



Your Rights and Benefits (Entitlements)

Diagnosis of a life-threatening disease and the prospect of a marrow or cord blood transplant can feel overwhelming. On top of the stress of diagnosis and the need to make decisions about your treatment options, you may find your ability to earn income and keep insurance coverage has suddenly changed. Or maybe you were uninsured at the time of diagnosis. You may be wondering how you will afford the health care you need.

You have rights and benefits (sometimes called “entitlements”) under United States law to help you. Because of these rights and benefits, you may be eligible for some government programs. The following information will explain these programs. This is a starting point to learn about possible options. Your transplant center or clinic social worker can help you access these and other relevant resources. It is a good idea to apply for these programs early, because the application processes can take a long time.

Disability

Many of the following programs refer to disability. You may not think of yourself as disabled, but you may qualify as disabled under the government’s definition. The government considers a person disabled if they can’t work or earn income because of a medically diagnosed condition that doctors expect to last for at least 12 months, or result in death. There are two basic types of government-sponsored disability programs. The Social Security Administration runs them both.

Social Security Disability Insurance (SSDI):

SSDI is a federal (U.S) program that pays monthly cash benefits to people who are unable to work for a year or more because of a disability. It is funded by Social Security taxes paid. Eligibility is based on your work history and Social Security taxes you have paid.

Supplemental Security Income (SSI)

SSI is a federal (U.S.) program that provides cash for basic needs. Unlike SSDI, general tax revenues fund this program. SSI is not based on your work history or taxes you have paid. To qualify, you must be disabled or blind and have a limited family income and few assets. Both children and adults can apply for SSI. In most states, if you qualify for SSI by meeting the minimum income requirements, you will also be eligible for Medicaid coverage.

Many disability applications are denied the first time. However, there is an appeals process if you are denied. SSDI benefits can be back-paid for up to a year from the date of the official disability, so it is a good idea to appeal a denial of disability benefits. To make an appeal:

- Your first step would be to file for Reconsideration. A different person will review your case than the person who made the initial denial decision. You can also present new evidence at this time.
- If you are not happy with the reconsideration decision, you can request a hearing. At this point, you might consider hiring a lawyer to assist you in the appeals process.
- If you disagree with the hearing decision, the next step would be Appeals Council.
- If the Appeals Council decision is unsatisfactory, you can file a civil suit in Federal District Court.

You may be concerned about the cost to hire a lawyer to help you with the appeals process. However, the Social Security Administration limits the amount that a lawyer can charge you (unless it reaches the Federal District Court level). You will only have to pay the fee if you win the appeal and qualify for benefits.

For more information:

Phone: 1 (800) 772-1213
or visit online at ssa.gov

For legal links and resources:

disability-links.com

COBRA

If you have health insurance, it is very important that you do not allow it to lapse. The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) is a federal act that allows individuals of most employer-sponsored health care plans to continue their health care group benefits. COBRA is only for a certain length of time after you lose your job—but at your own cost. This is available only if you already had a health plan through your job.

The maximum length an individual can use COBRA is usually 18 months. However, there are special rules for disabled persons, which may allow an 11-month COBRA extension beyond the 18 months. The Social Security Administration must determine that you are disabled within the first 60 days of electing COBRA. Because of this, it is very important that you apply for SSDI/SSI as soon as you choose COBRA. It is your responsibility to notify your employer once you have been determined disabled.

COBRA is a good option to maintain continuous coverage, but it can be very expensive to cover a family. Under COBRA, the entire cost of your insurance premium is your responsibility; your employer will no longer contribute. Though your employer health plan may have covered your entire family, COBRA allows you to choose to keep family coverage or change to individual coverage. Because of the expense, you might consider keeping individual COBRA for yourself and researching individual health care plans and other options for the rest of the family. Contact your employer (or former employer) to enroll.

For more information:

Phone: 1 (866) 4-USA-DOL

or visit online at

dol.gov/dol/topic/health-plans/cobra.htm

HIPAA

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides limited protection for working U.S. citizens and their families. HIPAA helps with the following:

- Limits the use of pre-existing condition exclusions;
- Prohibits group insurance plans from denying you insurance or charging you extra for insurance because of your (or any family member's) past or present poor health;
- Guarantees the right to purchase health insurance to certain individuals who lose job related insurance; and
- Guarantees, in most cases, that employers, or individuals who purchase health insurance, can renew the coverage regardless of any health conditions of individuals covered under the insurance policy.

You must meet certain conditions to qualify as a HIPAA eligible person. If you qualify for Medicaid or Medicare, you will **not** be HIPAA eligible. If COBRA was an option when you lost your insurance, you must have elected (and exhausted) COBRA benefits before you will qualify as HIPAA eligible. If COBRA was not an option for you, you may qualify as HIPAA eligible as soon as you lose your health insurance, if you met other eligibility requirements.

If you are not eligible for, or have exhausted, COBRA and you have a spouse who is covered under an employer plan, you may be eligible for special enrollment onto your spouse's plan. Special enrollment allows you to join your spouse's insurance plan when you lose your insurance, instead of waiting for open enrollment. Find out from the employer if you qualify for special enrollment into that plan (you must have previously turned down your spouse's group insurance plan because you had other coverage). You generally must request special enrollment within 30 days from losing your insurance.

For more information:

Contact your state's department of insurance, or visit the HIPAA website at

hhs.gov/hipaa/hipaa1/content/cons.asp

Medicaid

Medicaid is a federal-state run insurance program for individuals with low-income levels. Eligibility is different in each state, but usually includes pregnant woman, children, members of a low-income family, or aged, blind or disabled persons. You must meet state income and resource standards, as well as certain other requirements. Also, you must be a resident of the state, and be a United States citizen or a qualified immigrant. Families with private insurance may be eligible if large hospital bills are only partially covered. Some states cover children who are hospitalized more than 30 days, regardless of income. In most states, if you qualify for SSI by meeting the minimum income requirements, you will also be eligible for Medicaid coverage.

You must apply for Medicaid at your local Medicaid office, in the state where you live. You can find the phone number for your local office in the blue pages of your phone book. It is usually listed under medical assistance, or your local Social Security office can give you the number.

For more information:

Most states have toll-free numbers to answer questions. Find this online at cms.hhs.gov/medicaid/statemap.asp

Medicare

Medicare is a federal program that pays for medical care. You qualify for Medicare if you are over age 65 and retired, or if you are disabled. It is available to anyone who has been receiving SSDI benefits for at least 24 months.

For more information:

Phone: 1 (800) MEDICARE (633-4227)
or visit online at [medicare.gov](https://www.medicare.gov)

Veterans' Benefits

Veterans' Benefits offer pensions to veterans who have low-income levels and/or are disabled. Veterans' Benefits also provide health care through VA facilities; home loans, disability compensation; life insurance; burial; and other benefits. You can apply through your local Department of Veterans' Affairs.

For more information:

Phone: 1 (800) 827-1000 or visit online at http://www.va.gov/opa/publications/benefits_book.asp

Pre-Existing Condition Insurance Plan

The Pre-Existing Condition Insurance Plan makes health insurance available to people who have had a problem getting insurance due to a pre-existing condition. The Pre-Existing Condition Insurance Plan:

- Covers a broad range of health benefits, including primary and specialty care, hospital care, and prescription drugs.
- Does not charge you a higher premium due to your medical condition.
- Does not base eligibility on income.

For more information:

www.pcip.gov

Other rights and benefits

For information about other benefits to which you may be entitled, such as Public Assistance, Senior Services, Children's Medical Services, State Disability Programs, Energy Assistance Programs, or Food Stamps, you can contact your local or state Department of Human Services or Welfare Unit. You can also call the U.S. Department of Health and Human Services.

For more information:

Phone: 1-877-696-6775,
or visit online at: os.dhhs.gov

The following services help assess what programs may be available to you:

For individuals under age 55

The benefits.gov web site is a free, confidential, prescreening tool to help you search for benefits that you may be eligible for. This site does not guarantee eligibility for specific programs, but it does provide information about applying and which programs might be best for you. It is your responsibility to apply for all programs.

For more information:

Phone: 1 (800) 333-4636 or visit online at benefits.gov/benefits/

For seniors

BenefitsCheckUp is a program of the National Council on the Aging. It helps thousands of people every day connect to government programs that can help them pay for prescription drugs, health care, meals, rent, utilities, and other needs. This quick and efficient free screening service identifies programs for you to investigate further. It does not determine if you will receive benefits and it does not enroll you in any programs. It is your responsibility to apply for all programs.

For more information:

Visit online at benefitscheckup.org

ElderCare Locator provides individual counseling about senior programs. They connect older Americans and their caregivers with information on senior services. The Eldercare Locator helps older adults and their families and caregivers identify trustworthy local support resources. It is your responsibility to apply for all programs.

For more information:

Phone: 1 (800) 677-1116
or visit online at eldercare.gov

Be The Match® has a team dedicated to supporting patients, caregivers and families before, during and after transplant.

We offer you confidential one-on-one support, financial guidance and free educational resources—DVDs, booklets, online tools and more. Our goal is to get you what you need, when you need it.

Learn: BeTheMatch.org/patient
Order: BeTheMatch.org/request

Email: patientinfo@nmdp.org
Call: 1 (888) 999-6743

We offer support in more than 100 languages, including Spanish bilingual staff and translated materials.

Visit: BeTheMatch.org/translations

Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a physician's medical judgment or advice.

