

## 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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## The Emotional Side of Kidney Transplant

For a person with kidney failure, the process of getting—and keeping—a kidney transplant can be long and arduous. It can also be a roller coaster of emotions. How well patients and nephrology caregivers handle these emotions can have a significant impact on:

- **Transplant survival**—research suggests that the more positive a patient is about a pending transplant, the better the outcome when considering all other variables.<sup>1</sup>
- **Post-transplant adherence**—how patients think, feel, and act regarding their transplanted kidney affects their adherence with post-transplant care regimens.<sup>2</sup>
- **Decisions about transplant**—emotional reasons (fear of surgical pain, worry about rejection, disappointment, and acceptance of dialysis) were cited by a majority of transplant-eligible patients who decided not to pursue transplantation.<sup>3</sup>

### Pre-transplant

A consensus statement issued by the American Society of Transplantation (AST) recognizes the importance of a patient's emotional state prior to transplant and recommends an “in-depth psychological evaluation...for long-term patient well-being.”<sup>1</sup> No standard pre-transplant evaluation currently exists, however, and it is up to the

transplant team and the dialysis social worker to assess the emotional state of potential recipients.

Hope, fear, and uncertainty are common emotions among patients considering kidney transplant. If the kidney will come from a living donor (since 2000, the number of living kidney donors has exceeded the number of deceased donors<sup>4</sup>), the emotional concerns multiply. Interviews with kidney transplant recipients revealed numerous concerns about living donation, including risks to the donor, reluctance to depend on others, anxiety about inconveniencing others, and fear of the donor's reaction if the transplant fails.<sup>5</sup>

### Post-transplant

According to transplant researcher Bonita Siegal, PhD, “...how renal transplantation is experienced by the patient is a very complex combination of positives and negatives, which vary according to life cycle stage, education level, and socioeconomic status. Therefore, it is impossible to tell the potential recipient what life will be like after the kidney transplant.”<sup>2</sup>

Every aspect of the transplant recipient's life is affected, including:

- **body**—surgical scar, weight gain due to immunosuppressants, body shape changes (especially fat facial cheeks), feeling of physical well-being.

*(continued on page S4)*

# A Systematic Approach to Transplant Education

Nephrology social worker Kati Malarcher, LMSW, and the team at Collin County Dialysis in Plano, TX have developed a systematic approach to providing all their dialysis patients with education about transplant. “Our Medical Director, Dr. Mark Lerman, is also the Director of the Kidney/Pancreas Transplant Program at Medical City Hospital in Dallas,” noted Malarcher. The Collin County system is built on several key elements.

## Prompt Evaluation

“When a new dialysis patient is admitted to our clinic, we have the attending physician do a transplant evaluation right away,” advised Malarcher, “usually within the first 2 weeks.” If the patient is medically suitable for a transplant, the team is notified to schedule transplant education sessions.

## Thorough Education

To ensure important topics are adequately covered with each potential transplant recipient, Malarcher uses a “Transplant Readiness” checklist. The checklist includes a list of required topics (treatment vs. cure, types of transplant, the transplant process, financial issues, setting realistic

expectations, etc.) to discuss with each patient, as well as a list of optional topics. The form has space for notes and a place to record session dates.

“We go through each item one-by-one,” said Malarcher. “If a patient is ready to discuss the topic and wants more information, we provide it.” The teams set a goal of scheduling transplant education sessions within the first 30 days of working with a new patient.

## Monthly Status Tracking

“Often, new patients are not ready to discuss the option of transplant right away,” said Malarcher. “They need time to acclimate to dialysis.”

To make sure these patients have the opportunity to hear about transplantation when they’re ready, Malarcher has added a “Transplant Status” field to the dialysis center’s Monthly Care Plan spreadsheet. “It’s a reminder to everyone on the team to check back with patients and bring up the topic again,” she said.

## Proactive Social Work

“As a nephrology social worker, I take an active role when it comes

to educating patients about kidney transplant,” explained Malarcher. “I believe it’s my job to help our patients:

- understand their options
- access resources, e.g., UNOS, NKF, and encourage fundraising when needed
- make informed decisions
- navigate the transplant process, if that’s their choice

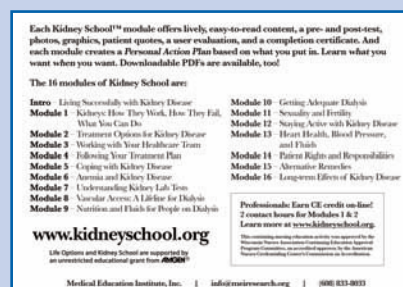
At every stage, Malarcher finds herself helping patients deal with their emotions. “With living organ donation, especially, patients wrestle with conflicting feelings,” she noted. “Patients who are parents have a difficult time accepting a kidney from a child,” she added. “There is just such fear.”

Malarcher and her team rely on information and conversation to help patients process these emotions. “We encourage them to ask questions and talk to their families,” she said. “It’s not our role to persuade patients to pursue transplant; that’s an individual decision, but we want patients to understand all their options and feel free to talk about them.”

## Order Free Kidney School Postcards!

Order free 5x7 Kidney School postcard handouts online at [www.kidneyschool.org](http://www.kidneyschool.org). You can give

the two-sided cards to patients and family members to let them know about Kidney School.



# Q & A: Ask the Experts

An interview with Amy Waterman, PhD, Health Psychologist and Assistant Professor of Medicine, Washington University School of Medicine, St. Louis, Missouri

*Dr. Waterman works closely with transplant patients at Washington University, and has done extensive research to explore recipients' and donors' knowledge and attitudes.*

## Q: What have you learned from transplant recipients about the stress they feel when pursuing a transplant?

**A:** CKD patients who are considering a transplant commonly report stress due to:

- 1) **Having to “jump through the hoops” of transplant evaluation.** The transplant process—referral, evaluation, getting on the list, and then the actual surgery and recovery—requires a commitment of time and energy, that can last months or years. Some patients get tired or frustrated; others find it difficult to juggle both dialysis and the medical tests required for evaluation.
- 2) **Not understanding what transplant evaluation and surgery will be like.** There’s a lot to learn about transplant surgery, possible complications, outcomes, follow-up care and medications, etc. Most patients worry about pain and being “laid up” for a long time during recovery. Others are concerned about the costs of transplant, whether disability income will be affected, and how they will manage work and family lives during surgery and recovery.
- 3) **Waiting for a kidney.** Patients may need to wait 3–5 years for a deceased donor kidney; others are unable to find a matching kidney. Waiting hopefully and patiently for months or years on the list for a deceased donor can be difficult.

## Q: Are there additional concerns if the transplant will be from a living donor?

**A:** If a patient is thinking about living donation—usually from a family member—they typically worry about both themselves and the donor. For themselves, they worry about how to inform loved ones that they want a kidney, how they will feel if a potential donor says “no,” and what effect the transplant will have on family relationships. For the potential donor, they worry that surgery might put the donor at risk for medical problems in the future or inconvenience the donor’s work or family life in some way.

## Q: What can patients do to work through their concerns and make an informed decision about getting a transplant?

**A:** We encourage potential recipients to talk about their feelings and concerns so they can arrive at the right decision about transplant. Patients find it helpful to talk to:

- A dialysis social worker**—these trained professionals can help patients identify and sort through complex emotions and think about different transplant options.
- Transplant coordinators**—Calling the transplant center to ask questions is a good way for patients to learn about transplant directly from the experts, and request additional information.


## Family members & close friends—

Honest, two-way conversations with family and friends can provide support and encouragement, and help to address the emotional issues of both patients and their loved ones. Talking to family members and close friends about transplant can sometimes result in finding a living donor.

**Potential recipients**—Listening to a first-hand perspective can help a patient stay hopeful and focused.

## Q: How can dialysis providers help their patients make good transplant choices?

**A:** Guidelines for quality care mandate that people with ESRD be informed about all their treatment options, including transplantation. Dialysis providers have a responsibility to make sure that every dialysis patient learns about kidney transplantation. Review the patient caseload, talk to the medical director about which patients should be referred for transplant, and ask these patients what they are thinking about transplant.

Most patients are both scared and hopeful about a transplant, but some may rule it out based on erroneous information. Explore the reasons behind patients’ concerns, and provide accurate information. Don’t be afraid to ask probing questions, or to call the transplant center to get answers. Dialysis care providers serve in a valuable role as the front-line source of good information. 

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## The Emotional Side of Kidney Transplant

- **mind**—pleasure mixed with sadness over body changes, irritability from high steroid doses, guilt because the kidney came from another’s loss (living or deceased)
- **behavior**—normalized libido and sexual function, need for multiple medications and complex drug regimen, improved appetite, better sleep cycle
- **finances**—high medication costs, potential for return-to-work
- **family interactions**—family time increases without need for dialysis schedule, role changes, interactions (possibly friction) between living donor and recipient
- **peer group interactions**—joy at the physical improvement, fear of transplant loss
- **work interactions**—concerns about ability to perform at work


The AST consensus statement notes that child transplant recipients and their families face major psychological stresses, despite physical improvements after transplant. Parents worry about the child’s future and well-being, social isolation, and financial burdens. “It is common,” AST reports, “for children to exhibit behavior problems, depression, poor social adaptation, and/or noncompliance with the medical regimen.”<sup>1</sup>

### Living Donors

As the number of living organ donors increases, more attention is being directed to the emotions experienced by donors. An International Forum on the care of the Live Kidney Donor was held in Amsterdam, the Netherlands in April, 2004; participants affirmed the “necessity for live donors to receive complete medical and psychological evaluation prior to donation.”<sup>6</sup> To ensure that this evaluation is unbiased, the AST recommends that *every living donor have his/her own physician advocate*.<sup>1</sup>

Donor advocates work to be sure that potential donors understand the risks and benefits of their decision to donate and that they are making their decision freely—without undue pressure from any source. In practice,

one study of potential kidney donors identified these common concerns: health and welfare of the designated recipient, their own surgery and recovery, fear/guilt if they did not match, lack of understanding of tests and surgery, medical expenses.<sup>7</sup> Despite the number of concerns, more than 90% of donors have said that they would make the same decision again.<sup>7</sup>

Making the decision to get—or give—a kidney transplant involves more than weighing medical risks and benefits. This momentous decision must be carefully evaluated from other perspectives as well. 

### Quiz Answers

1. True
2. True
3. False. More than half of kidney transplants in 2005 used living donors.
4. True
5. True

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# Patients *In* CONTROL

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## Kidney Transplant: an Emotional Issue

At some point, almost every person on dialysis thinks about a kidney transplant. The United Network for Organ Sharing (UNOS) reports that there were 15,671 kidney transplants in the U.S. in 2004, and 67,000 people waiting for a kidney donor. Making a good choice—yes *or* no—involves getting good information *and* facing a wide range of emotions.

### Consider Your Options

Your nephrologist will tell you if you are a good candidate for a kidney transplant. If you are, be prepared to face a mix of feelings, from hope and excitement to fear and even guilt. There are many things to think through—how well a transplant might work, costs, time commitments, family concerns, and more. You might feel overwhelmed, or even depressed. People who are thinking about a transplant often say that they feel stressed by the long and complex steps to be evaluated, make plans, and wait for surgery.

Take your time...if you are not ready to think about a transplant,

put the idea on hold. When you *are* ready, educate yourself about the process and all your donor options. Your dialysis social worker and/or a transplant coordinator can help you find the information you need. Talk with your family and friends about how you feel, and be sure to ask them to be honest about their feelings, too.

Be flexible and give yourself the freedom to change your mind. If you keep an open mind and remember that a transplant is a treatment, not a cure, you will be better prepared to deal with all your emotions.

### Finding a Donor

If you decide to seek a kidney transplant, you'll need to choose between waiting for a deceased donor kidney and finding a living donor. Some people feel uneasy about a deceased donor kidney at first (see patient story on page S4), but many transplant hopefuls choose this option.

Though more than half of the kidney transplants in 2005 used living donors, the idea of finding a living donor also troubles many people. If you share the facts and your feelings about transplant with your family and friends, a living donor may come forward on his or her own. Most living

*(continued on page P4)*

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## Choosing Transplant

For 55-year-old Tommy, the road to a kidney transplant was full of reflection, prayer, and hard choices. One thing Tommy knew right from the start: he did not feel comfortable asking anyone he knew for a kidney. Now living with a deceased donor kidney, Tommy reports that, “Transplant has changed my life for the better by 100%.”

### A Treatment Plan

Diagnosed with kidney failure in May of 1997 as a result of diabetes, Tommy started in-center hemodialysis shortly thereafter. “Almost immediately after being diagnosed with kidney failure I started thinking about a transplant,” Tommy recalls. “My social worker provided me with information, and I was put on the transplant list four months after I stabilized on dialysis.”

Tommy stayed active while on dialysis, working full-time in a management job and starting a mentoring program at his church. He and Marion, his wife of 36 years, also continued to travel. “I really tried to meet the challenge and be happy in my life on dialysis,” Tommy remembers. “Life was not always easy;

if it were not for my faith that this problem would be taken care of, my struggle would have been burdensome. In addition, my wife played a vital role in my care and still does. Her efforts will never go unnoticed.”

### Transplant Choices

Early on in his thinking about a transplant, Tommy realized that he did not feel comfortable asking anyone to donate a kidney. “If someone stepped

***“If someone stepped up [to donate a kidney] on his or her own, that’s fine, but I had to rely on myself and my God to get me through this.”***

up on his or her own, that’s fine, but I had to rely on myself and my God to get me through this,” he said.

Tommy’s first transplant option came in the form of a volunteer—his retired sister. “She went through all of the required tests and was a perfect match,” Tommy explains.

“Unfortunately, due to some medical issues she has, the staff wouldn’t allow her to donate.”

A second volunteer came forward—Tommy’s son, who was serving in the military in Bosnia and had a wife and three daughters living in Germany. “With my son, I thought about it, read some more about kidney transplants,

and decided that I didn't want to burden him and his family like that," Tommy remembers. "I also didn't want him to have problems with his military career. So, we talked about it and I decided that I wanted to wait it out." Tommy's wait was over in June of 2000, when he received a deceased donor transplant.

## Issues and Emotions

For Tommy, the hardest part of the transplant process was dealing with the idea of having another person's organ put in his body. "I had a buddy on dialysis and we always talked about the idea of a foreign organ in our bodies," Tommy says. "At first, I wasn't sure about a transplant, but then I thought, 'I'm not going to stay on dialysis the rest of my life!'"

Another issue for Tommy was the large number of medications he will have to take for the rest of his life. "Between the high blood pressure, the diabetes, and the transplant, the co-pays can get *very* expensive!" Tommy explains. "I wish

they had a single shot or serum I could take, since I have a clear tackle box I have to take with me with all of my medications and diabetes supplies. But, I'd rather have to do this than sit in a dialysis chair."

Tommy knew about the risks of transplant and now tries to stay healthy. "When I was on dialysis I always wanted water. Now I don't, but I have to keep hydrated and flush my kidneys—

that's a challenge for me," Tommy says. "I knew there were issues with choosing transplant as a treatment, but I believe we are put in situations to show faith and I choose to have faith and live through this."

## Looking Forward

In March 2006, Tommy retired and is feeling good and traveling a lot. "I go places and do things more now," Tommy reports. "I have the opportunity for normalcy with my family. This transplant has been a wonderful blessing for me." 🌟



(continued from page P1)

## Choosing a Treatment that Fits Your Lifestyle

donors feel good about their decision to donate—even if the transplant does not work.

If no one volunteers a kidney, think about asking people you know. How will you feel if you ask loved ones and they say no? It's hard to ask, and sometimes people feel that someone who says no does not love them. Please try to remember that there can be many reasons for saying no, including fear of surgery, time lost from work, etc. If you do decide to ask someone to donate, talk with a social worker or transplant coordinator for tips on how to ask and how to answer a potential donor's questions.

### Dealing with the Emotions

If you find that you need extra support to deal with your feelings about transplant, talk to a social worker. You can also talk

to someone who has received a transplant or is on the waiting list. Ask your care team if there is a support group in your area. Most importantly, do not put your life on hold. Continue to live a full life while you decide—and while you wait.

### To Learn More...

To learn more about the emotional issues of kidney transplant, visit the following websites:

- American Organ Transplant Association at [www.aotaonline.org](http://www.aotaonline.org)
- American Society of Transplantation at [www.a-s-t.org](http://www.a-s-t.org)
- National Kidney Foundation at [www.kidney.org](http://www.kidney.org)
- Renal Support Network at [www.RSNhope.org](http://www.RSNhope.org)
- Transplant Recipients International Organization at [www.trioweb.org](http://www.trioweb.org)
- TransWeb at [www.transweb.org](http://www.transweb.org)
- UNOS at [www.transplantliving.org](http://www.transplantliving.org)

### Transplant Emotions Quiz

Now that you have read about the concerns and emotions that surround transplant, try to answer the statements below to see how much you've learned (answers are on page S8).

1. In 2004, there were 67,000 people waiting for a kidney donor.  True  False
2. If you decide to seek a transplant, you will need to choose between waiting for a deceased donor kidney and finding a living donor.  True  False
3. More than a third of kidney transplants in 2005 used living donors.  True  False
4. Most living donors feel good about their decision to donate.  True  False
5. If you decide to ask someone to donate, talk with a social worker or transplant coordinator for tips on how to ask.  True  False

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