BE THE MATCH®

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 for your disease.

You may ask your doctor questions like, “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 to your doctor and loved ones about what is important to you will help you make a treatment decision.

WHAT ARE **TRANSPLANT OUTCOMES**?

Transplant outcomes show how a group of patients has done after transplant over time. Outcomes information comes from research studies.

Survival outcomes and **quality of life** outcomes are 2 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

Ava, transplant recipient, with her parents, Janet and Ron

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 you have a child who 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? _____

_____

_____

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 many **age** affect how I do after transplant? _____

_____

_____

_____

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. Some of these patients may have relapsed (disease returned) 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 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 and outcomes 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. Tell your doctor if this would help you make treatment decisions.

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:
BeTheMatch.org/patient-peerconnect
1 (888) 999-6743

RESOURCES **FOR YOU**

There are many resources available for you to learn about transplant as a treatment option, outcomes and life after transplant.

For general information about transplant and making treatment decisions, visit:

- **BeTheMatch.org/patient**
- **ExploreBMT.org**

For information about outcomes, visit:

- **BeTheMatchClinical.org/outcomes** for data on specific diseases
- **BeTheMatch.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**

As you journey through transplant, you're not alone. Be The Match® is ready to help.
We offer many free programs and resources to support you, your caregivers and family members before, during and after transplant. Connect with us in the way that works best for you.

LEARN: **BeTheMatch.org/patient**

EMAIL: **patientinfo@nmdp.org**

ORDER: **BeTheMatch.org/request**

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

Our programs and resources offer support in 11 languages, including Spanish bilingual staff, and interpreter services are available in over 100 languages.

VISIT: **BeTheMatch.org/translations**

BE THE MATCH®

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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