now, I might like to transfer that into a personal training certification so I can help people get stronger themselves.” 

(continued from page P1)

## In Control with In-center Self-Care

put in their own needles say it hurts much less, because they focus so closely on doing it right that they forget about the ouch! (Read Kineda's story on page S4 to learn about one person who is happy she can put in her own needles.)

### Benefits of Self -Care

Studies have shown that people who take an active part in their care have lower death rates and a better chance of getting a transplant. People who do their own dialysis at home or in a center also have:

- Fewer hospital visits
- More independence
- Higher self-esteem
- Less fear of dialysis

Other benefits include making good choices about your care, learning *why* things are done, and spending time with fellow patients who can remind, help, and encourage you.

### Making the Change

You don't have to do *everything* to take part in self-care. Even if you have poor vision or your hands don't work so well, there are aspects of your care that you can learn about and do. The more active you are in learning about and managing your dialysis, the more control you will feel over your life. After all, it is *your* body, *your* health, and *your* quality of life that are at stake. 🌐

*To learn more about self-care, ask your nephrologist, nurse, or social worker about your center's options.*

### Self-Care Quiz

Now that you've read about in-center self-care, try to answer the true/false statements below to see how much you've learned (answers are on page S8).

1. With in-center self-care, the staff are on hand to help you.  True  False
2. Self-care training goes on during your regular treatments.  True  False
3. When you do self-care, you may learn how to put in your own needles and chart your treatment data.  True  False
4. You are the only person in the world who can feel both the needle *and* your access.  True  False
5. You don't have to do *everything* to take part in self-care.  True  False

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