

Financial and Insurance Issues

It's an unfortunate fact: Transplants cost a lot of money. But you shouldn't let the price of a transplant scare you. Patients who need a transplant almost always find a way to pay for it with *health insurance*. There are private insurance plans and government programs, such as Medicare and Medicaid. Our *transplant financial coordinator* is here to help you. An expert on insurance issues, the transplant financial coordinator can help you find a way to pay for the care you need. Our *transplant social worker* can also help you sort through money issues and develop a plan that works for you.

This chapter will give you an overview of money and insurance issues that transplant patients face. But every patient's case is different. Please talk to the transplant financial coordinator or social worker if you have any questions. They're here to help you and your family.

How Patients Pay for Transplants

IN SHORT

Most people pay for a transplant with insurance.

There are two types:

- **Private.**
- **Government, such as Medicare and Medicaid.**

You may need two insurance plans:

- **A primary one that pays a big portion.**
 - **A secondary one that pays most of the remaining costs.**
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Health insurance – Programs that help patients pay for medical care. Private companies provide insurance. So, does the government.

Transplant financial coordinator – The transplant team member who helps you with insurance and financial issues.

Very few people can pay for a transplant without insurance. As shown in Table 1, page 19, the costs of a transplant add up quickly. First, there are the costs of the tests and exams you need before your transplant. Then, you have the expense of the surgery and your hospital stay. And the costs don't stop after you leave the hospital. Remember, you will need to take anti-rejection medicines for the life of your transplant. You may need to take other medicines as well. These drugs are costly, totaling more than \$10,000 a year.

How can you pay for all of these costs? The transplant financial coordinator will check whether your current insurance covers all the costs of a transplant. If you don't have enough insurance, the transplant financial coordinator will help you find proper insurance.

Some patients are able to pay for most of the costs with a single private insurance plan. Other patients need two different insurance plans to cover transplant costs. They have a primary insurer that picks up a large portion of the costs. Then, they have a secondary insurer that pays for most of remaining costs. For example, a patient might have Medicare as a primary insurer. Then, she might obtain a private insurance plan as a secondary insurance.

There are three basic steps to developing a financial plan for your transplant:

- You need to have good primary insurance.
- You may need to find a secondary insurer.

Transplant social worker – The University of Chicago Hospitals social worker who helps transplant patients with practical, financial, and emotional issues.

- You might want to consider other ways to pay transplant costs, such as fundraising.

Step One. Start With Primary Insurance

IN SHORT

A primary insurer pays a big portion of your transplant costs. Primary insurers include:

- Medicare.
- Medicaid.
- Private insurance plans.

Find out what your primary insurer will pay for. Do you have to pay for a lot? If so, find a secondary insurer.

A primary insurer is one that pays for most of the costs of a transplant. Many primary insurers will pay about 80-90% of transplant costs. But every plan is different.

It's very important to know what your insurance will cover—and *not* cover. You don't want to be caught with unexpected bills. So contact your primary insurer and ask them specific questions about your coverage. (See Table 2, page 20, for questions to ask an insurer.) For instance, you will need to know what your out-of-pocket expenses will be. If your out-of-pocket expenses are high, you may need to get secondary insurance to help you pay for these.

Many insurers ask patients to pay some or all of the following out-of-pocket expenses:

- *Deductibles* - an initial portion of medical costs. For instance, you may have to pay a \$1,000 deductible each year before the insurer will start paying 80% of your medical costs.
- *Co-pays* - a small amount such as \$20, each time you visit the doctor or get a prescription medicine filled.
- *Premiums* - a monthly or annual amount that you have to pay to keep your insurance active.

Below you'll find summaries of the main primary insurance plans that transplant patients use. Contact the insurer for more details.

Medicare. A federally funded plan, Medicare can help pay a large portion of a kidney-only or kidney-pancreas transplant. For details, see the *Medicare & You Handbook*. You can get one of these at your local Social Security office. The handbook is also at www.medicare.gov.

Are you eligible? You can get Medicare if you are age 65 or older or disabled. If you have kidney failure, you can also apply for Medicare's end-stage renal failure (ESRD) program. To get ESRD Medicare benefits:

- You must have worked at a full-time job that paid into Social Security. Married people may also be eligible under their spouse's work history.
- You must be on dialysis or about to receive a kidney transplant.

Deductibles –
An initial portion of medical costs that an insurer expects you to pay. For instance, you may need to pay the first \$1,000 of your medical expenses each year.

Co-pays –
A portion of the medical bill insurers expect you to pay when you visit the doctor or get a prescription filled. For instance, you may pay a \$20 co-pay every time you visit the Post-Transplant Clinic after your transplant.

Premiums –
A monthly or annual amount that you have to pay to an insurer to keep your insurance active. People who work often have their insurance premiums deducted from their paychecks. But sometimes people pay premiums directly to an insurer.

How do you apply? Your dialysis unit or center can help you apply for ESRD Medicare. You may have to wait a few months to receive ESRD Medicare benefits, depending on the type of dialysis you are on.

Patients who are eligible for Medicare because they are disabled or age 65 or older can apply through their local Social Security office.

What does this plan cover? Medicare benefits cover 100% (minus a deductible) of the hospital costs of a kidney transplant, including your surgery and hospital stay. All living donor medical expenses are also covered.

But Medicare only covers 80% of the outpatient care that you will need for a kidney transplant. This includes your pre-transplant exams and tests and your post-transplant clinic visits.

Plus, Medicare only pays 80% of the anti-rejection medicines that you'll need after a transplant. It does not pay for any other medicines that you will need. In addition, if you are on Medicare because of kidney failure, Medicare will only pay for anti-rejection medicines for three years after your transplant. However, if you receive Medicare because you are older or disabled, then Medicare will cover anti-rejection medicines for the life of the transplant.

At this time, Medicare does *not* cover pancreas-only transplants. But pancreas transplants are covered under Medicare if:

- you get a kidney transplant at the same time—in other words, a combined kidney-pancreas transplant.
- you receive a pancreas after you have a kidney transplant.

What do you have to pay for? Under Medicare, you have to pay:

- 20% of all doctor visits, tests, and exams.
- 20% of anti-rejection medicines, and 100% of other medicines that you need after a transplant.
- Various out-of-pocket expenses, including a deductible for your hospital care.
- 100% of your transportation or lodging costs.

So, if you only have Medicare, you will probably want to find a secondary insurer to help you pay for all of these out-of-pocket costs.

Illinois Medicaid and Medicaid Spend Down. Medicaid is a government-funded health plan for people who have low incomes. Medicaid is also called IDPA, Public Aid, or medical card. Some patients whose incomes are too high for straight Medicaid may qualify for the Medicaid Spend Down program. Medicaid Spend Down provides the same coverage as straight Medicaid. But you must pay a monthly deductible—or spend down—to receive the benefits. The exact deductible depends on your income and your assets (for instance, whether you own a home or a car).

Are you eligible? If you have a lower income, you may be eligible for Medicaid.

How do you apply? You need to make an appointment at your local Human Services Office to apply for Medicaid.

What does this plan cover? Medicaid covers both kidney and pancreas transplants. It pays for the following costs:

- The tests and exams you need before a transplant.
- Your transplant surgery and hospital stay.
- Your post-transplant clinic visits.
- All the medicines you'll need after a transplant, including anti-rejection drugs.
- Any medical transport you need.

Medicaid alone does *not* cover living-related donor expenses. But don't worry if you have Medicaid and are interested in a living-related transplant. Many patients who have Medicaid are also eligible for Medicare, which does pay for living donor transplants.

What do you have to pay for? You will not have any out-of-pocket costs if you have straight Medicaid. But if you have Medicaid Spend Down, you will need to pay a monthly deductible, which is based on your income. Most patients who have Medicaid do not need secondary insurance.

Indiana Medicaid. Indiana Medicaid cases are reviewed on a case-by-case basis. Contact your caseworker at Indiana Public Aid to discuss your case.

Private Insurance. The University of Chicago Hospitals accepts almost all major insurers. We also have special contracts with several insurers. These special contracts require patients to choose the University of Chicago Hospitals for transplant care in order to receive benefits.

Are you eligible? Most patients have group insurance through their job, a former job, or their spouse's job.

How do you apply? Most patients needing a transplant already have private insurance. If you are currently working and need to leave your job or cut back your hours, you should contact your Employee Benefits Office about applying for COBRA (Consolidated Omnibus Budget Reconciliation Act). This federal law may allow you to extend your health insurance for 36 months after you leave a job.

What does this plan cover? Private insurance coverage varies from insurer to insurer. Many major insurers cover both kidney and pancreas transplants. Preferred provider organizations (PPOs) often cover 80-90% of your medical costs, after you pay a deductible each year. Health maintenance organizations (HMOs) and point of service (POS) plans usually pay for most of the costs of a transplant.

If you are in a HMO or POS you will need to get a referral from your primary care doctor to start the transplant process.

This is very important. If you don't get this referral, you may be charged for some or all of the costs. You should ask your primary care doctor for "a blanket referral that lasts at least three months to cover your transplant evaluation."

What do you have to pay for? Again, the costs you can expect to pay will vary from insurer to insurer. If you are in a PPO, you will probably need to pay a deductible each year. Patients in HMOs and POS plans usually have co-pays for doctors' visits and prescription drugs.

Many insurers today offer "tiered" drug plans. These plans require you to pay different co-pays depending on the "tier" a drug falls under. Drugs on the first tier have a cheaper co-pay than drugs on the second or third tier. So some of your post-transplant drugs may cost you more out-of-pocket than others. For instance, first-tier drugs might cost you \$10 per order. But third-tier drugs may cost you \$40 per order.

Some private insurers also put a "cap" on the amount they will pay for medical services. For instance, a patient's insurance may have a lifetime cap of \$1 million. Once the insurer has paid out \$1 million in benefits for a patient, the company will stop paying for any medical services. Do you have a cap on your insurance? If you don't know, you should find out.

Many patients with private insurance need to get a secondary insurance plan, such as Medicare. Others don't need secondary insurance. It depends on your exact out-of-pocket expenses.

The only way to find out what your out-of-pocket costs will be is to talk to your insurer. (See Table 2, page 20, for questions to ask.) If your costs are high, you may want to consider getting secondary insurance.

Step Two. Find Secondary Insurance, if You Need It

IN SHORT

Secondary insurance helps pay for extra costs. We can help you find a secondary insurer.

Secondary insurance plans pay for many of the costs that primary insurance plans don't cover. For instance, secondary insurers will often pay for some of your deductibles and co-pays. They may also help cover the costs of drugs or medical transport.

Here are some popular secondary insurance plans to look into:

- **A supplemental or "Medigap" policy.** Many private insurers offer supplemental plans to help cover the medical costs that are not paid for by Medicare. An insurance agent can suggest some plans that might be good for you. You can also find a list of supplemental plans at www.medicare.gov. Supplemental insurance plans are usually only available to people age 65 and older. You will need to pay a premium or deductible on supplemental insurance plans.

- **Illinois Comprehensive Health Insurance Plan (ICHIP).** A state-funded program, ICHIP is available to people who live in Illinois. It accepts people with pre-existing medical problems, including those who need a transplant. However, ICHIP is somewhat costly, and it is hard to get into. The transplant financial coordinator can tell you if ICHIP might be an option for you.
- **Medicaid.** You can sign up for Medicaid as a secondary insurance as well as a primary plan.
- **Medicaid Qualified Medicare Beneficiary (QMB).** QMB is a program offered by Medicaid to help low-income people pay for costs not covered by Medicare. However, QMB and Medicare together will only cover some of your drug costs. Together, these plans will pay for your anti-rejection medicines. But they will not pay for the other drugs you may need for a transplant, which can run \$550 to \$1,500 a month. For this reason, straight Medicaid is usually a better choice for transplant patients because it will cover all your drugs. However, QMB may be a good choice for patients who are on dialysis.
- **Medicare.** Even if you have private insurance, you should apply for Medicare as a secondary insurer. If you or your spouse have worked, you are entitled to Medicare benefits. In fact, some private insurers require you to apply for Medicare if you become eligible. If you don't apply, you risk losing your private insurance policy. If you have private insurance,

the private insurer will remain primary for 30 months while on dialysis, and Medicare will be your secondary insurer. For instance, during this time, the private insurer may pay 80% of your medical costs, and Medicare may pay 20%. After this 30-month period, Medicare becomes your primary insurer and the private insurance becomes your secondary insurer.

Step Three. Consider Fundraising and Other Funding Sources

IN SHORT

Be careful how you go about fundraising. Talk to an expert first.

The transplant financial coordinator or social worker may be able to help you find other ways to pay for transplant expenses that are not covered by health insurance. Even with good insurance, you may need to pay for various things, such as a portion of your medicines, insurance premiums, childcare, and other costs.

Some patients qualify for various medical assistance programs. For instance, if you are a veteran, you may be able to get your anti-rejection medicines through a local VA Hospital. Or you may be able to get Social Security Disability Income.

Another way to cover expenses is fundraising. For instance, your friends or church members might offer to throw a bake sale or charity auction and give you the profit to pay for your

medical costs. We encourage you to fundraise. But be careful how you go about it. There are a lot of legal and money issues to consider. For instance, you will need to set up special bank accounts or trust funds for tax purposes. And the wording of fundraising materials must be very specific or you could get in trouble.

So always work with a professional fundraising organization that is familiar with all the legal and finance issues. The following non-profit groups can help with fundraising. They help transplant patients around the country raise money for medical expenses:

- National Transplant Assistance Fund at 800-642-8399 or www.transplantfund.org.
- National Foundation for Transplants, Inc. at 800-489-3863 or www.transplants.org.

A local transplant advocacy group might also be able to recommend a professional fundraiser. These groups include Organ Transplant Support (630-527-8649) and Transplant Recipients International Organization (312-922-0142).

Examples of How Patients Fund Transplants. The following case studies show how transplant patients pay for all their medical costs. The stories are fictional. But they are based on real patient experiences at the University of Chicago Hospitals.

Case Study #1: Paying with Medicare and Medicaid

Mary is 57 years old and has had type 1 diabetes since she was a child. Four months ago, her kidneys failed and she was put on dialysis. The staff at Mary's dialysis center helped her sign up for Medicare to pay for dialysis. Mary is eligible for Medicare's ESRD program because she has kidney failure.

Now, Mary has decided to get a combined kidney-pancreas transplant. Her doctor recommends that she go the University of Chicago Hospitals for a transplant. After attending an informational meeting at the Hospitals, Mary gets a call from the transplant financial coordinator.

The coordinator tells Mary that her Medicare insurance will not be enough to cover the costs of her transplant. Medicare will cover a large portion of Mary's transplant expenses, but not all of them. For instance, Medicare will only pay 80% of all the outpatient care she needs, including the tests and exams she'll need before a transplant. In addition, Medicare will only pay for 80% of her anti-rejection medicines—and nothing for the other medicines she may need.

The transplant financial coordinator advises Mary to get secondary insurance to help her cover the costs of her transplant. Mary says she can't really afford to pay very much for any insurance. She thinks she might be able to spare a few hundred dollars a month at most. So, the

transplant financial coordinator advises Mary to look into Medicaid as a secondary insurer. Straight Medicaid is free to people with low incomes. With Medicaid Spend Down, patients pay a deductible, which varies based on their income.

Mary makes an appointment at her local Human Services Office to apply for Medicaid. About four months later she receives a letter in the mail saying she has been approved for Medicaid Spend Down. The Medicaid Spend Down plan will pick up almost all of the costs of Mary's transplant that are not covered by her Medicare. However, Mary will need to pay \$200 a month as her spend down.

Case Study #2: Paying with Private Insurance

Ray develops kidney failure when he is 38 years old. He has a group health plan through his job. It's a preferred provider organization (PPO).

After being on dialysis for a few months, Ray looks into getting a kidney transplant. He has three sisters, and all of them are willing to donate a kidney. So, he thinks he may be able to get a living donor kidney transplant.

Ray calls his insurer to see if kidney transplants are covered. The insurer says yes. But, to get insurance benefits, Ray must go to one of three hospitals for a transplant. He chooses the University of Chicago Hospitals because of its excellent reputation.

Ray attends an informational meeting at the University of Chicago Hospitals. Afterwards, the transplant financial coordinator calls Ray's insurer to double check his coverage. It turns out that Ray's policy will cover most of his transplant costs, including the cost of the evaluation and surgery for the donor.

However, Ray will have some out-of-pocket expenses. He will need to pay a \$2,000 deductible each year. The insurer will only pay 80% of his medical costs until this deductible is met. After that, the insurance will pay 100% of his annual medical costs. Ray will also have to pay \$20 co-pays each time he has a doctor appointment. He also will have co-pays on his prescriptions. His insurer has a three-tier prescription plan. And his insurer lists many anti-rejection medicines as third-tier drugs, which have a high \$40 co-pay per order.

Even though Ray has good private insurance, the transplant financial coordinator encourages him to apply for Medicare. He is eligible because he has kidney failure. Once he is accepted, Medicare will help pick up his transplant costs that are not covered by his PPO.

Common Questions About Finances and Insurance

Q. Do I need to get any type of referral or authorization from my doctor or insurance company before I can start the transplant process?

A. If you are in an HMO or POS, you will need to get a referral from your primary care doctor to start the transplant process. You should ask your primary care doctor for "a blanket referral that lasts at least three months to cover your transplant evaluation."

All patients need a prior authorization from their insurer. Usually, the transplant financial coordinator will work with your insurer to get this authorization.

Q. What if I run out of funds before I get a transplant? What actions will you take?

A. Don't worry. We will try to help you find another way to pay for your transplant.

Q. How does the billing process work?

A. Staff at the University of Chicago Hospitals usually submits medical bills to your primary insurer. Then, the insurer determines how much of the bill they will pay. The bill is then submitted to your secondary insurer, if you have one, to see how much of the bill they will pay. After that, you will receive a notice in the mail that tells you what the insurers paid and what you need to pay, if anything.

If you do owe anything, the bill you receive in the mail will tell you how much. If you

have trouble paying a bill on time, you can call the phone number listed on the bill to talk about payment options.

Q. I have Medicare ESRD because I have kidney failure.

As I understand, Medicare ESRD will only pay for my anti-rejection medicines for three years after my transplant. How can I pay for these medicines after that?

A. Don't panic. We will help you find another way to pay for them after three years. If you are under age 65, we hope that you will be able to return to work after you get your transplant. Then, you can get insurance through your work to pay for your anti-rejection medicines.

If you are older or cannot return to work, you may qualify for Medicare because of age or disability. In these cases, Medicare will continue to pay for your anti-rejection medicines for the life of the transplant. Another option is Medicaid. We will work with you to help you find the best option for you.

Q. My spouse changed jobs. So I now have a new insurer. What should I do?

A. It's important that you let us know right away if there are any changes in your insurance. The transplant financial coordinator can call your new insurance company to make sure your transplant will still be covered.

Q. The cost of parking at the University of Chicago Hospitals can add up. Is there any way to save money on parking?

A. You can save money on parking by buying books of parking passes at the Parking Garage Office. Also, to receive a discount on parking, get your parking passes stamped at the clinic before you leave the hospital.

Table 1. What Can You Expect to Pay

A kidney and/or pancreas transplant, including pre-exams and surgery, costs well over \$150,000. After the transplant, you will need to take anti-rejection and other medicines, which can cost \$1,000-3,000 a month. Most of these costs are covered by insurance. But there are some hidden costs that you need to be aware of.

Costs that are usually covered by insurance.

Private or government-sponsored insurance often pays for most of the following expenses.

- Evaluation tests and exams
- Surgery and hospital costs
- Living related donor costs—evaluation, surgery, hospitalization, and clinic follow-up
- Post-transplant care, including all your visits to the Post-Transplant Clinic
- The prescription medicines you'll need after a transplant, including anti-rejection medicines

Hidden Costs

- Insurance deductibles and co-pays for doctor visits and prescription drugs
- Transportation to and from the hospital
- Parking at the hospital
- Childcare for any children you have while you're in the hospital or at clinic visits
- Food for yourself and your loved ones when visiting the hospital
- Lodging for your family and yourself if you don't live nearby
- Lost wages from your job if you need to take time off for surgery and recovery

Table 2. What to Ask Your Insurer

- Do I have to go to a certain transplant center to receive insurance benefits?
- If the transplant center is out of town, do you pay for my airfare and lodging? Do you pay for me to bring my family?
- Do I need to get a referral from my primary care doctor?
- Is there a waiting period for me to receive benefits? What is it? When does it begin?
- Do you require a second opinion? Do you cover it?

- What percentage of the following transplant costs do you pay for:
 - Pre-transplant exams and tests
 - The transplant surgery
 - My hospital stay
 - Living donor medical expenses—evaluation, surgery, hospital stay, and follow-up care
 - The follow-up care after my transplant
 - My anti-rejection medicines
 - Other medicines the transplant doctors prescribe
- What out-of-pocket expenses will I have?
- Are there any deductibles? What are they and when do I need to pay them?
- Are there any co-pays for outpatient care or on medicines?
- Does my plan have a “tier” plan for medicines? What are the co-pays of different “tiers”?
- Do I have a cap or maximum on my benefits? If so, what is it? Does this include my prescription medicines? Or is there a separate cap for medicines? Is it possible for me to extend my insurance cap?
- Do you cover rehabilitation care after my transplant?