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 CLL.

READ ON TO LEARN ABOUT:
- How transplant can treat CLL
- If transplant helps your type of CLL
- If transplant is right for you
- Questions to ask your doctor
- Transplant outcomes for CLL
- Initial treatment of CLL
- Making treatment decisions

ABOUT CHRONIC LYMPHOCYTIC LEUKEMIA (CLL)

Chronic lymphocytic leukemia (CLL), also called B-cell chronic lymphocytic leukemia, is a slow-growing cancer of a type of white blood cells called lymphocytes. Normal lymphocytes help your body fight infections. In CLL, the lymphocytes do not develop properly and don’t fight infections very well. These diseased cells (leukemia cells) eventually crowd out the bone marrow, preventing it from making healthy white blood cells, red blood cells and platelets that the body needs.

CLL mostly affects older adults, and it is very rare in children and young adults. In the United States, about 15,000 people are diagnosed with CLL each year. Doctors do not know what causes CLL.

HOW TRANSPLANT CAN TREAT CLL

A bone marrow or cord blood transplant begins with chemotherapy, with or without radiation, to destroy the diseased cells and marrow. The transplant replaces diseased blood-forming cells with healthy ones. There are 2 types of transplants: allogeneic and autologous. An allogeneic transplant uses healthy blood-forming cells from a family member, unrelated donor, or umbilical cord blood unit. An autologous transplant uses the patient’s own blood-forming cells, which are collected and stored.

An allogeneic transplant is usually preferred for most patients with CLL. With an allogeneic transplant, the patient gets chemotherapy, with or without radiation, before transplant 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 red blood cells, white 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. Transplant may still be a treatment option for older patients with CLL (or for younger patients with CLL and other health concerns) because of a type of allogeneic transplant that uses a lower amount of chemotherapy or radiation before the transplant. These are called reduced intensity transplants.
Chemotherapy alone, without a transplant, is the most common treatment for patients with CLL. Transplant usually becomes a treatment option when chemotherapy doesn’t work very well and the disease returns.

**Key points:**
- Transplant usually becomes a treatment option when chemotherapy doesn’t work very well and the disease returns
- Most transplants for CLL are allogeneic

**UNDERSTANDING IF TRANSPLANT WOULD HELP YOUR CLL**

Whether a transplant is right for you depends on several things, such as your overall health, and the stage of the disease. A transplant doctor will weigh the risk of the leukemia coming back against getting a transplant. A transplant may cure the leukemia, but may also cause other problems.

One way a doctor determines how likely the leukemia is to return is through **cytogenetic** testing. This means looking at the **chromosomes** in the leukemia cells. Chromosomes are thread-like strands of DNA that carry genetic information about your body. Certain changes in the chromosomes predict a lower risk of the disease returning. Others predict a higher risk.

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 your CLL has any of the following features:
- High-risk cytogenetics or other features
- A short period of remission after chemotherapy
- No or a poor response to chemotherapy

**Key points:**
- Ask your doctor about your specific risk factors and the possibility of remission or cure with or without a transplant
- If chemotherapy does not work well for you, 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 and current status of your disease.

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 doctor recommends 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 CLL

Outcomes data (information on how patients have done after their transplant) are used to estimate transplant outcomes. Outcomes data only show how other patients have done as a group. This information can’t tell you 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 2 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

INITIAL TREATMENT OF CLL

Treatment for CLL varies from no treatment at all (“watch and wait”), to more intensive treatments such as chemotherapy and transplant. When the disease is mild, patients may be watched carefully, and may have frequent blood tests. These patients may live many years without any treatment before the disease begins to cause problems.

When the disease becomes more serious and the patient starts having more symptoms, chemotherapy and other treatments may be used. Chemotherapy is a treatment that uses one or more drugs that destroy cancer cells or stop them from growing. Different drugs are sometimes combined to increase their ability to fight the disease.

There are also newer drugs called monoclonal antibodies. These medicines fight the disease by latching onto the surface of CLL cells and causing the body’s immune system to attack them. Monoclonal antibodies are a form of what is called targeted therapies. They may be used together with chemotherapy drugs.

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 help 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


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

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