

# Discussing Transplant Outcomes

*A guide to help you talk with your doctor*



Stephen, transplant recipient, with his doctor

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# Using Outcomes to Make Decisions

Transplant **outcomes** may help you make a treatment choice. Depending on your disease, there may be a lot of information available on transplant outcomes, or very little. This guide can help you talk with your doctor about outcomes, decide which information is most helpful for you, and learn how you and your doctor can use outcomes information to make decisions.

## What are Transplant Outcomes?

Transplant outcomes tell how patients have done after transplant. Outcomes are collected from transplant centers and research studies. Two types of outcomes important to patients are **survival outcomes** and **quality of life outcomes**. Both are important for patients and doctors to keep in mind when choosing a treatment for a disease.

**Survival outcomes** show the number of people with a certain disease who are alive at a specific point in time. This time period may begin when a patient is diagnosed or when a patient begins treatment.

**Quality of life** outcomes show how patients have done physically, emotionally, and socially after their treatment. This can include:

- Impact of any side effects from treatment
- Impact of any resulting health problems
- How well patients can do things that are important to them
- How patients relate to other people
- How patients feel overall

*“Patients can use transplant outcomes to help decide if transplant is a good treatment option for them. I’d encourage patients to talk with their doctor about outcomes for their situation.”*

—Willis Navarro, M.D.  
transplant physician



# What Outcomes Can and Can't Tell You

Outcomes **can tell you** how patients have done as a group. They give you an idea of how other patients (with a similar disease and treatment) have done.

This information **can't tell you** how you, as an individual, will do. No two people are exactly the same, and you may respond differently to your transplant than someone else.

Doctors may talk about outcomes with numbers. But doctors can also talk about outcomes with stories of common patient experiences. Many patients think stories of common patient experiences are helpful. Tell your doctor how you want to learn about outcomes.

Your doctor is the best person to explain what outcomes mean for you. Ask your doctor what survival or quality of life outcomes say about your **prognosis** and treatment plan. You and your doctor can use survival outcomes and quality of life outcomes to help decide if transplant is right for you.

*"I wanted to be educated about my disease and transplant, but only to a certain extent. I did not want to know percentages. That was too scary or me. I didn't want those numbers in my head. However, my husband did want to know. So there are definitely different informational needs and ways to learn and it's important that all are recognized."*

—Wendy, transplant recipient

## How You and Your Doctor Can Use Outcomes Data

### Prognosis

Outcomes can help you and your doctor understand your prognosis. A prognosis is an idea of the most likely path of your disease. Your doctor can tell you what might happen to you based on the experiences of others with your disease. Your doctor can also look at your age, health status, disease, and past treatments. However, no one, not even your doctor, can know for sure how your disease and body will respond to treatment.

### Treatment planning

Outcomes can be helpful when choosing a treatment. For example, doctors can use outcomes to help you decide when to get a transplant. Transplant outcomes can show how other people with a similar disease responded to transplant.

# Sample Questions to Ask Your Doctor

1. How do you use **outcomes** to help me make a decision about transplant? What data do you look at to help make treatment decisions?

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2. What are my **risk factors** that might affect my transplant outcomes?

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3. How will my **age** influence how I do after transplant? \_\_\_\_\_

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4. How does the **cell source** influence how I do after transplant?

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5. What are my chances of **living disease-free** if I get a transplant?

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If I don't get a transplant? \_\_\_\_\_

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6. What can you tell me about my **quality of life** if I get a transplant?

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If I don't? \_\_\_\_\_

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7. How might my **quality of life** change over time? \_\_\_\_\_

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Matt (right), transplant recipient, with his doctor

## Helpful Words

**Cell source** The three sources of blood-forming cells, which grow into red blood cells, white blood cells and platelets, are:

**Bone marrow** – the soft, spongy tissue inside of bones

**Peripheral blood stem cells** (or PBSC) – blood-forming cells from the circulating blood

**Umbilical cord blood** – the blood collected from the umbilical cord and placenta after a baby is born.

**Health status** A person's overall health. Sometimes people have other health problems, like heart disease or diabetes, that can affect a treatment outcome.

**Outcomes** The results of research studies that tell how well a treatment worked for a group of patients over a period of time. Sometimes doctors say *results* or *outcomes data*.

**Survival outcomes** – the number of patients with a disease who are alive at a specific point in time after diagnosis or after getting a specific treatment.

**Quality of life outcomes** – information about the physical, emotional and social experiences of patients who have survived after a treatment.

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

**Disease-free survival** The number of patients who are alive at a certain time after treatment without signs of the disease (relapse). Some other similar terms doctors say are *progression-free survival* or *event-free survival*.

**Prognosis** The likely path of the disease over time. For example, a prognosis might tell how fast or slow a patient's disease will grow.

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

**Risk factor** A feature of your health or disease that may affect the treatment result. Many times risk factors are things you can't change. These can include stage of disease, type of disease, age, or health status.

# 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.

Be The Match®, operated by the National Marrow Donor Program® (NMDP), can help you learn more about transplant outcomes.

## For general information about using outcomes to make treatment decisions:

- Visit [BeTheMatch.org/patient-considertransplant](http://BeTheMatch.org/patient-considertransplant)
- Contact a patient services coordinator. Call 1 (888) 999-6743 or email [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

## For information about survival outcomes and to access specific outcomes data:

- Visit [BeTheMatchClinical.org/outcomes](http://BeTheMatchClinical.org/outcomes) for data on specific diseases
- Visit [BeTheMatch.org/access](http://BeTheMatch.org/access) for data on specific transplant centers
- Visit [bloodcell.transplant.hrsa.gov](http://bloodcell.transplant.hrsa.gov) for additional survival outcomes information

## 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](http://BeTheMatch.org/patient)

**Request information:** [BeTheMatch.org/request](http://BeTheMatch.org/request)

**Email:** [patientinfo@nmdp.org](mailto: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 doctor's medical judgment or advice.



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