# Understanding Transplant Outcomes

*Your guide to learning what they mean and what to ask*

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Patient support for **your** life.

# How to Use This Information

This guide can help you understand the basics of transplant **outcomes data** and what that information may mean for you. Three important areas are: understanding your **prognosis**, what the data can and cannot tell you, and the usefulness of talking with your doctor. Sample questions are included on the back cover to help with conversations with your doctor.

# Helpful Terms

**Disease-free survival** The number of patients who are alive at a certain point in time without evidence of disease relapse.

**Outcomes (or outcomes data)** The results of a research study that describe how well a treatment worked for patients.

**Overall survival** The number of patients who are alive at a certain point in time. Some of these patients may have relapsed or may still be in treatment.

**Prognosis** An idea of how a patient's disease might change over time. For example, a prognosis might predict if a patient's disease will grow rapidly or slowly.

**Relapse** The return of disease after treatment.

**Risk factor (or health risk factor)** An aspect of your health or disease that may affect the result of a treatment. Examples include stage of disease, type of disease, age, or other health problems a patient has at the time of treatment.

**Survival curves** A type of graph showing the number of patients in a research study who have survived over a certain period of time.

**Survival outcomes data** A report of the number of people with a certain disease who survive for a certain period of time after diagnosis or after receiving a specific treatment.

**On the cover:** Stephen (right), transplant recipient, with his doctor

# Understanding Transplant Outcomes

## Many factors to consider

If a marrow or cord blood transplant is a possibility for you, it is normal to have a lot of questions. One of your first questions may be, "What are the possible risks and benefits of choosing a transplant?"

It will be easier for you to talk with your doctor and family about treatment options if you understand your prognosis, or how your disease may change over time, and the possible side effects of different treatments. Think about how the treatment you choose may affect your quality of life, or how the possible risks and side effects of a transplant may affect your ability to live your life as you want.

## What are outcomes data?

Outcomes data are gathered from hospitals that report on how patients have done after receiving a specific treatment. **Survival outcomes data** report the number of people with a certain disease who survive for a specific amount of time. This time frame may begin when a patient is diagnosed or when he or she begins treatment, such as a transplant.

Outcomes data show what other patients have experienced as a group. The data won't predict how any one person will do. However, it's possible to get an idea of how well you'll do based on the experiences of other patients with a similar disease and treatment.

There may be a lot of information available about your disease. You can choose which information is most helpful to you when you talk with your doctor about your disease and treatment options. Your doctor can explain what the information means to you.

# How You and Your Doctor Can Use Outcomes Data

## Prognosis

Outcomes data can help you and your doctor understand your prognosis. When a doctor discusses your prognosis, he or she carefully considers all the **health risk factors** that could affect your disease and treatment. He or she will look at your age, general health, disease status, past treatments and treatment response for your disease.

Your doctor will also compare your situation to other patients who have your disease. He or she will use all of this information to give you an idea of how your disease and treatment may affect your body. However, even your doctor cannot know for sure how your disease and body will respond to treatment.

## Treatment planning

Outcomes data can also help you make treatment choices. The data can show how other people with a similar disease responded to different treatments. You can also learn about the possible benefits and risks of different treatments. For example, studies may show that one treatment has higher risks earlier on than another treatment, but is more likely to prevent the disease from coming back in the long run.

## What outcomes data cannot tell you

Outcomes data cannot tell how you will do for sure. The data can only give you an idea of what may happen based on the experiences of other patients. No two people are exactly the same and so one person's response to treatment can be very different from another person's response.

Survival outcomes data alone will not tell you about treatment risks or side effects or how a treatment may affect your quality of life. For example, after a transplant, most survivors return to their usual activities within a year. However, some have complications that make it difficult to do usual activities for a long time.

Be sure to discuss the risks and benefits of transplant with your doctor, family and close friends before making a decision.

## Looking beyond the numbers

When you look at outcomes, keep these factors in mind:

1. **Number of patients included** Outcomes that include a larger number of patients can give a better idea of likely outcomes for other patients.
2. **When the patients were treated** The results of research studies will show how patients did at certain time points after the study ended (for example, six months, one year, or five years after the study ended). Short-term data can be helpful because they reflect the newest treatments, but they will not show how the patients are doing many years after treatment. Long-term data can be helpful because they show how patients are doing several years after treatment. However, the data is reported long after the treatment ended so there may have been improvements in the treatment since that time.
3. **Kinds of outcome reported** Study data may report different kinds of outcomes. For example, **overall survival data** may include patients who are alive but have **relapsed**, while **disease-free survival** data include patients who are alive without disease. Keep in mind that the quality of life of these two groups of patients can be quite different.

## Transplant survival outcomes data

The National Marrow Donor Program (NMDP) which operates Be The Match®, has survival data on diseases commonly treated with a transplant, including leukemia, lymphoma, aplastic anemia and myelodysplastic syndrome, and others.

The NMDP also publishes outcomes data (**survival curves**) for several different diseases. There are different curves for pediatric and adult patients. Visit **BeTheMatch.org/outcomes** to view.

# Sample Questions to Ask Your Doctor

1. How do you use **outcomes data** to make a decision about whether I should get a transplant? What numbers do you look at to make your decision? _____
_____
_____

2. Do I have **health risk factors** that might affect my transplant **outcomes**? _____
_____
_____

3. Will my age influence my risk? _____
_____
_____

4. How does my situation compare to other patients? _____
_____
_____

5. What are my chances of living disease-free if I get a transplant? If I don't get a transplant? _____
_____
_____

6. What can you tell me about my quality of life if I get a transplant? If I don't? _____
_____
_____

7. How might my quality of life change over time? _____
_____
_____

# Moving Forward

A transplant doctor is the best person to talk to about transplant as a treatment option. If you are not at a transplant center, ask your doctor if you should be referred to one.

For more information about understanding transplant outcomes, contact Be The Match® patient services at **1 (888) 999-6743** or **patientinfo@nmdp.org**.

# Additional Resources for Survival Outcomes Data

## For more information about outcomes data, here is a list of websites that may be able to help you:

**Center for International Blood and Marrow Transplant Research (CIBMTR):**
**cibmtr.org**
The Reference Center includes patient resources for outcomes data, such as **survival curves**, and follow-up care for patients after transplant.

**C.W. Bill Young Cell Transplantation Program** - Bone Marrow and Cord Blood Donation and Transplantation:
**bloodcell.transplant.hrsa.gov**
Provides transplant outcomes data managed by the Health Research and Services Administration, U.S. Department of Health and Human Services.

**National Cancer Institute:**
**cancer.gov/statistics**
Offers a glossary of survival statistics.

## About Be The Match®

Be The Match, operated by the National Marrow Donor Program®, is dedicated to supporting patients, caregivers, family members and friends, 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 help you get what you need, when you need it. We can help you learn more about transplant as a treatment option, plan for a transplant and learn what to expect after a transplant.

**Learn:** BeTheMatch.org/patient

**Request information:** BeTheMatch.org/request

**E-mail:** patientinfo@nmdp.org

**Call:** 1 (888) 999-6743

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. The information is not intended to replace, and should not replace, a phyisican's medical judgment or advice.

BE THE MATCH®

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