

TRANSPLANT AND CHRONIC MYELOGENOUS LEUKEMIA (CML)

Learning more about your disease and treatment options can help you make informed decisions about your health care. Be The Match® can help you understand how transplant may be used to treat CML.

READ ON TO **LEARN ABOUT:**

- How transplant can treat CML
- If transplant can help your CML
- If transplant is right for you
- Questions to ask your doctor
- Transplant outcomes for CML
- Making treatment decisions

ABOUT **CHRONIC MYELOGENOUS LEUKEMIA (CML)**

Chronic myelogenous leukemia (CML) is a slow-growing cancer of the bone marrow. It is also sometimes called chronic myeloid, chronic granulocytic, or chronic myelocytic leukemia. In the United States, more than 20,000 people have CML and about 6,000 new cases are diagnosed each year.¹ CML mostly affects adults, but a small number of CML patients are children. The cause of CML is unknown.

CML is typically related to the presence of an abnormal **chromosome** in bone marrow cells called the Philadelphia chromosome. Chromosomes are thread-like strands of DNA that carry genetic information about your body. The Philadelphia chromosome is an abnormal change where DNA from 1 chromosome exchanges with another. The Philadelphia chromosome tells the marrow to make too many white blood cells.

Doctors do not know what causes the Philadelphia chromosome to appear.

In rare cases, patients will have all the signs and symptoms of CML, but tests cannot find the Philadelphia chromosome. Doctors think that many of these patients may have 1 or more other abnormal chromosomes.

THE **3 PHASES** OF CML

CML has 3 phases: chronic phase, accelerated phase and blast phase. Most patients are diagnosed in the chronic phase. Without treatment, patients in the chronic phase will get worse, and will eventually enter the accelerated phase. The accelerated phase of CML is where there are too many blasts (immature white blood cells) in the marrow, blood, liver and spleen. Some new symptoms also develop such as fever, night sweats, weight loss, shortness of breath, and unusually pale skin.

In the blast phase the number of blasts in the blood stream grows rapidly. As a result, there are fewer normal blood cells (white blood cells, red blood cells and platelets). A patient in this phase may have severe symptoms such as fever, night sweats, weight loss, shortness of breath, bruises, bleeding and infections.



HOW **TRANSPLANT CAN TREAT CML**

A blood or marrow transplant is the only known cure for CML at this time. Transplant is not the first treatment tried. Transplant is only used if other medicines stop working or cause too many severe symptoms. **Allogeneic** transplants are used to treat patients with CML. An allogeneic transplant uses healthy blood-forming cells from a family member, unrelated donor or umbilical cord blood unit.

At the start of the transplant process, a patient gets chemotherapy to prepare his or her body for the treatment. Then the replacement cells are infused into the patient's bloodstream. From there, the cells find their way into the bone marrow, where they start making healthy white blood cells, red blood cells and platelets. The entire process, from the start of chemotherapy or radiation, until hospital discharge, can last weeks to months, followed by many months of recovery at home.

If transplant is an option for you, your doctor can talk with you about your risks and your chances of remaining disease-free with transplant.

Key points:

- Allogeneic transplants are used for CML
- Transplant may not be used first, but would be appropriate if CML medications cannot be used to keep CML in remission

UNDERSTANDING **IF TRANSPLANT WOULD HELP** YOUR CML

Whether a transplant is right for you depends on several things, such as your overall health, and what phase your disease is in. In the past, the chronic phase typically lasted 2 to 5 years before turning into the accelerated phase.

This has improved since the development of medications called **tyrosine kinase inhibitors** (TKIs). These medicines control CML by interfering with the action of the Philadelphia chromosome.

Now, many patients who are treated with TKIs are stable (getting neither better nor worse) 5 years after starting the drug.

If TKIs or related medicines don't work, stop working or you cannot tolerate them, then you should be referred to a transplant doctor. A transplant doctor can discuss treating your CML with a transplant.

There are medical guidelines for when someone should be referred for a transplant consultation, whether or not you might need a transplant at that time. Talking to a transplant doctor is especially recommended if any of the following are true²:

- CML doesn't get better after treatment with TKIs
- Disease progression
- Serious side effects from TKIs
- CML in accelerated phase at any point
- CML in blast phase at any point

Key points:

- TKIs are medicines that can keep many patients with CML in a stable, chronic phase for many years
- TKIs may not work for all patients and some may eventually need a transplant
- If your disease has any of the factors listed above, ask for a referral to a transplant doctor to find out if transplant is right for you



HOW A TRANSPLANT DOCTOR HELPS YOU **DECIDE IF TRANSPLANT** IS THE RIGHT TREATMENT

To find out if transplant is right for you, you will need a physical check-up by your transplant doctor. During the check-up, your lungs, heart, liver, kidneys and nervous system will be checked. The transplant doctor will also review your health history, including what medicines you previously took for your CML and how well (and how long) they worked for you.

You will also meet with other members of the health care team. A social worker or other professional will meet with you to talk about your concerns related to transplant (for example: emotional, financial, travel, lodging, work and/or school). The social worker can help you find resources to support you during your transplant journey. Most transplant centers (hospitals that do transplants) require you to have a dedicated caregiver to help you through the recovery process.

Key points:

- A transplant doctor will look at many things including your health history, disease status and the risks and benefits of transplant before recommending a transplant
- A transplant social worker is available to help you and your family with emotional and practical support

QUESTIONS TO ASK YOUR DOCTOR

It is important to ask questions so you are comfortable with the treatments that your doctors recommend and so you can make decisions about your treatment. Questions you may want to ask your doctor include:

- What are my chances of living disease-free if I get a transplant? If I don't get a transplant?
- What are the risks of waiting or trying other treatments before a transplant?
- Do I have any risk factors that might affect my transplant outcomes?
- How much does my age influence my risk?
- What are the possible side effects of transplant? How can they be reduced?
- What can you tell me about my quality of life if I get a transplant? If I don't?
- How might my quality of life change over time, with or without transplant?

Key point:

- Don't be afraid to ask questions so you understand which treatments are right for you

TRANSPLANT OUTCOMES FOR CML

Outcomes data (information on how patients have done after their transplant) are used to estimate transplant outcomes for patients with CML. Outcomes data only show how other patients have done as a group. This information can't tell how you will do for sure. It can only give you an idea of how other patients have done with a similar disease and treatment.

No two people are exactly the same, and you may respond differently to your transplant than someone else. Talk to your transplant doctor about how outcomes data may apply to your specific situation. Fortunately, transplant outcomes have continued to improve over time.

Key point:

- Transplant outcomes data overall are useful but only your transplant team can tell you what your chances are of doing well



MAKING TREATMENT DECISIONS

It is important to know your treatment options so you can make the best decision for yourself. Soon after your diagnosis, ask your doctor if a consultation with a transplant doctor is right for you. When you meet with a transplant doctor, there are 2 main decisions to make. The first decision is whether to have a transplant. A transplant doctor can help you understand the risks and benefits of transplant for your specific situation.

The second decision is when to have a transplant. Getting a transplant at the right time in the course of your disease may offer the best chance of a cure. The transplant doctor will work with you to decide what timing for the transplant is best for you.

OTHER RESOURCES TO HELP YOU LEARN MORE

Be The Match has a variety of free resources to help you learn about transplant. Visit **BeTheMatch.org/patient-learn** and choose the resources that best meet your needs. Here are just a few that you might find helpful:

- Webcast: *An Introduction to Marrow and Cord Blood Transplant*
- Booklet: *Transplant Basics*
- Brochure: *Understanding Transplant Outcomes*

REFERENCES

- ¹ Howlader N, Noone AM, Krapcho M, Garshell J, et al. SEER Cancer Statistics Review, 1975-2010, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2010/, based on November 2012 SEER data submission, posted to the SEER web site, April 2013.
- ² *Recommended Timing for Transplant Consultation*. Guidelines developed jointly by National Marrow Donor Program/Be The Match and the American Society for Blood and Marrow Transplantation (ASBMT). Available at: BeTheMatchClinical.org/guidelines

Most recent medical review completed August 2014



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 translation is available in more than 100 languages.

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 doctor's medical judgment or advice.