

# STEM CELL TRANSPLANT



*A Companion Guide  
For Breast Cancer Patients*



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For Breast Cancer Patients*

*This booklet is dedicated to the  
amazing spirit of breast cancer patients  
in their determination to get well.*

The mission of the National Bone Marrow Transplant Link (nbmtLink) is to reduce the burdens of those challenged by bone marrow transplantation through education and support.

The information in this guide should not be construed as medical advice. Consult with your physician regarding your medical decisions and treatment. The listed resources are not intended to be endorsements.

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# Stem Cell Transplant: A Companion Guide for Breast Cancer Patients

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# A Sister's Promise

The Susan G. Komen Breast Cancer Foundation was established in 1982 by Nancy Brinker to honor the memory of her sister, Susan G. Komen, who died from breast cancer at the age of 36. Nancy promised Suzy to help make it better for other women — to increase funding for breast cancer research, education, screening and treatment.

The Foundation is a national organization with a network of volunteers working through local affiliates and Race for the Cure® events across the country, fighting to eradicate breast cancer as a life-threatening disease. The foundation is one of the largest private funders of research dedicated solely to breast cancer. In addition to funding research, the Foundation and its affiliates fund innovative breast cancer education, screening and treatment projects for the medically underserved in communities across the country.

It began with a sister's promise. It ends with a cure.



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# INTRODUCTION

Volumes have been written about the treatment of breast cancer. The amount of information could fill a library. This booklet, while written for breast cancer patients, families, and friends, focuses on just one procedure: ***stem cell transplant***. Breast cancer is the number one diagnosis for which stem cell transplant is performed today. Due to the dramatic increase in the number of breast cancer patients having this procedure, a patient-friendly booklet had to be written.

Currently, only a limited number of the 180,000 women diagnosed yearly with breast cancer will need to consider the option of a stem cell transplant. If your physician or medical team has suggested a stem cell transplant to you or someone you know, this booklet will be a valuable resource and companion.

As a patient, you want to learn as much as possible in order to make the best treatment decision. The purpose of this booklet is first and foremost **to educate**. Because the subject of stem cell transplant can be complex and difficult to understand, the second goal of the booklet is **to clarify**. Coping with a difficult diagnosis and the anxiety of making major life decisions, breast cancer patients look for hope and encouragement. Thus, the third goal of the booklet is **to provide support**. There are many resources, including the Internet, which offer help to the breast cancer patient considering stem cell transplant. Therefore, the booklet's final goal is **to identify additional resources**.

Stem cell transplant for breast cancer is a procedure that is evolving. Much has been learned. Much is yet to be discovered. Without question, there is still debate on the subject. While the procedure is not a simple solution, it does offer a promising approach. To insure that you have the most current information, a new Web site <http://comnet.org/nbmtlink/breastcancerstemcellguide.html> is being planned. It will provide updates and new developments.

Use this booklet as a guide to enhance the recommendations of your physician and health care team. This booklet is not a substitute for medical advice or an endorsement for a particular procedure. Whichever path you ultimately choose, we hope this booklet makes the way easier.

*Italicized words may found in the Glossary.*

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## OVERVIEW

**Y**ou may be opening this booklet having experienced a recent breast cancer diagnosis. The shock of this news may still be difficult and fresh. Or you may be someone who has lived with breast cancer for years, coping with an unexpected recurrence of the disease. Your physician might have introduced the unfamiliar term, stem cell transplant, to you. Or you may have read about it on your own. How you view the prospect of a *stem cell transplant* may be influenced by factors such as your age, general health, marital status, or financial circumstances. For you and all other women in this situation, there are questions that require answers. And while your own “point of entry” in reading this booklet is important, the information is meant to be relevant to every woman considering a stem cell transplant for breast cancer.

Who qualifies for this procedure? Stem cell transplant is often suggested to women with advanced breast cancer that has spread to other areas (metastatic disease). Stem cell transplant is also recommended to some women with early breast cancer who are at high risk for relapse, such as those with many positive lymph nodes under their arm (*axillary nodes*), and to some women with locally advanced cancer, such as *inflammatory breast cancer*.

To learn more about stem cell transplant you must have some general understanding of *bone marrow transplant* (BMT). Nearly 100 years ago physicians began to experiment with bone marrow transplant. It was only in the past 30 years that real advances were made.

Bone marrow is the spongy tissue found in the cavities of the body’s bones. It contains special cells called *stem cells* from which all blood cells are produced. Each type of blood cell begins its life as a stem cell. The stem cells divide and form the different cells that make up your blood and immune system. These include:

- White cells that fight infection (*leukocytes*) and form the basis of the immune system (*lymphocytes*)
- Red cells that carry oxygen (*erythrocytes*)
- *Platelets* that help blood clot

You can see that any change in the function of the bone marrow would have powerful effects within the body. BMT is used in some situations to replace bone marrow that no longer works normally.

Simply explained, a BMT involves removing bone marrow cells from the bone with a needle and then giving it to a patient through a transfusion. Once the new marrow cells enter the bloodstream, they travel to the patient’s bones and begin to reproduce. Transplant procedures vary according to the disease being treated. Diseases such as leukemia, lymphoma, multiple myeloma, aplastic anemia, and various blood disorders are often treated with BMT. The steps involved in a BMT may differ slightly from one

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treatment center to another. Highly trained medical staff from centers specializing in bone marrow transplant handle the procedure.

There are several types of BMTs. They are categorized according to the source of the stem cells.

- *Autologous* transplant means the stem cells come from the patient.
- *Allogeneic* transplant means the stem cells come from a donor.
- *Syngeneic* transplant means the stem cells come from an identical twin.

The principles used in a bone marrow transplant have been adapted for use with breast cancer patients. Women having a stem cell transplant for breast cancer are, in fact, having a type of autologous BMT. Currently most transplants done for breast cancer are autologous, except for a few centers where allogeneic transplants are being done as an experimental procedure.

A stem cell transplant is the same as a bone marrow transplant except that stem cells are collected from the circulating blood instead of the bone marrow. Instead of inserting a needle directly into the bone marrow to obtain cells, drugs called *cytokines* or *growth factors* are given to “mobilize” stem cells; that is, to move them out of the bone marrow and into the bloodstream. They can then be collected using an *intravenous catheter* similar to those used for collecting blood. These cells are sometimes called *peripheral blood stem cells*.

The **source** of the stem cells and how they are collected are the main difference between peripheral blood **stem cell** transplant and **bone marrow** transplant. Peripheral blood stem cells are given to you as a transfusion and, like bone marrow cells, are able to make red blood cells, white blood cells, and platelets. Stem cells are collected from you and then frozen until the time of transplant. Just before transplant you are given high doses of chemotherapy and/or radiation. This kills cancer cells in your system. It also damages your bone marrow’s ability to make new blood cells. Your frozen stem cells are then thawed and given back to you. This is done by a painless transfusion and may be referred to as a “rescue.” The goal of the rescue is to restore normal blood production. This wouldn’t happen if normal stem cells were not given after high-dose treatment. Post-transplant recovery may take several weeks.

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## UNDERSTANDING THE PROCEDURE

### *Making An Informed Decision*

**M**aking the decision to have a stem cell transplant may be an emotionally demanding one for you and your family. It may seem overwhelming. When breast cancer is first diagnosed and treatments are discussed, there is much to learn. Complex medical terms and unfamiliar words make things more confusing. It is common to feel some fear, anxiety, self-pity, anger, or even self-blame. At times, your feelings will fluctuate. Making any decisions may be difficult.

There are no absolute guarantees about the stem cell transplant procedure for breast cancer. Because long-term study results have not yet been compiled, there is no definitive statement about the role of *high-dose chemotherapy* and stem cell transplant for breast cancer. Some initial studies, however, show good results. Stem cell transplant is a promising new weapon in the battle against breast cancer. In making your decision, approach the subject with your eyes open. Simply stated, you must consider that there is both promise and risk.

As you come to understand the stem cell transplant procedure, you'll be able to make a decision with greater confidence. Because the procedure is still new you need to research, question, and evaluate if it is right for you. In other words, do your homework. Approach the subject with an open mind. Remember that you are not alone in this. Stem cell transplant for breast cancer has become a "national phenomenon" with thousands of women considering it as their treatment choice. Read booklets like this one, talk to others who've been through it, and have frank discussions with your medical team. Enlist family members or friends to assist you.

Keep a notebook to record information. Have a family member or friend with you during discussions with your medical team. They'll provide support in understanding what was said. Don't hesitate to voice your concerns. There are no "dumb" questions. Ask the following when speaking with your physician/or medical team:

- Is there evidence that this is better than other, less toxic forms of therapy?
  - Am I a candidate for stem cell transplant?
  - What is my prognosis (chance of recovery)?
  - What are the benefits for me?
  - What risks will I face?
  - What are the potential side effects of this procedure?
  - What kind of quality of life can I expect after transplant?
  - What post-treatment changes (physical and psychological) should I expect?
  - What will it mean to my family?
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- How long will I be in the hospital?
- How long is the outpatient portion of my treatment?
- Where is the best treatment center for me?
- Does my insurance cover this procedure?
- What other expenses should I expect?
- Should I participate in a clinical trial?
- What other treatment options could I consider?

Evaluate responses from these questions. If you're doing your own research, remember that general statistics may include all age groups and types of diagnoses. If possible, look for specific answers. Ask directly about relapse-free survival rates for your age group, your illness, and your type of transplant.

You may be searching for statistical validation for your decision. High-dose therapy and stem cell transplant has undergone evaluation over the last two decades. Find reports that are current, understandable, and relate to your stage of disease. Your transplant center should be able to provide this information. In the near future, results of national studies will be available. Additionally, organizations like the Autologous Blood and Marrow Transplant Registry are compiling outcome data from 250 centers performing the procedure.

### ***Clinical Trials***

Part of making an informed decision involves learning about clinical trials. These are long-term research studies that evaluate promising cancer treatments. Hundreds of women take part in these breast cancer related studies. Clinical research studies are conducted in many forms. These include national studies sponsored by the National Institutes of Health, single institution studies, and cooperative studies between institutions.

Clinical research studies validate new treatments in three phases. Phase I research studies establish optimal dosage. In phase II studies safety and effectiveness are carefully defined. Phase III studies compare and contrast a new treatment with standard treatment. In this phase, women who participate are randomly assigned to receive one treatment or the other.

At the time of this writing, transplant data from breast cancer studies fall into two basic areas. Much of the data relate to studies focusing on cancer which has spread through the body — metastatic disease. Another area of focus is breast cancer (localized to the breast and local lymph glands) which is at high risk for spreading. This is referred to as high-risk primary disease.

Ask your oncologist or contact a medical center to locate where clinical research studies are being conducted. One source for a listing of independent clinical trials is the

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Physician's Data Query (PDQ). It is a computer database focusing on cancer treatment information. To find out about national studies, call the National Cancer Institute at 800-4-CANCER (see Resource Listing).

Several studies show that women in research studies often do better than women receiving the same treatment outside of the clinical trials. Potential benefits of participation include:

- Specialized care and adherence to strict protocols
- Careful monitoring during treatment and close follow-up afterwards
- Being among the first to benefit from a new treatment
- Active involvement by making this treatment choice
- Helping “future” breast cancer patients
- Treatment expenses may be lessened

Potential drawbacks may include:

- Unknown side effects
- May not be right for you
- Insurance coverage may be inadequate

Understanding clinical trials may help you in making your treatment decision. Next, you'll want to consider choosing a medical center.

### ***Choosing A Medical Center***

If you've made the decision to have a stem cell transplant, selecting a medical center will be your next step. There are clear advantages to choosing a large, experienced medical center. There may be one near you. If not, you may have to relocate temporarily, and this makes the choice more difficult.

Look for a center with a good track record for transplant. This is a confidence-builder and offers you a sense of security that the staff will be able to handle any unexpected situations that arise. Check the experience of the doctors and nurses in the transplant department. Find out how many stem cell transplants are done each year. Generally you should look for a center that does a substantial number of stem cell transplants annually. Talk with the bone marrow transplant coordinator about the center's program and what it has to offer you.

Choosing a center close to home allows you to remain near family and friends. It tends to be less disruptive. You'll be able to keep a strong support system close at hand. Travel expenses will be saved, and you'll avoid the hassle of moving to an unfamiliar place. You may already be acquainted with the doctors and staff at the local center.

If you lack confidence in the hospital near you, or if there is no medical center close to home that does stem cell transplant, continue your search. Ask for referrals, find out where

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clinical trials are being conducted that may apply to your circumstances, and talk to women who have had the procedure (see Resource Listing). Work with your physician to find the best place for you and your family. If you select a center far from home ask about lodging arrangements. Consult your insurance company regarding coverage at other hospitals. Contact the Blood and Marrow Transplant Newsletter for information on different BMT centers (see Resource Listing). If possible, visit the center.

This work can be tedious and time consuming. Sometimes getting answers to your questions may be difficult and frustrating, since some centers are reluctant to disclose information without first seeing you for a consult. Consider recruiting friends or your physician to help you in this task. Form a team to achieve this goal.

If you have access to a computer, you may want to view the Web site of a particular medical center. This is another way to get information (see Resource Listing).

Ask the following questions to narrow your search and help provide confidence in your choice.

- Does the hospital specialize in cancer treatment? Is it affiliated with a university or teaching program?
  - What kind of experience do the physicians and nurses have with transplant?
  - How many stem cell transplants has the center done this year?
  - Does the center have experience with current treatments like newer drugs or higher doses?
  - Is the center conducting any breast cancer or stem cell research studies?
  - If there are unusual transplant circumstances is the center equipped to handle them?
  - Will I have a team of physicians or just one who will oversee my care?
  - Can I receive my early chemotherapy close to home (if going to a distant center)?
  - Is the transplant also done on an outpatient basis?
  - What kind of follow-up program does the center have?
  - What happens if there are complications for an outpatient?
  - Are support services available for patients and families?
  - Does staff help with the emotional needs of the patient?
  - What is the visitor policy?
  - Are there previous stem cell transplant patients to speak with?
  - What kind of lodging is available for family or caregivers? Cost?
  - Will the center accept my insurance?
  - If my insurance is denied will hospital staff assist me in appealing it?
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## **Preparing for the Stem Cell Transplant**

Prior to the stem cell transplant, you'll undergo some laboratory and diagnostic tests. This is to make certain that you're in good shape for the stem cell transplant and to determine the extent of your disease.

Before your hospital admission for transplant, you'll undergo an outpatient procedure, sometimes under anesthesia, to insert a thin, flexible tube into your chest. It'll be placed into the large vein, just above the heart. The tube, called a *central line* or *central venous catheter* will remain in place during the transplant and for as long as you need it afterwards. The catheter makes it possible for blood samples to be drawn, drugs to be given, stem cells to be collected, and the actual transplant to occur with little discomfort. Because one end of the catheter is outside the chest it must be kept clean to avoid infection. You'll be instructed how to care for your catheter.

## **The Stem Cell Transplant**

The next step in the procedure involves collecting the actual stem cells. They are collected from your circulating blood. This painless process is called *stem cell retrieval* (*apheresis* or "*harvest*"). You'll be injected with drugs designed to *mobilize* the stem cells from the bone marrow into the bloodstream. You'll take these drugs before and during the stem cell retrieval. They are called *growth factors* or *colony stimulating factors*. Some patients receive a combination of chemotherapy and the growth factor to increase cell numbers. Once there are enough stem cells produced they are collected. Blood is withdrawn from your arm or central venous catheter and circulated through a machine that separates blood cells. Stem cells are removed and the remainder of the blood cells are returned to you. This outpatient process takes about two to four hours a day. The process is repeated for about three days or until enough stem cells are collected. Patients usually tolerate this procedure well. During apheresis some patients report numbness or tingling in the fingers or toes, hand or leg cramps, dizziness, chills or lightheadedness. Each of these is easily corrected. After this procedure is completed and enough stem cells are collected, they are frozen and stored for future *reinfusion*.

The next step in the process is called *conditioning* or *high-dose chemotherapy*. Its purpose is to destroy cancer cells in the body more effectively than is possible with standard doses of chemotherapy. Conditioning involves receiving a combination of chemotherapy in high doses and/or radiation. The general sequence of treatment will vary slightly from center to center. At some hospitals the first few days of conditioning may be done as an outpatient. At others you will be admitted to the hospital. Generally taking 5 to 10 days, conditioning is completed one or two days prior to the reinfusion (returning) of your stem cells.

These doses of chemotherapy are much higher than you have received before. Your physician will discuss the drugs being administered. You will rest for a day or so after the high-dose chemotherapy. When the drugs are gone from the body, the stem cells will be

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returned. Once again the central line or catheter is used. The stem cells, taken from you earlier and stored, are made available. They are thawed in a warm saline solution. Slowly, the cells are reinfused into your bloodstream. You may develop a bad taste in your mouth during this time due to a preservative used in protecting the frozen cells. Some patients report that it tastes similar to garlic or oysters. Others report a metallic-type taste. Try sucking on a hard candy at this time. Although you are not sedated during the reinfusion, you may wish to rest or sleep during the procedure. If you choose, family or friends may stay with you during the reinfusion.

Medications are used to minimize side effects from the chemotherapy such as nausea, vomiting, and diarrhea. You may expect to experience poor appetite, hair loss, and fatigue. These side effects are temporary, lasting from a few days to a few months (see Short-Term Side Effects).

Because the high-dose chemotherapy dramatically lowers the blood count, the risk of infection increases. This is referred to as being *immunocompromised*. The medical staff will watch you carefully. They'll check for mouth sores, sinus infections, skin conditions, coughs, and urinary problems. You'll be asked to report any unusual changes or fever. Antibiotics are commonly needed to get you through this low immunity period.

You'll begin to feel better as your white blood cell count increases and returns to normal. For many women having a stem cell transplant, this is generally about nine or ten days. About two weeks after the *rescue*, platelet counts will also return to normal. You can expect to have several outpatient clinic visits in the weeks following transplant.

### **Care During Transplant**

Increasingly, the standard protocols for stem cell transplant using well established treatments, are being combined with outpatient care. You may receive part of your treatment in the hospital and part of it as an outpatient. Extended hospital stays of 20 to 21 days, once considered mandatory for transplant, have been replaced by shorter stays of 8 to 9 days. This allows you and your caregiver to move to nearby lodging more quickly. Each day you'll return to the hospital for outpatient treatment.

Much of your transplant-related care may now be done out of the hospital. This living arrangement is more "home-like" than the hospital. You're given a greater sense of control and may feel less like a sick patient when returning to your apartment at the end of a day. Wearing your own clothes instead of hospital gowns is a welcomed perk. Some patients express concern about the risk of infection while out of the hospital. There is no significantly greater risk of infection in the outpatient setting. In fact, it may actually be safer away from hospital organisms.

While you are an outpatient you will require a caregiver(s) 24 hours per day (see Role of the Caregiver). This is a big job. However, most friends or relatives are willing to assume this responsibility. For some women, there may be no one readily available to serve in this

role. When this is the case, it may influence where and how post-transplant care is given. Sometimes full inpatient care may be the best option.

If your transplant center does not have a lodging facility nearby, and you are still asked to consider outpatient treatment, pose the following questions:

- What happens when complications occur?
- Is there access to a transplant physician 24 hours a day, 7 days a week?
- Are visiting nurses used for outpatient care?

Be concerned about the medical center's quality of care and the availability of all kinds of services when considering outpatient treatment. Let this information determine where you have your transplant, not whether or not it is done on an outpatient basis.

### ***Continued Recovery Following Transplant***

The next phase is the transition to a more normal life. It is time to return to your home. You'll be feeling somewhat stronger. Most women look forward to leaving the treatment center environment with joy and anticipation. This happiness, however, may be mixed with a sense of fear and anxiety. Sometimes the transition is not easy. Things were taken care of for you at the hospital. Responsibility for your care is gradually being given back. As previous family demands will continue be prepared to delegate them to others (see *Role of the Caregiver*). You now will be expected to make occasional follow-up visits to the transplant center. What kind of timetable can you expect for return visits? As you recover, your visits will decrease. Most health concerns will lessen over time.

Although you will gradually return to normal activities, your immune system is still affected by the transplant. Because the body is less able to defend itself against infection, antibiotics may be necessary. To help prevent infection, wash your hands often. Wash before eating and handling foods, taking medication, and after using the bathroom. Use special antibacterial soaps. Your medical team will instruct you about the do's and don'ts during the early post-transplant period. These may include meal preparation, care of young children, and other issues. Some general suggestions may include avoiding the following: others who are obviously sick, molds and working with dirt, smoke and aerosol sprays, or certain foods. Ask someone else to take care of your pets.

### ***Short-Term Side Effects***

High-dose chemotherapy is stressful on organs of the body, including the heart, lung, liver, kidney, and digestive system. Side effects of high-dose chemotherapy will vary according to the type of drugs used. Immediate side effects include nausea and vomiting. Mouth sores, loss of appetite, hair loss, fatigue, bleeding, memory problems, and bone pain are common short-term side effects.

It is normal to feel anxious about these possible side effects of treatment. Most are temporary and reversible. If you feel extremely anxious, speak to a counselor at the bone marrow transplant center.

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## ***Nausea and Vomiting***

These are common side effects of chemotherapy. They usually decrease in severity in the days following chemotherapy. Some patients never experience them at all. Severe anxiety will make nausea and vomiting worse. For this reason, relaxation techniques become very important. The good news is if you do experience nausea or vomiting, there are ways to control it. Ask your physician for medication. Other suggestions might include eating frequent, small meals; eating slowly; sitting quietly after a meal; avoiding sweet or spicy foods; choosing bland, low fat foods; serving foods at room temperature or cold; and avoiding foods with strong odors.

## ***Mouth Sores***

These may occur soon after chemotherapy. Your mouth may be reddened, sore, and small white patches may appear. Avoid anything that might be irritating such as acidic, spicy, or hot foods. No alcohol or tobacco products should be used. Increase fluid like apple juice to avoid dryness. Brush your teeth gently after meals and before bedtime. Ask your physician for medication if mouth sores appear. There are effective treatments.

## ***Loss of Appetite***

A loss of appetite may be a byproduct of the chemotherapy, radiation, antibiotics, or illness. It is not always easy to stay well nourished during chemotherapy. A hospital dietitian may offer you nutrition supplements if eating is difficult. Good nutrition is very important to your recovery. Its role is to help your body build new cells while increasing strength and energy levels. If you've lost your normal appetite, try to eat frequent small meals. Cold foods may taste better. Try high calorie drinks, like milkshakes instead of water. Make meals enjoyable by socializing. Use plastic utensils, if you have a metallic taste in your mouth. Brush your teeth or rinse your mouth before eating. If you develop a dislike for meat, substitute chicken, fish, or eggs.

## ***Hair Loss***

Hair loss or *alopecia* is a result of the chemotherapy. It usually affects the hair on your head. Eyebrows, eyelashes, pubic, and underarm hair may be affected as well. Hair loss depends on the drugs used in chemotherapy. It usually happens 2 to 3 weeks after the first treatment. It is temporary and when it grows back it may be thicker, wavier, or darker. You may wish to get a short haircut just prior to treatment. Try a pH-balanced shampoo for gentleness. Baby powder on the neck and back reduces itching from hair loss. Mineral oil or soothing creams will help with scalp irritations. If a wig interests you, have yourself fitted prior to treatment so it will match your natural hair color. Some women report the sensation of coldness with hair loss. Wearing turbans or a favorite hat will help contain body heat.

## ***Fatigue***

Chemotherapy affects the production of red blood cells. When your red blood cell count is low a condition called *anemia* occurs. The result is that the tissues and organs do

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not receive enough oxygen. You may feel tired, dizzy, chilly, or become short of breath. Headache or a rapid heartbeat are symptoms. Your skin may appear pale. Inform your physician. Blood transfusions may help correct this condition. Take frequent naps. Save your energy. Move slowly from one position to another.

### ***Bleeding***

Platelets help your blood to clot. They are greatly reduced after treatment. When *thrombocytopenia* or a decrease in platelet count occurs, there is a potential for bleeding. You'll notice things like easy bruising, blood in the urine or sputum, or little purple-red blood blisters under the skin. Although you'll be under close scrutiny, consult your physician if you notice any of the above. Protect yourself against bruising or falls. Don't lift heavy objects. Avoid dental floss. Use an emery board to trim nails instead of a clipper.

### ***Side Effects of Growth Factor Drugs***

Some common side effects include rash, fever, moderate bone or muscle pain, insomnia, headache, or chills. These disappear when the drugs are stopped.

### ***Long-Term Side Effects***

Some potential long-term side effects for women having stem cell transplantation include self-image, premature menopause, neuropathy, shingles, and relapse and secondary cancers. These are, for the most part, related to the conditioning phase of high-dose chemotherapy and radiation.

### ***Self-Image***

You'll be facing significant changes in self-image. It is difficult to predict how you will react as each woman approaches them differently. Some immediate issues will include hair loss, and possible weight change due to medications. The presence of a chest catheter and the scar it leaves is another body-image factor. If you have had a mastectomy, you may still be adjusting after surgery. There may also be some skin and nail changes following treatment.

Other self-image issues may include a generalized sense of loss. You may feel a "difficult to describe" loss of the woman you once were. You may fear that you'll never be the same again. Your energy level, something taken for granted before, now may be viewed as something that is lost. Your place within the family dynamics may be changing as well from caregiver to receiver of care. If you were employed prior to your transplant and are now unable to return to work, your feelings of not being productive may surface. This status change may be felt as a loss. You may generally feel more vulnerable to many things, including a strong fear of relapse. Feeling less control over events in your life is common. All these feelings are normal. Communicating them throughout the entire experience is very important. Talk about how you feel. Speak with others who've been through this experience. Hospital counselors, private psychotherapy sessions, or empathetic family and friends can be helpful in sorting out feelings. There may be some losses but there will also be gains.

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### ***Premature Menopause***

Breast cancer treatments often produce an early menopause. Chemically-induced menopause is the result of chemotherapy during treatment. Your body no longer produces the same amount of female hormones.

Symptoms that may occur are absence of menstrual periods; hot flashes; weight gain; mood swings; and vaginal dryness, itching, and loss of elasticity. There are concerns of bone loss and heart disease. Most experts would discourage hormone replacement at least in the early years post-transplant.

There are often recommendations to decrease discomfort and ease the symptoms of menopause (see Sexuality). Dietary supplements, such as calcium and vitamin D, as well as exercise may help prevent bone loss. Ask your physician about other ways to manage menopausal changes.

### ***Neuropathy***

Neuropathy is a result of the chemotherapy. It is a condition of the nerves that causes tingling, numbness, or a change in sensation. Usually involving the hands and feet, cases vary from mild to severe. Many women having a stem cell transplant never experience it at all.

### ***Shingles***

A significant number of women will experience shingles, a reactivation of the herpes zoster (chicken pox) virus. It may occur any time after transplant, but it generally occurs within the first six months. This is due to your weakened immune system. Report any rash or unexplained pain to your physician. Early start of medication may reduce discomfort and possibly serious complications of shingles.

### ***Relapse and Secondary Cancers***

Some women may have their disease return even after transplant. In a small number of women, a different malignancy may occur. This may be due to the chemotherapy used prior to transplant. Or it may be the appearance of a cancer that would have occurred anyway. If this happens you and your physician will discuss treatment options.

### ***Role of the Caregiver***

Shortly after making the decision to undergo a stem cell transplant, you'll be asked to choose a person(s) to serve as your caregiver. This person will be with you during your hospitalization and afterward for outpatient care. It is an important decision. Admission to the hospital may be delayed if caregiver arrangements have not been finalized. Enlist several close relatives or friends to serve in this role. The reasons for having more than one include:

- Two or more caregivers will allow each time to rest and return fresh
  - You'll have a change of companion
  - It is less disruptive to the caregivers' lives or work
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- More than one caregiver offers a safeguard should either of them be unable to help

Decide who your caregivers will be. Use the following basic criteria: Choose someone you feel close to and who cares for you deeply. Choose someone who is comfortable in a hospital setting. Choose someone who handles stress well.

There are a number of tasks for a caregiver. Some responsibilities include:

- Providing emotional support
- Helping with medications
- Providing hands-on care during and post-hospitalization
- Communicating with the hospital staff
- Gathering information
- Keeping family and friends up to date
- Preparing meals and housekeeping post-transplant
- Providing transportation to and from treatment center

You and your caregivers will receive extensive instructions. The commitment and proper training of the caregiver is critical to the success of the outpatient program. After the transplant and during the outpatient stay at a lodging facility, the caregiver's tasks will specifically include taking care of your catheter, keeping records of what your fluid intake and output are, checking your vital signs like blood pressure, and helping with meals. They will keep a record or diary of daily care routines. They are taught to recognize adverse effects and know when to contact the physician in an emergency. Your dietary concerns are part of their responsibilities. They'll learn what to do if your blood counts are very low. They will offer you frequent emotional support and encouragement. Caregivers will keep in close contact with your medical team throughout. Specific national organizations offer assistance to caregivers (see Resource Listing).

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## COPING WITH FEELINGS

### *Emotional Preparation for Transplant*

Facing breast cancer and a stem cell transplant is, without question, difficult. During the stem cell transplant process, medical concerns are likely to take precedence. But your emotional needs should not be minimized. You will probably experience strong emotions ranging from anger, fear, panic, dread, and helplessness. If you have recently had a mastectomy, the prospect of a stem cell transplant may demand more of you emotionally. At times you may feel emotionally numb. Expect these moments. There'll be days when you'll want to face the prospect of a transplant alone. It is a personal issue in many ways. More often, family and friends will be there to share your concerns and listen to your needs. Coping will occur in a variety of ways.

One immediate coping style is to gather medical information. This is a common and expected response, but it may leave you feeling overwhelmed and confused. It can be exhausting. If you were recently diagnosed with breast cancer, you may find yourself researching both the disease and the stem cell transplant process. Focus on the most current information possible. Get organized. Gathering information can help regain a sense of control. Ask friends or family to help sort out information.

You may experience resentment towards others. They don't have this "issue" hanging over them. It is normal to be angry and questioning. Try to sort out emotions like these and recognize them. Rely on your communications skills. Let people close to you know what you are feeling. Don't bottle up your emotions. Give yourself permission to express all your emotions. Be understanding and gentle with yourself. Ask your family and friends to do the same. You may also benefit from private counseling.

Another factor to consider is your age. At the present time, the average age for women having this procedure is in the late 30s. If you are young, some issues may be different for you. Body image and fertility questions may be high on your list of concerns.

Think back to how you coped with things in the past. What skills got you through? Rely on those positive skills again. Remember that you are more than a "cancer patient." Let your other life roles and uniqueness help emotionally support you.

Go with your strengths. Your ability to cope will be affected by your own life experiences. Trust that you can do it. Let others help by forming a "circle of support" around you. If, however, you find yourself feeling helpless or guilty much of the time, seek advice from a trained medical counselor. A support group may also prove beneficial. Your medical center will make recommendations.

Try the following suggestions that may help prepare you emotionally for the transplant:

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- Read about the experience.
- Contact breast cancer survivors who have had stem cell transplants.
- Focus on success stories. Make a book of “good news” and refer to it often.
- Learn stress management skills. Try muscle relaxation, yoga, breathing techniques, imagery, visualization, meditation, or others.
- Keep your routine as normal as possible.
- Make a plan to delegate tasks to others. Get things in order.
- Take time for yourself.
- If a spiritual life is important to you, meet with a religious counselor.
- Develop support teams, i.e., family, friends, other women, medical team.
- Have a creative outlet like writing in a journal, painting, crafts, etc.
- Participate in activities that you enjoy.
- Seek outside counseling for yourself and your family, if needed.

The expression “attitude is everything” applies in this circumstance. The way you view the transplant will definitely influence your emotions. It may be a love-hate scenario. Maybe you actually can’t wait to begin treatments. You understand that you’ll feel sick but at least you’re actively fighting your breast cancer! The transplant represents a challenge! It’s your chance for a new lease on life.

You can expect fluctuations in your moods. There will be highly emotional moments. There will be times of relative calm. Each is part of the transplant experience. You may take an active role in the process, choose to hand over controls to others or do some combination of the two. Do whatever feels most comfortable to you.

### ***Coping Strategies During and After Transplant***

You may find the transplant experience emotionally difficult. It may be easier than you expected. By the time you are facing a stem cell transplant, you already may have dealt with physical changes such as a mastectomy and/or reconstruction. Issues surrounding body image may become secondary to fears of recurrence and spreading cancer. Maybe you have lost your hair before, dealt with those kinds of things and moved beyond it. Issues such as losing some of one’s privacy, adapting physically, or being away from home, may affect you differently depending on past experience. If you are newly diagnosed you are being asked to cope with cancer and transplant at once. This will require a different game plan. It is a major life disruption that comes with tremendous stress.

**Take it one day at a time.** Much of what you are feeling will be temporary. Daily medications may affect your mood. Sleep loss is a common problem that could affect your mood. Forgive yourself if you lash out at those closest to you. They’ll understand. Coping positively with breast cancer and stem cell transplant is largely based on your

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attitude and the **taking one day at a time** view. While your breast cancer may not have been in your control, your treatment attitude is. Attitude is an important aspect of the experience. Every morning you have a choice of what attitude you will embrace for the day. You are 100% in charge of that!

***Some suggestions to guide you through are:***

- Express your needs. Be assertive. Be specific. Communicate, communicate, communicate. Don't assume that something obvious to you will be clear to others. Let people know what kind of food you want, what kind of care you'd like, what schedule is best for you. Find out what options or services are available. It never hurts to ask. Let your medical team know how you cope best with information. Do you prefer all information up front or as needed?
- Keep your sense of humor. Rent some funny movies. Make jokes. Enjoy the company of others. Laughter can be a powerful ally.
- Set realistic goals for yourself. Don't expect to bounce back immediately. Transplant is an energy-draining experience. Be kind to yourself.
- Cherish and appreciate the support you receive from family and friends. This can be the single most important factor in predicting how well you will cope. They will have the need to do things to help you. Let them. It will decrease their feelings of helplessness.
- Have someone check up on the emotional well-being of family members too. A comment like "how are you holding up?" should be directed toward caregivers often. This kind of nurturing is good for you and for those who care for you.
- Ask about services like BMT support groups and/or breast cancer support groups. Talk to social workers at the transplant center to discover what is available.
- If you have computer skills, check out the online BMT support groups (see Resource Listing).
- Speak with your clergy, if this gives you additional support and strength.
- Read books with positive affirmative messages.
- Use diversions like soothing music or a new hobby.

If you are from a rural community or have chosen a transplant center far from home you may feel somewhat isolated. You may have concerns surrounding childcare or other family issues. Rely on the social work staff at the treatment center. **There are people to help you through this experience.**

### ***Understanding Feelings***

Given the dramatic nature of a stem cell transplant, it is reasonable to expect emotional reactions and feelings to be greatly heightened. It may help to identify some of the most common responses.

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### ***Fear and Anxiety***

You wouldn't be normal if you didn't experience some fear and anxiety regarding your stem cell transplant. It can be scary. Sometimes the fear goes beyond the transplant itself. You may be anxious about how your family will cope, time away from work or issues like inadequate insurance coverage. Recognize when anxiety appears. Signs would include the inability to sleep, difficulty focusing at work, or having trouble understanding what your physician tells you. Talk about your fears with your physician, family, and friends. Communicating how you feel may provide some relief.

### ***Depression***

You may have bouts of feeling deeply sad and tearful. A cancer diagnosis can naturally have that effect. Depression occurs when there is a severe and enduring state of extreme sadness, negative thinking, and changes in eating or sleeping. There is a tendency to become isolated and withdrawn from others. This vicious cycle can lead to loneliness and greater depression. If you have had a history of depression or have taken medication for "nerves," be sure to inform your doctor.

The episodes of feeling depressed can usually be worked through. If you come to feel that others are very concerned about your deep sadness, or that life is not worth living, it's time to get help from a professional therapist. Certain medications may also produce symptoms of depression. Discuss this with your physician or transplant team.

### ***Guilt***

If children or family members are left at home while you're having your stem cell transplant, there may be additional worry and guilt. It is natural that you be concerned about their well-being in your absence. If you've been the primary family caregiver, you may feel guilty about the role-reversal you're experiencing as a patient. Now your family is taking care of you. Another aspect to cancer-induced guilt is during the recovery period. Recovery is not totally under your control. You may feel guilty if your recovery takes a turn that is unexpected and temporarily disappointing. Take credit for your treatment successes but do not take on guilt if progress slows. Be patient and allow your family to offer this support.

### ***Anger***

"Why me?" You've probably said words like this in response to your breast cancer diagnosis. It can reflect anger or sadness. Short tempers, family disputes, and problems working with the medical system or insurance companies can all contribute to the anger you may feel. You may initially feel angry at being "caught up" in this entire experience.

You may get frustrated when medical information is not easily available. Do not suppress these angry feelings. Recognize them and decide how you want to confront them. Talk it out, yell, use the "punch-something" method, or whatever will free you from the anger. Release it. Try to direct this energy toward healing and recovery.

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## ***Stress***

There is an enormous amount of stress on you, your caregiver and your family at this time. You're all being challenged in different ways by a traumatic illness and procedure. Each of you is struggling with the physical, emotional, and perhaps, financial issues surrounding this treatment. It is a huge life disruption. If you must make a quick decision about transplant due to the condition of your breast cancer, stress will naturally be magnified. Any time there is change, stress results. Don't wait for the stress to become unbearable; learn how to manage stress early. Try to handle one thing at a time. Allow others to offer support.

## ***Relationships and Outlook***

A healing environment is created when one person cares for another. Whether it's your family, caregiver, friends, nurses, or others, the nurturing relationships that are built will serve you well—before, during, and after your transplant. Much of this caregiving will be invisible, happening quietly. For you, the patient, this support will be invaluable, positively affecting your outlook on life. As strange as it sounds, you may hear women report that the cancer-transplant experience actually was life-enhancing. Life is richer for them now. There is a greater appreciation of every day and the importance of loved ones.

Relationships with family members may become even closer. However, a change in roles and responsibilities can also produce increased family tension and strain. Your family relationships may become more intimate or distant. Friendships may also change and take on new meaning. Some will be enriched and others will fade under the stress of the transplant experience.

The diagnosis of breast cancer may produce feelings of isolation even though you're surrounded by well-meaning family and friends. It may be difficult to talk about your situation. Perhaps on an emotional level you may feel more comfortable in the company of women who have had breast cancer or stem cell transplant (see Resource Listing).

## ***Coping with Other Issues***

After stem cell transplant, dealing with other potential issues can require additional coping skills. It's possible that you may experience difficulty with some or all of the following.

### ***Concentration or Memory***

You may not feel as "sharp" in your concentration or memory skills after your transplant. Be prepared for this and try not to be frightened by it. For the most part, this is temporary. But, it may last longer than you expect. As you progress in your recovery, memory and concentration will improve. Practice using your "brain" skills. Play word games, do puzzles. Keep mentally active. Sometimes, time will be the best healer for this.

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## ***Sexuality***

There may be changes in your sex drive following transplant. Due to the stress of the experience, and other factors, resuming normal sexual activity may be delayed until you're feeling more like yourself. Discuss issues of intimacy with your physician. When you are ready to resume sexual activity, a water-based lubricant is suggested to manage vaginal dryness or possible painful intercourse. Realize that even though sexual desire may temporarily diminish, the need for intimacy is still important. Communicate with your partner. The need to be physically close can still result in an intimate sharing of affection.

Fatigue greatly inhibits your sexual desire. Plan sexual activities that are not physically demanding. Find times when you have just rested or had a full night's sleep.

Adapting to a body image change is another factor that inhibits sexual desire. If you've had a mastectomy or your hair has fallen out, you'll need to deal with your feelings about being desirable. For some women this is the most difficult part of having breast cancer. Other women report that they struggle with the guilt about not meeting their partner's sexual needs. Don't ignore these feelings. Discuss them openly with your spouse or speak with a counselor at the hospital. Here, again, is a time when **your attitude** will mean so much. Your spouse may take his signals from you. Keep the lines of communication open.

## ***Chronic Fatigue***

You may have underestimated how much a stem cell transplant exhausts you. Feeling tired all the time after a transplant is common. This is an effect of high-dose chemotherapy. You'll eventually feel better, but it takes months to return to normal. You'll recover at your own pace. Do not compare your progress to other women. Plan your activities according to how you feel on a daily basis. Don't push yourself. Try to do one or two tasks per day. Let others help you. Follow the signals your body sends you. If you feel tired, get some rest.

## ***Eating Problems***

Good nutrition is vital to your recovery. If you are not able to eat food while in the hospital, you'll be given nutrition intravenously. After transplant you may experience a loss of taste or appetite due to chemotherapy and radiation. Speak to a dietitian about the best way to add calories and protein into your diet. It may be recommended that you follow a low-bacterial diet following your transplant until your immune system returns to normal. You'll be asked to avoid any foods that contain bacteria. Eat only well-cooked foods and peel any fruits or vegetables. The hospital dietitian will instruct you about general eating guidelines. Food intake problems, such as difficulty swallowing or tolerating foods, should be reported to your physician.

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## CONSIDERING OTHER ISSUES

### ***Financial Concerns***

It should come as no surprise that stem cell transplant, and all that it entails, is costly. If you can anticipate expenses, you can plan out how they will be met. A preliminary list of expenses, other than those covered by insurance, might include:

- Lodging for follow-up care
- Follow-up office visits
- Home care
- Childcare
- Prescriptions
- Transportation and parking
- Telephone costs
- Supplies

### ***Insurance Coverage***

Although it's a secondary concern to your breast cancer treatment, the high cost of transplant must be addressed. Many health insurance companies now cover most breast cancer therapies, including stem cell transplants. The key question to be considered as you plan your care is whether your health insurer is in the majority and will provide coverage, or whether coverage is going to be a problem. The sooner this question is answered the better. Obtaining insurance approval may be time-consuming, difficult, and may require legal assistance. Make use of family and friends to help you manage this effort.

The transplant center will start the insurance approval process by sending your health-benefit insurer a letter requesting pre-approval of your treatment. The insurance company may request a complete history of your physical condition, a copy of the treatment protocol, the *informed consent* document, your laboratory and x-ray results, and your physician's recorded treatment recommendation. Make sure that these materials are sent out promptly, if requested.

Insurance companies sometimes delay a decision pending the results of early chemotherapy. At other times the companies need to be reminded that time is important. Repeat requests for pre-authorization should be mailed. Insurance issues must be resolved before admission for transplant. You cannot begin this process too soon.

The "paper trail" between your transplant center and your health insurer may be an essential part of a legal action if coverage is denied. Organize your own paper trail file. Encourage your transplant center to send detailed information and documentation supporting the treatment planned for you. The more evidence presented the better.

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If pre-authorization of coverage is denied or is not quickly forthcoming, begin to educate yourself about your insurance coverage. Request a copy of your health insurance policy. This document is sometimes called a certificate or at other times an employee-benefit plan. The company and/or employer are required by law to make this document readily available to you. Call your employee benefits representative, your insurance company, or the person who sold you the insurance. If you have any difficulty getting a copy of the insurance coverage language, write a letter. Insurance companies generally want to avoid paper trails that reflect failure to provide information.

Legal problems arising from insurance coverage denials for breast cancer patients seeking stem cell transplant have received much media attention. Over the past decade women have won many dramatic lawsuits seeking transplant coverage for their care. The insurance climate is much improved and more encouraging today. But some companies persist in denying coverage, and claim that they will not include stem cell transplant as a benefit until the clinical trial results conclude that it is superior to conventional chemotherapy.

Insurance companies, generally, want to help patients. Often medical directors, who are physicians, make the decisions about what would be the best care. Approaching them as people who want to help is the way to begin.

If you receive a denial of coverage, time is of the essence. Many companies provide only a short period of time for an appeal. You will need to appeal directly to the insurer before you will be permitted to file a lawsuit.

A denial must be in writing. It should include information about how to appeal. If it does not, request that information (in writing). Don't panic. A "no" at this stage may really mean either "probably not," or "provide us with more information and we will reconsider." There is almost always room for more discussion. Although you may feel angry or hurt, don't be disheartened. There are ways to fight back.

Consider the reasons given for denial of coverage. Does the insurance company consider the transplant to be "experimental" or "investigative?" Is the denial based on a pre-existing condition? Is there some reason you are not entitled to certain benefits while others are? Involve your physician and transplant center. Often insurers will change their minds once provided with strong documentation from doctors.

If your insurance is paid for by an employer, find out if the employer can and will make efforts to help. Sometimes the employer may pay for the treatment rather than hassle with the insurer. At other times, the employer can put pressure on the insurer, particularly if the employer spends a lot on health-benefit coverage.

Most importantly, do everything required by the insurer to submit an appeal. Keep the time limits carefully in mind. They may be as short as 30 days. Successful strategies for appeal include the following:

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- Request that your physician intervene and send a detailed report, medical articles, scientific information, and other materials that are responsive to the reasons for denial
- Keep careful records of the paper trail you have developed, and do not be afraid to do your own research
- Contact the patient advocate office or a BMT social worker at your transplant center
- Ask your employer to assist you if your health coverage is through your employment or your spouse's employer
- Seek information from organizations serving bone marrow transplant patients
- Retain an attorney with expertise in this field to help you

More and more women with breast cancer are finding success in these insurance disputes. Do not give up (see Resource Listing).

If you are underinsured or have no coverage for transplant expenses, you may have to borrow funds or plan fund-raising activities. Family, friends, or your employer may offer help with these activities. Contact the BMT social worker. Request names of organizations that not only provide financial support but will help you plan strategies for raising funds (see Resource Listing). You may want to consider participation in a clinical trial as expenses are sometimes less.

Even if you have coverage, there may be expenses beyond those that your insurer will pay. This may be stressful, financially and otherwise, to you and your family. Circumstances vary. If you must hire childcare, this will add to the cost of your treatment. If you stop working, the household budget will probably have to change. Single moms may need to turn to family and friends for support and assistance more often.

If you are a Medicare or Medicaid patient, contact the treatment center's BMT social worker or finance services department to discuss your options. Medicare does not currently cover stem cell transplant for breast cancer patients. Medicaid approves coverage on an individual basis that is dependent on specific criteria. Your treatment center will help you to obtain approval.

### ***Future Directions***

As more is learned about breast cancer treatment, new strategies are being considered. Listed below are a few of the investigative/experimental treatments being studied. Consult your physician for further information.

#### ***Allogeneic Transplant***

Allogeneic transplant uses stem cells from another person, related, unrelated or even from an umbilical cord. Theoretically, this source of stem cell is excellent because it is not contaminated by tumor. A few institutions are studying allogeneic BMT for some women with bone marrow that has been affected by breast cancer. Additionally, these allogeneic



stem cells may carry an antitumor effect, which may eliminate any remaining cancer cells. However, allogeneic transplant carries a significantly higher risk of transplant complications than autologous transplant.

### ***Anti-angiogenesis Agents***

Tumors require a blood supply to live and grow. They produce angiogenesis factors that cause small blood vessels to grow into the tumor to support its growth. New compounds (anti-angiogenesis factors) may block this vessel growth, thereby starving the tumor of nutrients and oxygen. In the future, anti-angiogenesis agents may be used in combination with transplant, surgery, chemotherapy, or other treatments to eliminate the possibility of a recurrence.

### ***Purging***

*Purging* is an additional step in the bone marrow transplant procedure. It occurs on the day of the stem cell “harvest,” prior to transplant. Through a special machine that serves as a kind of filter, diseased stem cells are separated out. The stem cells returned to the patient have a reduced potential of contaminated tumor cells, thereby reinfusing only “pure” cells. The effect of “purging” in decreasing relapse after a transplant has not yet been proven.

### ***Tumor Vaccine Therapies***

Studies are being conducted to determine whether it is possible to immunize patients with proteins derived from their own breast cancer in a similar manner to vaccinating people with the influenza virus. The antibodies formed may help destroy or delay tumor recurrences. Tumor vaccines may help the body reject tumors. The goal is to prevent the cancer from returning.

## ***Conclusion***

You will be empowered in your breast cancer battle when you become knowledgeable, discerning, and involved in your treatment decisions. Your physician, health care team, family, and friends will form a strong circle of support. You are not alone.

Begin your journey with a better understanding of what to expect and how best to get through it. Use this booklet as a companion to guide you.

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## Appendix

# Resource Listing

### *Information and Support*

#### **Adelphi Breast Cancer Hotline & Support Program**

Garden City, NY 11530, 516-877-4320 (In NY: 800-877-8077)

<http://www.adelphi.edu/nysbreastcancer>

*provides information and emotional support*

#### **AMC Cancer Information & Counseling Line**

1600 Pierce St., Denver, CO 80214, 800-525-3777

<http://www.amc.org>

*provides information and support from professional cancer counselors*

#### **American Cancer Society's Breast Cancer Network**

1599 Clifton Rd., NE, Atlanta, GA 30329, 800-ACS-2345 (800-227-2345)

<http://www.cancer.org/bcn/bcn.html>

*publishes breast cancer material and offers support program*

#### **Autologous Blood and Marrow Transplant Registry (ABMTR)**

International Bone Marrow Transplant Registry (IBMTR)

Medical College of Wisconsin, P.O. Box 26509

8701 Watertown Plank Rd., Milwaukee, WI 53226, 414-456-8325

<http://www.biostat.mcw.edu/IBMTR>

#### **Blood and Marrow Transplant Newsletter**

1985 Spruce Ave., Highland Park, IL 60035, 847-831-1913

<http://www.bmtnews.org>

*publications, attorney referrals, peer support*

#### **Bone Marrow Transplant Family Support Network**

P.O. Box 845, Avon, CT 06001, 800-826-9376

*provides emotional support for families*

**BMT-Talk online "chat" group:** To subscribe, send an e-mail message to:

BMT-talk-request @ai.mit.edu Put only the word subscribe in the message.

#### **Cancer Care, Inc.**

1180 Ave. of the Americas, 2nd Fl., NY, NY 10036, 800-813-4673,

<http://www.cancercare.org>

*provides support services, materials and referrals*

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**Cancer Information Service (CIS) National Institute of Health (NIH)**

Bldg. 31, Rm. 10A16 , Bethesda, MD 20892, 800-4-Cancer (800-422-6237)

<http://cancernet.nci.nih.gov>

*provides information, publications in English or Spanish*

*also available through Cancer Fax (Call 301-402-5874 and follow instructions)*

**The Cancer Wellness Center**

215 Revere Dr., Northbrook, IL 60062, 847-509-9595 or 847-509-9494

<http://www.cancerwellness.org>

*offers emotional support to cancer patients and families*

**Cancer Hope Network**

2 North Rd., Suite A, Chester, NJ 07930, 877-467-3638 (877-HOPE-NET)

<http://www.cancerhopenetwork.org>

*offers peer support to cancer patients and family members*

**Coping Magazine**

P.O. Box 682268, Franklin, TN 37068, 615-790-2400

**National Alliance of Breast Cancer Organizations (NABCO)**

9 E. 37th Street, 10th Fl., NY, NY 10016, 888-80-NABCO (888-80-2226)

<http://www.nabco.org>

*provides breast cancer information and advocacy*

**National Bone Marrow Transplant Link, (nbmtLINK)**

29209 Northwestern Hwy., #624, Southfield, MI 48034

800-LINK-BMT (800-546-5268)

<http://comnet.org/nbmtlink>

*provides peer support and publications about BMT or stem cell transplant*

**National Breast Cancer Coalition**

1707 L Street NW, Suite 1060, Washington, D.C. 20036, 202-296-7477 [www.natlbcc.org](http://www.natlbcc.org)

*action, advocacy and policy group*

**National Cancer Institute (NCI) (see Cancer Information Service)**

National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Ave, 5th Fl., Silver Springs, MD 20910, 301-650-8868

<http://www.access.digex.net/~mkragen/index.html>

*advocates to eliminate the stigma of cancer in insurance, employment, and legal rights*

**National Self-Help Clearinghouse**

25 W. 43rd St., Rm. 620, NY, NY 10036, 212-354-8525

<http://www.selfhelpweb.org>

*refers to regional self-help groups*

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**Oncology Nursing Society**

501 Holiday Dr., Pittsburgh, PA 15220, 412-921-7373

<http://www.ons.org>

*publishes directory of BMT centers*

**Susan G. Komen Breast Cancer Foundation**

5005 LBJ Freeway, #250, Dallas, TX 75244, 800-I'M AWARE (800-462-9273)

<http://www.breastcancerinfo.com>

*raises funds in support of research, education and outreach projects*

**Wellness Community**

10921 Reed Hartman Hwy., #215, Cincinnati, OH 45242, 888-793-9355

<http://www.brugold.com/wellness.html>

*provides educational materials on cancer and self-empowerment*

**Y-ME Breast Cancer Organization**

212 W. Van Buren, 5th Fl., Chicago, IL 60607, 800-221-2141 or 800-986-9505 (Spanish)

<http://www.y-me.org>

*provides publications, hotline and support groups*

## ***Clinical Trials***

**Community Clinical Oncology Program (CCOP) 800-4-CANCER**

*medical centers, selected by the National Cancer Institute, participating in clinical trials*

**Physician Data Query (PDQ) 800-4-CANCER**

<http://cancernet.nci.nih.gov/pdq.htm>

*computerized database on treatments, organizations, doctors involved in cancer care*

“What Clinical Trials Are All About?” (booklet) (available in Spanish) 800-4-CANCER

“Taking Part in Clinical Trials, What Cancer Patients Need to Know”(booklet)

800-4-CANCER

“Patient to Patient: Cancer Clinical Trials and You” (video) 800-4-CANCER.

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## ***Infertility***

### **American Society of Reproductive Medicine**

1209 Montgomery Hwy., Birmingham, AL 35216, 205-978-5000

<http://www.asrm.org>

*offers information and publications*

### **Genetics and Invitro Fertilization Institute**

3020 Javier Rd., Fairfax, VA 22301, 800-552-4363

<http://www.givf.com>

*offers information on ovary freezing*

### **Resolve Inc.**

1310 Broadway, Somerville, MA 02144, 617-623-0744

<http://www.resolve.org>

*offers education, advocacy and counseling*

## ***Insurance, Financial Assistance, and Fund Raising***

### **Association of Community Cancer Centers**

11600 Nebel St., # 201, Rockville, MD 20852, 301-984-9496

<http://www.assoc-cancer-ctrs.org>

### **Barbara Anne DeBoer Foundation**

2069 S. Busse Rd., Mt. Prospect, IL 60056, 800-895-8478

<http://www.deboerfoundation.org>

### **Bone Marrow Foundation**

981 First Ave., #129, NY, NY 10022, 212-838-3029

<http://www.bonemarrow.org>

### **Health Insurance Association of America**

555 13th St. NW, #600E, Washington, D.C. 20004, 202-824-1600

<http://www.hiaa.org>

### **National Foundation for Transplants (formerly Organ Transplant Fund)**

1102 Brookfield, #202, Memphis, TN 38119, 800-489-3863 or 901-684-1697

<http://www.transplants.org>

### **National Transplant Assistance Fund**

P.O. Box 258, Bryn Mawr, PA 19010, 800-642-8399 or 610-527-5056

<http://www.transplantfund.org>

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**My Friends Care BMT Fund (MI residents)**

148 S. Main St., #101, Mt. Clemens, MI 48043, 810-783-7390

<http://www.myfriendscare.org>

**Patient Advocacy Coalition**

850 E. Harvard Ave. #465, Denver, CO 80210, 303-744-7667

<http://www.patientadvocacy.net>

**Patient Advocate Foundation**

780 Pilot House Dr., #100C, Newport News, VA 23606, 800-532-5274

or 757-873-6668

<http://www.patientadvocate.org>

***Transportation Support***

**Airlifeline**

50 Fullerton Ct. #200, Sacramento, CA 95825, 800-446-1231

<http://www.airlifeline.org>

**Corporate Angel Network Inc.**

Westchester County Airport, 1 Loop Rd., White Plains, NY 10604, 914-328-1313

<http://www.corpangelnetwork.org>

**National Patient Air Transport Helpline**

4620 Haygood Rd., #8, Virginia Beach, VA 23455, 800-296-1217

<http://www.mercymedical.org>

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## **Cancer Information on the Internet**

The Internet is a valuable tool for medical research. It offers a wealth of information, some helpful, some misleading. Evaluate Internet material by asking: “What is the source of this information?” “Is it factual or opinion?” “Is it based on someone’s experience?” “How current is this information?”

Additional information may be found by using a “search engine.” Search engines are powerful searching programs that are helpful in finding information anywhere on the Web. Some of the popular ones are:

- Yahoo <http://www.yahoo.com>
- Infoseek <http://www.infoseek.com>
- Alta Vista <http://www.altavista.digital.com>

Begin searching with specific terms. Use broader terms next. For example, specific terms would be “stem cell transplant” and “breast cancer.” A broader term would be only “breast cancer.” Using quotation marks will result in a more specific search, but use the “Help” key to find out how to enter search terms correctly. If you are not comfortable using a computer, ask staff at the public library for assistance.

**Breast Cancer Information Clearinghouse:** <http://www.nysernet.org>

**CancerAnswers:** <http://canceranswers.org>

**CancerNet:** <http://cancernet.nci.nih.gov>

**Oncolink:** OncoLink: <http://oncolink.upenn.edu>

**PDQ:** <http://cancernet.nci.nih.gov/pdq.htm>

## **Clinical Trial Web Sites**

<http://breast-cancer.sciweb.com>

<http://www.nabco.org/trials>

<http://cancertrials.nci.nih.gov>

<http://cancernet.nci.nih.gov/trials>

<http://www.centerwatch.com>

<http://www.askcnet.org>

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## Books

*Bone Marrow Transplant Resource Guide, Friends Helping Friends*

National Bone Marrow Transplant Link (800-LINK-BMT)

*Breast Cancer: The Complete Guide*

Yashar Hirshaut, M.D. and Peter Pressman, M.D.

*Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain and Illness*, Jon Kabat-Zinn, Ph.D.

*Guide to Stress Reduction*,

John Mason, Ph.D.

*Heal Yourself: A Step-by-Step Program for Better Health Through Imagery*

Martin Rossman, M.D.

*Holding Tight, Letting Go: Living with Metastatic Breast Cancer*

Musa Mayer

*Hope is Contagious: The Breast Cancer Treatment Survival Handbook*

Margit Esser Porter

*Love, Judy*

Judy Hart

*Not Now...I'm Having a No Hair Day: Humour and Healing for People with Cancer*,

Christine Clifford

*The Race is Run One Step at a Time: My Personal Struggle and Every Woman's Guide to Taking Charge of Breast Cancer*, Nancy Brinker

*Survivors' Guide to a Bone Marrow Transplant, What to Expect and How to Get Through It*, Keren Stronach (800-LINK-BMT)

*We're All in This Together: Families Facing Breast Cancer*

Irene Virag

Please visit the following Web sites for additional listings and updates:

<http://comnet.org/nbmtlink>

<http://comnet.org/nbmtlink/breastcancerstemcellguide.html>

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## GLOSSARY

**Adjuvant chemotherapy** – Drugs used to kill cancer cells. They are given with other treatments, such as surgery or radiation, to destroy areas of tumor.

**Allogeneic transplant** – The person donating the bone marrow or stem cells is a closely matched family member, usually a brother or sister. Or the person donating the bone marrow is a closely matched unrelated donor.

**Alopecia** – A partial or complete hair loss, usually a temporary side effect of the chemotherapy.

**Anemia** – A condition that occurs when the body's red blood cell count is low.

**Antibody** – A protein produced by white blood cells (leukocytes) to battle foreign substances that enter the body, such as bacteria.

**Apheresis** – The peripheral blood stem cell collection process in which blood is taken from a patient and circulated through a machine that separates out stem cells. The remaining cells are returned to the patient.

**Autologous transplant** – The patient donates his/her own bone marrow or stem cells prior to treatment for reinfusion later.

**Axillary nodes** – Lymph nodes located in the armpits.

**Bone marrow** – The spongy tissue found in the cavities of the body's bones where all blood cells are produced.

**Bone marrow transplant (BMT)** – A procedure developed to treat some forms of cancer and other diseases. There are several types of BMTs, depending on who donates the marrow (see autologous, allogeneic, and syngeneic).

**Central line or central venous catheter** – A small, plastic tube inserted in a large vein to inject or remove fluids. The central line used in a stem cell transplant allows blood samples to be drawn, drugs to be given, and the actual transplant to occur with little discomfort.

**Chemotherapy** – Treatment with one or more anticancer drugs to try to stop or slow the growth of cancer cells.

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**Clinical trials** – Long-term research studies that test new cancer treatments.

**Colony stimulating factor or growth factor** – The proteins given to stem cell transplant recipients before and during the harvest to increase the number of stem cells in the blood.

**Conditioning** – A phase in the stem cell transplant process designed to destroy cancer cells more effectively than with standard doses of chemotherapy. Conditioning involves combining high doses of chemotherapy and/or radiation.

**Cytokines** – Naturally occurring substances that can make cells grow (growth factor).

**Engraftment** – Process in which transplanted stem cells begin to grow in the recipient's bone marrow and produce new white blood cells, red blood cells, and platelets.

**Erythrocytes** – Red blood cells that carry oxygen.

**Graft failure** – Complication after a transplant in which the stem cells do not grow in the recipient's bone marrow and do not produce new white blood cells, red blood cells, and platelets.

**Growth factor or colony stimulating factor** – The proteins given to stem cell transplant recipients before and during the harvest to increase the number of stem cells in the blood.

**Harvest or stem cell retrieval** – The process of collecting stem cells from the circulating blood.

**Immunocompromised** – A condition in which the patient has a much higher risk of infection due to a weak immune system.

**Immune system** – The group of organs and cells in the body that fight infection and other diseases.

**Inflammatory breast cancer** – A rare, aggressive type of cancer. Symptoms include redness, warmth, and the appearance of ridges, welts, hives, or wrinkles.

**Informed consent** – Hospital form, signed by the patient, that documents an understanding of medical procedures.

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**Infusion** – Slow introduction of fluid into a vein referred to as an IV (intravenous).

**Leukocytes** – White blood cells that fight infection.

**Lumpectomy** – A surgery to remove only the cancerous lump and some other tissue.

**Lymphocytes** – A type of white blood cell that is part of the immune system.

**Mastectomy** – A surgery to remove all or part of the breast and sometimes other tissue.

**Metastasis** – The spread of cancer from one part of the body to another.

**Mobilization** – Moving more stem cells from the bone marrow into the bloodstream through chemotherapy and/or a growth factor.

**Peripheral blood stem cells** – Stem cells that circulate in the blood.

**Peripheral blood stem cell transplant or stem cell transplant** – Stem cells are removed from the blood, frozen, thawed, and returned after high-dose chemotherapy.

**Platelets** – Blood cells that act as clotting agents to prevent bleeding.

**Prognosis** – The predicted or likely outcome.

**Protocol** – A specifically designed treatment plan.

**Purging** – The process of removing certain types of cells from bone marrow before transplanting it to a patient. In autologous transplants, marrow may be purged of lingering cancer cells.

**Radiation therapy** – Treatment to kill cancer cells using high-energy rays from x-rays, electron beams, or radioactive isotopes.

**Red blood cells** – Cells carrying oxygen to all parts of the body (erythrocytes).

**Re-infusion** – The return of healthy stem cells into a transplant recipient's body.

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**Remission** – Complete or partial disappearance of cancer cells and symptoms.

**Rescue process** – Another term for a stem cell transplant. The reinfusion of healthy stem cells following high doses of chemotherapy or radiation.

**Staging** – The process of determining and describing the extent of the cancer.

**Stem cells** – The “parent cell.” Every type of blood cell in the body begins its life as a stem cell. The stem cells then divide and form the different cells that make up the blood and immune system.

**Stem cell retrieval or harvest** – The collection of healthy stem cells from the circulating blood stream.

**Stem cell transplant or peripheral blood stem cell transplant** – Stem cells are removed from the blood, frozen, thawed, and returned after high-dose chemotherapy.

**Syngeneic transplant** – The person donating the bone marrow or stem cells is an identical twin.

**Thrombocytopenia** – Low platelet count.

**White blood cells** – Cells that help fight infection and disease (leukocytes).

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# STEM CELL TRANSPLANT



*A Companion Guide  
For Breast Cancer Patients*

**National Bone Marrow Transplant Link**

BARBARA ANN  
**KARMANOS**  
CANCER INSTITUTE

*The Detroit Medical Center  
Wayne State University*