ISSUES for Today’s Transplant Recipients — A Guide

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The NKF would like to thank Roche Pharmaceuticals for supporting the discussions upon which this book is based.

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Dear Friend of the National Kidney Foundation,

We are pleased to present you with a companion booklet to our recent phone discussions on Medicare, depression after transplant, and patient empowerment—all part of our series called “Living Well After Transplant: Issues for Today’s Recipient.” Your interest, questions, feedback and support helped make these discussions—heard by transplant recipients across the country—possible. Thank you.

At the NKF, it is our mission to help people live well after transplantation. If you have any additional questions that we didn’t cover in our discussions, please visit us at www.transplantrecipients.org. You can also e-mail us at transactioncouncil@kidney.org or call us at 800-622-9010.

As a member of the NKF transAction Council, you can receive our free newsletter called Transplant Chronicles. Simply call us at the number above to receive your first copy or request a subscription on our Web site, www.kidney.org.

We are all part of the People Like Us initiative, which fights to make lives better for all people with kidney disease or who are in need of a transplant of any organ. This initiative also facilitates the organ donation process for donor families and living donors.

We are committed to helping recipients live well after transplantation. Stay tuned as we update you on our efforts to improve policy, health care and wellness for transplant recipients across the country.

We gratefully acknowledge Roche Pharmaceuticals for providing the support for this companion book.

Thank you and good health,

Ken Howard, Chancellor
National Kidney Foundation
Introduction

Medicare is a federal health insurance program for Americans 65 and older; those with kidney failure who need dialysis or a transplant; or those with disabilities, including those with transplants. However, whether or not people with transplants can get Medicare, how long they can keep it, and how Medicare pays for care depends on their unique circumstances, such as the type of transplant; when and where surgery took place; their citizenship or immigration status; other insurance they might have; their own, their spouse’s or parents’ work history; and—for the first time because of recent changes in Medicare—income and assets.

The telephone audio conference, called “Getting the Most Out of Medicare” (May 2005), emerged after the National Kidney Foundation asked transplant recipients what they wanted to know more about. Not surprisingly, Medicare was on a lot of people’s minds. Medicare can be confusing for transplant recipients. Keeping up with Medicare’s changes can be a challenge.

The National Kidney Foundation assembled two resident experts on the “nuts and bolts” of Medicare and the anticipated changes under the Medicare Prescription Drug and Modernization Act of 2003. The discussion, which included questions from transplant recipients around the country, was sponsored by Roche Pharmaceuticals. In it, the experts discussed the basics of Medicare, such as who can get it and when; how long it lasts; and how the latest changes affect recipients.

For an actual transcript of the conference go to www.transplantrecipients.org.
Right now, around 41 million Americans have Medicare. Among the people who have Medicare because of a disability, an estimated 2.4 percent have kidney failure. Medicare (and Medicaid, the program for low-income Americans) is run by the Centers for Medicare and Medicaid Services, or CMS.

To understand how Medicare works, it helps to visualize Medicare as a big building. In the U.S., almost everyone is either inside this “building,” or waiting to get into it. The only way to get in is through one of four “doors.” The first, biggest, and probably most well known door is the one that lets people in once they turn 65.

Another is the disability door. This lets in people under age 65 who have become sick or injured and who are not expected to be able to work for at least a year. When these people receive Social Security Disability Income (SSDI) checks for at least 24 months, they can enter the Medicare building through the disability door. This is the door that people who get non-kidney transplants or who have a transplant over 36 months may use to get or keep Medicare benefits.

The third door opens for people on dialysis whose kidneys have failed. As long as you are on dialysis, you can keep Medicare.

The last door is for people who have had a kidney transplant and were never on dialysis. For these people, Medicare starts the first of the month they have their transplant. There are also some very specific
situations where Medicare may start even earlier, which we will discuss later. But, in general, if you have a kidney transplant on April 15, your Medicare begins April 1.

Although being on dialysis and having a kidney transplant could technically render someone disabled, people with disabilities and those with kidney failure have separate doors because the government treats them somewhat differently.

**If you get Medicare through that last door, after a kidney transplant, your Medicare will only last for 36 months, or three years.** The only way to extend Medicare after that three-year period is to get back in the building through one of the other doors, perhaps by turning 65 or by having another disability and receiving SSDI checks for 24 months.

To expand the analogy, you can imagine the Medicare building as having different floors. One floor of the building is **Part A**, the section of Medicare that pays for **hospital and nursing home care**. You must pay a set amount called a “**deductible**” and you may have to pay a daily charge.

**Part B**, the second floor, is basically **outpatient insurance**, or what care the government pays for outside of an institution. If you don’t have insurance through an employer and Medicare is your primary payer, **Medicare Part B pays 80 percent of Medicare’s allowed charge**, which means you’re on your own for the remaining 20 percent. You could have to pay more if your doctor does not accept Medicare “assignment.” Medicare assignment means that the doctor or health care provider must accept what Medicare says is a fair price and not bill any higher.

You get Medicare Part A when you enroll in Medicare. **Medicare Part B is optional. You must choose to take it**, sign up separately and pay a monthly premium, which goes up every year. In 2005, it is $78.20. You should have received information about Part B when you signed up for Part A.

Whether or not Medicare Part A is premium-free depends on your age and whether you’ve worked long enough. You earn a credit when you make enough on your job to have Social Security taxes taken out of your check. You can earn up to four work credits a year. Children can get Medicare under a parent’s work record. Adults who were disabled before age 24 need only to have earned six credits in the last three years to get Medicare Part A without paying a premium. The older you are, the more work credits you need. If you’re 62, you’ll need the maximum, or 40
credits, to get Medicare Part A free. Contact the Social Security Administration at 800-772-1213 to see if your Medicare Part A will be free.

Up until now, Medicare has only paid for a few prescription drugs in certain cases. As a primary payer, Medicare Part B pays 80 percent of the allowed charge for immunosuppressive (anti-rejection) drugs, which can be very helpful. (For kidney dialysis and transplant patients who have employer-based insurance, Medicare is a secondary payer for the first 30 months.) You can visualize this as a secret room on the Part B floor that transplant recipients and a few other groups of Medicare beneficiaries have the key for.

But there is one condition: Medicare Part B will pay 80 percent of the cost of your anti-rejection drugs if Medicare Part A did or could have paid for the transplant itself, either alone or in combination with other plans. This means you had to have Medicare at the time of the transplant, and have the operation in a Medicare-approved facility, for Medicare to pay for anti-rejection drugs. Most hospitals that perform kidney transplants are Medicare-approved. However, some hospitals are not approved by Medicare to perform heart, lung and liver transplants.

This is an important condition, since many organ transplants performed in the U.S. aren’t paid for by Medicare. In fact, nearly half of kidney transplants and most other solid organ transplants are covered by private insurance companies or Medicaid. If these transplant recipients do not have Medicare at the time of their transplant and do not have the procedure in a Medicare-approved facility, Medicare Part B will not pay for their transplant drugs.

And even though Medicare Part B pays 80 percent of the approved cost of anti-rejection drugs as a primary payer, you are left to pay 20 percent of the bill, which can be very substantial. But you can use extra insurance to help cover unpaid costs from Part B. If your income is low, there are programs that may help you pay for these additional costs as well as your Medicare Part B premium cost. There are also supplemental insurance plans called “Medigap” that help you pay the remaining 20 percent. This chapter will discuss those insurance plans in more detail. Other insurance, such as through an employer or an individual plan, can help pay costs Medicare doesn’t pay.

If we keep thinking about Medicare as a building, the government always oversees the building, but Medicare contracts with insurance companies to pay Part A and Part B claims.
What Are My Medicare Options?

Assume now that you can go into any room and see any doctor in one wing of the building. This wing is called **Original or Traditional Medicare**, or fee-for-service. In another wing, you can only get into rooms to see those doctors if someone with a key lets you in. This is how a Medicare Advantage plan—which is a Health Maintenance Organization (HMO) or Preferred Provider Organization (PPO)—works. Most people have Original Medicare. But you should know that you also have the option to join a Medicare Advantage plan. Original Medicare will not pay for routine dental, vision or hearing.

In 2006, some Medicare Advantage plans may offer these services. Each Medicare Advantage plan will be different. See page 16 for more of the “pros” and “cons” of Original Medicare versus Medicare Advantage.

However, be aware that people with kidney failure and on dialysis are not eligible for a traditional Medicare Advantage plan, but can enroll in a “special needs Medicare Advantage plan,” if one is available in their area. Dialysis patients can, however, stay in a Medicare Advantage plan if they had it before their kidneys failed. A kidney patient can, however, enroll in a special needs Medicare Advantage plan, if he or she had a successful transplant and is still covered under Medicare. In that case, the beneficiary will have to submit a letter to the Medicare Advantage plan from the transplant facility. If you have kidney failure and want to join a special needs Medicare Advantage plan, contact CMS at 800-MEDICARE to see if you can.

When Does Medicare Start and End?

The vast majority of people with kidney failure are eligible for Medicare. If you are not yet enrolled, contact the Social Security Administration hotline at 800-772-1213.

People who have kidney failure can get Medicare when they start dialysis after a three-month waiting period. The waiting period is waived if someone chooses to do home dialysis or self-care in a clinic. You can get Medicare the month you are admitted to a Medicare-certified hospital for a kidney transplant. Medicare may also cover you up to two months before your transplant if you are admitted for tests before your transplant and your transplant is delayed. Specifically, if the transplant is delayed beyond the two months after they are admitted to the hospital, Medicare
starts two months before the month the transplant actually takes place. Talk to your transplant social worker or financial counselor right away if you are not sure if you’re enrolled.

But remember that, if your kidney transplant was successful—meaning it lasted for 36 months and you have no other disability that keeps you from working, your Medicare coverage stops 36 months after the month you were discharged from the hospital after your operation. Plan for how you will pay for your care once Medicare ends. However, Medicare coverage will not end if you need to restart dialysis or get another kidney transplant within that 36-month window after transplant. If that happens, you get another 36 months of Medicare coverage that starts with the second transplant. You get at least three years of coverage after a successful transplant; you can also get Medicare coverage again if you need dialysis or a transplant anytime in the future.

Alternatively, as we already mentioned, your Medicare continues if you enter the building through one of the other doors—such as by turning 65 or disability and receiving SSDI checks for 24 months.

How is Medicare Changing?

The government keeps working to make Medicare better suit people’s needs. While change is often good, it may also be hard on you. It requires you to keep up with what’s new to make sure you’re still getting the most out of Medicare.

The biggest Medicare change is its new prescription drug coverage. Going back to our earlier example, the Medicare building currently has two floors, Part A and Part B. Medicare is adding a new floor, which will hold a new section of Medicare. This new section, called Medicare Prescription Drug Coverage, will help you pay for prescription drugs if you sign up. You might have heard this new plan referred to as Part D.

Part D, like Medicare Part B, is optional, and you have to choose to join to use it. You can join starting November 15, 2005 to get the coverage as soon as it starts on January 1, 2006. It will also have a monthly premium, which will vary from plan to plan and may go up each year. If you’re not receiving a monthly Social Security check, you will be billed separately for that premium. People receiving Social Security checks will still pay a premium for the new drug plan, which
can be deducted automatically from their monthly checks. Those with limited income and resources (assets) will not have to pay a premium.

**Medicare Part D will be run by private insurance companies, which will have a list of drugs they will cover. These lists of covered drugs are called “formularies.”** Formularies are very important because they describe what each Medicare Part D plan will and will not pay for.

You will choose which private insurer you want to get the new drug plan from, and you should make that decision based on which Medicare Part D plan covers the most of your expensive drugs. Keep in mind you may need different drugs over time as your health changes and as you choose or need different treatments. Talk with your doctor about what drugs you should take and choose a Part D plan that works best for you.

In mid-October 2005, insurers that will offer drug coverage through Medicare started advertising what drugs they will be including in their formularies. In the fall of 2005, those of you with Medicare should also have received the *Medicare & You 2006* handbook in the mail, which includes information about Medicare Prescription Drug Plans, or PDPs, available in your area. The Medicare Web site, [www.medicare.gov](http://www.medicare.gov), provides information about plans, pharmaceutical costs and formularies to help you choose a plan.

If you don’t want to use the Web, call 800-MEDICARE. If you are hard of hearing and use a TTY, you can call 877-486-2048.

Another resource about the new drug plan is your State Health Insurance Assistance Program, or SHIP. Every state has its own SHIP, whose purpose is to help those with Medicare understand their coverage, manage their costs, and file appeals. The *Medicare & You* handbook contains the telephone numbers for your local SHIP, or you can call 800-MEDICARE to find out the number. Though SHIP counselors traditionally have most of their training and experience helping the elderly and disabled, they can help you too.

**Important Information on How Medicare Part D Works**

There are a few things transplant recipients have to be aware of with this new Medicare prescription drug coverage. **Drugs that you need may not be in the standard Medicare Prescription Drug Plans offered to you.** That is why choosing a plan carefully is...
important. You may have a choice of plans that cover more drugs than what the standard plan offers, but you will have to pay a little more for these enhanced plans. The list of drugs available with each plan is called a “formulary.”

The National Kidney Foundation is paying close attention to which drugs are included on the formularies. Some drugs transplant recipients take can be sold in a generic form, which is generally cheaper, and insurers often try to encourage patients to use these drugs. However, many physicians won’t prescribe transplant drugs in generic form. Furthermore, pharmacists should never switch transplant recipients from a brand name drug to a generic drug or from one brand of generic to another brand of generic without checking with you and your doctor first.

So if you are considering a Medicare drug plan and a drug you normally take is included only in a generic form, ask your doctor if that generic drug is okay for you to take instead. If not, your doctor can ask for an exception so you can take the brand name drug. If approved, you could pay more for the brand name drug.

Companies can also withdraw a drug from a formulary with only 60 days’ notice. There will be an appeal process if a drug you take is removed from your plan’s formulary.

Except for those with both Medicare and Medicaid, those who sign up for Part D will only be able to change plans once per year.

Also, not all pharmacies will accept all insurance plans. Once you find a Medicare Prescription Drug Plan you like, you will need to find out what pharmacies participate in the plan and will bill Medicare directly for you. Or, you can ask your favorite pharmacy for a list of plans in which they participate.

The Math

The most important thing for transplant recipients to understand about the new Medicare drug plan is that the plan covers more or less of your drug costs depending on how much you spend on drugs, unless you qualify for extra help that is available for those with limited income and resources.
If you don’t qualify for extra help from the government for those with low income and resources, under the new Medicare drug plan, in addition to your monthly premium, you will pay:

- The first $250 of your covered drug costs each year (called your deductible)
- 25% of your covered drug costs from $251 to $2,250 or $500
- 100% of the next $2,850 (called the donut hole)
- 5% of covered drug costs over $5,100 each year (called catastrophic coverage)

In other words, you get nothing for the first $250 worth of drugs; then the new Medicare drug plan covers 75 percent of drug costs up to $2,250; then you get nothing again from $2,251 to $5,100, after which Medicare pays for 95 percent. So you get the most coverage out of Medicare only after your drug costs exceed $5,100. It’s been calculated that after you spend $3,600 out-of-pocket on covered drugs, Medicare will pay for 95% of your drug costs.

Now, this additional provision is very important: the $3,600 only includes drugs on the plan formulary and purchased in the U.S. Say a person receiving Medicare buys a drug that is not on a formulary, at his or her own expense. The cost of that prescription will not count.

Changes for People on Medicaid and Others with Limited Income and Resources

Thankfully, the government is offering a few programs that people with low income can use for Medicare Part D. Most importantly, the government has made some important decisions for people receiving both Medicare and Medicaid, the health program for low-income Americans. When Medicare Part D begins January 1, 2006, Medicaid will no longer pay for prescription drugs for those with both Medicare and Medicaid who are covered by the new drug plan.

Instead, the government has decided to enroll people with both Medicaid and Medicare into the Medicare Prescription Drug Coverage plan (Medicare Part D) starting January 1, 2006.

When Medicare Part D begins, state Medicaid programs will no longer pay for prescriptions for those who are eligible for both Medicaid and
Medicare benefits. Beneficiaries who qualify for benefits under both of the government health care programs, Medicare and Medicaid, are often referred to as “dual eligibles.” Effective January 1, 2006, the prescription drug coverage for dually eligible beneficiaries will be provided solely through the Medicare Prescription Drug Coverage plan (Medicare Part D).

Dually eligible people must choose a Medicare Part D plan by December 31, 2005 or they will be randomly enrolled in a Part D plan by the government. This may result in enrollment in a plan that is not the best choice for that individual. If they’re assigned to a plan and prefer a different one, they will have the opportunity to switch plans before January 2006 or any month afterwards. This means if you have both Medicare and Medicaid, on January 1, you will automatically have the new drug plan. The benefit of choosing your own plan before you are automatically enrolled is that then you can make sure your preferred pharmacy participates in your plan and that the plan has the drugs you need in the formulary. If you have both Medicare and Medicaid, you can change plans throughout the year, rather than wait for a once-a-year enrollment period.

The purpose of automatic enrollment is to make sure people with both Medicare and Medicaid don’t lose their drug coverage. However, people on both Medicare and Medicaid have to be very careful, because their new drug plan may not cover the same drugs that Medicaid did. If your new prescription drug plan won’t pay for a drug you got under Medicaid, ask your doctor if it’s okay to substitute the old drug for another, covered medication. If not, your doctor can also file an exception request asking the plan to cover the drug you have been taking if there is a medical reason why you should take it instead.

For people now eligible for both Medicare and Medicaid, the government will cover the cost of the monthly premium, the yearly deductible, but there will be small co-pays for drugs. If someone with Medicare and Medicaid chooses a plan that covers more drugs but has a higher premium, they may need to pay the difference in premiums to get better coverage.

Those receiving SSI checks and who don’t get Medicaid or who get help from their state to pay their Medicare premium will have until May 15, 2006 to sign up before a plan will be chosen for them. They, too, will not have to pay a premium or deductible and will pay a small copay per covered drug.
Extra Help for Drug Costs

People with Medicare who make too much money to qualify for Medicaid but still have low income and resources may pay a lower premium and $50 deductible or less and either a small co-pay per covered drug or 15 percent of the cost of the covered drug, depending on their income and resources.

People with limited income may still be eligible for state pharmaceutical assistance programs. 25 states now help low-income people with Medicare pay for prescription drugs, even if they don’t qualify for Medicaid benefits. Some states offer this help only to people over 65, while other states offer help to anyone who is disabled, no matter what their age. Contact your SHIP or transplant social worker to see if you qualify for this, if you haven’t already.

On www.medicare.gov you will find something called a Medicare Prescription Drug Benefit Subsidy Eligibility Information Tool. This tool will help you find out if you are eligible for extra help with premiums, deductibles, and co-pay costs and what you will need to do. You can also call 800-MEDICARE. You can apply for extra help at your local Social Security, public assistance or Medicaid office. The extra help is designed for people with limited income who enroll in a Medicare Part D plan.

There’s also Medigap, a supplemental insurance program. Standard Medigap plans pay the 20 percent cost of anti-rejection drugs not paid by Part B.

Medigap cannot help with Part D co-payments. It is important to check the benefits available under your Medigap plan since policies differ.

Please note that there will be changes in Medigap when the Medicare drug coverage begins. Plan carefully before dropping a Medigap plan. If you drop your Medigap plan, you may not be able to re-enroll.

Other non-government funded programs help transplant recipients pay for drugs, and may continue to help once Medicare Part D begins. For instance, pharmaceutical companies that make and sell drugs for transplant patients may continue to provide drugs for free to those who qualify. If you have Medicare Part D and a drug is covered, you may not qualify for help from one of these programs. Again, your social worker should know about programs to help with drugs you need.
Extra Help For Other Costs

People who don’t qualify for Medicaid but still have low income and assets can use Medicare Savings Programs to help pay for non-drug related Medicare costs.

There is also a program called Qualified Medicare Beneficiary Program, or QMB, which pays Medicare Part A and B premiums, deductibles and coinsurance and provides Medicaid coverage to help pay for services Medicare covers. Another program, called Specified Low-Income Medicare Beneficiary Program, or SLMB, pays Medicare’s Part B premium, as does a program called Qualifying Individual, or QI, which helps people pay part of patients’ Medicare premium. Your state Medical Assistance Office administers these programs.

How Does Part D Help Transplant Recipients?

There are some concerns about the new drug plan, and there’s still a lot we don’t know because it is new. But generally, if recipients don’t have any drug coverage outside of Part B, the Medicare Prescription Drug Coverage could really help.

However, you may have other options that could enable you to save more money than Medicare can. These include getting drugs from the companies that make them using patient-assistance programs, or asking for help from your state. However, these options may not always exist and, if you sign up late for Medicare Part D, it may cost you more.

Every patient has different medical and financial needs, so it’s impossible to say whether the new Medicare drug plan will help all transplant patients. The National Kidney Foundation thinks Medicare Part D could help you pay for prescription drugs you take at home, such as:

- Medications for high blood pressure
- Drugs that lower lipids or cholesterol
- Oral infection treatments and antiviral agents

If you feel like you’re spending too much out-of-pocket on these drugs, you should probably consider enrolling in the new drug plan.
Medicare Part B will continue to provide immunosuppressive drugs until Congress decides otherwise. Under Medicare Part B, Medicare pays 80 percent of the allowed cost of medications and you pay the balance, called a co-payment, if Medicare is your primary payer.

However, you cannot count out-of-pocket expenses for Part B drugs towards the $3,600 you need to spend to get 95% coverage under Part D. So you have to spend $3,600 on drugs other than anti-rejection ones covered under Part B before Medicare Part D pays 95% of the cost of your drugs.

If Medicare Part B does not pay 80 percent of your anti-rejection drugs, they may be covered by Part D. But if Part B does pay 80 percent of your anti-rejection drugs, Part D will not cover the 20 percent, or any percent, of the cost.

The National Kidney Foundation was initially concerned about the lists of covered drugs—again, called formularies. However, CMS now requires insurance companies that administer Part D plans to cover every anti-rejection drug but not all drugs that kidney patients take.

Formularies are available at www.medicare.gov.

There may be some good news for people who become eligible for Medicare after their transplant. For these patients, Medicare Part D will cover transplant drugs, even if the program didn’t pay for your transplant or it wasn’t performed at a Medicare-approved facility. As we explained before, this is a requirement for Part B—this program will only pay for anti-rejection drugs if Medicare paid or could have paid for your transplant and if you had the surgery at a Medicare-approved transplant facility.

If you sign up for Medicare Part D and the insurer takes one of your drugs off its formulary, people who have Medicare and Medicaid can change plans any time—and will have access to continuous open enrollment. However, other people cannot.

People not enrolled in Medicare and Medicaid may only be able to change plans once a year during an open enrollment period (November 15 to December 31 every year) or under certain limited conditions. If you can’t change plans, you can ask for an exception to have a drug covered under your new prescription drug plan if your prescribing physician feels that all covered drugs for the treatment of the same condition are not as effective for you, or would affect you adversely. Again, no one is exactly
sure yet how the exceptions and appeals process will work, so stay tuned for more information when we get it.

As it stands now, you can appeal if you don’t agree with how much Medicare has paid for a claim, you want coverage for an uncovered service, or if you don’t agree with a denial of coverage. You get a Medicare Summary Notice in the mail from the company that handles your Medicare bills. This notice describes how you can appeal. Your state’s SHIP can help you appeal Medicare decisions.

How to Sign Up

The new prescription drug plan is available to everyone who qualifies for Medicare, and has Part A or Part B. For transplant recipients, this means anyone 65 and older, people who have received SSDI checks for at least two years, or people receiving Medicare for kidney failure for up to 36 months after the month of transplant.

You can sign up with the plan you choose starting November 15, 2005. Initially, there will be a six-month enrollment period. Later, those new to Medicare have six months to sign up before paying a higher premium. As discussed earlier, transplant recipients who are entitled to both Medicare and Medicaid will be automatically enrolled in the new prescription drug plan if they don’t choose a plan by December 31.

If you enroll after the six-month enrollment period, you may have to pay 1 percent per month extra. So you really have to start thinking now about whether you want to have Medicare Part D. Then, when November comes, you can enroll without a penalty, if that’s what you think is best for you.

Original vs. Advantage

There are some basic pros and cons of using Original Medicare, run by the government, and a Medicare Advantage plan (HMO/PPO). Obviously, every person needs to decide for him or herself what is best. Remember, if you have kidney failure, you must have had a successful transplant, and be free of dialysis, before you can sign up for Medicare Advantage. Special needs Medicare Advantage plans for dialysis patients may be created in the future.
Most transplant recipients have Original Medicare, but it’s nice to have a choice.

**Pros of Medicare Advantage:**

- Medicare Advantage plans have typically provided some form of coverage for prescription drugs—until 2006. However, with the new Medicare prescription drug coverage, Medicare Advantage will not be the only plans to offer this coverage.

- Medicare Advantage may save you money because some plans don’t require premiums or deductibles. Instead, you pay a small co-payment each time you see a doctor, providing you use HMO doctors and follow the insurance plans rules about your care.

A **PPO will typically charge higher monthly premiums than an HMO, but will pay for some of your costs if you visit doctors or facilities outside the insurer’s network.**

- Some Medicare Advantage plans will cover expenses Medicare won’t. Original Medicare will only pay for services that are considered medically necessary, as well as several preventive services. But Medicare Advantage plans often pay for eye and hearing exams, glasses and hearing aids, dental care and podiatry. However, they also often limit how much of these expenses you can have.

Also, it’s important to realize that, **to use Medicare Advantage, you must be enrolled in both Part A and Part B.**

**Cons of Medicare Advantage:**

- You often need approval from your primary care doctor before your plan will pay for a visit to a specialist.

- You can’t see doctors outside of the insurer’s network except in an emergency.

- You don’t always get every benefit the Medicare Advantage plan offers because the company administering the plan will decide for you how much care you need.
Medicare Advantage plans can change their rates or decide to withdraw from Medicare, so you run the risk of having everything change, or losing some or all of the benefits you signed up for.

If you have Original Medicare and a supplemental Medigap plan and switch to a private insurer, you may save money by dropping Medigap. But if you decide to switch back to Original Medicare, be aware that you might not be able to get back your Medigap coverage. You may be refused coverage because you have an existing (pre-existing) medical condition.

Drug Discount Cards

Until January 1, 2006, when Part D begins, you have the option of enrolling in a Medicare drug discount card program. This drug discount card program began in June of 2004 and will end when you enroll in Part D or on May 15, 2006—whichever is earlier.

Right now, you can get a drug discount card issued by a private company that has been approved by Medicare. Each card is different, but they can cost less than $30 and give you discounts between 10 and 25 percent off the retail price of some drugs.

Each card has to provide discounts on at least one drug from each class, but the drugs that are covered can change at any time. You can start using your new card at the beginning of the first month after you apply.

Unfortunately, not every pharmacy is a member of every drug card’s network.

There are also other, non-Medicare drug discount cards, such as those offered by American Association of Retired People, or CVS pharmacy. You can also get drugs from the Veterans Administration if you qualify for those benefits.

Which card works best all depends on the individual. The card that’s best for you depends on what medications you take and your income. Here are two Web sites that can help you decide which card is best for you:

- [www.medicare.gov](http://www.medicare.gov) includes a tool that allows you to compare cards and find which one is best for you.
www.benefitscheckup.org includes a tool that asks you for your particular needs, then recommends drug discount cards.

People without a computer or who don’t want to use the Internet can always ask an Internet-savvy person with a computer to help. Or visit your local library, which should have Internet access, and ask the librarians for help.

Alternatively, your SHIP or local agency on aging should help you make the decision about which card is best for you. The needs of the elderly and transplant recipients in choosing a drug card have many similarities. Do not assume, however, that the counselors know the details about how Medicare Part B covers medications for some transplant recipients, though a counselor should have the contacts to make some calls and find some information out for you. Each Medicare region has an End Stage Renal Disease specialist who can disseminate information to the trainers and counselors who talk to beneficiaries with kidney transplants like you. Other Medicare specialists have special training for people with other disabilities (which include heart, lung and liver transplant recipients). The number for the local agency on aging should be in your local phone book. You can also call 800-MEDICARE to ask for help, or call your SHIP counselors, listed in your Medicare & You Handbook. The Medicare & You Handbook is “general” in parts, so ask your transplant social worker to help you figure out specific details for transplant patients. If you’ve had a kidney transplant, you can also read the Medicare booklet Medicare Coverage for Kidney Dialysis and Kidney Transplant Services.

If you have a low income, the government will cover the cost of your Medicare drug discount card and up to 95 percent of the covered drugs for a maximum of $1,200 for both 2004 and 2005. That’s a $600 limit per year, but if you didn’t use all $600 in 2004, you can carry the rest over into 2005. However, if you didn’t apply in 2004, you are no longer eligible for that $600. Unfortunately, the later you enroll in 2005, the less of the $600 you receive.

When that money runs out, the card will only discount certain drugs, the same system that applies to people with drug discount cards who do not qualify for this low-income program.

In order for the government to cover the cost of your drug discount card, you have to earn less than a certain amount as a single person or as a couple. Ask your transplant social worker if you qualify for that program.
Frequently Asked Questions

Q: How does Medicare work with other insurers?

A: It depends quite a bit on who that insurer is. Say you have ESRD and you have insurance through an employer—either you or your spouse’s. If you opt for Medicare in addition to your other insurance, Medicare requires that the other insurer be your primary payer, and Medicare will be a secondary payer.

However, after 30 months, even if you are still getting insurance through an employer, the situation flip-flops, and Medicare now becomes your primary payer. The clock starts when Medicare starts, even if you had your transplant months after you began Medicare.

For more information about how Medicare works with employer insurance, call the National Coordination of Benefits Contractor at 800-999-1118, or 800-318-8782 for TTY and TDD.

Q: How will the new Medicare drug plan will work with Medigap, the supplemental insurance plan?

A: There are Federally monitored Medigap plans A through J. Each has different benefits and premiums. Remember, only Medigap plans H, I and J cover part of your drug costs—less than what Part D will pay. Basically, the general rule appears to be that if you have Medigap when Medicare prescription drug coverage starts and you enroll in the new drug plan, you will lose your drug coverage if you were in Medigap plans H, I or J. The other benefits under H, I, and J will continue. You also have the option to switch to another Medigap plan sold by your current company that does not have drug coverage and probably costs less.

Similarly, after January 1, 2006, when the new Part D drug program starts, you can no longer enroll in the most expensive Medigap plans, H, I and J for the first time. However, the Federal government does not believe any Medigap plan is at least as good as the new Part D prescription drug coverage. So if you enroll late in the Medicare drug coverage because you have Medigap drug coverage, it is likely you will have to pay a penalty of 1% per month you delay signing up for Part D.
If you drop your Medigap policy, there is no guarantee you will be able to enroll in a Medigap plan in the future. Plan carefully to assure you have a way to pay the Medicare Part B 20% balance if you drop your Medigap coverage.

Q: Which is better, Medigap or the new Medicare prescription drug coverage?

A: Well, Medigap and the Medicare prescription drug coverage will provide different benefits—both may be very valuable. The less expensive Medigaps will cover the 20 percent co-pay that accompanies Medicare Part B. Medicare prescription drug coverage is considered by CMS to be a better deal than Medigap H, I and J plans. You can still keep the less expensive Medigap plans and have the new drug plan, which is a great option, if you can afford it.

Q: When a transplant recipient loses insurance coverage—perhaps due to job loss—and cannot afford their medications, will Medicare help pay for services until they find another insurer, even if the recipient is not receiving Medicare at the time?

A: The only way transplant recipients can get help from Medicare is if they are still eligible—meaning, they are at least 65 or disabled for another reason, or had a transplant within the past three years. But remember, Part B will only pay for anti-rejection drugs if the procedure was done at a Medicare-approved hospital, and you had Medicare at the time of the transplant, even if Medicare didn’t pay for the procedure. So if you’re applying for Medicare Part B after the procedure, it won’t pay for your anti-rejection drugs.

You can sign up for Medicare Part D and it will pay for anti-rejection medications if the transplant doesn’t meet these criteria, but only if you are entitled to Medicare because of age or disability. Even if you sign up late, you won’t have to pay a higher premium if you had similar coverage to Part D through your employer.
Q: Is it true that if I become eligible for Medicare before or at the same time I am eligible for COBRA I can have both? Is it true that COBRA will terminate only if I receive it after I receive Medicare?

A: If you had another insurance, including Medicare, before the COBRA “qualifying event,” such as getting laid off from your job, you can keep Medicare. However, COBRA can stop if you get another type of insurance after COBRA starts. However, if you just became eligible for another type of insurance while on COBRA—perhaps you turn 65 or undergo transplantation—COBRA won’t stop if you don’t sign up for that insurance.

So if you have Medicare before COBRA starts, you can keep them both. But if you are already enrolled in COBRA and then enroll in Medicare, your COBRA may end.

For example, a woman was on COBRA through her husband’s former employer, and then she turned 65. She signed up for Medicare Part A, but not Part B. When COBRA found out she had Medicare, it terminated her coverage, and actually asked her for money to pay for the claims it covered while she was on both plans.

In this situation, the woman had decent coverage through COBRA, so she should have waited until it ran out before signing up for Medicare. If people already have Medicare, it’s generally best to get COBRA if their savings from COBRA equal more than the monthly premium. Note: Having Medicare, even as a second payer, can keep your costs lower, because it limits what health care providers can bill you. If you have Medicare, providers can only bill you up to an amount equal to Medicare-approved charges.

Q: I’m a 61-year-old man with a kidney transplant. My 36-month limit on Medicare coverage ends in February, and I want to know if I can get an extension, which I heard is possible for some patients.

A: Unfortunately, right now, kidney recipients with Medicare due to kidney failure have only 36 months of coverage after their transplant. At the National Kidney Foundation, we are trying to extend that coverage for kidney transplant recipients, but it hasn’t happened yet.
Q: How will your income affect Part B Premiums?

A: The government has also decided that people who have higher incomes should pay more for Medicare Part B. On January 1, 2007, people who earn more than $80,000 per year will have to pay a higher monthly Part B premium. Premiums will be adjusted using a sliding scale based on your income. The more you earn, the more you’ll pay.

Summary

As of January 1, 2006, Medicare changed. The biggest change is the addition of a prescription drug benefit, which may help transplant recipients who do not already have drug coverage. If you are unsure about whether you should enroll in the new Medicare prescription drug plan, talk to your transplant social worker. There are other changes as well, such as Medicare now paying for an annual physical exam for beneficiaries and some new preventive services.

We at the National Kidney Foundation want to remind everyone to turn to their transplant social worker if they have any additional questions that we couldn’t answer. They know you and they know the state you live in, so they can give you very personalized help and advice. Use them.

We also want to urge you all to continue to rely on the resources available from the National Kidney Foundation. Visit us at www.kidneydrugcoverage.org to stay up-to-date and to get answers to any questions that we didn’t get to. We will also use the site to keep you posted on any new information we get about these upcoming changes to Medicare.

If you have anything to share about Medicare, post messages on the message board using the topic “Medicare Changes,” or send us an e-mail at transactioncouncil@kidney.org. You can also call us at 800-622-9010.

If you want to take action, we also encourage you to be part of our TransAction Council. Just send us an e-mail or call. It’s free!

For more information on Medicare and financial resources turn to page 40.
Understanding Depression

Introduction

Depression is extremely common in the United States, and it can have a unique impact on transplant recipients. Practically every transplant recipient has likely felt—or fought off—depression at some time or another.

Living with a new organ has daily challenges. These include medical bills and getting used to a new body. Some transplant recipients may also feel they are burdening their loved ones with constant doctors’ visits and a general need for extra help. All of this comes on top of the trials and tribulations that arise for everyone, transplant recipient or not.

It’s normal to have a range of feelings after a transplant. We at the National Kidney Foundation (NKF) hope that all recipients find a way to cope that works for them. And for all recipients who haven’t, that’s what we’re here for—to help people deal with depression after transplant.

We decided to address depression after asking transplant recipients what they wanted to know more about. Not surprisingly, many said they felt depressed after their transplants, and wanted to learn about coping with those feelings. We at the NKF believe that depression is one of the biggest issues people face, and something a lot of health care workers ignore.

This chapter, a companion to the NKF telephone audio conference “Understanding Depression” (June 2005), addresses why transplant recipients get depressed, what’s out there to help, and why treatment is so important. For an actual transcript of the conference go to www.transplantrecipients.org.
What is Depression?

Research shows that, in any given year, **almost 10 percent of the U.S. population is depressed.** That's **19 million adults, with and without transplants.** And in people with chronic illness, the incidence of depression is much higher. Some research suggests that up to **25 percent of people with illnesses become depressed at some point in their lives.** So, if you are a transplant recipient and you feel depressed, you are definitely not alone.

But how do you tell when you’re depressed and not just discouraged because of declining health or other bad life events? Clearly, everybody feels “down” sometimes, especially when bad things happen. Everyone can feel discouraged after a particularly hard day. This is a totally normal and an expected way to feel.

But depression is different. It’s not just a bad mood, which is something everybody feels. Being depressed means that people feel at least five symptoms of depression for two weeks or longer. A bad mood should only last a couple of days. Depression is also more intense than a bad mood, and it interferes with regular life. It can affect sleep, appetite, and even how the body feels.
Why Does Depression Happen?

Depression is a medical condition, like high blood pressure and diabetes. It occurs because of a chemical imbalance in the brain. Our brains rely on two chemicals, serotonin and norepinephrine, to regulate our mood. When people develop a deficiency in these chemicals, depression can occur. This process can be triggered by difficult events, such as transplantation or other chronic illness.

It can be hard to admit to feeling depressed, and it’s not something everybody is comfortable talking about. But people generally don’t hesitate to talk to their doctors about high blood pressure and make sure that it is treated. Why can’t we think of depression in those terms?

Symptoms of Depression

Here are nine symptoms of depression:

- Feeling depressed for most of the day, almost every day.
- Lack of enjoyment of activities you once enjoyed, such as going to work or visiting friends.
- Weight changes (gaining or losing).
- Sleep problems (too much or too little).
- Feeling restless.
- Lacking energy, feeling easily fatigued.
- Feeling worthless or guilty.
- Trouble concentrating.
- Frequent thoughts of suicide.

Remember that people have to have at least five of these nine symptoms for at least two weeks before doctors will diagnose depression. This is to make sure that people who have bad days here and there are not misdiagnosed.

Depression After Transplant

Unfortunately, depression after transplant is extremely common. People who were prone to depression before their transplant are equally at risk afterwards, if not more so because of the added
stress from the transplant. Studies also show that up to one-quarter of people who are depressed after a physical illness had depression before they became ill. So in many cases, a transplant recipient’s depression may have nothing to do with his or her illness.

However, in some cases, transplant can actually trigger depression. As we mentioned earlier, people are often more likely to develop depression when life gets harder, like after a transplant. But on top of that, there are some transplant medicines that can cause depression as a side effect. For instance, steroids such as prednisone, which many recipients take to avoid rejection of their new organ, can cause depression.

Prednisone may cause a range of other side effects, such as violent mood swings. Some people may get a feeling of euphoria from prednisone. A small number of people also have psychotic episodes from the drug. So it’s a drug that can save a transplant recipient’s life, but it’s not always an easy process.

The stress of having a transplant can trigger depression. Having a transplant is a life-altering experience. The range of emotions people feel as a result of the procedure can definitely trigger depression in those who are susceptible to it.

It can be incredibly difficult for people to accept that one of the organs they were born with no longer works. For many, organ failure can feel like a profound loss. Some really grieve over it, which is totally understandable. Unfortunately, this grief can also lead to depression.

Having a transplant can create another loss, by changing recipients' lives in an irreversible way. They may grieve that they can no longer lead the same life as before, now having to rely on doctors and medications to stay well. That can be hard to accept.

Some recipients may also find it hard to accept that they are more dependent on their families. They may feel like their illness disrupts their families’ lives, and they are dependent on them emotionally and sometimes financially. For recipients who are used to being the sole providers for their families, that can be really tough.

Financially, many transplant recipients also worry about their futures and how to afford the medicines they’ll need for the rest of their lives. People with kidney transplants often worry about their health insurance, knowing that they lose Medicare after three years.
Many transplant recipients worry about their futures in general. This may be the first time they have faced a serious health risk, and that can be very scary. And when they feel bad physically, that makes all the fear, frustration and uncertainty even harder to bear.

Some people say they feel pressure to be happy all the time after their transplant. There aren’t enough donor organs to go around, and people say they feel they need to be grateful all the time for theirs. But it’s not possible to feel happy all the time. Recipients are, indeed, blessed to receive a new organ. But that doesn’t mean they have no right to feel sad ever again, or to get discouraged about the burden this organ places on them.

Having a transplant does not mean a recipient is cured, which the average person may not understand. For that reason, friends, family and co-workers may think recipients are now good-as-new, and all their health problems are solved. It will take time for people to understand that recipients have a new set of challenges.

Some recipients also say that they feel guilty for taking an organ from another person. If it’s a kidney, maybe they got this wonderful gift from a loved one. They can never thank their donors enough, or repay them enough. Some recipients feel sad that someone had to die to give them their new organ. They don’t like the fact that they are benefiting from someone else’s tragedy.

All of these feelings—which are totally natural reactions to transplantation—also come on top of anything else recipients are dealing with at the time, another reason why depression is so common after transplant. Family, career, finances—these make life challenging for everyone, transplant recipient or not.

However, a recent study sheds light on what it means to be happy with a chronic illness. The researchers asked people on dialysis how happy they were, then asked the same question of people not on dialysis. Both groups of people gave the same ratings on a happiness scale.

This suggests that people both on and off dialysis are equally happy. However, the researchers also asked dialysis patients to say how happy they thought they would be if they had never developed kidney disease. On average, they all said they thought they would feel happier.
But from the previous results, the investigators knew that dialysis patients were already as happy, on average, as people who weren’t on dialysis. So why would they be happier if their kidney function improved?

To the investigators, this suggested that, even though chronic illness is very difficult, it doesn’t necessarily affect our happiness. Recipients are likely just as happy now and just as fulfilled as they were before their transplant. Because they are sick, they may think they are less happy, but this study suggests that may not be true at all.

The study was never meant to imply that people with chronic illness aren’t really depressed. It simply makes the point that being ill is very difficult, but we can adapt to it. We are capable of adjusting and still feeling happy, even when we’re sick.

**Physical Influences on Depression**

Our physical condition, like pregnancy and menopause, can influence depression. Many people may have heard of postpartum depression, the form of depression that can strike women after they’ve just given birth. It can be very intense. This is something to consider for transplant recipients who are pregnant or who recently were. If they are feeling depressed, it may be postpartum depression.

There are many factors in pregnancy that could increase women’s risk of depression. On top of dealing with their transplant, pregnant or post-natal women have intense changes in hormones and weight, and undergo stress from suddenly being totally responsible for another human. New babies also need constant feeding, which disrupts parents’ sleep. With all of this going on, it’s not surprising that new moms are particularly at risk for depression.

Menopause is also a time when recipients may be more vulnerable to depression, for similar reasons. Women’s hormones are totally “out of whack”; their bodies are changing radically; and all of this compounded with a transplant can make them vulnerable to depression.

Studies show that teenagers are also very much at risk for depression, perhaps because, like in pregnancy and menopause, their bodies are undergoing intense hormonal shifts. The teenage years are also a time of intense life changes, as people transition from children to adults.
People start to look at teenagers differently; they have more responsibilities; and they need to start making important decisions about school and careers.

Dealing with Depression

**Treating depression is simply a matter of life or death.** There are a lot of misconceptions out there about depression, and one of the biggest ones is that it’s possible to “snap out of it”—that a simple shift in attitude or circumstance will make depression go away.

That’s simply not true. **Depression is a medical condition, like diabetes.** No one can “snap out of” diabetes, and it’s the same with depression. **People need professional help, in the form of therapy or medication, to treat depression. Without treatment, they may even get worse.**

It’s also self-defeating to believe that depression is something people can overcome by willpower, because it implies that if they can’t snap out of it, they’re weak. It implies that if they were stronger, they wouldn’t be depressed. **Being depressed is definitely not a sign of weakness. But admitting you have a problem and taking action to help yourself is definitely a sign of strength.**

**Treatment for depression can save a recipient’s physical health** as well. Research shows that people who are depressed are less likely to take their medications and stick with rehabilitation programs. Plus, they are more likely to develop additional illnesses, like heart problems. For people with chronic illness—like transplant recipients—those who are depressed tend to fare worse over time. But **when people are diagnosed and treated for depression, they recover better from physical illnesses.**

The reason why depression appears to affect a person’s physical health remains unclear. Depression causes stress, which can raise levels of free radicals and fatty acids, the harmful molecules that can damage blood vessels. Mental stress can also cause changes that may block blood flow.

**Depression can affect recipients’ families, as well.** It hurts loved ones to see them feel this way, and research shows that if people are depressed, their spouses are more likely to become depressed, too.
Treating Depression

The two principle types of treatment for depression are therapy and medication. Each one has pros and cons, and it’s up to recipients to decide which one they prefer, or if they want to try both in combination.

The most common type of therapy is called cognitive behavior therapy, or CBT. As part of the cognitive portion of the treatment, a therapist helps people correct any negative thought patterns that may be causing a depression. For instance, if people are constantly feeling hopeless, or that there’s no point in living, their therapist works with them to try to change those feelings.

The other part of cognitive behavior therapy is the behavioral part. This focuses on how people behave in certain situations, if those behaviors aggravate a depression. A therapist may help people avoid behaviors that are really self-defeating, such as sleeping all day, or avoiding things they used to enjoy.

There are also other types of therapy, such as interpersonal and behavior therapy. And if people don’t want to speak to a professional one-on-one, they can always sign up for group sessions.

Typically, one-on-one sessions last for 45 to 50 minutes, during which people talk about their feelings—whatever is on their mind. A therapist will also ask them questions, to make sure what they are talking about is helpful for their depression. If recipients attend a group session, they share their experience with others and listen to others talk about themselves. Sometimes hearing other people’s stories helps alleviate feelings of isolation or loneliness that can come from living with a chronic illness.

If you believe you are depressed, the first thing you should do is talk to your doctor. He or she should know reputable mental health professionals near you. It’s best to go with a therapist who has experience treating people with chronic illness.

Another great resource is a transplant social worker, or anyone on a transplant team who can help find a therapist with the right training for an individual transplant recipient’s situation.

However, insurance plans may not cover every therapist. People who want to make sure they’re covered should contact their insurer for a list.
of covered therapists in their area. Then they need to call or visit some of them and choose someone they are comfortable with.

In addition to therapy, medication can do a lot to ease depression in transplant recipients. We know the last thing many transplant recipients want to do is take another pill. But a lot of research shows that certain drugs can help people with illnesses, without unbearable side effects.

There are two main types of antidepressants: tricyclic antidepressants, or TCAs, and selective serotonin reuptake inhibitors, or SSRIs. These medicines work by correcting the chemical imbalance in the brain that causes depression.

Most often, doctors will start people on an SSRI. Each drug works a little differently in different people, so people may have to adjust their dose or switch drugs if it doesn’t feel right the first time. This is really common and it doesn’t mean that the drugs don’t work.

Older adults tend to react differently to antidepressants than younger people. For this reason, doctors may at first try different drugs with elderly patients than they would with younger people.

There are potential side effects that can come from antidepressants, but they can all be managed. Let your doctor know about any side effects.

A word of caution: A lot of people use herbal medicines to treat a variety of conditions. One very popular herbal medicine is St. John’s Wort, which people use to treat depression. One reason for its appeal is that people can buy it at a health food store, without a prescription. However, a crucial thing to remember about St. John’s Wort is that it interferes with other drugs transplant recipients are taking. One of the drugs it interferes with is cyclosporin, which people take to prevent transplant rejection. Transplant recipients have lost their organs after taking St. John’s Wort.

When it comes to depression, some of the best medicine is also the most accessible: communication. People who feel depressed should talk about their feelings, if they can. That’s why therapy is so successful.

So many feelings that can cause depression—feeling alone or scared about the future—can be alleviated by talking to others. It makes intuitive sense that keeping things bottled up inside can make people feel a lot worse.
Think of life’s trials and tribulations like a shaken soda bottle with a loose top. A transplant is worth at least 10 shakes, then add more shakes to represent whatever other challenges recipients are facing. If they don’t let out that accumulated air slowly, through talking about their feelings with others, that bottle’s going to explode.

For some recipients, a transplant support group provides the emotional support they need. Sharing with fellow recipients who know what they are experiencing can be a great comfort. Some groups are run by social workers and some are run by peers. Both allow recipients to help each other, and to get help from the community. People can form some really close friendships and build a network that will get them through tough times. Transplant social workers can help recipients find a group.

If people are at all hesitant to visit a therapist or support group, they should consider at least talking to anyone they feel comfortable with. This can be a family member, friend, health professional, or someone at their place of worship.

They can also consider some creative ways to express themselves. These can be very private, so they work for people who don’t feel comfortable talking to others. This can include writing about feelings in a journal, in poetry, or even in fiction. If people are writing a short story about fictional characters, they still write out what’s inside of them, and that keeps it from bottling up.

People who don’t like writing can try painting, pottery, drawing and other forms of art. Some say that art and creative activities allow people to express themselves, without considering what other people will think. If we write for ourselves, we don’t think about how other people will react to what we write. We don’t have to worry about seeming ungrateful for our transplant, or complaining too much, or thinking negative thoughts.

In fact, writing and art are both types of therapy, and there are professionals who are trained to use art and writing to help people deal with depression.

It may be best to just let creativity flow without second thoughts—perhaps by writing without using punctuation, or painting without lifting the brush off the page. This helps people really get into a flow, and let out things that are very deep.
No one needs to write or paint for hours a day to overcome depression. But a few minutes per day or an hour or two per week, at least, will help people express their feelings. And that will help them deal with depression. Depression is something people fight against every day, which takes a lot of energy. It may not be too much to ask to use a few minutes per week for these activities, if it results in lots of other minutes of feeling less depressed.

Artistic expression along with professional help can be a good combination.

Paying for Treatment

Many private insurance plans provide drug coverage, and pay for at least some of the bills. Transplant recipients should contact their insurance provider to find out whether some or all of their therapy or antidepressant medicines are covered.

People on Medicare are covered for a lifetime maximum of 190 days at an inpatient mental health facility. For outpatient care, Medicare pays for half of the number of sessions they think people need. Unfortunately, Medicare does not cover antidepressants.

Medicaid, the government program that helps people with low income, will pay for a limited amount of inpatient and outpatient care. The program will only pay for Medicaid-approved drugs.

Some people may also qualify for assistance from drug companies that sell antidepressants. In some instances, they will send the drugs for free. Recipients should talk to their transplant social worker to see if they are eligible.

People with concerns about medication and treatment costs can obtain the transcript from the NKF discussion on Medicare, which discusses state and federal programs that help transplant recipients pay for health care, and they can refer to the previous chapter in this booklet.
Spotlight: David’s Story

I am a transplant recipient and I have dealt with depression. It has been a real challenge, and it’s something I continue to deal with every day.

However, I’ve gotten through some really tough times, and I hope that sharing my story will help some of you get through your own. Life is full of crummy stuff, on top of everything else you deal with being a transplant recipient. Having a transplant can make it all that much harder to cope with other challenges in your life, putting you at risk for depression.

I’d like to say that having a transplant positions you precariously on a cliff, looking over the edge. If nothing else goes wrong in your life, you can turn around and walk back to safety. But if something does go wrong, it’s very easy to fall off. Whether or not you do depends on how you respond to what happens. I almost fell off my cliff a few years ago, when I got very close to taking my own life.

In the end, I didn’t. I landed on a ledge and am working hard to climb back up.

For me, depression was much harder than having my transplant. The transplant was a procedure and it ended. And, as long as I take my medication and try to stay healthy, it’s not an issue. But depression is something I fight every day. It’s a constant.

Here is my story.

I received a kidney transplant in 1987 and I’ve had very minor complications from it. However, in the 17-plus years since, I’ve taken 10 milligrams of Prednisone daily, which I now understand can affect your mood.

Another contributing factor was that, before my kidneys failed, I was the sole wage earner for my family. My father had raised me to believe that was what men did. But when I got sick, my wife had to go back to school and start working to pay our bills.
It was very difficult for me, because I had been raised to believe my family should depend on me, not the other way around. Then, a few years after my transplant, a tragic thing happened. My daughter was in a car accident and died.

Unfortunately, my wife and I responded very differently. She embraced God and was very expressive about how upset she was. I, on the other hand, kept my feelings more bottled inside. Sort of like Mary Beth’s soda bottle (page 32)—I was just being shaken over and over and not letting my feelings out by talking about them with other people.

And, of course, there was more. A few years ago, I learned that I had contracted hepatitis C during my transplant, either from the organ or donated blood.

So it was one thing after another. One night, I came unglued and tore up my house. I brought a rifle to the place on the road where my daughter had died with the intention of hurting myself. It was a beautiful spot, actually, and I sat there half the night.

I came very close to taking my own life. But I mustered up the strength to go home. Getting so close to suicide told me I needed professional help, so I made an appointment with a psychiatrist.

Now, I still see him, many years later. I also take antidepressant medication. It’s hard to swallow yet another pill, but I’m sticking with it.

Unfortunately, tragedy happens in everyone’s life, and having a transplant made it that much harder for me to deal with mine. The added burden of feeling different, the constant healthcare visits, and taking a handful of pills every day made it more difficult for me to handle my daughter’s death.

Now, to stay positive, I still see my psychiatrist. I don’t agree with everything he says, but I believe that he helps me. It’s hard to keep up with yet another doctor, but feeling positive is very important.
I also try to express my feelings more now, often through writing, which I really enjoy. Even if I don’t show anyone what I write, it keeps me from bottling up everything, which I now know isn’t good.

I’ve also looked into my past, at the circumstances that shaped how I look at things. It’s a very difficult thing to do, to face some of the unfortunate things that happened to you before, perhaps as a child. Maybe you were hurt or not well taken care of. That’s hard to face. But ultimately it’s very freeing.

It also helps me to distance myself from my transplant a little bit. I like feeling that I’m just like everyone else. I don’t want to be seen as “sick” or that I have special needs because of my transplant. I referee high school soccer; I hike; and I ride motorcycles. I still have to be careful, but it’s worth the risk. All of that stuff makes me feel like I’m alive.

Spotlight: Molly's Story

I received my new heart in October 1995 under somewhat unique circumstances. I went into the hospital planning on getting open-heart surgery. Unfortunately, it didn’t go well and I was given two weeks to live. I received a transplant within days. So the last time I was conscious, I went into open-heart surgery, expecting to keep my heart. When I really came to, I had a new heart.

During the days of waiting, I had horrible hallucinations. I thought I had run over two children with my car and that my cousin was dead. I had started seeing a psychologist before my transplant, just to prepare for the open-heart surgery. I continued to see her after my transplant and she diagnosed me with post-traumatic stress disorder, or PTSD.

I think the PTSD came from the trauma of suddenly having a transplant and the emergency circumstances. I became overwhelmed by the hugeness of it all and I also felt very claustrophobic. My life would no longer be the way it was before because of the changes that come after a transplant. This made everything feel very final. My heart was gone and there was no going back.

All of a sudden, my future was uncertain. I worried about rejection, infections and how long my heart would last. It was really terrifying.
I also believe my antirejection medications might have also influenced my feelings, even my hallucinations. I started taking prednisone and I know that affected me, too.

I also felt some pressure, knowing that I was carrying someone else’s organ inside of me. I knew the circumstances of my donor, who was a 15-year old boy, because my mother’s cousin worked with his father.

When I received his heart, I felt pressure to try to live this boy’s life for him. I wanted to do something really meaningful and impressive to make something great come out of his death and have his gift be worthwhile. But that was a very tall order, impossible to fill. The first year after my transplant, I spent a lot of time trying to figure out how I could win a Nobel Peace Prize. I also developed some classic signs of depression: I was over-sleeping. I no longer felt like being social, which was very unlike me. I also felt really hopeless.

To deal with these feelings, I kept seeing my psychologist and she really helped. She specializes in working with people who have chronic illnesses, and she made me realize I was having a totally normal reaction to my situation. That was a relief, of sorts.

Soon after my transplant, I also starting taking antidepressants and I still take them to this day.

I decided to treat my mental health like my physical health. My antidepressants are just as important as my antirejection medicines and I take them every day.

It was hard to start taking them, at first. Like other transplant recipients, I felt like I should be happy all the time, since I was lucky enough to receive a transplant.

I actually stopped my antidepressants once and I felt so sad and helpless afterwards that I had to start them again. That showed me how important they are.

As a young person (I’m only 31.), I’m in a strange position. I feel like it’s hard to find a community that really understands where I’m coming from. I’m a lot younger than most transplant recipients. I love my friends, who are my age, but they are all buying houses, getting married and having kids. Having a
transplant affects how I think about these life choices because I worry I won’t be well enough to take on responsibilities. I want to get married and have children, but what if I die early? I don’t want to leave my family.

Then, a few years ago, I took a writing course called “Healing Through Writing, Writing Through Healing” at an independent writing center in my area. Many other students were my age and had their own health issues. One had received a lung transplant and another had Crohn’s disease.

The class was wonderful. Writing about my experiences was really cathartic and hearing other women share similar feelings and worries made me feel so understood and validated.

Now that the class is over, six of us still get together once a month and continue to write and support each other.

And—don’t get me wrong—I’ve gotten a lot of help from my friends and the transplant community, too. I attended a transplant recipient support group for two years after my operation, and that was great. I also have a great sense of adventure, which my friends share. When I turned 30, two of my friends and I went to South Africa. They understand that I want to live my life to its fullest now and not wait until I retire.

One thing I learned is that you may have to fight for your own mental health. Right after my transplant, my doctor couldn’t handle it if I cried. All I needed were some words of encouragement, someone who said they understood my grief and being suddenly uncertain about my future. He once joked that I should not go shoot myself.

So I switched programs, and I now go to a different hospital with a different doctor, who is much more respectful. I think we all need to advocate for our own health—mental and physical—and our own rights as transplant recipients. Lastly, for me it was vital to give myself permission to live my life differently than my peers and to give myself permission to grieve the losses that come with transplantation.
Summary

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e at the NKF want to express our profound thanks to Molly and David, for being so open about their experiences. We know it’s not easy to talk about depression, but it really is incredibly common and when people can be open about it, it helps other people to be open about their own experiences, too.

To sum up, depression is not “just in your head.” It is a medical illness like diabetes or hypertension. And, like other illnesses, people can’t just “snap out of it.” If it’s not treated, depression can have serious consequences—it can affect people’s future and the outcome of their transplant.

Being diagnosed with depression doesn’t mean people are “crazy.” Not at all. It means they have a physical condition that makes them vulnerable to depression. This condition can be corrected with therapy or medicine. There are a lot of treatment options, and it make take time to find the one that’s right for each person, but it’s out there.

Being depressed is certainly not a sign of weakness. But admitting you have a problem and taking action to help yourself is certainly a sign of strength.

We at the NKF want to encourage everyone to take advantage of the resources available to them to help them deal with depression. Transplant recipients should contact their transplant social workers if they have any additional questions that we didn’t answer. They can provide very personalized help and advice. Use them.

There are also many resources available from the National Kidney Foundation, including the NKF transAction Council, for more information and support about depression. Visit us at www.transplantrecipients.org to stay up to date and to get answers to any questions we didn’t address. We will also use the Web site to keep people posted on any new information we get about depression.

If you have anything to share about depression, send us an e-mail at transactioncouncil@kidney.org. You can also call us at 800-622-9010.

If you would like some more written materials about depression, the National Kidney Foundation has a wonderful book called From Illness to Wellness: Life After Transplant, which was written by and for transplant

Understanding Depression
recipients. It addresses the emotions and changes recipients go through. Call us at 800-622-9010 to request a copy.

You can call that number to start receiving a copy of our free newsletter called *Transplant Chronicles*, or request a subscription on our Web site [www.kidney.org/recips/transaction/chronicles.cfm](http://www.kidney.org/recips/transaction/chronicles.cfm).

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Learn more about Medicare Prescription Drug Coverage at [www.kidneydrugcoverage.org](http://www.kidneydrugcoverage.org).

This Web site is an undertaking spearheaded by NKF in partnership with many kidney community organizations. Find fact sheets at [www.kidneydrugcoverage.org/patients.htm](http://www.kidneydrugcoverage.org/patients.htm) on topics such as:

- Choosing a Medicare Prescription Drug Plan
- Obtaining Help for People with Low Income
- What you Should Know about Medicare’s New Drug Coverage

Visit NKF’s teleconference archive to listen to a series of Web casts on the prescription drug coverage at: [http://www.kidneydrugcoverage.org/proTeleconferencePast.htm](http://www.kidneydrugcoverage.org/proTeleconferencePast.htm)

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Contact the NKF and request a copy of the newly published book “Taking Control: Money Matters for People with Kidney Disease” to help answer questions about financing transplantation and kidney disease.

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Visit NKF’s message boards: [www.transplantrecipients.org](http://www.transplantrecipients.org) to share with other recipients.
Helping Others While Empowering Ourselves

Introduction

We all face challenges after our transplants. We can’t always control what happens, but we can control how we respond. And how we respond makes a huge difference in how we recover from whatever life throws our way.

When something bad happens—say, our health takes a turn for the worse, we argue with a loved one, we get a big medical bill—we have a very important decision to make. We decide how to respond to that bad news.

What follows is a recap of a conversation between four recipients about how they stay healthy, based on the NKF telephone audio conference “Helping Others While Empowering Ourselves” (July 2005). Included are insights from recipients nationwide who have contacted us by e-mail, letter and phone. This discussion has allowed us, the recipient panelists, to share with you what has worked for us as we strive to respond to life in a proactive, helpful and healthful way. Each recipient is unique and individual in how they approach their recovery after transplant. However, all of us have demonstrated a desire to live fully that has gotten us this far. Continuing to nurture a zest for life is of the utmost importance. Living life fully is a powerful feeling.

We found that being empowered allows us to stay intrinsically involved in our lives and in decisions affecting our health care. Even if we have a close network of friends and family, we have found that nobody cares more about our lives than us! No one cares more about our transplant than we do. For this reason, it is vital that we stay on top of our health.

To that end, this chapter includes our stories about how we stayed generally happy and healthy. Recipients can’t control everything that happens...
after their transplant, but there are things people can do to stay happy and healthy. And being empowered means taking advantage of every one of those opportunities.

There are many non-medical things transplant recipients can do to keep their health on track. For instance, we have a lot of control over our attitude and outlook when positive or negative things happen. Outlook has a significant effect on how well people recover from setbacks and other negative events.

Quite simply, being empowered can make the difference between life and death. Join us in this discussion of how we help ourselves and others through the process of sharing and empowerment. Come with us on our discussion of our journey of transplantation.

“Helping Others While Empowering Ourselves”
Audio Conference Panelists:

Tamra Wiley Lewis
Tamra received a living donor kidney transplant in 2004 from her younger brother. She speaks before audiences of transplant and health care professionals, sharing her story of kidney dialysis and successful transplantation and its impact on family. Tamra lives in Texas and is President of her own company that provides motivational speakers and educational programs.

James Gleason
Jim, a heart recipient since 1994, is an IT professional and the author of an online book about his experiences “A Gift from the Heart.” A U.S. Transplant Games athlete and medal winner, Jim met his donor family at the 2002 Donor Recognition ceremonies. He is the recipient of the American Society of Transplantation’s outstanding contribution award.

Rachael Wong, MPH
After living with lupus for 12 years, Rachael received a kidney from a deceased donor in April 2002. She works in end-of-life care, coordinating a palliative care capacity grant in Hawaii. Rachael is the President of the Transplant Association of Hawaii, and also is a member of the National Kidney Foundation’s transAction Council Executive Committee at the national level. She also practices yoga, plays tennis, and is involved with a natural foods co-op.
Helping Ourselves First is Empowering

Empowerment can mean something very simple: being proactive about your health, and doing everything you possibly can to stay happy and healthy. A principle that guides empowerment is involvement—staying involved in what’s going on around you. We know that it is sometimes extremely hard to stay on top of your health when you are not feeling well. Consequently, the first thing transplant recipients need to do in order to become empowered is to concentrate on becoming healthy. Remember, transplantation is a new therapy you need to learn how to manage. If you’re not feeling well, you can’t be strong enough to take care of yourself, which is what empowerment means. All of us panelists enjoy helping others. We recognize that, in order to help others, we have to first help ourselves by becoming as strong as we can be.

Becoming as Strong as We Can Be

To get started, try to understand what’s medically going on with your organ. Ask questions and listen. As you your health improves, you may find you have more confidence. This confidence can help you find more joy in life and allow you to help others—the final stage of empowerment—which can make us feel even better about ourselves and our lives.

First, we found that we needed to sleep and eat well and exercise. Some recipients had a lot of work to do to get back on track after years of living with end stage renal disease. Some of us were on very restricted diets and needed to learn to eat again. Some of us had to learn to recognize true hunger, and that it was OK to drink lots of water and eat protein. Some of us found that consulting a hospital dietitian helped. Did you know that for kidney transplant recipients and diabetics, under the Medical Nutritional Therapy Act (MNT), Medicare will pay for two to three hours of professional diet counseling each year if it is provided by a registered dietitian? Your doctor must prescribe and order the consultation.

We make time to do whatever exercise our bodies enjoy—walking, yoga, weights. Joining a gym was a treat for some of us. Most of us like to walk and you can take it as slowly or quickly as you want, watching yourself
get stronger and into better shape. Yoga is also great because it addresses both the physical and spiritual side of health, and you are not measuring yourself against anyone else. It is all about listening to your body. We are all different. **Remember to consult with your doctor for advice before starting any exercise program.**

**Partnering with your Transplant Team**

**You are part of your transplant team, the most important member, in fact.** Communicating clearly with the team members can be essential to your recovery. For a transplant to succeed, all members of the transplant team have to meet their responsibilities, plain and simple. Don’t be afraid to ask questions. The *Transplant Recipients Bill of Rights and Responsibilities* is a document devised by recipients and professionals to help assure that you get the care and answers you need. Single copies are available by calling 800-622-9010.

But that doesn’t mean that transplant recipients are off the hook, and they can just pass all responsibilities off to others. Again, the most important member of a transplant team, without question, is the transplant recipient. Recipients may have less medical training and experience, but we are the most vested in our success, and we want this organ to work more than anyone else. We are the only one on call 24 hours, 7 days per week. So, as Tamra says, “You are the captain of your ship!”

Even if transplant recipients trust their doctors completely and without question, recipients are the most vested in their health. Doesn’t it make sense that they should be involved with every aspect of their medical care?

Why is this so important? Unfortunately, even in a perfect system, mistakes can happen. What if a doctor, by mistake, adds a zero to a dose of medication? Or forgets to mark on a chart that a patient has already received a dose of medication? Or forgets to mark on a chart that a patient has already received a dose of medication?

In both cases, transplant recipients can protect themselves if they keep track of what they’ve received, and how much. And, if we are alert, empowered and involved, we will protect ourselves from mistakes that can always happen, even in the best medical team.

This system forces team members to sometimes take extra time to discuss decisions with patients. It adds time to their busy day, but transplant recipients only need a few extra minutes and, by asking for this, they are
keeping themselves safe. This saves everyone time in the long run.

But how can we really get involved in our medical care, without any medical knowledge or training? How can we be the most active member of our team if we have the least amount of expertise?

The best place to start is with the day-to-day interactions with a transplant team.

**When recipients meet with their doctors, nurses, social workers and dietitians, they should listen to what their team members have to say. Ask questions, to check that you really understand what they’re saying.** Be 100 percent sure you got it all.

Transplant recipients have all the medical information they need, right at their fingertips. They don’t need to run out to the library or get on the Internet and read everything they can find about transplantation. That’ll take years, because there’s so much out there. And too much information can be a bad thing, in its own way.

Instead, start with pamphlets at a doctor’s office. Take one, bring it home, read it, and understand everything that’s in it. Subscribe to the free NKF newsletter, *Transplant Chronicles*.

And, again, this is critical: always ask questions. Whenever anything happens, get a full explanation, and listen hard. You may have to ask team members to repeat themselves, just to make sure you’ve understood everything correctly. It only takes them a few extra moments.

Marge wrote us that **the better her relationship was with her team, the easier it was to ask questions.** To get answers without being too pushy, Marge says she would put things in the “personal,” by saying “this is very frightening for me, could you please explain in detail what will happen.” It was hard to stay involved when she felt anxious or not well physically, but she knew it was important. She writes that being her own advocate made her feel more empowered.

Remember, don’t overload yourselves with information about transplantation—a little can go a long way. For instance, if you’re having side effects from medication that are extremely uncomfortable, do a little research or ask questions to see what else is out there. Don’t be afraid to let your doctor know the depth of your distress. Sometimes we try to impress our doctors and not let them really know how we feel because
we want their approval and to seem grateful for your gift. Maybe your doctor can switch your drugs, or change your dosage.

**If you find some interesting information, bring it to your health care team** to see if what you found is an option. You may have thought of something they didn’t. Just a little bit of effort can make you feel a whole lot better.

Anne B., a living kidney donor for her son, Matt, now in the seventh grade, explained that Matt’s urologist of six years was suddenly let go, and they were faced with a new doctor who wanted to change his treatment. She says that if she hadn’t asked a lot of questions along the way of Matt’s previous doctor, she wouldn’t know about other options. She writes: “I feel things could fall through the cracks if questions aren’t asked of everyone, and patients should question everything that a physician says to them about future care.”

**Keeping Records**

Another way transplant recipients can stay involved in their own care is by keeping track of their lab values. Rachael created a spreadsheet using the computer program Excel to track lab values over a multi-year period. In a couple of seconds, you can see where things have gone up and down, to visualize your progress. If you don’t have a computer or use Excel, a notebook and a pencil will serve the same purpose.

To figure out which blood work values are most important to follow, ask your doctor, nurse, or social worker. Anyone who has a few minutes to spare can sit down and discuss which values are most important, what’s a normal range, and what changes are a sign for concern.

Jim once met with a new doctor who took blood work and saw he had really high levels of uric acid. Since the doctor was new, he didn’t have a record of Jim’s previous blood tests. The doctor thought Jim had gout but, before he could do anything, Jim checked back with his own records and saw that his uric acid was always really high. He didn't have gout. If he hadn’t kept track of his blood work, he could have been treated for something he didn’t have.

This can be an issue anytime you see a new doctor—maybe you’re on vacation, or you have to visit the emergency room. If you have your
blood work history on hand, you can avoid a similar problem.

Rachael explains that, when you start tracking your blood work, ask your doctor for the actual numbers. Sometimes health care workers will say something’s “fine” or “high.” To keep a chart up-to-date, you need actual numbers.

Tamra explains that the most important thing she does to stay healthy is to follow the advice of the transplant team. When a doctor recommends steps to reduce blood pressure, she take them. When a dietitian explains which foods are okay to eat, and how to prepare healthy and tasty meals, she listens. She listens to social workers, and every other team member. Ken notes the importance of taking his medicine on time.

Another piece of advice for keeping your health on track from Jim, Tamra and Rachael is writing down any questions you have for your health care team, and bringing them to appointments. Jim likes to bring someone along to appointments, and then discuss the doctor’s recommendations with the doctor afterwards, to make sure they both heard the same thing.

Clearly, keeping up with your health can get frustrating. It’s time and energy, when you’ve got so many other things to take care of. We know that being involved isn’t easy.

“It may help to think of a transplant as a new baby,” Tamra, a mother to two boys tells us. When you first bring a new baby home from the hospital, you don’t understand him at all. He’s scary, and confusing, and frustrating. You want to love him, but first you’ve got to understand him. If you dedicate time to the baby, you will understand him. You figure out when he wants to eat and sleep, and how to make him happy. This, in a way, describes what eventually happens if you take the time to get to know your transplant. You are carrying something new inside of you. Once you get to know it, it will feel a lot less scary, confusing, and frustrating.

Being empowered with your health takes work, but we wouldn’t be advocating it if we all didn’t truly believe that it’s worth it in the end. Doing this work now saves you from a lot of extra work later that comes from getting sick more often and feeling worse.
Living Life Fully

Once transplant recipients feel better physically, they can start to concentrate on their personal lives. When we are sick, sometimes pieces of our lives go on hold—relationships, studying, careers. Now we can jump back in, meet people and go places. Taking care of your personal life outside of your physical health can mean your relationships, hobbies, or anything else that makes you feel whole again.

For Jim, getting back to work was a big step in his recovery. Once he felt well enough, he returned four months after his transplant, eager to get back to work. It went really smoothly, partly because he had engaged his colleagues in the whole transplant event by giving them regular updates, and also because his employer was understanding and supportive. As a result, he expanded his support network and taught people about transplantation and recovery. None of his co-workers had known anything about heart transplants before, so they didn’t know how much was possible after Jim’s transplant. The day he came back to the office, his colleagues cheered.

Rachael, on the other hand, took one year off to “luxuriate” and enjoy being well. She took dance classes, learned sign language—you name it. When she felt up for it, she started volunteering, to ease herself back into a regular schedule. This let people in her field know that she was “back” and things started flowing from there. She got some contracts and now she’s steadily employed as a consultant, her original profession. She says it feels really good to be back, like she’s regained her health.

Before Tamra got sick, she was a motivational speaker for her own company. Her job was a great fit for her new situation as a dialysis patient, and as someone waiting for a transplant. She took all of her new challenges and developed motivational and educational programs for patients, families and the health care industry—thus expanding her career reach. So, from a work perspective, Tamra says this journey has been a blessing. Who would think you could say that about a transplant? Now, she loves talking about dialysis and the transplant process. Her mission is to motivate and encourage those who are on this journey.

Jumping back into life can also mean looking into job re-training, retirement, or looking for an entirely new job. It can mean getting a handle on medical bills and insurance, which is not much fun but necessary for our financial well-being. Don’t hesitate to call your social worker to find out what your options are and what resources may be available to you.
You may be eligible for vocational rehabilitation assistance. Getting back to work can be a necessity for many transplant recipients who will need employer-based health insurance after Medicare coverage ends—which, for kidney transplant recipients, runs out after 36 months.

Tamra tells us that, if you no longer have Medicare, you should consider contacting a transplant social worker about choices for insurance. You may be eligible for a high-risk pool. For additional information about insurance, refer to our earlier chapter about Medicare to learn more about the program and how to get the most out of the upcoming changes.

Feeling a Wide Range of Emotions

Recipients should focus on their emotional health after a transplant and on building skills to stay positive about their transplant and the future.

Sometimes we transplant recipients like to talk “shop” and trade “war stories” with each other. This type of sharing can remind us that, no matter what obstacles we face, we are not alone; others have been down the path of illness and wellness. Acknowledging fears and sharing them with other people can be empowering. At the same time, remembering the positive side of going through a transplant, deciding to embrace life and fight for our health should remind us that we have done something very brave and survived it. When we have a positive attitude, we keep the people around us positive, and they will, in turn, help us when we feel down. There are so many ways that being positive helps your health.

There’s a lot that goes into being happy. A big part of it is gratitude. It helps to decide to not take anything for granted. Sure, there are days when you may not feel as well as you would like. So pinch yourself, to remember that you’re alive. You can laugh and breathe. You can look at what you have and be grateful for it. As transplant recipients, we can use this gratitude to change our attitude. Tamra likes to say, “Use your gratitude to change your attitude. Just with the power of positive thinking.”

To truly be positive, we need to say goodbye to our old organs, and our previous way of life. Some of us struggle with guilt—wondering if we could have done something different to keep our organs from failing; wondering why someone else had to die so we could receive a new organ. To feel empowered and strong after transplant, we have to forgive ourselves for whatever we could have done or think we could have done...
differently and move on. We now have a new organ now that needs us, needs our attention.

But let’s be clear: None of this applies if you are clinically depressed. If so, you can’t “snap out of” what you’re feeling, just by deciding to be positive. With depression, it’s never that easy. Depression is a serious illness needing treatment. For more information, check out our earlier chapter on depression.

Giving and Receiving Support

One way to stay positive is by having and making friends. Everybody struggles at different points in their lives. A supportive friend, family member or peer can help by sharing what they have overcome, how they have handled their own challenges. So when recipients go through their transplant, the strength of their buddies can give them confidence, and remind them that it’s possible to overcome adversity. And recipients can, in turn, serve as examples for their supporters.

Friends, as much as we appreciate them, can be exhausting to keep up with when we’re not feeling well. Rachael sent group e-mails to chronicle her days, and left outgoing messages on her answering machine so well-wishers could hear her voice and leave their own positive messages. This way, she got their support when she needed it, and didn’t feel pressure to check in with people until she felt better.

You can find support in surprising places, if you’re simply open to it. After Jim’s transplant, he was diagnosed with prostate cancer and had to undergo 42 radiation treatments. Every time he went to receive another treatment, the same cancer patients were in the waiting room, there for the same reason he was.

Over time, they got to know each other and became a wonderful source of support. They would kid around, and it got so that Jim would actually look forward to his treatments. Just knowing he could spend time with these wonderful people made the experience much more bearable. And if Jim’s friends could show up for treatments and have a positive attitude, he knew he could, too.

Before Tamra’s kidney transplant, she had to go through dialysis. As luck would have it, she found an old friend she hadn’t seen for 10 years who was also undergoing dialysis at the same time. They reconnected. For
Tamra, it really helped to know someone who understood exactly what she was going through, like Jim found with other people dealing with cancer. They would talk to each other and support each other when one of them thought they couldn’t keep going with dialysis or couldn’t cope with a transplant.

In the end, they both received kidneys from their brothers, and they’re thriving today. Because of this, Tamra recommends that everyone find a transplant buddy, someone who you really enjoy and respect who is going through a similar experience. They can help you feel very understood and take away the loneliness and isolation that often come from feeling badly, physically.

Helping Others

There are so many ways transplant recipients can help others. You can be a supporter for someone who’s on the transplant waiting list. Bob Meyers in Michigan explains how he enjoys being a peer mentor for kidney patients. He encourages them when they feel down and helps them look to the future, when they will feel better. “It’s my way of saying ‘thanks’ to all of those people who have helped me along my path, past and present,” he writes. How satisfying, don’t you think?

Telling our stories can help others. When we feel good, we are great examples of how great life can be. And it feels great to be an example, doesn’t it? Tamra tells us she loves telling people she is a kidney transplant recipient. “Sometimes, it feels like it’s part of my name. ‘Hi. I’m-a-kidney-transplant-recipient.’” It’s often the first thing she tells people, because she’s so proud. She’s also proud to say that she is on her way to becoming a person who’s had her transplant for 30 years.

It’s important to recognize that patient empowerment can take the form of speaking up and speaking with those who make the laws that affect us all. During Spring 2005, Rachael helped the Hawaii Coalition on Donation pass a bill providing employee paid leave for living donors. Rachael explains that this was a whole new experience for her: writing letters to legislators, scheduling appointments and meeting with elected officials, and testifying before committees.

Rachael says it has been rewarding to see the bill pass through the legislature, and she’s enjoyed meeting with lawmakers and presenting a
personal side—meaning, a real face—to donation and transplantation. She believes her involvement made a difference.

Recently, the NKF launched a new organization called “People Like Us,” dedicated solely to patient empowerment. As part of the program, the NKF will encourage, mobilize and educate people with kidney disease and transplants to speak publicly about the issues that are relevant to their lives. Do you have something to say about transplantation? Is there a law that you think is detrimental to the transplant community? You can write your congressperson or be a spokesperson for the transplant community. Over the years, the NKF, through its advocacy, has successfully improved Medicare and expanded drug coverage for immunosuppressive medication, among other accomplishments.

Writing letters, visiting Capitol Hill and other types of advocacy simply work. And it’s easy to be an advocate. To contact your legislator, simply call his or her office. Ask to speak with the aide who handles health care issues. Identify yourself as a constituent, and be concise about why you are calling.

If you decide to meet with a legislator, you’ll likely have only a few minutes. So, again, be brief. Include your personal story, since that will be very compelling.

To find out more about advocacy for transplantation, contact the NKF Office of Scientific and Public Policy at 800-889-9559. Or, log onto the Web site at www.kidney.org/general/pubpol/.

For Rachael, it helps to be involved. She is President of a local transplant support group, The Transplant Association of Hawaii, and she’s also involved with the Hawaii Coalition on Donation—one of many local chapters of a national organization.

Rachael, Tamra and Jim all volunteer with local organ donation/donor organizations as well as the National Kidney Foundation. (Yes, heart, lung and liver recipients do volunteer for the NKF, too!). Discussion Moderator Ken Howard is the NKF Chancellor.

There are a lot of organizations and events around the country. Look around and see what’s out there in your local community. Take your time and find out what part of the transplant community you want to be involved with. Some groups focus on increasing organ donation by raising awareness about organ and tissue donation; some focus on support
for recipients or donor families; and others focus on legislative initiatives.

We’ve heard a lot of inspiring stories from transplant recipients who’ve gotten involved in the community. For instance, Theodore Marchion of Montana is a member of the Governor’s Council on Organ and Tissue Donor Awareness in Montana, and holds a yearly picnic for donors, recipients and the general public. This event welcomes at least 100 to 200 people each year, he tells us. Theodore says he also helps support a walk every year to promote donor awareness.

**Recipients Relationships with Living Donors and Donor Families**

Rachel called the local organ procurement organization the day after her surgery to find out how to write a letter to her donor family. She wrote and, though she’s not heard back from them, the OPO family liaison has been in touch with them, and this gives Rachael comfort. She believes that writing to the donor family was important for her because she believes the donor family is, by virtue of their life connection, part of her life and her family, too. Tamra is forever grateful to her younger brother for his gift of a living donor kidney. Jim Gleason attended the National Donor Recognition Ceremony and Workshop in Washington, D.C., to honor our country’s donors and believes strongly that when recipients write to donor families, it can be helpful to donor families as they cope with the death of a loved one.

**Parting Words from Our Speakers**

**Jim Gleason:** As a patient we have many people to help us deal with the daily challenges every patient must face. Be open to that support but, at the same time, to whatever degree your illness allows, stay responsible for your own life. That includes not just the black-and-white, live-or-die part, but the quality-of-life part that is your daily opportunity.

Stay optimistic, but realistic. Be honest with your team about how you are feeling, but expect the best outcome and share that outlook with those supporters in every way you can. They will take their lead from your example and that, in turn, will get you their best effort on your behalf.
As I often say to those who ask about my heart, “When I got up this morning, I looked down and said—‘Damn! Above ground another day. This is going to be a good one!’” And you know what? It always is.

I hope and pray that you can say the same every day of your own life. You are empowered by your own attitude and, in that, you have the opportunity of a choice every day. What is yours today?

Tamra Lewis: you are on an incredible journey of receiving life again! While traveling on this new journey, you want to be as whole as possible. You want to encourage yourself as well as others. You want to take the time to wear your “attitude of gratitude.” Be kind to yourself and you will be kind to others.

As you continue through this experience, take time to say “thank-you” to those who have helped you to get this far. Renew your mind and spirit every chance that you get. Take the time to smile and laugh—for this will heal your soul.

Empower yourself with every tool of life that you can get your hands on.

I also like to recommend that people take the “instead of” approach. Instead of going against the wind, be like the trees and dance with the wind. But you can also be proactive in dealing with your illness. Listen and learn everything that you can. Another way of looking at it: Instead of going against the storm, act like the eagle and meet it head-on. Take it on, baby. Say “yes” to “I will do whatever it takes to stay on this planet.” Say “yes” to doing whatever it will take for your body to be in compliance. Remember we cannot get another you. You are it. Let the earth smile and rejoice in your being here.

Rachael Wong: I believe that patient empowerment is a choice we can all make. It’s a personal choice, whether or not to take an active role in one’s own health and life. It’s about moving forward and moving in a positive direction.

We’ve talked about many forms of empowerment, and it’s up to each of us to find the right combination that works. Do things that are fulfilling and affirming. Be of service to others and ask for help when needed. Good luck to everyone and stay in touch! As we say in Hawaii: “Aloha, a hui hou!” Translated, that means “Goodbye, and until we meet again!”
Final Thoughts

If you have questions we couldn’t answer or want to share experiences about helping yourself and helping others, we recommend contacting your transplant social workers. They know you, so they can give you very personalized help and advice. Use them. We also want to urge you all to continue to rely on the resources available from the National Kidney Foundation, including the NKF transAction Council, for more information about empowerment. Visit us at www.transplantrecipients.org and share your experiences on our message board so you can give and receive support.

You can also send a personal e-mail to us: transactioncouncil@kidney.org. You can also call us at 800-622-9010.

We are all part of the People Like Us initiative, which fights to make lives better for all people with kidney disease or those in need of a transplant of any organ, and facilitates the organ donation process for donor families and living donors.

As a member of transAction, you can receive our free newsletter called Transplant Chronicles. Simply call 800-622-9010 to start receiving a copy or request a subscription on our Web site, www.kidney.org.

We at the National Kidney Foundation acknowledge Roche Pharmaceuticals for their support of this program. We wish you, our readers, happiness and good health.