

Words You Might Hear When Talking About Outcomes

Health status

Your overall health. Sometimes people have other health problems, like heart disease or diabetes, that can affect a treatment outcome.

Overall survival

The number of patients who are alive at a certain time. For some of these patients, their disease may have relapsed or they 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. Some similar terms 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

When the disease comes back after treatment.

Results

Another word that also means outcomes. Transplant results tell how patients have done after transplant over time.

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.



Talk To Others Who Have Been Through Transplant

Transplant outcomes aren't just about numbers — especially when it comes to quality of life outcomes. You and your caregiver may find that it's helpful to hear about other patients' experiences.

We can connect you and your caregiver with someone who has been through the transplant journey. Our trained peer volunteers are available to talk by phone or email.

Request a connection:
nmdp.org/peerconnect
1 (888) 999-6743

Resources For You

There are many resources available for you to learn about transplant outcomes.

For information about outcomes, visit:

- nmdpclinical.org/outcomes for data on specific diseases
- nmdp.org/access for data on specific transplant centers in the U.S.
- bloodcell.transplant.hrsa.gov for additional survival outcomes information



At Every Step, We're Here To Help

The **NMDPSM Patient Support Center** provides support, information and resources for transplant patients, caregivers and families.

All of our programs and resources are free.

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

Monday through Friday, 8 a.m. – 5 p.m. CT

Email: patientinfo@nmdp.org

VISIT: nmdp.org/one-on-one

Order Materials: nmdp.org/request

Other Languages

We offer translated resources in 11 languages and telephone support in more than 100 languages. For more information, visit nmdp.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 doctor's medical judgment or advice.

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Transplant Outcomes & Treatment Decisions

A guide to help you
talk with your doctor



You likely have many questions if your doctor has talked to you about getting a blood or marrow transplant.

You may be thinking, “Will transplant work for me?” or “What will my life be like after transplant?” or “What if I choose not to have a transplant?”

Learning about transplant outcomes (sometimes called results) may help answer some of those questions, and help you decide if transplant is the right treatment for you. It can be difficult to understand transplant outcomes, so it’s helpful to talk with your doctor.

This guide will help you learn about different types of outcomes. Talking with your doctor and loved ones about what is important to you and your goals for treatment may help you make decisions that are right for you.

What Are Transplant Outcomes?

Transplant outcomes show how a group of patients have done after transplant over time. This information comes from clinical trials and other research studies.

Survival outcomes and **quality of life outcomes** are two types of treatment results. Both are important for patients and doctors to keep in mind when choosing the best treatment for a disease. If your doctor doesn’t tell you about outcomes for your disease and transplant, you or your loved one may want to ask about them.

Survival outcomes tell you how many people with a certain disease are alive at a specific time after diagnosis or after a specific treatment, like a transplant.

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

- Ongoing side effects from treatment
- Health problems after treatment
- How well patients can do things that are important to them
- Relationships with other people
- How patients feel overall



Patsy, transplant recipient, with her husband, Steve, and her doctor

What Outcomes Can And Can't Tell You

Outcomes are one piece of information that can help you make a treatment decision. But outcomes don’t tell the whole story.

Outcomes **can** tell you how patients with a similar disease and treatment have done as a group. Your doctor can also use outcomes to help you decide when to get a transplant.

Outcomes **can't** tell you how you will do. No two people are exactly the same. You may respond differently to your transplant than someone else. Your doctor can't know for sure how your body and the disease will respond to treatment.

Remember, your doctor is the best person to explain what outcomes may mean for you.



I wanted to be educated about my disease and transplant, but only to a certain extent. I didn't want to know percentages. That was too scary for me. However, my husband did want to know. There are definitely different informational needs and ways to learn and it's important all are recognized.

—WENDY, TRANSPLANT RECIPIENT

Tips For Talking To Your Family

Family members or close friends may also be involved in helping you make treatment decisions. It's important for them to understand what transplant outcomes might mean for you.

In addition to outcomes, many other factors may play a role in your decision-making process. Some tips for talking with family and friends include:

- Talk about what you think is important about your treatment. For example, if you want to be treated at a center close to home or by a specific doctor.
- Talk about how involved you want your loved ones to be in helping you make treatment decisions.

If your child is getting a transplant, talk with your transplant team or clinic social worker about ways you and other family members can get support as you're making decisions. If your child is a teenager, you might also want to ask for help involving them in treatment decisions.

Questions To Ask Your Doctor

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

If I don't get a transplant?

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

If I don't get a transplant?

3. How might my quality of life change over time?

4. What risk factors do I have that might affect my transplant outcomes?

5. What are the typical transplant outcomes for patients like me at the transplant center where I am considering having my transplant?

6. What is the prognosis (likely path over time) for my disease if I get a transplant?

If I don't get a transplant?

7. How might my age affect how I do after transplant?