

# In CONTROL

A Medical Education Institute/Life Options Publication

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## About *In Control*

Being *In Control* is the key to a long life with chronic kidney disease. That's the philosophy behind the Life Options program. And, that's why we put together this newsletter (formerly the *Renal Rehabilitation Report*). What you learn here will help put you and your patients *In Control* – with practical, how-to guides and tips.

**2-in-1 design.** The newsletter is designed to be easy to use. The eight-page format is divided into two parts. For professionals, there are four pages of information on how to put key concepts into practice. For patients, there are four pages of easy-to-use patient education, complete with a quiz to test what they've learned. And, there are lists of resources for both professionals and patients.

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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## Diabetes + Dialysis

Four out of 10 dialysis patients in the U.S. have diabetes. For these patients, coping with not just one, but two chronic diseases can be overwhelming. This issue of *In Control* looks at why managing this combination of diseases presents special challenges—for patients *and* professionals alike.

### Life Disrupted

People who live with a chronic disease must make lifestyle adjustments. The extent to which these adjustments disrupt valued activities and interests has been called "illness intrusiveness." Many factors contribute to illness intrusiveness. These include treatment time, difficulties in performing daily activities, fatigue, and other symptoms.

Patients' perception of the intrusiveness of diabetes is often high. The disruption of daily life can be overwhelming: continual choices, 24 hours a day, about food, activity levels, medications, testing for blood glucose levels, foot care, and more.

Now, add dialysis. Trips to the clinic, long treatment sessions, restrictive diet, binders and medications, fatigue, and other symptoms can create significant disruptions to normal life.


"ESRD creates unique psychosocial issues and losses," says Teri Arthur, LSW, renal social worker at FMC, North Avenue Dialysis Clinic,

in Chicago. "Dialysis plus diabetes more than doubles those issues," she notes. "We need to think of these patients as ESRD-*plus*."

The biggest disruptions diabetic dialysis patients must manage are time demands and schedules for both dialysis and meals. In addition, diet rules can be confusing and hard to follow. Can you still drink orange juice if you're feeling "low?" Are fruits and whole grains still okay? Some patients worry about which set of rules is most important. Others simply give up.

### Helplessness

"Intrusive" illnesses like kidney failure and diabetes often cause depression. Depression, in turn, limits patients' ability to respond to education and follow treatment guidelines. It is easy for patients to feel helpless; the result is non-compliance and poor outcomes.

Professionals who recognize the powerful impact of "illness intrusiveness" for patients with both illnesses can work to clear up the confusion and integrate diabetes and kidney disease care. An integrated approach can make it easier for patients to understand the connection between kidney disease and diabetes, and learn self-management skills. Better self-management can improve outcomes and go a long way toward putting patients back "in control." 

## In-center Diabetes Education Gets Results

A team effort by Dr. Phillip Alscher, Marie Cole, ARNP-c, and Linda Hopper, RD, CSR, LD to provide diabetes education for dialysis patients at Mercy Dialysis Center in Mason City, Iowa, has increased the number of patients doing daily self-monitoring of blood glucose from 42% to 94%, and virtually eliminated A1C levels over 8%. Here's how.

### Wake-up Call

In 1999, two dialysis patients from Mercy Dialysis Center were admitted to the hospital after episodes of diabetic ketoacidosis. "It was a wake-up call," said Hopper. "We realized we could help patients do a better job with diabetes management. After all, we see them three times a week," she observed.

### Education Project

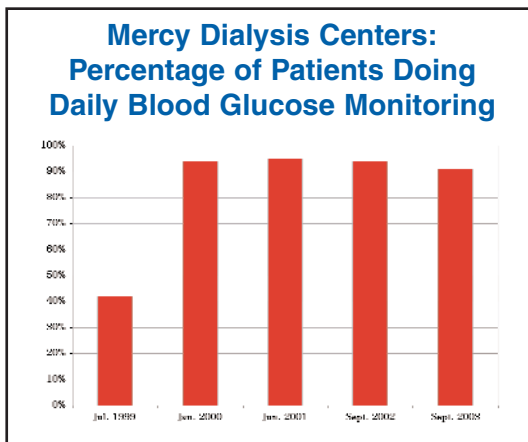
Hopper and the Mercy Dialysis team put together a CQI project to focus on diabetes education in the clinic. They began formal data collection, using July of 1999 as the benchmark. They also identified preliminary goals:

- Prevent hospital admissions
- Increase daily glucose monitoring
- Reduce A1C levels

They planned to achieve these goals through education—specifically, by teaching self-management skills during monthly monitoring and diabetes education in the clinic.

### Initial Efforts

"We started simple," said Cole. "We had to make sure all our patients had blood glucose meters



To assess the situation, staff began asking patients to bring their blood sugar records to dialysis. What they found was a real eye-opener. "Three-fourths of the patients did not check blood sugars accurately or at all," noted Cole. "Some were taking diabetes medications inappropriately, and many had not had any diabetes education for 20–30 years!"

*(continued on page S4)*

## Paying for Diabetes Education

Providing diabetes education in the dialysis clinic can improve self-management skills. But, how do clinics get reimbursed for these educational services?

Legislation passed in 1997 provided Medicare payment for diabetes self-management training (DSMT). Expanded coverage in 2000 opened the door for dialysis clinics to bill Medicare for diabetes education. Few clinics have sought payment for DSMT and some have been frustrated in their attempts to get reimbursed. Here are a few key facts:

- The clinic must obtain accreditation from the American Diabetes Association (ADA), the Indian Health Service, or other Medicare approved accreditation organization. This requires data collection for six months prior to application. (For details about how to get ADA certified, visit [www.diabetes.org/for-health-professionals-and-scientists/recognition/edrecognition.jsp](http://www.diabetes.org/for-health-professionals-and-scientists/recognition/edrecognition.jsp).)

- Education must be provided by specified personnel who use the National Standards for Diabetes Self-Management Education and collect specific outcome data.
- Patients must meet specific criteria and be referred by a physician or non-physician practitioner for diabetes education for Medicare to pay for training.
- Dialysis providers should bill their Part A Intermediary using G108 (individual) and G109 (group of 2-20) billing codes. Unless specified criteria are met, most DSMT training is to be done in a group.

Network 5 has developed a brochure to help dialysis providers set up a diabetes self-management education program. To learn more, visit [www.esrdnet5.org](http://www.esrdnet5.org) or e-mail [marc@nw5.esrd.net](mailto:marc@nw5.esrd.net).

# Q & A:

## Ask the Experts

*Betty Wedman-St.Louis, PhD, RD, LD, CNS, is a past president of the American Association of Diabetes Educators. She is the author of numerous publications about diabetes, nutrition and health management. She works with diabetes and kidney disease patients in her private practice and at a St. Petersburg, Florida dialysis clinic.*

The prospect of living with chronic illness forces people to make adjustments. It's difficult, but most can manage. A second chronic condition changes everything, however. Frustration, guilt, and confusion, especially for people with diabetes and kidney failure, can create a great deal of stress.

### Q: Why is stress such an issue for dialysis patients with diabetes?

**A:** Several reasons. One, diabetic patients are afraid of hypoglycemic episodes. If they cannot eat "on schedule" during dialysis, that fear is at a peak. As a result, they may think every symptom they experience during dialysis is due to hypoglycemia. Two, stress itself can elevate blood sugar levels. And, three, persistent stress reduces the ability to make good self-management decisions.

*(Note: Dialysate dextrose can reduce the chances of hypoglycemia episodes during dialysis.)*

### Q. What can patients do to reduce stress?

**A:** Exercise! It works wonders. Exercise can take their minds off the stress of coping with chronic disease. In addition, exercise increases circulation and gets micronutrients to all the body's

extremities. Both are good things for diabetics. Exercise is not just about weight loss. Our patients need to know what else it can do.

### Q. How can staff reduce patient stress in the center?

**A:** Before each dialysis session ask, "When did you last eat a meal?" If you know how long it has been since your patient has eaten, you will be prepared to respond to patient worries about having a hypoglycemic episode.

Diabetic patients often interpret *any* symptoms experienced during dialysis as related to low blood sugar. Asking about food intake can help staff reassure a worried patient while waiting for on-the-spot blood sugar testing.

Every clinic should have an emergency diabetes kit with glucose tablets or dextrose syrup. Even honey packets will work as a fast-acting source of sugar. Patients will be less stressed if they know you are prepared to respond quickly.

### Q. Do some patients have particular problems with stress?

**A:** Teens and men, in particular, seem to have a high rate of denial

about kidney disease...and that can lead to stress. For teens, it is especially hard to accept that their young bodies are not perfect. Adult men have worry and guilt about taking care of their families or being dependent. Caregivers who recognize that these emotions cause stress—and may delay the acceptance of the disease and the treatment regimens—will be prepared to be more understanding.

### Q. How can we help patients follow their diabetic/renal diet?

**A:** Here are things every educator can do to help patients improve their compliance:

**Soften the approach** – Scare tactics add stress. They also cause patients to tune out and give up.

**No "forbidden" foods** – Banning favorite foods creates unnecessary guilt, and adds stress. Almost any food can be fit into a diet if amounts are carefully controlled.

**Portion size** – Out-of-control portions are the biggest problem for most of our patients—and the American diet, in general. 🍷

For more information about Dr. Wedman-St. Louis and her publications, visit [www.betty-wedman-stlouis.com](http://www.betty-wedman-stlouis.com).

## For More Fistula Information...

### Kidney School™


[www.kidneyschool.org](http://www.kidneyschool.org) – Interactive, on-line learning tool for people with chronic kidney disease.

- Module 5: *Coping with Kidney Disease* – Discusses common emotional responses that people with kidney disease and their families experience: panic (crisis), isolation, anger, depression, and rebuilding.
- Module 9: *Nutrition and Fluids for People on Dialysis* – Provides targeted diet information, including specific guidance for diabetic people on hemodialysis and on peritoneal dialysis. Topics include getting the right amounts of key nutrients, vitamins, dealing with thirst, using food value books, planning meals and eating out, and tips for gaining and losing weight.

### Other Resources

- [www.kidney.org/professionals/CRN/index.cfm](http://www.kidney.org/professionals/CRN/index.cfm) – Features resources on diabetes education and diet from the National Kidney Foundation’s Council on Renal Nutrition.
- [www.renalweb.com/topics/out\\_diabetes/diabetes.htm](http://www.renalweb.com/topics/out_diabetes/diabetes.htm) – A valuable listing of resources on diabetes and nutrition for patients and professionals.
- [www.cms.hhs.gov](http://www.cms.hhs.gov) – This website has information for providers and beneficiaries, including Medicare rules, provider manuals, and more.

### Journal Articles

- McMurray SD, Johnson G, Davis S, McDougall K. Diabetes education and care management significantly improve patient outcomes in the dialysis unit. *Am J Kidney Dis* 40(3): 566–75, 2002 

## Quiz Answers

1. False. A dietitian can help you learn where the two diets overlap.
2. True
3. True
4. True
5. True

(continued from page S2)

## In-center Diabetes Education Gets Results


and knew how to use them. We also spent a lot of time on re-education about diet and diabetes medications.” Next, the team focused on bi-monthly blood sugar reports, with changes in medication and meal planning as needed, along with self-management education. “We developed a lot of simplified patient education materials,” reported Hopper, “including information on diet, medications, A1C results, and management of illness.”

In just the first year, the Mercy Dialysis Center team met all its goals. There were no acute admits, 94% of patients were monitoring blood glucose daily, and A1C levels over 8% decreased from 42% of patients to 30%.

Mission accomplished? Yes, and no. “You’ve got to keep doing the follow-up,” said Hopper. “As a trial, we quit asking for blood sugar records for a two-month period. Without regular monitoring, several patients stopped checking them. We found that ongoing monitoring is a necessity.”

### Better Outcomes

The Mercy Dialysis Center team set new, tougher goals for 2002 and 2003. And, they’ve added monthly foot checks. Outcomes continue to improve. Currently, more than 90% of patients check blood sugars daily, and fewer than 10%

have A1C levels over 8%. “The results are worth the effort,” said Cole. “Based on the much lower A1C levels, our patients are much less likely to suffer complications like amputations and blindness.” 

### 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](mailto:lifoptions@meiresearch.org)

[www.lifeoptions.org](http://www.lifeoptions.org)  
[www.kidneyschool.org](http://www.kidneyschool.org)

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## Living with the “Double Whammy” of Diabetes and Kidney Failure

If you are living with the “double whammy” of diabetes and kidney failure, even day-to-day tasks can seem hard. Between the dialysis treatment time, doctor’s visits, watching your blood sugar, and planning meals, there hardly seems time to have a “normal” life!

But staying in control of your health is key to living long and well with diabetes and kidney failure. For most people facing the challenge of the double whammy, meal planning, limited free time, and feeling down are the biggest hurdles.

### Meal Plan Changes

If you are just starting dialysis, or if dialysis is in your future, you’re probably thinking “but how am I going to fit the kidney failure diet into my diabetic diet?” It may seem confusing at first, but working with your

dietitian will help you realize that there are many places where the two diets overlap. Make a list of your favorite

foods, as well as your current meal plan, and work with your dietitian to try and fit them into a diabetic/dialysis meal plan.

As a diabetic with kidney failure, one of the key things you can do is to eat about the same amount of food at about the same time each day. This will help you avoid highs and lows in your blood sugar levels, which can lead to symptoms such as thirst, restless legs, feeling sick to your stomach, cold sweats, dizziness, hunger, and shaking. Talk to your care team if you need help managing these symptoms.

Many people who use diabetic medications find that their dosage needs to change once they are on dialysis. In fact, many diabetics on dialysis can use lower doses of medications than before.

### Time Demands

The time demands of diabetes and dialysis can feel like they are taking over your life. But the time and effort you put into your treatments is what decides how well you feel and how well you live! However small, the treatment involved for *any* chronic disease requires a daily effort.

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## Living with Diabetes *and* Dialysis

Meet three people living with dialysis and diabetes: Lisa, Ken, and Sandra. Each of them has found a way to make peace with diabetes and dialysis and live a full life.

### **Lisa: Living with Three Chronic Diseases**

Lisa, 39, has had type 1 diabetes since age two. By 25, she had kidney disease. “Growing up, I didn’t take care of myself, especially during my teenage rebellion,” shares Lisa. “I wish I would have kept my blood sugar under control.”

At 34, Lisa had a triple bypass. “Until my heart surgery, I wasn’t taking care of myself,” she recalls, “then I realized I had to change my life.” Lisa now combines a diabetes diet with a low fat one. “I do miss tacos, and treat myself every six months or so.”

Lisa kidneys failed at 37, and she began hemodialysis and an insulin pump.



“The pump has worked very well and I have better glucose control and more leeway with food choices.

***“Until my heart surgery, I wasn’t taking care of myself—then I realized I had to change my life.”***

Once a week I have eggs, because the kidney doctor wants me to eat more protein, but I have to limit them because of my heart disease,” she explains. “I eat lots of veggies and try to stick to my diet because I know it will pay off in the long run—I don’t want more complications!”

### **Ken: Staying Active is the Key to Success**

“My reaction to my kidney failure in 2003 was blasé,” says 53-year-old Ken, a Type 1 diabetic since age eight, and full-time director of marketing for a power company. “Kidney disease comes with the territory with diabetes and high blood pressure; it’s no big deal.”

That’s not to say that Ken hasn’t had rough days. “I may shed tears sometimes,” he says, “but I’ve never felt overwhelmed. Rather, I believe if I were, God forbid, affected by a third disease, I’d handle that, too!”

Kidney disease hasn’t required Ken to make many changes. “The essence of my being is maintaining my good health through a balanced diet and exercise,” he explains. “There are no foods I miss; ‘everything in moderation.’ If you have self control and know the rules, you can handle what and how much you eat.”

Ken knows he needs to make careful choices. “I am aware of the heart, bone,

***“I have learned how to manage and control [my chronic diseases] instead of letting them control me.”***

and other conditions that dialysis and diabetes might bring,” he says. “I am doing everything—positive thinking, prayer, exercise, and diet—to make sure these things do not happen.”

Three days of hemodialysis has limited Ken’s time, but he hasn’t slowed down. Ken walks, cooks, collects stamps, bicycles, travels, plays tennis, and volunteers.

“Having two chronic illnesses has not and will not affect my life until I am dead and buried,” says Ken. “They are not my burdens; I have learned how to manage and control them instead of letting them control me.”

### **Sandra: Motivated to Do Well**


“At 30, I got type 2 diabetes and started insulin,” says 55-year-old Sandra. Doctors briefed Sandra on her risks, but it was still a surprise when her kidneys failed in 2001. “I knew how diabetes affected my body,” she explains. “My biggest worry was how to put the kidney diet into my diabetes diet. I said ‘you can take anything away except my fruit!’”

Sandra’s first step was to make a list of foods she had to have—like fruit—and

meet with a renal dietitian. “I can enjoy basically any food in smaller quantities,” she notes. With smaller portions came positive changes. Since Sandra eats less, she needs less insulin and has fewer symptoms. “When I started dialysis I had leg cramps and was sick to my stomach. When I controlled my diet, that all stopped.”

Sandra’s biggest challenge is a lack of time. “When I sit for four hours, I get tired, and need a two hour nap,” she says. “I feel like I’ve wasted a day.” Sandra finds time to be outdoors with her family. “I like walking, picnics, and daytrips,” she says. “Due to vision loss, I had to retire from being a big-rig helper to my husband, which I loved—we traveled and lived in the rig with our cat, and saw so many things!”



Sandra’s main motivation for following her treatment plan is the chance of a transplant. “I’m trying to show that I can take care of a kidney. You have to say in your mind that you will make this work, or it won’t.” 

***“You have to say in your mind that you will make this work, or it won’t.”***

Expanded version of these stories can be found on the Life Options website at <http://www.lifeoptions.org/patient/community/stories/index.shtml>.

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## Living with the “Double Whammy” of Diabetes and Kidney Failure


### Feeling Down

All of the changes brought on by adding dialysis to a diabetic routine can make you feel angry, depressed, and/or helpless. Talking to a counselor, social worker, or fellow patient can help you get the support you need.

You can also talk to your health care team, go to the library, or get on-line to learn more about your health problems. Being informed about diabetes and dialysis will help you stay in control of your treatments and your life.

### For More Information

To get answers to your questions about having diabetes and kidney failure, talk to your health care team or visit the following resources:

- Kidney School™ Module 9: *Nutrition and Fluids for People on Dialysis* at [www.kidneyschool.org](http://www.kidneyschool.org)
- *Diabetes and Dialysis: A Balancing Act*, from the Northwest Kidney Centers “Nutrition: The Art of Good Eating” at [www.nwkidney.org/images/website/docs/nutrition/diabetes.htm](http://www.nwkidney.org/images/website/docs/nutrition/diabetes.htm)
- *Diabetes and Kidney Disease* from the National Kidney Foundation at [www.kidney.org/general/atoz/](http://www.kidney.org/general/atoz/) 

### Diabetes + Dialysis Quiz

Now that you’ve read about having diabetes and kidney failure, let’s see how much you’ve learned! See if you can answer the questions below (the answers are on page S8):

1. Work with your social worker to see where your diabetes and kidney failure diets overlap.  True  False
2. Eat the same amount of food at about the same time each day to avoid high or low blood sugar levels.  True  False
3. It is normal to feel angry about the changes brought on by adding dialysis to a diabetic routine.  True  False
4. Staying in control of your health is key to living long and well with diabetes and kidney failure..  True  False
5. Many diabetics on dialysis need changes in the amount of medications they need.  True  False

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##### 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](mailto:lifoptions@meiresearch.org)

[www.lifeoptions.org](http://www.lifeoptions.org)  
[www.kidneyschool.org](http://www.kidneyschool.org)