Candidate Education Booklet

Bone Marrow Transplant

INTERLINK®

COE NETWORKS & PROGRAMS

Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Candidate Education Booklet

Dear potential transplant candidate,

This booklet was created to share information about the transplant process and to help guide you in selecting a transplant program. This includes:

- **Basic information about bone marrow transplant**
- **Frequently asked questions**
- **List of helpful organizations and links**

We encourage you to discuss this information with your physician and case manager. As you better understand the transplant process, we hope this guide will help you ask the right questions, encourage you to seek additional information, understand the way bone marrow transplant programs vary, and ultimately select the right center for you. If you have already selected your center, this booklet will help you understand the many new experiences you will have in the weeks and months ahead.

As we emphasize in many places in this guide, the ultimate decision is yours to make. Your doctor, your case manager, and physicians and staff at proposed transplant centers can provide the expert guidance you may need to make this very important decision.

We wish you the best on your journey to health.

Candidate Education Booklet

Disclaimer:

As you and your physician review this information, understand that this booklet and the information contained within is provided for informational purposes only. It does not mean nor imply that a transplant is medically necessary, is medically appropriate for your condition, is a covered benefit, or meets your plan criteria. Those decisions are rendered solely by your health benefits program sponsor.

Candidate Education Booklet

Table of Contents

Candidate Education Booklet

Candidate Education Booklet

What is bone marrow?

Bone marrow is the soft, fatty tissue inside of bone cavities. Components of blood including red and white blood cells and platelets form in bone marrow.

What does bone marrow do?

Bone marrow makes nearly all the cellular components of blood. It's responsible for creating billions of red blood cells daily, along with white blood cells and platelets. Bone marrow also stores fat that turns into energy as needed. Bone marrow contains stem cells which are the primitive precursors of all other types of blood cells.

Can you live without bone marrow?

Bone marrow makes the components of the blood that are needed for survival. Bone marrow produces red blood cells that carry oxygen, white blood cells that prevent and fight infection and platelets that control bleeding. The absence of bone marrow can be fatal since it's an essential part of the body.

Can I donate bone marrow?

Yes. Because bone marrow is constantly producing new cells, removing a portion (harvesting) of the cells will be quickly compensated by new production.

A bone marrow transplant takes healthy cells from a donor and puts them into the recipient's bloodstream. See below for more details. The donor's cells ultimately land back in the bone marrow area and replace absent or diseased bone marrow cells in the recipient. The transplanted bone marrow produces new healthy blood cells for the recipient.

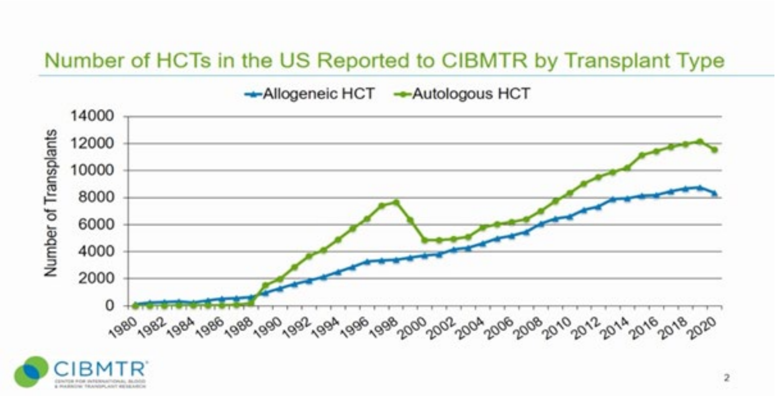
Introduction to Bone Marrow Transplants

Bone marrow transplants are referred to as Hematopoietic Cell Transplantation (HCT) or sometimes Hematopoietic Stem Cell Transplantation (HSCT) in the medical world. Stem cells are the primitive cells that develop through several steps into types of mature red blood cells, white blood cells, and platelets that circulate in the blood. The term hematopoietic stem cell therapy refers to all forms of therapy that provide blood-forming cells found in the bone marrow to treat an underlying disease.

HCT is typically used to treat patients with various forms of blood cancers that have not responded to conventional chemo- and/or radiation-therapy, or that are not expected to respond well to conventional treatment. Today, through advanced techniques called cytogenetics, it is possible to determine the actual genetic makeup of tumor cells. Cancer doctors can use such information to predict with a high degree of accuracy whether a given cancer will respond to conventional therapy. The genetic analysis may suggest a condition less likely to respond to conventional treatment. Early referral to a center that specializes in patients with these more unique diseases allows for early consideration of HCT when that approach offers the best chance for a good long-term outcome.

HCT may also be used to treat patients with non-malignant blood diseases such as immune deficiencies like Severe Combined Immunodeficiency (SCID or “bubble boy” disease), acquired immune deficiencies, certain inherited diseases like Hurler’s disease, certain abnormal red blood cell conditions (such as sickle cell anemia), severe collagen vascular diseases (lupus and others), aplastic anemia, Fanconi’s anemia, and other disorders of the blood-forming tissues, including myelodysplastic syndrome.

There are two types of HCT: autologous and allogeneic. In autologous HCT, the patient’s bone marrow cells are removed and then given back after chemotherapy. In allogeneic HCT, the donor cells come from someone else who may or may not be related to the recipient.



Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Seeking Transplants on a National Basis

Seeking Transplants on a National Basis

National Transplant Programs

Transplantation is fortunate to be served by extensive and well-established registries in which each program's operations and outcomes are carefully recorded and analyzed. As one might expect, centers' results can vary. This enables companies like INTERLINK to analyze and create Centers of Excellence (COE). COEs are transplant centers whose processes and outcomes are identified to exceed national averages and represent the highest quality programs. INTERLINK COE Networks and Programs offers access to exclusive networks comprised of the most experienced transplant centers and prominent medical teams.

There are more than 200 bone marrow transplant centers in the US, but they are not evenly distributed around the country. Some people choose national medical centers because there are no transplant centers in their area, many select them because of their proven performance and outcomes and others select them because they are a benefit offered through their health plan. Major transplant centers have specialized Transplant Coordinators to help you and your family prepare to receive care at their medical center. In this booklet, we will provide you with information to help you explore the many opportunities within the transplant community.

INTERLINK works with most insurance companies and health plans. As a national transplant network servicing thousands of transplants annually, we maintain all medical information at the highest level of confidentiality, which exceeds any stated federal guidelines.

We may provide information about a transplant center that is a considerable distance away because they may specialize in treating patients with your condition. Health plan case managers can provide information about other transplant center options. If you would like even more information about a national transplant center, that information may also be obtained through your case manager, or you may contact the medical center transplant coordinator directly.

Checking Your Benefits

INTERLINK wants to help patients understand health insurance benefits before anyone accesses Bone Marrow Transplant care. Most health plans have pre-certification programs, and once notified of the proposed treatment program, the plan will likely choose to monitor your care from thereon. Many insurance companies and health plans use case managers to help coordinate care for people with complex medical needs and can be valuable resources coordinating care and your benefits.

Seeking Additional Information

We understand that after reviewing the information in this booklet, additional questions may arise. Locating a person who is qualified to answer your questions is often difficult. Here are some suggested places to search for answers:

- Health plan sponsor
- Health plan case manager
- The transplant coordinators at a transplant center
- The Resource Guide at the back of this booklet
- The National Marrow Donor Program (NMDP) website marrow.org

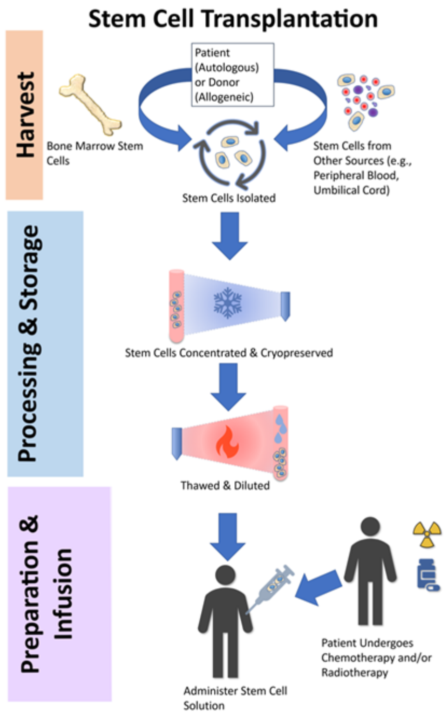
Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

How Hematopoietic Stem Cell Transplantation Works

How Hematopoietic Stem Cell Transplantation Works

Autologous



It is something of a misnomer to refer to this procedure as a transplant. The basic idea behind an autologous HCT is to cure certain types of cancer by giving the patient high doses of chemotherapy (HDC) with or without total body radiation therapy (TBI) in an attempt to eradicate the cancer. In the process of giving this much treatment, the bone marrow is destroyed. This would be fatal. To prevent this from happening, a patient’s bone marrow cells are harvested prior to treatment. After the treatment period, the previously harvested cells are returned. In effect, patients are “rescued” by an infusion of their own stem cells. Sometimes, physicians call this high-dose chemotherapy with stem cells rescue rather than transplant. If all cancer has been eradicated, the patient will be cured. Since the patients receive their own cells back after the HDC and TBI, they usually do not face any of the long complications of an allogeneic HCT (see below). However, during the period when their stem cells are re-populating, called the aplastic phase, the reduced amount of immune activity in the bone marrow leaves these patients susceptible to infections.

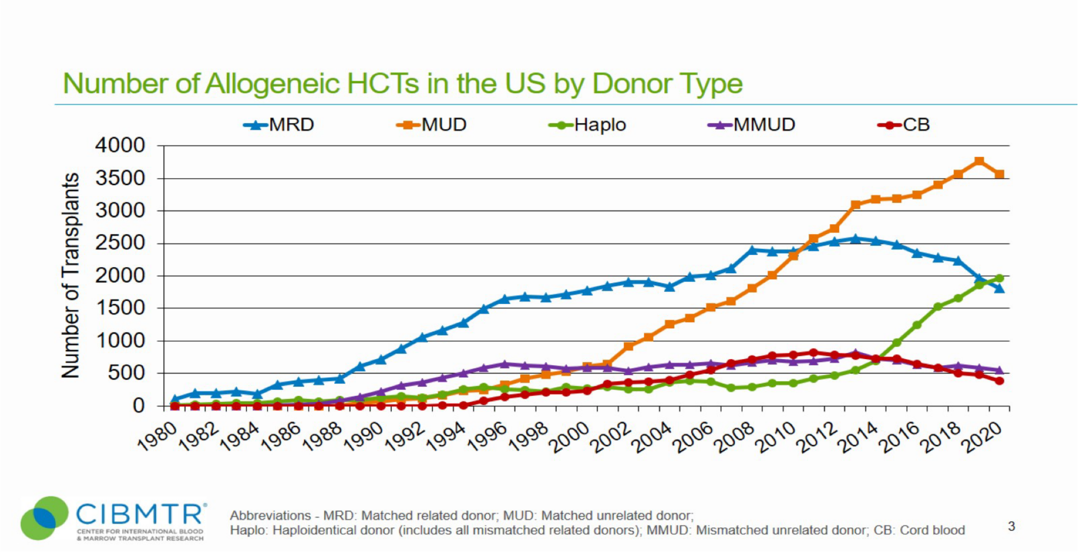
Allogeneic

In contrast to autologous HCT, in allogeneic transplants, the patient’s bone marrow is repopulated (rescued) with a different person’s bone marrow cells after the pretransplant HDC and TBI has been completed. The challenge with allogenic transplants is that the donor and recipient are genetically different. The immune systems of donor and recipient will recognize each other as foreign, and each will try to destroy the other. When the recipient cells try to reject the donor, this is called rejection; and when the donor cells (called the graft) try to reject the recipient, it is called graft versus host disease (GVHD). One would think that a patient who received marrow from a genetically identical sibling (syngeneic transplant) would have the best results. However, recipients of syngeneic transplants have a much higher rate of cancer recurrence compared with patients who receive transplants from imperfectly matched donors (allogeneic). These results led to the understanding that the donor’s immune cells can react against residual tumor cells in the recipient (Graft Versus Tumor Effect or GVTE) in addition to repopulating the patient’s marrow with healthy cells. As a consequence, clinicians today design allogeneic transplants to take advantage of the GVTE which helps to reduce the toxicities of the pre-transplant treatment regimen.

Cell Sources

Physicians can select autologous or allogenic donor cells from hematopoietic cell sources for patients in need of transplantation: 1) bone marrow, 2) peripheral blood stem cells (PBSC), and 3) umbilical cord blood. Allogenic transplants are further classified by donor source as: Matched Related Donor (MRD), Matched Unrelated Donor (MUD), Haplo-identical (Haplo) donors who share ½ of identical genes with the recipient, Mismatched Unrelated Donors (MMUD), and Cord Blood (CB) donors. Physicians select the hematopoietic cells based on a patient's characteristics, disease, and disease status.

Currently, the most common graft choice is peripheral blood stem cells, which are used in 80% of all transplants. Bone marrow and umbilical cord blood are used in 13% and 8% of transplants, respectively.



Number of Allogeneic HCTs in the US by Donor Type

Abbreviations - MRD: Matched related donor; MUD: Matched unrelated donor; Haplo: Haploidentical donor (includes all mismatched related donors); MMUD: Mismatched unrelated donor; CB: Cord blood

In 2020, a total of 22,013 HCTs were performed in the United States and reported to the Center for International Blood and Marrow Transplant Research (CIBMTR). Of these, 4,864 (22%) were unrelated transplants and 4,160 (19%) were related transplants.

More than three-quarters (77%) of the unrelated transplants and three-quarters (80%) of related transplants were performed using peripheral blood in 2020.

Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Indications for HCT

Indications for HCT

Leukemia and Myelodysplasia

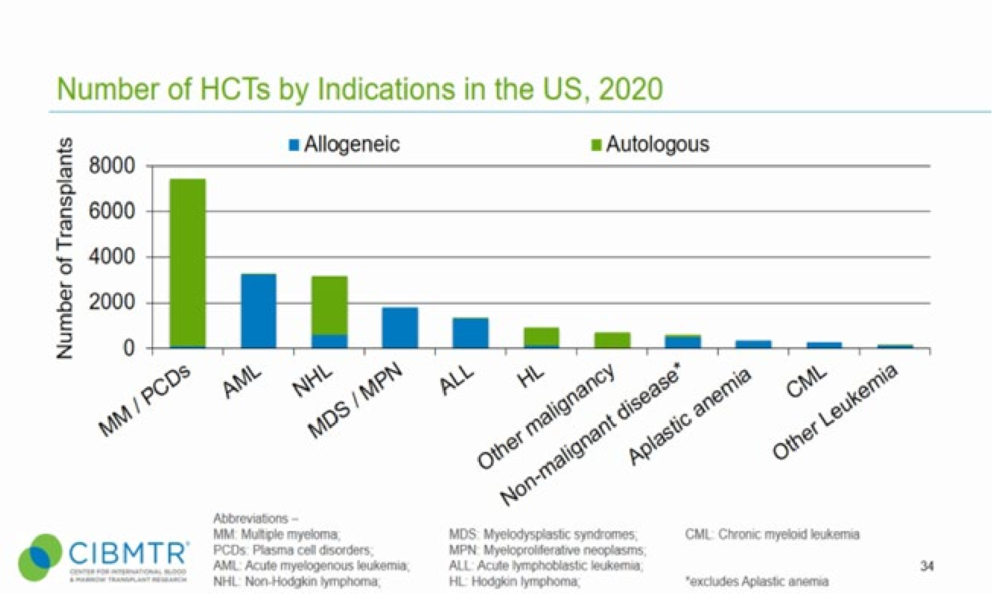
- Acute Myelogenous Leukemia (AML) - Adult
- Acute Myelogenous Leukemia (AML) - Pediatric
- Acute Lymphoblastic Leukemia (ALL) - Adult
- Acute Lymphoblastic Leukemia (ALL) - Pediatric
- Myelodysplastic Syndromes (MDS)
- Chronic Myelogenous Leukemia (CML)
- Chronic Lymphocytic Leukemia (CLL)

Lymphomas and Multiple Myeloma

- Non-Hodgkin Lymphoma
- Hodgkin Lymphoma
- Multiple Myeloma

Non-Malignant Disorders and Other Diseases

- Severe Aplastic Anemia and Other Marrow Failure Syndromes
- Sickle Cell Disease
- Thalassemia
- Immune Deficiency Diseases
- Inherited Metabolic Disorders
- Other Diseases



Number of HCTs by Indications in the US, 2020

Abbreviations –
MM: Multiple myeloma;
PCDs: Plasma cell disorders;
AML: Acute myelogenous leukemia;
NHL: Non-Hodgkin lymphoma;
MDS: Myelodysplastic syndromes;
MPN: Myeloproliferative neoplasms;
ALL: Acute lymphoblastic leukemia;
HL: Hodgkin lymphoma;
CML: Chronic myeloid leukemia

*excludes Aplastic anemia

Changing Indications

The indications for autologous and allogeneic HCT are changing rapidly as more is known about the cytogenetics of leukemias and lymphomas and as newer methods of addressing the specific cancer cell defects associated with these illnesses are developed. The first well-known example of this advance was the introduction of Gleevec© which specifically inhibits an enzyme (tyrosine kinase) that is overproduced in patients with Chronic Myelogenous Leukemia (CML). CML patients treated with Gleevec have a high probability of achieving a durable, long-term remission. As a result, the number of HCT transplants for CML has declined dramatically in recent years.

Other such advances are being investigated and should be anticipated. Among the most exciting are drugs that modify the immune functions, and T-lymphocytes (a form of white cells) being engineered in the laboratory to fight specific blood and solid cancers.

Patient Selection Criteria

Patients with diseases known to respond favorably to HCT will also need to meet specific general medical criteria. Criteria below are typical for most centers. Each center will be happy to share their specific selection criteria.

- Good physical condition with no serious neurologic or psychiatric condition
- Normal renal function
- Normal heart function
- Normal lung function
- Normal liver function
- Patients must be HIV negative and have no active infections
- Patients must be willing to sign informed consents and cooperate with extensive follow-up examinations
- Patients must have evidence of their source of financial support (insurance) for the transplant

Contraindications

- HIV+ status whether or not clinical AIDS is present. (This is not absolute. Certain centers might be willing to evaluate patients who are HIV+ under certain circumstances under investigational protocols.)
- Significant systemic or multi-system disease
- Severe non-correctable cardiac, vascular, or lung disease
- Active or extrapulmonary infection
- Significant liver disease
- Significant kidney disease

- Cachexia or morbid obesity with BMI < 20 or > 35
- Current cigarette smoking
- Drug or alcohol abuse
- Psychiatric illness
- Severe osteoporosis
- For myeloablative allogeneic transplants, generally age > 55 years is considered on a case-by-case basis. The newer, non-myeloablative techniques are more well-tolerated by older patients. This opens more treatment possibilities for patients older than 55 years.

Donor Selection

A potential HCT recipient and a prospective donor are screened to assess the degree of genetic similarity between the two. Siblings with the same parents can be one haplotype match (also called haplo identical), meaning that ½ of the genes are identical. Because of this partial genetic similarity, researchers have found that this is the best circumstance to create graft versus cancer effect without causing vigorous rejection or GVHD reaction. Birth parents are always haplo-identical matches, but there can be other health or family challenges that limit the ability of older people to be good HCT donors. In fact, some centers will not screen parents because of this. If there is no well-matched related donor, unrelated donors become the next best source for hematopoietic stem cells. If the patient is an infant or a child and the center has expertise in cord blood transplants, they may search for a cord blood donor. Otherwise, the HCT center will conduct a nationwide search for a well-matched unrelated donor through the National Marrow Donor Program or NMDP. The NMDP maintains a registry of all people in the United States who have said they are willing to be hematopoietic cell donors. Currently there are more than 10.5 million potential donors and nearly 185,000 cord blood units (CBUs) registered. The Donor registry also has partnerships with international and cooperative registries that provide access to 20.5 million potential donors and 590,000 CBUs worldwide. For more information, visit the NMDP website at https://network.bethematchclinical.org/about-us/

Harvesting Stem Cells

Bone marrow transplant teams can procure (harvest) donor cells using different methods. Adults have a small number of bone marrow stem cells always circulating in their blood. Through a process called apheresis, these stem cells can be filtered out of the donor’s blood over a period of several hours.

Sometimes, more than one apheresis session is required to retrieve enough cells for a successful transplant to the recipient. Donors are generally pretreated with special medicines called colony-stimulating factors or CSFs that stimulate production of more than the usual number of stem cells to make the collection easier and faster. The procedure is virtually painless for the donor and is similar to donating blood at the Red Cross except that in this case, the donation is a continuous process that can last for several hours. Only the stem cells are removed from the donor's blood.

Donor cells can also be harvested directly from the bone marrow. This is usually done by lightly anesthetizing the donor and placing a needle directly in the bone marrow, usually in the hip bone (pelvis). There are very few complications, but donors may experience some mild, short-term pain at the site for a day or two afterwards. Each case is different, and the transplant team will help determine which method for obtaining stem cells for transplant is best for each donor-recipient circumstance.

Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Variations in Allogeneic HCT

Variations in Allogeneic HCT

Non-myeloablative HCT (“mini-allogeneic HCT” or “mini-allo”)

Non-myeloablative allogeneic HCT or “mini allo” transplants are types of HCT aimed at trying to induce the recipient’s native stem cells to coexist with the donor’s stem cells. This state where two individuals’ cells survive together is called mixed chimerism. The goal is to reduce the toxicity from completely ablating the recipient’s bone marrow and still generate a robust graft versus tumor response, limit or avoid the recipient rejecting the donor cells and avoid graft versus host disease. In a non-myeloablative HCT, the patient is given a reduced dose of the conditioning regimen and may or may not have TBI. The goal is to suppress the recipient’s immune system sufficiently to allow engraftment of the donor marrow which will then attack the residual tumor. Immunosuppression in the post-transplant period must achieve a delicate balance to minimize rejection of the donor cells by the recipient’s immune system and the severity of graft versus host disease (GVHD), while not immunosuppressing so much as to prevent the graft versus tumor effect. Frequently, these patients will receive boosts of donor cells to further enhance the graft versus tumor effect. These are given in the form of donor lymphocyte infusions (DLI).

Typically, a DLI infusion is performed in an outpatient setting. Because the non-myeloablative HCT is associated with less toxicity from pretransplant conditioning treatment, this approach has expanded treatment possibilities for older patients with leukemia, lymphoma, and multiple myeloma who would not ordinarily be candidates for allogeneic HCT. In many centers, the upper age limit for eligibility has been increased to 70 years for suitable candidates.

Haploidentical HCT

In haploidentical HCTs, the donor can be a parent or a sibling of the potential recipient. In this instance, the patient will share ½ of the genes with the donor. Patients who receive cells from their mother tend to do better than when their father is the donor. The hypothesis is that the patient has been exposed in utero to maternal cells and has developed a certain amount of tolerance to maternal antigens. Although the numbers are increasing, haploidentical transplants are more difficult than the typical unrelated allogeneic HCT and fewer centers in the US perform these.

Cord Blood HCT

Cord blood HCT is an emerging area. Like haploidentical HCT, this therapy is limited to certain centers that are developing particular expertise. In theory, cord blood transplants should be better tolerated by the recipient since the stem cells in cord blood come from newborns and should be better able to adapt to the new host. In practice, cord blood HCTs are associated with a longer length of stay, the possibility of more immediate complications due to delayed engraftment, and a higher chance of failure to engraft, all because the patient is receiving a smaller dose of cells. This means that it takes a longer time to achieve the critical marrow cell mass necessary to support the recipient.

Tandem HCT

Tandem transplants (a planned HSCT followed by another planned HSCT) are being performed in many centers. This can include autologous to autologous, allogeneic to allogeneic, and autologous to allogeneic transplants. In adults, these have been proposed in the treatment of multiple myeloma. In children, tandem transplants have been done for the management of neuroblastoma and other solid tumors. This is an area that is currently being studied extensively.

Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Pre-Transplant Period

Pre-Transplant Period

Important people you'll want to get to know!

The following people will be very important as you progress through the transplant process.

- Your local doctor
- Your health plan case manager
- Transplant physician
- Transplant coordinator
- Transplant social worker
- Transplant financial coordinator

The Transplant Procedure

The conditioning process:
After completing the pretransplant tests and procedures, patients begin a process known as conditioning. During conditioning, transplant candidates undergo chemotherapy and possibly radiation to:

- Destroy cancer cells for cancers that may spread to other parts of the body
- Suppress the immune system
- Prepare the bone marrow for the new stem cells

The type of conditioning process depends on several factors, including the disease being treated, the overall health of the candidate, and the type of transplant planned. Patients may have both chemotherapy and radiation or just one of these treatments as part of the conditioning process.

Side effects of the conditioning process can include:

- Nausea and vomiting
- Diarrhea
- Hair loss
- Mouth sores or ulcers
- Infection
- Bleeding
- Infertility or sterility
- Anemia
- Fatigue
- Cataracts
- Organ complications, such as heart, liver, or lung failure

Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Medications or Other Measures That Can Help Reduce Side Effects

Medications or other measures can help to reduce such side effects.

Reduced-intensity conditioning

Based on the candidate’s age and health history, patients may receive lower doses or different types of chemotherapy or radiation for the conditioning treatment. This is called reduced-intensity conditioning. Reduced-intensity conditioning kills some cancer cells and suppresses the immune system. Then, the donor's cells are infused. Donor cells replace cells in the patient’s bone marrow over time. Immune factors in the donor cells may then fight the cancer cells.

What you can expect

During the bone marrow transplant

Usually, a bone marrow transplant occurs after the completion of the conditioning process. Stem cells are infused through a central intravenous line. The transplant infusion is painless and does not require sedation or anesthesia.

After your bone marrow transplant

When the new stem cells enter the body, they travel to the bone marrow. In time, they multiply and begin to make new, healthy blood cells. This is called engraftment. It usually takes several weeks before the number of blood cells return to the standard range. In some people, it may take longer.

In the days and weeks after the bone marrow transplant, blood and other tests are necessary to monitor engraftment and the patient’s general condition and manage any complications. Sometimes, patients need to stay in the hospital for several days or longer. Depending on the type of transplant and the risk of complications, patients often need to remain near the hospital for several weeks to months to allow close monitoring.

HCT recipients may also need periodic transfusions of red blood cells and platelets until the bone marrow begins producing enough such cells on its own.

Patients may be at greater risk of infections or other complications for months to years after the transplant. Over the long term, recipients meet regularly with their health care provider to check for late complications.

Re-transplantation

Distinct from tandem transplants, which are planned to be a series of HCTs as part of a defined treatment protocol, there are instances where a patient has received an initial autologous HCT as part of a definitive treatment plan but has suffered a relapse. In this instance, a second HCT may be offered. This will likely be an allogeneic HCT and may be offered as part of a research study often referred to as an investigational protocol or a clinical trial (see below). In these situations, newer treatments under study are reasonable choices and should be carried out under the authority of an investigational review board (IRB) at the treating center. See https://clinicaltrials.gov for more information. Prominent among these new agents are the monoclonal antibodies (Rituxan and Campath, for example) that are directed at specific cell lines. These are important in the body's natural defenses against the tumor or help the body to accept the new graft. Another novel approach is to bind therapeutic agents to a monoclonal antibody so that they will be delivered selectively to a specific cell line (Zevalin and Bexxar, for example).

Clinical Trials

As you can see from the previous discussion, HCT is a dynamic and rapidly evolving field. Newer agents are being introduced all the time through clinical trials. As a result, there are many early and later phase clinical trials being run by HCT centers in the US. Clinical trials are specially designed to answer questions about the safety and tolerability of new treatment regimens and are the most important way for the field of HCT to advance.

Candidates for HCT are frequently referred to centers conducting these clinical trials either because first line care has not been completely successful or because preliminary testing has indicated that a clinical trial protocol might have better chances for success. All participation in clinical trials is voluntary. However, sometimes participation in a clinical trial may be the only option for specific and less common conditions that would not otherwise be treatable with traditional therapy. In fact, in major HCT centers, the majority of patients may be offered treatment in clinical trial protocols.

Many clinical trials are conducted in multiple centers at the same time to get more information about a specific treatment faster. All clinical trials must be reviewed and approved by the medical center's Institutional Review Board (IRB) and are frequently sponsored by national organizations like the National Institutes of Health (NIH), National Cancer Institute (NCI), and various national or regional cooperative oncology groups.

Sponsored clinical trials should not require patients to bear additional costs. Many health plans have exclusions for treatment that is considered investigational or experimental. All treatments that are not standard of care should be tested in clinical trials that meet the federal regulations for the protection of human subjects (see https://www.hhs.gov/ohrp/index.html) which among other requirements include using IRB-approved protocols. Clinical trials are the backbone of HCT programs in large academic centers and may offer the best treatment for many illnesses where standard care no longer offers a reasonable chance for a cure. It is always advisable for patients considering enrolling in a clinical trial to seek an independent evaluation of the proposed treatment plan and protocol by an independent reviewer.

Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Frequently Asked Questions

Frequently Asked Questions

Evaluating Different Centers and Programs

Important factors to take into consideration when evaluating an HCT program include:

- The transplant program is part of a tertiary care center recognized as a leading transplant center with a regional and/or national reputation. The center will receive referrals from other major medical centers in the area because of their expertise
- The center offers all three types of transplants: autologous, related allogeneic, and unrelated allogeneic transplants.
- The program meets or exceeds an annual minimum volume of ten (10) transplants for each transplant type. If they have a pediatric program, they should have experience in transplanting children under the age of ten.
- The program should be in existence for at least three years with substantially the same professional team.
- The program director has had at least three years of experience as a stem cell transplanter and is engaged in HCT full-time.
- The center follows ASBMT guidelines (American Society for Blood and Marrow Transplantation).
- The center is FACT accredited (Foundation for the Accreditation of Cellular Therapy).
- The center is a member of the NMDP (National Marrow Donor Program).
- The center participates in multicenter clinical trials sponsored by government or highly regarded industry sponsors.
- The center is affiliated with a university, and if it has a post-graduate training program, that program meets ASBMT standards.
- The program meets one or more of the following criteria: participation in NCCN, the NCI Clinical Trials Network, has designation as an NCI Comprehensive Cancer Center, or is an NCI Clinical Cancer Center.
- All care is performed under institutionally approved protocols for standard established care or care is delivered through clinical trials that meet OHRP guidelines and has been reviewed and approved by the center’s Institutional Review Board (IRB).
- All patients are evaluated within the program and patient selection is performed using institutionally approved protocols administered by an institutionally based patient selection committee.
- The transplant takes place, and all subsequent care is rendered, through the institution where the patient was evaluated.
- All pre-and post-transplant care is coordinated by full-time employees of the institution.
- There is close communication with the referring physician and health plan.
- Housing is available for families and patients near the center and the center staff assists the families with these arrangements.

How do I go about evaluating and comparing program statistics?

Evaluating and selecting a transplant center is a decision best made between you and your physician. Current donor and transplant program statistics are listed on

https://network.bethematchclinical.org/
https://www.cibmtr.org/ReferenceCenter/SlidesReports/USStats/Pages/index.aspx
https://bloodstemcell.hrsa.gov/data/donation-and-transplantation-statistics/transplant-activity-report

Is there a single statistical indicator that would indicate the "best" program?

No. You can get excellent services and results at any qualified medical center. Using a national transplant center is not a guarantee for superior outcomes. However, experience is often a reliable predictor of a favorable outcome. The number of years the medical center has been certified, the total number of transplants performed since inception, and the number of transplants performed annually are all good indicators of experience. Large, national HCT programs typically have the depth and breadth of experience that produces more consistent medical outcomes with fewer complications.

Questions To Ask When Choosing a Center

What types of transplants do you do?

INTERLINK strongly recommends that patients be referred to large, academic, or academically oriented centers that have had considerable experience with both autologous and allogeneic HCTs. We require that our centers be members of the NMDP and accredited by FACT (Foundation for the Accreditation of Cellular Therapy) for all aspects of autologous and allogeneic HCTs.

INTERLINK feels it is important for our members to use centers that perform the full range of HCT transplants because the transplant center has the option to choose the transplant regimen best suited to individual patient needs. If a center offering only one type of HCT is chosen, treatments may be biased toward the procedure they offer.

Centers that participate in high quality clinical trials also provide more options to patients and usually employ some of the most respected clinicians in the field.

How long has your program been in existence?

Experience in transplantation is important. The longer the team has been together, the better. Like other complex medical procedures, patients may expect the best outcomes from the most experienced teams. In general, candidates should consider programs where the entire team, including the HCT team, the other medical specialists and subspecialists, the nurses, the coordinators, the social workers, the pharmacists, and so on have been working together for at least three years in the center you are considering for your care.

How many of each type of HCT did you do last year and the year before?

Outcomes in HCT are often correlated with the experience of the team and the center. In general, high-volume programs produce better results.

What are your outcomes?

Centers should be willing to share their experience. The only publicly available data on transplant outcomes is found on the NMDP website (https://bethematch.org/). Outcome data varies after HCT because different diseases for which the transplant is done have different survival characteristics. There are many different combinations of diseases, clinical states and types of transplants to compare and a relatively large number of centers. And, in general, each center does a relatively small number of HCTs for specific diagnoses, making it difficult to generalize about results. Often, programs doing most forms of HCT will have the best outcomes for very sick patients. It is more important to understand the types of conditions being managed at a center, the number of transplants of each type being done, the indications for each type of transplant, the experience of the transplant team and the ability of the hospital to support a very complex program. Large, national centers such as those in the INTERLINK Transplant Network offer the best possibility of a good outcome. By using an INTERLINK credentialed transplant center and program, you receive the benefit of professionals who have already assessed the facility's ability to provide a full range of complex transplant services.

What is the experience of the physicians on your staff?

The more years of experience the transplant physicians, subspecialists and other medical specialists have, the more likely they will be able to select the best treatments for individual conditions and patients to avoid complications and successfully treat complications should they arise.

What is the experience of your nurses?

Like the physicians, the experience of the individual nurses and the nurses working together is an important consideration. A high-functioning support and care team with transplant experience directly influences outcomes and how well overall the program performs.

What special training do the nurses and other professional staff receive?

Expect that any program will have a formal training program for the nurses that staff the transplant care units. Most of the training will be done on the job with close supervision and a formal mentoring program. Most centers will have regular education and update sessions for their staff.

Can you put me in touch with one or more patients who have undergone the same transplant being recommended for me?

Because of privacy concerns, some centers may be reluctant to share the names and contact information of previous patients. But prospective patients should ask. The large HCT programs are very proud of their accomplishments and have developed very active survivorship programs. These patients are often very willing to talk to transplant candidates. Past recipients' experience can be invaluable. They can provide important insights into the whole HCT process and whether the center in question is a good fit.

Do you have a support group for patients and their families?

Support for patients and their families is very important throughout the transplant process. Almost every HCT center will have well-organized patient support and caregiver support groups. Many questions and concerns are best addressed by people who have experienced the process and care involved. Look on the center's website for information on their support group(s) or call the transplant financial coordinator, transplant social worker, or transplant coordinator at the center and ask for more information.

What is your visitation policy?

Most transplant centers have liberal visitation policies for critically ill patients. However, immediately after a HCT transplant, patients are usually maximally immunosuppressed, and in general interaction with outsiders is limited to prevent them from spreading an infection during this vulnerable time. Each center will have its policies for handling this period. Patients and families should ask the transplant coordinator how they regulate the flow of visitors.

Do you allow rooming-in?

Many centers provide some type of accommodation in the hospital itself to enable families to be close to the patient during critical times. Because of the infectious risk during the period immediately after the transplant while the immune system is recovering, the center may not allow rooming-in during that period. Ask the transplant coordinator.

Insurance and Other Financial Questions

What are my in-network and out-of network benefits?

Most health plans have at least two levels of transplant benefits: in-network and out-of-network. In-network benefits pay for the most coverage even though the plan may restrict patients to use only certain doctors and hospitals. Out-of-network benefits usually offer a wider choice of doctors and hospitals but typically require the beneficiary to pay more “out of pocket” for services with these providers.

Patients need to check with their insurance carrier about whether the transplant center to which they are referred is in-network or out-of-network. This may have important financial consequences. In general, it is a good idea to be evaluated at an in-network center for transplant care. The INTERLINK Transplant Network chooses its participating centers with great care. Only the foremost national centers have been invited to participate in this network. Other centers may or may not have the years of experience and comprehensive facilities that are available through INTERLINK centers. Patients should understand their benefits fully and the advantages one center may offer over another before deciding.

Is there a limit on how much my health plan will pay for my transplant?

In general, insurance plans control transplant costs by declaring a maximum allowable (procedure limits) fee. Insurance reform has mandated that annual limits on the dollar value of “essential health benefits” may not be established, unless that plan has “grandfathered” status and is sold on the individual market. We advise patients to contact their plan to understand their transplant benefit and the type of plan in which they are enrolled to determine coverage and the plan’s interpretation of “essential health benefits”.

Does my insurance cover the full cost of Stem Cell donation?

You must check with your plan.

All medical costs for the donation procedure are covered by the National Marrow Donor Program® (NMDP), which operates the Be The Match Registry®, or by the patient's medical insurance, as are travel expenses and other non-medical costs. The only costs to the donor might be time taken off from work.

If my insurance does not cover all of the cost, where can I get financial assistance?

The first place to turn to is the transplant center of choice. Speak with the financial coordinator. The financial coordinators in large national centers have had years of experience working with patients to solve the most challenging financial questions. This experience is yet another example of the depth and breadth of experience one finds in large national transplant centers that may be lacking in smaller programs.

Note: Also, check the Financial Assistance section in the Resource Guide at the end of this booklet. Some organizations are listed that may be able to provide direct support or advice.

Coordination of Benefits (COB)?

In addition to your health plan, there may be additional insurance coverage available. These resources include Medicare and Medicaid. There are programs for specific illnesses (Medicare coverage for certain patients with end-stage renal disease or ESRD, for example) or for individuals with disabilities (Medicare coverage under certain circumstances for patients with chronic disabilities). The financial coordinators at individual centers are very familiar with program eligibility criteria for these programs and possibly others.

Travel and travel benefits

Some health plans offer financial assistance for travel, lodging, meals, and incidental expenses while away from home for transplant-related care. Frequently, the benefit may only be available while the patient remains in the network and utilizes an in-network participating national transplant center.

Housing

Most national transplant centers can arrange temporary housing for patients and their families. Many centers own apartment units that are available to transplant candidates and recipients' families. The cost for facility-owned housing ranges from nothing to a small charge that is well below what you would expect to pay if you rented the same apartment or hotel room. If the center does not own housing, they usually have arrangements with nearby hotels, apartments, or corporate housing units for their patients and families who must remain in the area for an extended period. For further information, check with the transplant financial coordinator or transplant social worker at the center of choice. Schools for children who can't be left with relatives during the pre-transplant and post-transplant periods are available at many of the large transplant centers as well.

Jobs and income

Every employer has its policy. Most employers will be very understanding of the needs of the entire family. But this is a highly individual decision, and one employer's policy may be very different from the next. Local laws for paid or unpaid family leave may also come into play.

Initial Evaluation

Where will it be done?

The pre-transplant evaluation is done at the chosen transplant center.

How much of it can be done by my local doctor?

Most of the testing can be ordered and supervised by your doctor. However, most transplant centers will insist on doing the tissue matching themselves or through the NMDP if for patients being considered for a matched unrelated allogeneic HCT. The doctors at the transplant center will work with local doctors to coordinate the testing. The results will be shared with the local doctor and the specialists at the transplant center.

Will it be inpatient or outpatient?

In general, all pre-transplant testing can be done as an outpatient if the patient's condition does not require hospitalization before the transplant. Occasionally, centers do require that the patient be admitted to the hospital for testing. Patients should check with their chosen center to learn about their pre transplant policies and procedures.

How long will it take?

A new patient evaluation generally takes 1-3 days. These are typically full days. The evaluation process involves appointments with the physicians and coordinators who will work with patients for the entire time they are at the center, from pre-transplant through the post-transplant period. If specialized testing is necessary, it will be scheduled at the time of the initial evaluation.

How soon after the evaluation will they let me know if I am a candidate for the HCT and what will be the best type of HCT for me?

This varies quite a bit from one center to another and even from program to program within a center. A lot depends on how complex the individual case is, whether additional or specialized testing is required, how many patients they are evaluating, and other factors that determine the work schedule at the transplant center. In general, most centers will provide a report to your physician within a few days following your evaluation.

Selection Criteria

What factors do the transplant centers take into consideration when evaluating me for an HCT?

Every center has different selection criteria depending on their experience, specific conditions they treat or the research interests of the medical team. All HCT programs adhere to basic guidelines and are accredited by the Foundation for Accreditation of Cellular Therapies (FACT). Refer to the previous sections for the typical indications, contraindications, and patient selection criteria used at most large centers.

The Selection Committee?

As soon as all test results are available following the evaluation, candidates' cases will be presented to a selection committee. At national centers, the selection committee is made up of the entire transplant team including the transplant medical specialists and subspecialists, nurse coordinators, the head nurses of the inpatient transplant unit and HCT clinic, transplant pharmacist, social workers, financial coordinators, and the program director. Patient selection is a group decision within the committee. Selection is made based on FACT criteria, the latest scientific evidence and the experience of the center.

If I am turned down by one center does this mean that I will be turned down by every center?

No. Each center looks at potential candidates with their own lens and applies their own criteria. Patients not meeting one center's criteria may be accepted by a center that specializes in taking care of patients with specialized conditions or that has a research interest in newer treatments for rarer conditions. It may be advisable to check with a prospective center to learn more about their selection guidelines.

Can I be listed at more than one center?

Yes, however there is no advantage to doing so. All candidates for an allogeneic transplant who have no suitable family donors have access to the NMDP. All doctors, centers, and candidates have access to the same database. It is a truly national search. Thus, the search results and donor availability are the same regardless of who is requesting the search or where the patient is being treated.

Who pays for the second (or third) evaluation?

Some health plans may allow a second evaluation at another center for candidates who have been turned down at the first center. Each health plan has its policy, so candidates are advised to check with their plan.

Finding A Stem Cell Donor

How do I know if a relative is a good match for me?

Candidates have blood samples drawn to determine the tissue type. The tissue type is made up of genetically determined cell markers that stimulate and control the immune system. After this is done, close relatives who are willing to be a donor will be screened. Donors must be in good health and meet other selection standards at that center. If a relative is found who is willing and able to be a donor, a sample of their blood will be tested to see if their tissue type is a favorable match.

What happens if I do not have a relative who is a good match?

In this case, the transplant center will contact the NMDP to request a preliminary search of the NMDP database for suitable donors throughout the US and the rest of the world, if necessary. If it appears that there are one or more people who could be a suitable donor, the transplant center will work with the NMDP to complete the evaluation of the potential donors and coordinate the harvesting of their stem cells at the appropriate time. There are additional stem cell registries focused on individual ethnic groups that could assist in the search for a suitable donor. See the Resource Guide at the end of this booklet.

Being A Stem Cell Donor

How do you get the stem cells from the donor?

The primary source of stem cells has changed dramatically in the past few years. Traditionally, stem cells have been obtained from marrow inside the bone. In recent years, harvesting stem cells through processing the donor’s blood (apheresis) has become the most common source. Because these stem cells reside within the circulatory system and not in the bones, they are referred to as peripheral stem cells (PSC). This has the obvious advantage of being a much less invasive and less painful procedure for the donor. Apheresis does not require anesthesia or a surgical procedure. Donors are pre-treated with colony-stimulating factor (CSF) drugs to stimulate the production of stem cells. Usually, the harvesting is done in several sessions until a sufficient number of cells have been obtained.

Where will the harvesting be done?

The collection process is done in a hospital laboratory or clinic that has met FACT accreditation standards and participates with the NMDP registry. If the donor is a relative, the transplant center’s doctors will arrange for the donation and work with the closest collection center to the donor. If the donation is being done through the NMDP or another registry, they will make arrangements for the donation.

Does it hurt?

No. Donating peripheral stem cells is just like donating blood. It takes more time, however, and more than one session may be needed. In rare instances, the stem cells must be taken directly from the donor's bone marrow. This is potentially uncomfortable. To make the donor more comfortable when the bone marrow is accessed directly (usually from the hip bone), a general anesthesia is used similar to a wisdom tooth being pulled. Afterward, there may be some soreness for several days at the sites where the marrow was extracted. Because of the discomfort and need for anesthesia during bone marrow donation, peripheral collection of stem cells from the circulatory system is the preferred source for stem cells.

What happens to the stem cells after the donation?

In certain cases, there are special procedures, usually done in specialized laboratories, that may be applied to enhance the donated stem cells. After the collection and any additional processing, the cells will be frozen until they are needed. They are stored in blood bags much like standard donated blood.

Are there any long-range side effects from the donation?

No. No complications or adverse health risks have been reported related to donating stem cells. All donors are followed by the NMDP to see if there are any long-term unknown consequences. After many years of experience, no long-term consequences have been found. The NMDP will continue monitoring all donors for the foreseeable future.

How long will the donor be hospitalized?

The collection of stem cells from the peripheral blood (apheresis) is an outpatient procedure and does not require hospitalization. If the collection must be done directly from the bone marrow, the procedure is usually be done in the "day surgery center" of the collecting hospital.

Do I have to move to the city where I will get my transplant?

Probably not. Most of the large national centers specialize in managing HCT patients at a distance, even internationally.

How close to the hospital do I have to be?

This is not as critical as it is when waiting for solid organ transplants since HCT is generally scheduled electively, in advance. However, transplant recipients will have very frequent follow-up at their center in the early post-transplant period. Most HCT centers accept patients who come from great distances for treatment and can arrange for short term housing near the center.

Many of the large national centers in the INTERLINK Transplant Network have sizeable numbers of international patients. Check with the center(s) under consideration.

Who will help me when I go to the transplant center?

The transplant financial coordinators, transplant coordinators and social workers will help you with housing and local transportation. Most often, transplant candidates arrange to bring a "caregiver" to be with them through the transplant admission and following stay. A caregiver is typically a family member or close friend. Caregivers are special people who play an important role and do not need any specific medical training before they arrive.

Will anyone help me with the expense of going to and from the center and the cost of lodging when I am there?

Check with the health plan. Some plans have a transportation and lodging benefit that will help to pay for some, if not all, of the expenses associated with traveling to the transplant center.

Can my caregiver get time off from work?

Caregivers play an important role in supporting transplant recipients along their journey. This is highly variable from employer to employer. Different states have laws regarding family leave and paid family leave. Employees can check with their employer or the care giver's employer human resource departments.

Do I need to have any special immunizations before a transplant?

Because the HCT transplant causes a temporary immune compromise, HCT programs require that candidates are fully vaccinated before the transplant, ideally before the evaluation process is completed. This is to ensure that recipients are as protected against these infections as possible by eliciting an immune response to the shots at a time when the immune system is most able to respond. Individual programs have different vaccine requirements, and these requirements should be explored with them at the first encounter.

Do I need to have any special dental work done before the transplant?

In general, patients undergoing chemotherapy and/or HCT are to have all necessary dental work done prior to the beginning of treatment. There can be very significant dental complications if this is not done. A thorough dental history will be part of the initial evaluation at a HCT center.

What is my local doctor's role?

The transplant center will keep your local doctor completely informed along the way. Before and during the evaluation process, more care will be done by local physicians working closely with the doctors at the transplant center. For the first several months following the transplant, most care will be managed by the transplant center. Generally, depending on progress and specific treatment protocols, most transplant centers want you to return to the care of a local doctor following the transplant and will work closely with them to help this happen as quickly and smoothly as possible. Of course, there may be a need to return to the transplant center according to their treatment protocols and the recipient's recovery. They will send your doctor regular updates after you visit the transplant center. Transplant centers communicate frequently by phone and in writing with local doctors regarding the recipients' transplant care.

Transplant Period

How will I know when my stem cells are ready?

Transplant centers stay in close contact with their patients and donors. In the case of an autologous transplant, the program will inform the patients when enough cells have been collected. For allogeneic transplants, several steps are required to identify and secure a donor and the program will keep candidates informed as these steps progress.

How do I get to the hospital?

The coordinators and social workers help to arrange transportation to and from the transplant center and, when needed, can also help with temporary housing. As mentioned above, HCT transplants are scheduled, elective procedures that can be planned in advance so transportation and housing can be arranged ahead of time.

Can HCTs be done as an outpatient?

Yes. Many centers will schedule autologous HCTs as an outpatient procedure. Admission will generally not be necessary unless there are complications from the chemotherapy prior to the transplant. On the other hand, patients treated with a fully ablative allogeneic HCT always are hospitalized. Generally, these patients are admitted at the start of the final cycle of chemotherapy and total body irradiation therapy and remain hospitalized until blood counts recover enough to avoid bleeding or infectious complications.

Patients receiving non-myeloablative (reduced intensity) allogeneic transplants may or may not be hospitalized depending on the diagnosis, overall condition, the protocol the center is using for the transplant and the center’s general policy concerning non-myeloablative transplants.

How long will I stay in the hospital?

In general, patients receiving autologous or non-myeloablative allogeneic transplants are hospitalized for a few days. Patients receiving fully myeloablative allogenic or cord blood transplants may be in the hospital for 2 to 4 weeks and longer. The primary discharge criteria after a HCT is restoration of near normal blood counts.

Can my family stay with me?

Most transplant centers encourage family members, and especially the primary caregiver, to stay with the recipient throughout the transplant period. Many facilities will make special arrangements so loved ones can be close during this critical time.

Post-Transplant Follow-Up and Care

How long do I have to stay in the city?

After the transplant, each center has different policies. Usually, in the first few weeks after your discharge, the transplant team will schedule follow-up visits several times a week. For this reason, centers like to be sure that recipients are close to the center in the early transplant period. After that, the period between clinic visits will gradually increase and patients can be managed more easily from a distance.

How often do I have to come back?

Each program will have somewhat different schedules or protocols that they follow. Follow-up visits are very precisely scheduled to ensure recipients are seen at the right time for important blood tests and other necessary exams. For patients enrolled in clinical trials, the study protocol will determine the follow up schedule.

What happens if I have a complication?

Transplant programs want to stay closely in contact with their patients and will give each recipient emergency contact information to reach a coordinator, day or night. Coordinators are specially trained to evaluate any possible complications and will give advice to return to the transplant center or to go to your local hospital immediately. If referred to a local doctor or hospital, the coordinator will inform them about the immediate concern and history. The transplant team will be talking with the other physicians at every step to ensure that the local team treats HCT patients correctly.

What happens if I get a fever?

Programs provide detailed instructions to recipients to guide them in managing their post-transplant symptoms. Most centers will want to know if a recipient has a fever after transplant. Fever after HCT and especially after allogeneic transplants, may indicate new infection. Because most allogeneic transplant patients will take immunosuppressive medications, they may be less able to fight the infection. The center will want to know immediately about the fever so they can initiate treatment for the possible infection as early as possible.

Medications

Immunosuppressive medications

Every transplant program uses a similar but slightly different protocol for medications during conditioning before the transplant and, in allogeneic transplants, to suppress the immune system afterwards. There are many sites providing detailed information of these drugs. See https://www.drugs.com/condition/bone-marrow-transplantation.html or https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/stem-cell-transplant/process.html

Who pays for my medicine?

Most health plans cover the cost of medications after an HCT. All candidates should check with their health plan to get a full picture of medication coverage and all other out of hospital treatments. If an individual health plan does not cover the cost of the medicines, many of the hospitals and drug companies have programs to help defray some of the costs. Most programs have specialized pharmacists to help guide medication selection and provide patient information about insurance coverage.

Other medicines

Most transplant recipients will be immunosuppressed for some time after the transplant. All post-transplant protocols include infection prevention medications. Viral and fungal infections that are rare in immune-intact people are much more common after transplant. For this reason, HCT recipients are prescribed antiviral and antifungal medication after transplants. These preventative medications are also covered by most insurance plans.

How much does the medicine cost?

Post-transplant medications and their costs vary tremendously depending on the type of transplant (autologous vs. allogenic), the individual center's medication protocol, the amount and type of immunosuppressive medication used for allogeneic transplants, antiviral and antifungal preventative medications chosen and whether infections or other complications develop. Transplant centers can provide rough estimates for expected out of pocket costs depending on the type of transplant and the recipient's insurance coverage.

Complications of the Transplant

What are the potential complications?

Following an allogeneic HCT, patients can be susceptible to potentially serious complications including GVHD, infection, hemorrhage, and failure of the graft to “take”. Patients who have an autologous HCT or a non-myeloablative HCT are less likely to encounter these complications because these patients retain some of their native bone marrow though the transplant process.

Graft vs. Host Disease (GVHD)?

This occurs when the donor cells (graft) react against the recipient’s native tissues. This happens to a certain extent in all allogeneic transplants except transplants from identical twins. Immunosuppressant medicines that are prescribed after all allogeneic transplants are given to control GVHD. Most patients take these medications for at least one year after the transplant and possibly longer.

Infection?

Infection can be a serious complication after an HSC transplant. After the chemo- and radiation- therapy that is necessary to destroy the bone marrow, patients are vulnerable to infection because the bone marrow that produces the immune cells no longer functions. It is replaced by the transplanted cells that must grow to take over the production of the immune cells. To prevent infections, recipients are given antimicrobial medicines to protect against the most common bacterial, fungal, and viral infections that afflict patients in the post-transplant period.

Failure to engraft?

Occasionally, the donor stem cells do not “take”. This is referred to as failure of engraftment. When this happens, the usual recourse is to repeat the HCT.

Physical Deconditioning?

The conditioning regimen and transplant recovery can be stressful physically and emotionally. Many studies have shown that maintaining as much physical conditioning as possible during this period reduces complications and speeds up recovery time. Many programs will provide physical therapy and exercise programs to keep patients in the best physical condition possible.

Recurrence of the underlying illness?

Some types of blood cancer can relapse after an HCT. These rates vary depending on the type of cancer, the conditioning regimen, the degree of genetic match with the door and a variety of other factors.

Social Issues

Dependence on others?

During the conditioning and early post-transplant period, having a very strong support system is important for getting through the process. Depending on others during this period can be difficult. Caregivers' encouragement and emotional support are crucial factors.

Caregiver's needs?

Caregivers get tired and have their own needs during this time. There are many support groups available for caregivers. Some of these are included in the Resource Guide and in the Recommended Reading at the end of this booklet. Most programs have caregiver programs to help educate and create a network. Caregivers should make use of all the resources that they feel they need, and transplant center coordinators and social workers will help guide them to available resources.

Diet?

As always, a healthy diet is key to staying strong and recovering well, especially during transplant treatment. Transplant centers have dietitian experts that specialize in fulfilling the dietary needs of transplanted patients. These professionals will provide specific advice about what foods to eat and what foods to avoid. Because transplant patients are highly immunosuppressed during the conditioning and early post-transplant period, recipients need to avoid foods that can introduce infections. The dietician spends lots of time educating recipients about these higher risk items.

Sex?

The transplant team advises patients about when it is safe to resume having sexual relations.

Job?

The goal of the transplant is to return to normal activity and good health. This means that recipients should be able to return to work provided that the work environment does not pose a high risk for infections. Recovery time is variable, but most recipients return to work between 3 and 6 months after the transplant.

Promoting
Medical Excellence

Candidate Education Booklet
BONE MARROW TRANSPLANT

Patient Resources

Patient Resources

Glossary of Frequently Used Terms

Allogeneic – Tissue or blood that comes from a genetically different member of the same species.

Apheresis – A filtration process that collects stem cells from circulating blood.

Autologous – Tissue or blood that comes from the same individual.

Bone Marrow - The inner part of your bones where blood cells are made. In adults, bone marrow generally is found in the pelvic bones, long bones, breast bones, ribs, bones of the spinal column (vertebra), and the skull.

CALGB – Cancer and Leukemia Group B, a multicenter cancer clinical trial consortium focused on lymphoma and leukemia.

COG – Children's Oncology Group, a multicenter cancer clinical trial consortium for children

CTN – Clinical Trials Network sponsored by the National Institutes of Health

Cord blood - Blood obtained from the umbilical cord of newborn babies. Cord blood is particularly rich in stem cells.

Cytogenetics - The study of the genetic makeup of a cell. It is becoming increasingly important to understand the cytogenetics of each individual cancer to be able to more precisely tailor cancer treatments and match donors to recipients.

Donor Lymphocyte Infusion (DLI) - Donor lymphocytes (lymphocytes are a type of immune cell in the white blood cell [WBC] category) are frequently given to patients after allogeneic transplants to reinforce the graft vs. tumor effect of the transplant.

ECOG – Eastern Cooperative Oncology Group, a multicenter cancer clinical trial consortium for adults in the eastern US.

Graft vs. Host Disease (GVHD) – A condition where the donor's immune cells attack the recipient's cells. Immunosuppressive medications are given to mitigate GVHD. Symptoms include fever, rash, nausea, loss of appetite, vomiting, or diarrhea.

Graft vs. Tumor Effect (GVTE) - This is similar to GVHD except in this case the donor immune cells are attacking the recipient's cancerous cells that may have been left after the chemotherapy conditioning given before the HCT. In non-myeloablative HCT some of the recipient's cancerous bone marrow is not destroyed and the treatment relies on GVTE to attack the cancer. This also provides the added benefit of less overall immunosuppression.

Haploidentical - Material that shares ½ of the genes with the recipient. Haploidentical donors can be parents, a sibling, or a child. Half (haplo in Greek) of the genes are the same.

Hematopoietic Cell Transplant (HCT) - This is the generic term that covers both bone marrow transplants and PBSC (Peripheral Blood Stem Cell) transplants. Many people still refer to these transplants as "bone marrow transplants" or "BMTs." Today, most are done using peripheral blood stem cells, so using the terms "BMT" or "bone marrow transplant" is not entirely accurate. Bone marrow transplant is an old term based on the source for hematopoietic cells from donors in the early years of this kind of transplant.

Institutional Review Board (IRB) – This is sometimes called a Human Subjects Research Committee. Any center doing clinical research supported by the federal government is required to establish this committee and meet certain standards. IRB's are designed to ensure that potential subjects to be enrolled in clinical research studies are fully informed of the risks and benefits of the study, and that the study itself poses minimal risks beyond the standard of care for enrollees. Many HCT studies are conducted in several centers simultaneously and each center's IRB must review these protocols. This provides an added protection for the patients who can be assured that many different sets of eyes around the country have independently reviewed and approved the study.

National Institutes of Health (NIH) – The NIH is a government-funded group of research institutions with its headquarters in Bethesda, MD, a Washington DC suburb. The NIH is the principal US government funding and oversight agency for medical research activities.

National Cancer Institute (NCI) – The NCI is a branch of the NIH and is the principal research and oversight agency of the US government for cancer research. The NCI designates certain centers around the US meeting certain qualifications as Comprehensive or Clinical Cancer Centers. These centers engage in basic research, clinical research to bring the basic research to the bedside, and patient education and outreach programs. The list of NCI-designated Cancer Centers can be found at https://www.cancer.gov/research/infrastructure/cancer-centers/find.

National Comprehensive Cancer Network (NCCN) – The NCCN is an organization of 32 of the most prestigious cancer centers around the US.

National Marrow Donor Program (NMDP) - The NMDP is headquartered in Minneapolis, MN, and is the organization that maintains a registry of over 39 million potential donors and nearly 806,000 cord blood units worldwide. (https://bethematch.org/)

Non-Myeloablative Transplant ("mini-allogeneic HCT" or "mini-allo") - In this type of HCT, patients do not receive as high a dose of chemotherapy and/or radiation therapy prior to the transplant. Their bone marrow is not completely "ablated" leaving some of the recipient's bone marrow intact. This makes it easier on the patient and leads to fewer complications. The advantage of this approach is that a "mini-allo" is not nearly as hard on the patient and allows for HCT in older patients. It also allows for the desirable GVTE.

Peripheral Blood Stem Cells (PBSCs) - PBSCs are the stem cells that normally circulate in the bloodstream. There are not many of them at any one time, but it is normal to have them in your blood. This is the preferred source for stem cells for most patients undergoing an HCT.

Stem Cells - Stem cells are primitive cells that can mature into many different kinds of cells. Hematopoietic stem cells (also called blood stem cells) can give rise to red blood cells, white blood cells, and platelets.

SWOG – Southwest Oncology Group, a multicenter cancer clinical trial consortium for adults in the Southwestern US.

Syngeneic – Tissues or blood that comes from an identical twin

Resource Guide

What follows is a table of resources that are available to you on the internet. The list is not necessarily complete and INTERLINK does not endorse any of the organizations whose contact information is presented. You should investigate any source of information carefully before making important decisions.

You should take advantage of all these resources in your search for information on your upcoming transplant. It is always important to remember that the best source of information about your transplant will be your physician, the transplant physician, and the support team at the transplant center or centers you are considering.

Web Links

National Comprehensive Cancer Network	https://www.nccn.org/
National Cancer Institute	https://www.cancer.gov/
National Institutes of Health	https://www.nih.gov/
American Society for Transplantation and Cellular Therapy	https://www.astct.org/
HRSA Blood Stem Cell	https://bloodstemcell.hrsa.gov/
Blood & Marrow Transplant Information Network	https://www.bmtinfonet.org/
National Bone Marrow Transplant Link	https://www.nbmtlink.org/
National Marrow Donor Program	https://bethematch.org/
Center for International Blood & Marrow Transplant Research	https://www.cibmtr.org/
Organ Procurement and Transplant Network	https://optn.transplant.hrsa.gov/
American Cancer Society	https://www.cancer.org/

Clinical Trials

FDA – Clinical Trials	https://www.fda.gov/patients/clinical-trials-what-patients-need-know
National Institutes of Health	https://www.clinicaltrials.gov/
Blood and Marrow Transplant Clinical Trials Network	http://www.bmtctn.net/
Alliance for Clinical Trials in Oncology	https://allianceforclinicaltrialsinoncology.org/
Children’s Oncology Group	https://childrensoncologygroup.org/
Southwest Oncology Group	https://www.swog.org/
ECOG-ACRIN Cancer Research Group	https://ecog-acrin.org/

Financial Assistance/Information

Children’s Organ Transplant Association	https://cota.org/
National Foundation for Transplants	https://transplants.org/
Needy Meds	https://www.needymeds.org/
Patient Advocate Foundation	https://www.patientadvocate.org/
Air Charity Network	http://aircharitynetwork.org/
Angel Flight	http://www.angelflight.com/
Mercy Medical Angels	https://www.mercymedical.org/
Corporate Angel Network	https://www.corpangelnetwork.org/

Support Organizations - Patients

Merck Manual – Consumer Version	https://www.merckmanuals.com/home/
Cancer Care	https://www.cancercare.org/
Stand Up to Cancer	https://standuptocancer.org/
Cancer.Net	https://www.cancer.net/
Cancer Support Community	https://www.cancersupportcommunity.org/
Leukemia & Lymphoma Society	https://www.lls.org/
BMT Support Online	https://bmtsupport.org/
American Childhood Cancer Organization	https://www.acco.org/
The Empowered Patient Coalition	https://www.empoweredpatientcoalition.org/
Vital Options International	https://www.vitaloptions.org/
Women’s Cancer Resource Center	https://www.wcrc.org/

Cleaning for a Reason	https://cleaningforareason.org/
Livestrong	https://www.livestrong.org/
Patient Advocate Foundation	https://www.patientadvocate.org/

Support Organizations – Caregivers

National Respite Network	https://archrespite.org/respitelocator
Family Caregiver Alliance	https://www.caregiver.org/
Family Voices	https://familyvoices.org/
The National Alliance for Caregiving	https://www.caregiving.org/
Cancer Support Community	https://www.cancersupportcommunity.org/
Well Spouse Association	https://wellspouse.org/

Support Organizations – Clinical

American Society of Clinical Oncology	https://www.asco.org/
Merck Manual – Professional Version	https://www.merckmanuals.com/professional

Candidate Education Booklet

Disclaimer:

As you and your physician review this information, understand that this booklet and the information contained within is provided for informational purposes only. It does not mean nor imply that a transplant is medically necessary, is medically appropriate for your condition, is a covered benefit, or meets your plan criteria. Those decisions are rendered solely by your health benefits program sponsor.

INTERLINK®
COE NETWORKS & PROGRAMS

4660 NE Belknap Court Suite 209 Hillsboro, OR 97124 | www.Interlinkhealth.com