

# Understanding Additional Transplant Expenses

This document summarizes financial information and advice to help you plan for transplant.

## Taking Control of Your Finances

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Developing a list of your income and expenses is the first step to taking control of your finances. With this information, you may be able to adjust some household expenses to improve your financial situation. Other people and resources are also available to help you manage your existing household expenses and prepare for additional transplant costs.

### What You Can Do

**Look for the little expenses.** Smaller expenses such as cable TV, newspaper delivery and eating out can quickly add up to a large monthly cost. Review your monthly expenses and see if there are smaller items that you could cancel, suspend temporarily or change to a less-expensive service.

**Reduce monthly payments.** Sometimes you can resolve issues on your own. For example, you can call creditors (the companies to whom you owe money) and explain your medical situation. Often creditors understand and are able to work with you. Sometimes a creditor will lower the monthly payment. Or, you may have disability waivers that allow you to skip payments for a certain amount of time.

**Plan for income taxes.** You may be able to claim a medical expense deduction on your income taxes. Or, you may be able to deduct medical expenses over a certain amount. Keep track of all expenses, such as medications, mileage and parking fees for office visits, lodging and any special equipment; and talk with your tax preparer.

**Discuss a change in income with a school's financial aid office.** If you or your child is in school, it is often worthwhile to discuss any serious health situation with a school counselor or advisor. These advisors may be able to adjust payments or may offer other assistance.

**Discuss early retirement plans.** If early retirement after transplant is a possibility, you may want to talk with a financial advisor about how your age may change your monthly Social Security income and other retirement income.

### How Others Can Help

**Discuss your needs and concerns with your transplant center staff of the NMDP Office of Patient Advocacy or a financial advisor.** These experts can direct you to local, state, and federal programs and resources and can provide advice to help you manage your expenses.

**Talk with transplant center staff, the NMDP Office of Patient Advocacy or a financial advisor.** These experts can direct you to local, state, and federal programs and resources and can provide tips for helping you take control of your expenses.

**Consider fund raising.** Friends, family members and co-workers may want to help. First, make sure fund raising won't cause the transplant patient to lose benefits from other programs such as Medicaid. Sometimes fund-raising organizations are needed so that certain expenses can be tax deductible. For more information on fund raising and how to find a good organization to work with, see: Mapping the Maze. This guide helps bone marrow and cord blood transplant patients plan for the costs of transplant.

**By finding answers to your financial concerns now, you can better focus your energy during and after your transplant on getting healthy.**

# Other Considerations

## Health Insurance

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It is important to make sure that the patient has health insurance and that coverage does not lapse. Insurance topics to discuss with family and others include:

- Making sure the health insurance premiums are paid during and after the transplant. This is especially important when the **premiums are paid through the patient's employer** because the patient may not be working for several months.
- Learning about government programs. Medicare may be an option if the patient is physically disabled. Medicaid may be needed if the household income changes.

### Also, consider these age-related insurance coverage concerns:

**0-17 years** - During childhood years, a child qualifies for insurance coverage under the parents' policy.

If parents do not have insurance, the child may qualify for Medicaid, the state children's health insurance program (SCHIP) or another government program. If the child is nearing the age of 18, find out when this program considers the child an adult. After turning 18 or 19 (in some cases, up to age 23 if the patient is a full-time student), the patient is dropped automatically from some of these policies. This age may be 23 if the patient is a full-time student.

**18-23 years** - It is important to make sure the insurance coverage does not lapse. Options to research include:

- Keeping the patient on the family's policy as long as possible. Some policies allow a full-time student to appeal for "disabled student" status.
- Insurance through the patient's school.
- Insurance through the patient's employer.
- Medicare if the patient is physically disabled.
- Medicaid. The requirements vary by state. Survivors of childhood cancer should look into Medicaid's Early and Periodic Screening, Diagnosis and Treatment program. If the patient was on Medicaid as a child, check the policy closely. After turning 18 or 19 (in some cases, up to age 23 if the patient is a full-time student), the patient may be dropped automatically from some of these policies. This age maybe 23 if

the patient is a full-time student.

- Continuing the patient's current insurance through COBRA, the Consolidated Omnibus Budget Reconciliation Act. (This government program gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan).
- An individual policy.

### **24 - 44 years**

If the patient is a veteran, check the benefits of the federal government's Veterans Health Administration.

If continuing the patient's current health insurance is an issue, consider:

- Medicare if the patient is physically disabled.
- Adding the patient to the health insurance policy of his or her spouse.
- The risk pool program of the state where they live. (This program is for people who have difficulty getting health insurance).
- Continuing the patient's current insurance through COBRA, the Consolidated Omnibus Budget Reconciliation Act (This government program gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan).

**45+ years** - Patients considering early retirement often need to talk with their financial advisor about many topics, including health insurance.

**If the patient is still working** and continuing current insurance is a concern, consider:

- Adding the patient to the health insurance policy of his or her spouse.
- The risk pool program of the state where they live. (This program is for people who have difficulty getting insurance.)
- Continuing the patient's current insurance

through COBRA, the Consolidated Omnibus Budget Reconciliation Act (This government program gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan.)

**If the patient is eligible for Medicare** and enrolls in both Parts A and B, the transplant may be covered for certain diseases.

**If the patient is a veteran**, check the benefits of the federal government's Veterans Health Administration.

## **Potential Additional Monthly Expenses**

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While the patient is in the hospital, the caregiver must live nearby. Many transplant patients are in the hospital for several weeks or months. The length of the hospital stay depends on the patient's treatment plan, the transplant center's procedures and the patient's recovery time after transplant. Sometimes the patient will leave the hospital after a short stay, but must remain nearby for outpatient treatment.

Talk with the transplant center staff about how this patient's type of cells for transplant and preparative regimen may affect the length of hospital stay.

The potential living expenses in your summary are based on national averages. These amounts may need to be adjusted for the specific city.

**Lodging** may be needed for the caregiver during the time the patient is in the hospital, until the patient returns home. Also, the patient may be released from the hospital but is required to remain within a certain distance of the center for a specified time. Some transplant centers have nearby housing. Be sure to indicate lodging needs for both the caregiver and patient.

**Travel** costs may be needed for the patient and the caregiver, such as travel to and from the transplant center, and possible visits home for the caregiver. These costs can vary according to the number of people traveling and individual traveling preferences. Talk with your case manager at the NMDP Office of Patient Advocacy or your transplant center staff to see if financial help for travel costs is available for your situation.

## Returning Home Expenses

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After a transplant, a patient's immune system is very weak and cannot fight infections. Until the patient's immune system becomes stronger, infections can be life-threatening. Preparations for a patient's return home may result in new expenses.

### Child-care costs:

**If you have children at home**, discuss with your doctor or transplant center staff about how your family can limit your risk of infections. You and your family will need to discuss who child-care for young children and how to lower the risk of infections that your children may bring home from school or daycare.

### Household costs:

**To lower the risk of infection.** Carpets and curtains and drapery need to be cleaned to reduce normal household dust, fungus and bacteria. Furnace filters and air conditioner filters need to be changed.

### **To improve mobility and access for the patient.**

Because the patient may have difficulty walking, a ramp placed over entry steps may be helpful for a wheelchair, or the patient's bed may need to be moved to a different floor.

### New clothing needs for:

**A different size may be needed** if the patient loses or gains significant weight.

**Soft texture** or **easy closures**, such as zippers, fasteners or elastic waistbands may be needed if the patient experiences certain side-effects.

### Food costs:

**Special foods may be recommended** by the transplant center. The patient's nutrition plan may include more protein or calories than usual. It may also include foods that make eating easier if the patient has mouth sores or other digestive issues after the transplant.

### National Marrow Donor Program® *Office of Patient Advocacy*

The National Marrow Donor Program's Office of Patient Advocacy supports patients and families from diagnosis through survivorship. OPA offers programs, resources and services that meet each patient's needs through one-on-one counseling, educational materials or information in other languages. In addition to print, audio and visual materials, OPA has a bilingual (Spanish/English) case manager and LanguageLine interpreter services available for callers.

### Contact a Case Manager

Call toll free in the  
United States:

**1 (888) 999-6743**

Outside the United  
States call:

**1 (612) 627-8140**