

INTRODUCTION TO  
**ALLOGENEIC  
BLOOD AND MARROW  
TRANSPLANT (BMT)**





# INTRODUCTION TO BMT AT ROSWELL PARK COMPREHENSIVE CANCER CENTER

Dear Patients, Families, and Friends:

Welcome to Roswell Park Comprehensive Cancer Center. You or someone you love may be considering an Allogeneic or Autologous Blood or Marrow Transplant (BMT) at Roswell Park.

Our BMT team has developed this manual to answer your questions and to serve as a source of important information during the various phases of the BMT process. Please read this manual carefully and, for easy reference, bring it with you when you come to the hospital.

Here at the nation's first cancer research, treatment, and education center, we perform BMTs for pediatric and adult patients. Undergoing a BMT is an intensive endeavor requiring a major commitment from patients and families. We will support you every step of the way.

The patient and his/her family are our primary focus. If, at any time, you want more information or have specific questions, please do not hesitate to ask. We welcome your questions and want you to always feel free to talk with us.

Roswell Park's multidisciplinary team of cancer experts and its cutting-edge treatments mean that patients receive the best possible care available today. BMT research is pioneered here, and our facility is accredited by the National Marrow Donor Program (NMDP), as well as by the Foundation for the Accreditation of Cellular Therapy (FACT), as a Transplant, Collection, and Apheresis Center.

The members of Roswell Park's BMT team know this is a difficult time. We will do everything we can to soften the stressors of treatment and recovery. We strive each day to treat our BMT patients with dignity and compassion, and keep you informed about your treatment. Each patient becomes the most important member of their BMT team, and each patient's family becomes part of the Roswell Park family. We will work together to fight this battle.

Sincerely,

Your BMT Team

## **DISCLAIMER:**

This booklet is provided for information purposes only and does not constitute a legal contract or agreement between Roswell Park and any person or entity unless otherwise specified. Although every reasonable effort is made to present current and accurate information, as a result of ongoing program revisions, some content is subject to change and amendment without prior notice.

If you find anything that does not make sense or appears contradictory, please let your transplant coordinator or physician know.

For any comments or concerns please email: [michelle.steward@roswellpark.org](mailto:michelle.steward@roswellpark.org)

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# ABOUT BUFFALO, NY

## **Roswell Park**

Elm & Carlton Streets

Buffalo, New York 14263

General Information: 1-800-ROSWELL (1-800-767-9355)

716-845-2300

[www.roswellpark.org](http://www.roswellpark.org)

Roswell Park is centrally located in the City of Good Neighbors, 10 minutes from the world-famous Albright-Knox Art Gallery, Delaware Park, Buffalo Zoo, and Erie Basin Marina, and within two blocks of historic Allentown, a community noted for artists, antiques, gourmet restaurants, coffeehouses, and Victorian homes.

Buffalo is located at the eastern end of Lake Erie, 30 miles from Niagara Falls, and less than a two-hour drive from Toronto, Canada. Lake Erie moderates winter and summer temperatures and provides outstanding recreational activities. The hills, fields and forests surrounding the Queen City afford excellent winter skiing, summer hiking, and camping

The Buffalo metropolitan area – Erie and Niagara counties – has a population of 1.25 million. Although Buffalo is the second largest city in New York and has the cultural and social advantages of a large city, it offers a relaxed pace of life and easy access to the surrounding countryside.

The downtown theater district boasts many theaters in active production. Cultural centers include the Albright-Knox Art Gallery, internationally known for its collection of modern art, and Kleinhans Music Hall, home of the Buffalo Philharmonic, which is consistently ranked among the top 10 symphonies in the nation.

There are several sports teams including the NFL Bills, the NHL Sabres, and the MiLB Buffalo Bisons.

Other local attractions include Artpark, Buffalo Science Museum, Letchworth State Park, Tifft Farm Nature Preserve, Shakespeare in the Park, Botanical Gardens, Allentown Art Festival, Galleria Mall, Buffalo and Erie County Historical Society and the Naval and Servicemen's Park. Restaurants offer the finest in dining and a variety of ethnic cuisines, including French, Polish, Italian, Chinese, Indian, Mexican, Thai, Greek, Japanese, Ethiopian, and Burmese.

**[www.visitbuffaloniagara.com](http://www.visitbuffaloniagara.com)**



# LOCATION, MAPS, & DIRECTIONS

## THE BUFFALO NIAGARA MEDICAL CAMPUS MEMBER INSTITUTIONS WWW.BNMC.ORG

The Buffalo Niagara Medical Campus is a consortium of the region's leading health care, research, and medical education institutions, all co-located on 120 acres in downtown Buffalo, New York. Nine "member institutions" lead the charge to develop an innovative, world-class campus for clinical care, research, education, and entrepreneurship in downtown Buffalo.

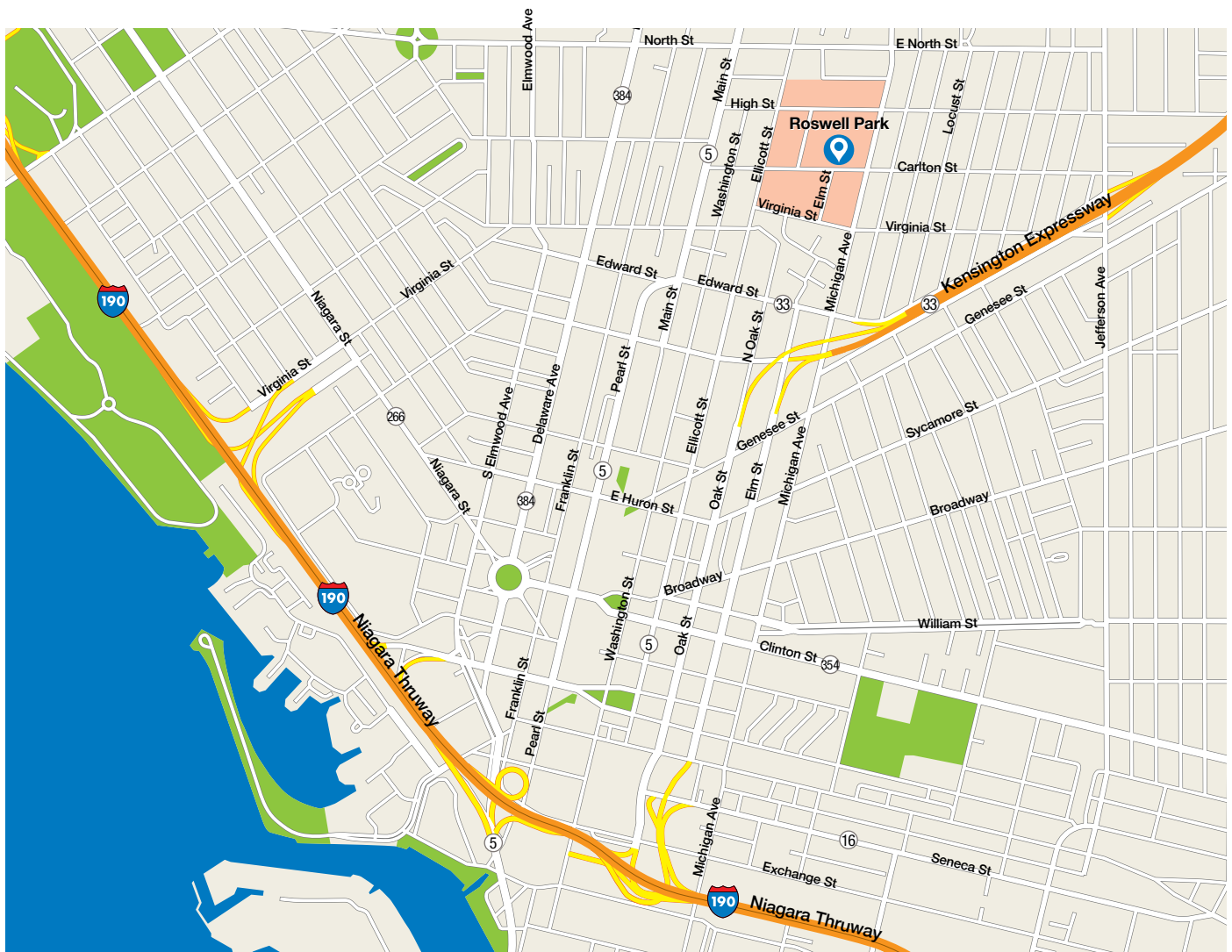
## The Buffalo Niagara Medical Campus Board Members

- Allentown Neighborhood
- Buffalo Common Council
- Buffalo Hearing and Speech Center
- Buffalo Medical Group
- Center for Hospice & Palliative Care
- City of Buffalo
- County of Erie
- Fruit Belt Neighborhood
- Hauptman-Woodward Medical Research Institute
- Kaleida Health
- Olmsted Center for Sight
- Ross Eye Institute
- Roswell Park Comprehensive Cancer Center
- School of Medicine & Biomedical Sciences, University at Buffalo
- Upstate NY Transplant Services (UNYTS)
- University at Buffalo



### BUFFALO NIAGARA MEDICAL CAMPUS

- |   |   |  |  |   |
|---|---|--|--|---|
| 1 Innovation Center                               | 8 Hauptman-Woodward Medical Research Institute                                  | 13 Kevin Guest Houses                              | 20 Kaleida Health - Community Mental Health Center and Service Response Center                                 | 25 Patient & Visitor Parking                          |
| 2 dig   | 9 Roswell Park Cancer Institute   | 14 Cleveland BioLabs                               | 21 UB Research Institute on Addictions   | 26 Olmsted Center for Sight/Ross Eye Institute        |
| 3 UB Educational Opportunity Center               | 10 UB - New York State Center of Excellence in Bioinformatics and Life Sciences | 15 Buffalo Medical Group                           | 22 Buffalo Hearing & Speech Center   | 27 Patient, Visitor & Employee Parking                |
| 4 UB - Downtown Gateway                           | 11 Roswell Park - Center for Genetics and Pharmacology                          | 16 Doubletree Club by Hilton Hotel                 | 23 Kaleida Health - Gates Vascular Institute, UB Clinical and Translational Research Center & Jacobs Institute | 28 Kaleida Health - HighPointe on Michigan            |
| 5 Visitor & Employee Parking                      | 12 UB Jacobs School of Medicine & Biomedical Sciences                           | 17 Conventus                                       | 24 Patient, Visitor & Employee Parking - Partial Opening 2017  | 29 Roswell Park - Clinical Sciences Center            |
| 6 Innovation Center Annex                         |   | 18 Kaleida Health - Oishei Children's Hospital     |  | 30 Roswell Park - Patient, Visitor & Employee Parking |
| 7 Allen/Medical Campus<br>NFTA Metro Rail Station |   | 19 Kaleida Health - Buffalo General Medical Center |  | Electric Vehicle Charging Station                     |



Roswell Park is located in Western New York in the heart of the city of Buffalo. It is easily accessed from the Buffalo Niagara International Airport, major highways, including the New York State Thruway (Interstate 90), and Canada via the Peace Bridge.

## TO REACH ROSWELL PARK:

**From Points East of Buffalo:** Take the New York State Thruway (I-90) to Exit 51W (33W). Exit 33W at Locust Street. Turn right at the first traffic light (Michigan Avenue). Continue two blocks to Carlton Street; turn left. Follow signs to Roswell Park's Main Entrance.

**From Points West of Buffalo:** Take the New York State Thruway (I-90) to the Downtown Section (I-190). Exit at Elm Street and continue on Elm until it ends at Goodell Street. Turn left onto Goodell and continue to Ellicott Street; turn right. Take Ellicott to Carlton Street; turn right. Follow signs to Roswell Park's Main Entrance.

Bus and rail lines are convenient to Roswell Park. The bus station is located at 181 Ellicott Street. Visitors may take the No. 8 Main Street bus line to Roswell Park. For Metro Rail, use the Allen/Medical Campus Station at Main and Allen Streets near Roswell Park. For schedules, fares and routes, call the Niagara Frontier Transportation Authority at **716-855-7300** or visit [www.nfta.com/metro](http://www.nfta.com/metro)

If you have transportation problems or any questions about travel to and from Roswell Park, contact our Department of Social Work at **716-845-8022** or your local unit of the American Cancer Society at 1-800-227-2345 or visit [www.cancer.org](http://www.cancer.org).

**Using GPS:** Enter zip code 14263 in your GPS for directions to Roswell Park.

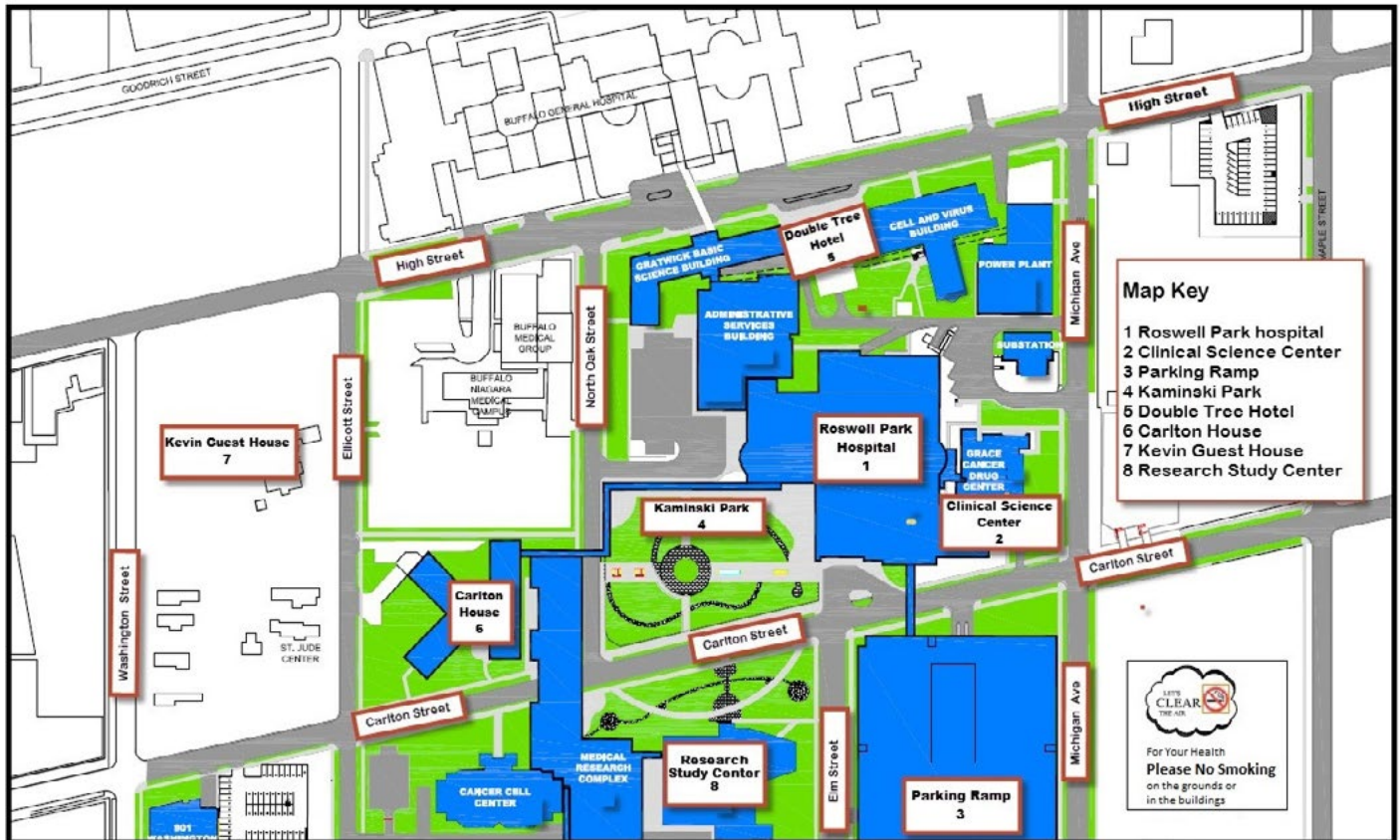


# CAMPUS MAP



# PARKING RAMP MAP

(CARLTON AND ELM STREET)



# SUPPORT AND INFORMATION FOR PATIENTS

## WE'RE IN THIS TOGETHER!

The process of a blood or marrow transplant is very complex. All of the responsibilities and possibilities, in addition to the long recovery, may feel overwhelming to patients and their families. Here at Roswell Park, we are committed to helping you each step of the way by staying attuned to your medical, emotional, and physical needs.

You and your family may have many questions about what to expect during the actual BMT process. You will find answers to many of your questions here. We also urge you to share your concerns and questions with members of your BMT team.

## YOUR BMT HEALTH CARE TEAM

Many people will be helping you through your BMT procedure. Together, they make up your multidisciplinary BMT health care team. Your team members are constantly communicating with each other to ensure that you receive the best possible care. We consider you and your family to be important parts of this team, and we encourage you to ask questions and share information with us. Communication is not only welcome; it is a key part of your treatment and recovery.

A successful BMT requires a medical team of BMT experts – doctors, nurse practitioners, physician assistants, nurses, transplant coordinators, social workers, physical therapists, case managers, pharmacists, and dietitians – who can recognize problems and emerging side effects promptly and know how to react swiftly and properly. Psychosocial support is important throughout the BMT process and will be available to you and your family.

## **BLOOD AND MARROW TRANSPLANT COORDINATORS (RN)**

Your Transplant Coordinators (TCs) are all registered nurses (RN) with specialty training for BMT patients. Your TC is a key contact and resource person, who will manage your schedule through your stem cell collection, pre-transplant evaluation, and the admission process. Your TC will help navigate your complex appointments and be your advocate until you arrive to the BMT inpatient unit.

## **PHYSICIANS**

BMT physicians are experts and have ultimate responsibility for patient care. Your clinic physician will meet with you to develop your specific treatment plan and will participate with the other attending physicians during both inpatient and outpatient care.

## **NURSE PRACTITIONER (NP) AND PHYSICIAN ASSISTANT (PA) – ADVANCED PRACTICE PROVIDERS (APP)**

A Nurse Practitioner (NP) is an advanced practice nurse, an RN who has earned a separate NYS license as an NP through advanced clinical nursing education (master's or doctorate) in a distinct area of practice. They may hold National Board Certification (BC) in a specialty. NPs may diagnose, treat, and prescribe for a patient's condition that falls within their specialty area of practice. A PA is a master's degree graduate who is nationally certified and state-licensed to practice medicine with the supervision of a physician.

Your Blood and Marrow Transplant (BMT) NPs/PAs are specifically trained to care for you during your transplant experience. They will perform comprehensive and focused physical examinations. Your NP/PA may diagnose, treat, order and interpret diagnostic/laboratory tests, and prescribe medications and therapies for you. Performing procedures, obtaining consults, and providing patient education are among the activities performed by your NP/PA. All BMT NPs/PAs maintain a close working relationship with your BMT physician and consult daily on your plan of care.

## **BMT FELLOWS**

The Hematology-Oncology Fellowship program provides clinical and laboratory training in hematology, medical oncology, and bone marrow transplantation with specialty training in hematology/oncology. There is usually one fellow who cares for BMT patients on a monthly basis.

## **TRANSPLANT UNIT STAFF NURSE (RN)**

BMT staff nurses are all registered nurses (RN) with specialty training in caring for BMT patients. They will answer your questions, provide support, and encourage you and your family to be actively involved in your care.

Your BMT patient education will occur with the RN staff that will be directly involved with your care. They are your care providers, educators, and advocates while you remain a BMT patient.

## **NURSE MANAGERS**

The inpatient nurse manager and the administrative charge nurse supervise the clinical staff in the inpatient units. The nurse manager is responsible for the administration, direction, and coordination of quality nursing care on the BMT units. Your nurse manager is always available to you and can answer any questions you may have about standards of care. You can expect to see the nurse manager and/or the administrative charge nurse regularly, checking in during your stay to make sure you feel safe, comfortable, and well-informed.

## **NURSE CASE MANAGERS**

Case management is a collaborative process that assesses, plans, implements, and evaluates the options and services needed to meet a patient's health care needs when they are discharged from the hospital into the outpatient setting. RN case managers help to educate and assist patients, their families, and the health care team members to understand what services, equipment, medications, and home care options are covered by the patient's insurance plan. Your nurse case manager will coordinate all aspects of your BMT process to help you, your family, and the BMT clinicians develop a comprehensive plan of care. The case manager will assist with this process and work with the team to obtain the most therapeutic and cost effective drug for you.



## **FINANCIAL COUNSELORS**

Your financial counselor is an account representative available for any insurance or financial questions or problems. You should contact your financial counselor if you change insurance coverage or receive any bill from Roswell Park or the Clinical Practice Plan that you do not understand.

## **REGISTERED DIETITIANS NUTRITIONISTS (RDN)**

A registered dietitian nutritionist is available to you during your hospital stay. The dietitian works closely with your health care providers and makes recommendations to ensure your nutritional needs are met. Good nutrition is especially important while you are receiving cancer treatment. During treatment, taking in enough calories, protein, vitamins, and minerals will help maintain your weight, promote the healing process, and make you stronger.

Before and after your treatment, a healthy diet based on moderation, variety, and balance will help to promote a good immune system, give you energy, and enhance your overall health. Our Nutrition and Food Service team provides nourishing meals and nutrition care to improve your quality of life throughout your BMT experience.

## **PHARMACISTS**

The pharmacist on the transplant service is a Pharm D, a clinical specialist who provides drug information to you, your family, and the BMT clinicians. During daily interdisciplinary patient rounds, the pharmacist will check your medications and dosages to prevent drug interactions and reduce side effects. Your pharmacist will carefully monitor your drug regimen and recommend adjustments to your drug therapy, as needed. They also assist with preparing medications to make sure you will be taking the right medication while at home. You will be counseled about your medications before discharge. Information will include generic and brand names for the drugs, doses, why you are taking the drug, instructions on when and how to take it, managing common side effects, and when to call us. You will receive a medication pillbox and a medication schedule to help you take your medications correctly at home.

## **MEDICAL SOCIAL WORKERS**

The Department of Social Work is committed to providing the best psychosocial care to all who seek treatment here by addressing the social, environmental, and emotional impact of a BMT.

Your BMT medical social worker can handle many of the issues that you and your family may face including counseling, crisis intervention, and support throughout the BMT process. For patients with issues of long term care, it is critically important to work with your social worker to meet these needs.

The Department combines the skills and resources of licensed social workers and psychologists to work with patients and families on the challenges created by a cancer diagnosis. In addition to the services above, the staff offers assistance with financial concerns, parenting issues, disability information, advance care planning, legal concerns, intimacy issues, rehabilitation or nursing home placements, transportation resources, interpreter services, hospice information, local lodging arrangements, and coping with anxiety, fears, depression, and life changes. They provide emotional support and connect patients with Roswell Park and community resources that can address challenges and barriers you may face.

If you are in need of handicap parking, please ask our social worker for the Department of Motor Vehicles Handicap Form. Our BMT clinicians will fill it out and you will then need to return it to the DMV.

## **PEDIATRIC PSYCHOSOCIAL SUPPORT TEAM**

If your son or daughter is having a BMT, the pediatric psychosocial support team will offer services and activities to meet your child and family's psychosocial, emotional, and developmental needs. Upon referral, a one-time consultation can be offered for children of adult patients, with referral for long term support as needed.



## REHABILITATION SERVICES

### Physical Therapists (PT)

Your physical therapist will help you develop and maintain strength and endurance through a specially designed daily exercise program. The PT will evaluate you on the day of admission and instruct you in a variety of exercises to maintain your strength, endurance, and balance. Activities may include walking laps around the unit, using the treadmill or cross-trainer recumbent bike, performing step-ups, using weights for arm exercises, and balance exercises (standing on one foot). Make sure you bring shoes and clothing appropriate for exercise.

During your stay your energy level will fluctuate. PT will visit Monday through Friday to monitor and modify your program. If you are not able to exercise independently, the therapist will supervise your program.

### Occupational Therapists (OT)

Occupational therapists have the knowledge and expertise to modify activities and environment so patients can do the things that they want and need to do to maintain a maximum level of independence and quality of life. At Roswell Park, the role of Occupational Therapy is to enable each patient to reach his or her maximum functional performance, both physically and psychologically, in everyday living skills, regardless of his or her life expectancy.

Cancer and its treatment can cause interruptions in daily routines affecting how individuals perform their self-care, work, leisure, or social activities. It may bring fatigue, pain, weakness, problems with memory or clear thinking, anxiety, depression, and changes in how we see ourselves. The goal of OT is to restore function, and it may address many of the issues listed. Home exercise programs improve strength and mobility teaches patients how to adapt every day activities, and conserve energy in the workplace, home, or community.

## DENTISTS

The dental team will explain how treatment may affect your mouth, and how to prevent potential problems. They will make suggestions about how to care for your mouth during and after your treatment and make recommendations to correct any problems that occur. You will be evaluated by the dental team before your admission to the BMT Unit. The dental team is always available for treating all of your dental needs, or for consultation.

## RESPIRATORY THERAPISTS

Your respiratory therapist will perform pulmonary (lung) function tests and cardiac (heart) and/or pulmonary stress tests to find out how well your heart and lungs are working. Your health will be evaluated so that you may receive the care and treatment you need. Treatments may include assisted ventilation, supplemental oxygen, oxygen mixtures, chest physiotherapy, and aerosol medications. If your discharge plan includes oxygen or respiratory therapy, your therapist and the BMT team will work closely to take care of both your specific equipment and patient/family educational needs.

## PASTORAL CARE

Pastoral Care staff at Roswell Park work with physicians, nurses, and other members of the psychosocial oncology team to ensure the total care of patients and their families. They provide pastoral counseling and minister to the spiritual, emotional, and psychosocial needs of patients, family members, and friends at all stages of the treatment process.

Protestant and Roman Catholic chaplains and the pastoral care staff provide spiritual care to all persons regardless of their religious affiliation. Chaplains are available 24 hours a day to respond to the urgent spiritual and emotional needs of patients. Sacraments and religious literature are available upon request. A rabbi is available to assist with the rituals and traditions of the Jewish faith. Area clergy of most faith denominations are available to support patient and

family needs at Roswell Park. The all faith chapel is located on the first floor of the hospital (Room 1401) and is open to patients, family members, and friends for prayer and meditation. They can be reached at **716-845-8051**.

## PATIENT ADVOCATE

Patient advocates play a unique and vital role for patients and their families; acting as a mediator; a connection between you and your healthcare team. They work with patients and staff to resolve concerns and to improve effective communication among patients, families, and your Roswell Park care giving team. They are here to ensure your questions are answered and your concerns are met. Contact them when you:

- don't know whom to ask for help
- are experiencing difficulties during your hospital stay or visit
- have questions or concerns about any aspect of your care or service
- are unable to resolve issues with your clinical team

You or your family member can meet with an advocate via telephone, mail, or in person. They can be reached at **716-845-1365**.

In addition to advocacy services, the department represents patient interests on the Institutional Review Board, Patient Review Payment Committee, Ethics Committee, Quality Improvement Committee, Quality of Life Committee, and Patient Safety. Their goal is to provide the highest quality health care.

## THE YOUNG ADULT PROGRAM AT ROSWELL PARK

The Young Adult Program is a support and resource program designed specifically for cancer patients and survivors in their 20s and 30s. The team is dedicated to helping you throughout your cancer journey – from diagnosis to post-treatment. They are here to help with the challenges that you may face after your treatment is over. They are about keeping you informed, helping you make connections, and most importantly, keeping you on the positive side of your cancer journey.

### ***What does the Young Adult Program have to offer?***

**Support Team:** They offer a consultative service to provide you with more information about their program, assess any needs you may have, and provide additional services. Their team consists of a physician, a psychologist, and a social worker who are all available to meet with you. They also offer counseling on how cancer and its treatment can affect fertility. Ask your doctors or nurses to set up a consult to meet with them before you begin treatment.

**Social Events:** Whether its dinner, the movies, a sports game, or a concert, they offer various events for the young adult community... FREE of charge! Don't let your cancer diagnosis get in the way of being the fun, social person you are. Come out and meet some other great local young adults and get to know their supportive community.

**Support Network:** They offer monthly programs where young adults can discuss topics that are important to them, like intimacy and fertility, finances during and after cancer, wellness and nutrition, and getting back to work or school. Join them each month for a candid conversation about what it means to be a young adult with cancer, and talk to other individuals who "really get" what you mean.

Please be sure to discuss  
fertility preservation/options  
and the availability of clinical  
trials with your physician.  
You'll be glad you did!

**Annual Wellness Retreat for Young Adults:** Every April, at the beginning of National Young Adult Cancer Awareness Week – which is the first full week in April, for those of you who may be wondering – they host an all-day informative retreat focused on just you! Bring a friend, a sibling, or a parent, and learn about a variety of pro-health initiatives you can implement in your day-to-day routine. From nutrition to yoga to art therapy, you never know what cool ideas will be discussed. The offerings may vary from year to year, but the goal remains the same: hanging out with other young adults and celebrating you!

Please check out the Young Adult Program on: [www.facebook.com/RoswellParkAYA](https://www.facebook.com/RoswellParkAYA) or contact them at [aya@roswellpark.org](mailto:aya@roswellpark.org) or **716-845-3356**.

## **SMOKING CESSATION PROGRAM**

If you smoke, quitting should be part of your cancer treatment and Roswell Park can help. Roswell Park's smoking cessation program offers support, counseling, pharmacotherapy, and more. For more information, please call **716-845-1300 x7851 or toll free 1-800-ROSWELL (1-800-767-9355)**.

## **CANCER PAIN MANAGEMENT SERVICE**

The Cancer Pain Management Service (CPMS) at Roswell Park uses a team approach to reducing pain in cancer patients. The expertise of anesthesiologists, psychologists, nurses, physical and occupational therapists, nutritionists, and social workers merges into a comprehensive pain management plan designed to meet the individual needs of each patient. The first step is to assess your level of pain from the information provided on the Comprehensive Pain Assessment Questionnaire. This knowledge pinpoints the areas and nature of your discomfort and guides the team in selecting the most appropriate treatment or treatments for you.

The CPMS uses individual and family counseling, printed materials, and videotapes to help the patient and the family better understand cancer pain and its treatment.

## **SUPPORTIVE & PALLIATIVE CARE PROGRAM**

Coping with advanced illness is stressful – not only for the patient but also for those who love and care for them. Palliative Care is a medical specialty focusing on symptom control and pain management with a heightened regard for the emotional, social, and spiritual needs of the patients and families at Roswell Park. They work with clinical dietitians and members of the pastoral care and psychosocial oncology departments to manage symptoms and maintain an optimal quality of life for patients and caregivers.

It is a common misperception that palliative care is offered only for patients who are ending curative treatment. The Supportive & Palliative Care Team at Roswell Park works with your attending physician and can join your care process at any time.

## **INTENSIVE CARE UNIT**

The 8,000-square-foot unit is located on the eighth floor of Roswell Park's main building. Should you ever need to be transferred to the ICU (for critical care), the BMT and ICU clinical teams will collaborate in your care. You will receive the expertise of all required clinical management.

Visitors are allowed any time except between 7:00 and 9:00 in the morning and evening.

## RESOURCE CENTER FOR PATIENTS & FAMILY

The Resource Center at Roswell Park offers patients and their families a caring and personalized experience. They offer information, support, assistance, resources, and materials designed to educate and guide you through every step of your journey. The Resource Center is open to all.

- Roswell Park pamphlets, brochures, and pathway books that educate in an easy-to-use format. If you need additional assistance, the Patient Education Department staff is available to help you with a more detailed search for information.
- Publications and reference materials from the National Cancer Institute and other national patient and professional organizations.
- Lending library of laptops, books, and DVDs; available laptops with Wi-Fi access and printers.
- Wig Boutique that provides one free new wig and hat per year to people who have hair loss due to cancer treatment. A second wig and hat may be purchased at cost.
- Uplifting and educational programs.

The Resource Center is located on the 1st floor of the hospital, inside the Sunflower Café cafeteria.  
Hours: Monday – Friday, 9:00am to 4:00pm. For more information, please call **716-845-1729**.

## CANCERCONNECT® – ONLINE COMMUNITY

Roswell Park's online community is a place where you can safely share your thoughts, successes, and concerns with others who face the same struggles. It's easy to register and all members of the Roswell community can take part in the conversations of the national communities. Visit us at **[www.cancerconnect.com/roswellpark](http://www.cancerconnect.com/roswellpark)**

# WHY A TRANSPLANT?

- A BMT is a way to aggressively treat and/or cure a potentially fatal disorder or disease. A BMT can potentially re-establish blood cell production and the immune system.
- A BMT comes with serious complications and risks and should never be taken lightly.
- Although a BMT does not prevent a disease reoccurrence, it can increase the likelihood of a cure, prolong the period of remission, or keep your disease from progressing.
- A BMT can be a difficult process and requires a great deal of commitment from the patient, their family, and educated caregivers.

Most hematopoietic cells (cells that produce/form blood cells) are in your bone marrow. Some make their way from the bone marrow into the blood that circulates through your body. Bone marrow hematopoietic cells turn into red blood cells, white blood cells, or platelets to help your body stay healthy. If your bone marrow is attacked by a disease, it may no longer make normal blood cells. In other situations, the amount of chemotherapy and/or radiation that was needed to conquer your disease also destroyed your existing bone marrow. In a BMT, healthy hematopoietic cells are placed in your body through a central venous line to help restore your bone marrow.

## **There are two main types of transplants.**

- An **allogeneic** transplant is when you receive hematopoietic cells from a donor.
- An **autologous** transplant is when you receive your own hematopoietic cells. This treatment is considered a rescue.

## **This manual is about allogeneic transplants.**



# A BETTER UNDERSTANDING: ALLOGENEIC BMT

An allogeneic transplant is one in which the donor and the recipient are different people. Your hematopoietic cells are replaced with new, healthy hematopoietic cells from a donor or from donated umbilical cord blood. It involves:

- pre-BMT evaluation, planning, and preparation
- chemotherapy, or a combination of chemotherapy and radiation therapy, is given to wipe out the cancer cells, suppress the patient's immune system, or both.
- transplant: infusing your thawed hematopoietic cells into your bloodstream through your central venous line (an IV that goes into a large vein) to replace the marrow that was destroyed by your treatment (This procedure is similar to a blood transfusion)

Finding a suitable donor is critical for the success of an allogeneic transplant. Your immune system can tell the difference between your own cells and cells from another person – and it can attack the ‘foreign’ cells, a condition called graft versus host disease. To avoid complications that can be serious and difficult to treat, your donor's tissue type should match yours as closely as possible.

## YOUR BMT CONSULTATION: FACTORS TO CONSIDER BEFORE MOVING FORWARD

You have been referred by your hematologist/oncologist or your primary care physician to be evaluated by the Roswell Park Transplant Team for a possible blood or marrow stem cell transplant.

This may be the first of multiple BMT Center appointments. We will confirm your diagnosis and the status of your disease. (For example, you may need more chemo or radiation before being considered for a BMT.) An allogeneic transplant may not be appropriate treatment for all patients. However, there are other

factors that must be considered before moving forward, including:

- are you able to stop smoking well before being admitted for transplant
- did you have a good response to chemotherapy/radiation
- how well your heart, lungs, liver, and kidneys are working
- do you have adequate health and activity level
- reliable caregivers who will be available to assist with your medical care and transportation
- ability to follow detailed instructions related to your medical care
- ability to control anxiety (to cope with a prolonged hospitalization) and impulsive behavior
- ability to stay within 45 minutes from Roswell Park for at least 3 months for an allogeneic transplant (relocation)

Your transplant team will review your medical situation carefully before approving your BMT. This is for your safety and benefit.

If you do not meet the criteria for a safe and effective BMT, the following may be suggested:

- a clinical trial, if one is available
- therapy at another hospital
- other types of treatments/chemotherapy/radiation
- palliative care

Please feel free to discuss this with your transplant coordinator or BMT physician.

# PREPARATION

## PSYCHOSOCIAL EVALUATION

You will be evaluated by a medical social worker to determine whether there are any psychological factors that would make it difficult or too dangerous for you to have a BMT. The stability of your support network will also be evaluated, as well as available caregivers.

If necessary, the medical social worker may involve a medical psychologist and/or psychiatrist to evaluate your psychosocial needs and collaborate with them to develop an effective plan of care. The medical social worker will also review Health Care Proxy and Advance Directive forms with you.

## FERTILITY CONSIDERATIONS

Male patients may want to consider the option of sperm banking before their BMT. Female patients may have concerns regarding fertility. If so, you should ask a BMT clinician for information. You may also call:

**Buffalo Infertility & IVF Associates: 716-839-3057**  
or visit [www.buffaloivf.com](http://www.buffaloivf.com)

**Strong Fertility Center: 585-487-3378** or visit  
[www.urmc.rochester.edu/ob-gyn/fertility-center](http://www.urmc.rochester.edu/ob-gyn/fertility-center)

## REQUIRED PATIENT AND CAREGIVER ORIENTATION CLASS

In order to proceed with a transplant, you will need at least one primary caregiver. Having a second or third caregiver is optimal. Having a committed caregiver is essential to moving ahead.

You and your caregivers will be expected to attend the Required Patient and Caregiver Orientation meeting. This program provides information that you and your caregivers will need to successfully cope with the demands of the transplant and the post-transplant phase of recovery. A caregiver is expected to assist you with all of your daily needs. This includes medication administration/filling pillbox, transportation to and from clinic visits, meal preparation, and monitoring for signs of infection. A caregiver's involvement is a 24 hour-a-day, 7 day-a-week obligation. A caregiver is expected to remain with you at all times after your discharge and until your transplant physician feels you are able to care for yourself safely. A caregiver's role is significant in the post-transplant phase. This role will be further explored and discussed during the class.

## **SMOKING, ALCOHOL, AND OTHER DRUG USE**

If you smoke, it is important that you quit to be eligible for transplant and to minimize risks to your health. You and your household members must stop smoking; otherwise you will increase your chance of dying from complications or suffering permanent and serious lung damage. Smoking marijuana could cause a lung infection and prevent you from having a bone marrow transplant. Likewise, smoking after your transplant increases your risk of developing and dying from pneumonia. (<http://www.nysmokefree.com/> 1-866-NY-QUITS)

The existence of liver disorders before your BMT can increase your risk of developing severe liver complications during or after BMT. Various tests are done before, during, and after your BMT to evaluate and monitor your liver function.

Alcohol can damage your liver. You should avoid all alcohol before and after your BMT. Alcohol is a bone marrow poison. Alcohol also can damage your transplanted cells or decrease their ability to work the way they should.

No e-cigarettes, no vaporizing of tobacco or other products (vaping), and no aerosolization of oils, all are irritating to the lungs.

## **NUTRITION CONSULTATION**

During your consultation, you will meet with a Registered Dietitian Nutritionist (RDN). Your medical history will be reviewed as well as your nutrition requirements. The dietitian will perform an assessment to identify your energy and protein needs, make recommendations for your nutritional care, and address any problems with your oral nutrition.

Meals are provided by the Food and Nutrition Department. You will be on a diet to reduce your exposure to bacteria and prevent food-borne infections and illnesses. Upon admission to the hospital, you will receive a Room Service menu to make your meal selections. A dietitian reviews your meal selections, monitors your tolerance of foods and beverages, and can guide your meal choices as needed.

## **PHYSICAL THERAPY CONSULTATION**

Before your transplant, it is important to determine your current physical status and performance level. The therapist will ask questions about any pre-existing conditions that may affect your ability to exercise during your hospital admission. Wear comfortable clothing and appropriate shoes as you will be asked to participate in a series of standardized tests to assess your strength, mobility, endurance, and balance. These tests help with assessing your future needs during treatment.

The therapist will educate you and your caregivers about the importance of staying active during your hospitalization. The goal is to develop an appropriate exercise program to prevent the loss of function. Early PT intervention is essential. You may be referred to PT to increase and maintain a healthy lifestyle.

## **DENTAL CONSULTATION/ PREVENTION OF MOUTH SORES (MUCOSITIS)**

The dental team will conduct a comprehensive oral exam, including full mouth x-rays, before your BMT to look for any conditions that could compromise your transplant. If you visited your own dentist within the last year, please obtain a copy of your x-rays and a note from your dentist explaining any work completed. You will be advised if a thorough cleaning or any dental work is necessary. Because your mouth is a potential source of infection, good oral hygiene plays a key role in your successful transplant.

Your mouth and throat may become very sore or dry during treatment. Good oral hygiene is important before, during, and after your transplant. Without attention to regular oral care, an infection can occur and spread to other parts of your body. Mouth sores and infection can be very painful. You can significantly reduce the risk of developing mouth sores and infection by following your prescribed mouth care program. If you do develop mouth sores, the frequency of mouth care will increase. You will be given pain medication to reduce your discomfort. The pain medication can be given orally, intravenously, or as a skin patch. It is highly recommended that you take pain medications to minimize discomfort. As your white blood cell count increases, your mouth will improve too.

## **FAMILY MEETING**

Your family meeting is an important opportunity to meet with multiple members of the BMT Team. Your caregiver(s) and family members should attend. At this meeting, your treatment protocol or your non-protocol plan is reviewed in detail. We will review with you the specifics of your treatment schedule, medications, and short and long-term side effects. This time has been scheduled to discuss and clarify the many aspects and challenges of your BMT.

## **PHARMACY CONSULTATION**

You will meet with a pharmacist at the family meeting to review your current medications, drug/food allergies, and past medication experiences. The pharmacist will convey this information to the transplant clinicians and nursing staff.

# TESTS AND PROCEDURES BEFORE BMT

Once you have met these eligibility requirements, and if you wish to proceed, your BMT Coordinator and BMT physician will plan your next steps toward transplant – insurance coverage and setting a date for transplant. Financial counseling will contact your insurance company, or covering agency, to get the proper authorization. Roswell Park has contracts in place with major local, regional and national insurance companies.

Successful blood and marrow transplantation requires healthy blood and/or bone marrow for infusion. In addition, you must be healthy enough to endure the rigors of the BMT process. To determine whether you are an appropriate candidate, your doctor will consider your age, general physical condition, diagnosis, and stage of disease.

Tests, procedures, and evaluations will determine when you are ready to have the treatment needed before the transplant. The tests must be completed between 30 and 60 days before you are admitted to the hospital. Occasionally, some tests may need to be repeated due to a delay.

Listed below are the most common tests done before a transplant. The tests you will need will depend upon your disease and your transplant protocol or non-protocol therapy. (Sometimes an insurance carrier will not cover protocol therapy.)

## TESTS/PROCEDURES

(Not all are required for every patient. Refer to Glossary for more information)

- 24-hour Urine Collection
- Blood Tests (multiple tubes of blood will be drawn)
- Bone Marrow Biopsy and Aspirate
- Chest X-ray
- Computed Tomography (CT) Scan
- Dual-energy X-ray Absorptiometry (DEXA) Bone Density Scan
- Electrocardiogram (EKG)
- Magnetic Resonance Angiogram (MRA) Scan
- Magnetic Resonance Imaging (MRI) Scan
- Multigated Acquisition (MUGA) Scan or Echocardiogram
- Physical Exam
- Positron Emission Tomography (PET) Scan
- Pulmonary Function Tests (PFTs)
- Skeletal Survey



## **EVALUATIONS**

- Psychosocial
- Dental
- Physical Therapy
- Radiation (may not be required)
- Nutrition
- Additional consults as needed

Please be honest with your transplant team about smoking, marijuana, alcohol, vaporizing of tobacco, other drug use, and any issues that you are unable to cope with, as these issues are very important. The goal is to get you through BMT safely. In order to do that, the BMT team will need to know if you have any alcohol or drug related problems or concerns. The BMT clinicians will then direct you to the right professional and resources for help. Some of these issues may lead to damage to lungs, heart, kidneys, and liver.

## **MESSAGE FOR PATIENTS, FAMILY, CAREGIVERS, AND LOVED ONES**

Family members should make sure that the BMT clinic Coordinator, and nursing station has more than one phone number, and that they are correct. Emergency contacts include home number, cellphone number, caregiver home number, caregiver cell phone number, caregiver work number, etc.

# YOUR DONOR'S PERIPHERAL BLOOD AND STEM CELL COLLECTION OR BONE MARROW HARVEST

In most cases, we collect hematopoietic cells, sometimes called stem cells, from your donor by collecting the blood that is circulating in his/her blood stream (peripheral blood). Less often, we have to get (harvest) the cells from his/her bone marrow.

## MOBILIZATION AND COLLECTION OF PERIPHERAL BLOOD

Stem cells can be collected from a donor's circulating blood — known as peripheral blood stem cells (PBSCs) — using a procedure called pheresis (see apheresis). Unlike a bone marrow harvest, pheresis does not have to be done in an operating room, and the donor does not have to be under anesthesia.

A few days before the procedure, donors are usually given a medication called granulocyte colony stimulating factor (G-CSF/filgrastim/Neupogen®) that makes stem cells leave the bone marrow and move into the circulating blood where they can be collected during pheresis. G-CSF is given as a subcutaneous (under the skin) injection. It may cause flu-like symptoms and bone pain in the days before and after the procedure.

Your donor's peripheral veins will be checked before the procedure to make sure that they can be used for pheresis. A peripheral intravenous (IV) catheter will be placed in the antecubital area (the crease where your arm bends) of both arms on each day of collection. If we cannot use your donor's peripheral veins, a special pheresis catheter will be placed in the chest or neck area. The catheter placement is usually done as an outpatient procedure on the 1st day of collection and the catheter is removed when collection is completed.

The collection process is also an outpatient procedure. It takes 4-6 hours per day, for a minimum of 2 days, to collect enough stem cells for the transplant. After a brief physical exam, your donor's peripheral IV or pheresis catheter will be connected to a machine that circulates the blood. As blood flows through the machine, it separates out the stem cells and sends the rest of the blood (plasma, red blood cells and platelets) back into the donor's vein. The collected stem cells are either used immediately or are frozen and stored. When the procedure is over for the day, the donor is disconnected from the apheresis machine.

A member of the clinic team, often your BMT Coordinator, will let your donor know when enough hematopoietic cells have been collected. On the rare occasion that your donor did not successfully complete hematopoietic cell collection within the 2 day collection process and more stem cells are needed for the required cell dose, your BMT physician may require a 3rd collection day or a bone marrow harvest.

## **BONE MARROW HARVEST AT ROSWELL PARK**

Your BMT physician may recommend a *bone marrow harvest* to collect the hematopoietic cells. Bone marrow harvesting is performed in an operating room, under anesthesia. Your donor will not need stitches, but will have some pain and tenderness at the site of the harvest for about a week.

In preparation, your donor will complete a health history, have a physical examination, and be evaluated by an anesthesiologist. Your donor will be educated about the bone marrow harvest procedure and sign consent forms.

Refer to the Bone Marrow Harvest Brochure for instructions in preparation for a bone marrow harvest at Roswell Park.

## **DAY OF HARVEST**

On the day of the harvest, your donor needs to come to the hospital early in the morning. Your donor must not eat or drink anything after midnight the night before the harvest or the procedure will be delayed or canceled. After changing into a patient gown, your donor will be escorted to an area immediately outside the operating room. An IV will be started to give medications before the procedure. Once asleep, the donor will be placed on their stomach (abdomen) and the procedure will begin.

## **PROCEDURE**

Once asleep, the collection of bone marrow begins by inserting a special needle into the hip bone, attaching a syringe to the needle, and pulling the liquid marrow into the syringe. This is repeated until the required amount of bone marrow is collected.

When the collection is complete, a bandage will be applied to the area. The bone marrow harvest procedure takes 2-3 hours. The filtered bone marrow may be processed for freezing and kept frozen until it is time for a BMT.

The harvest procedure affects only the red blood cell count. Red cells can be replaced through blood transfusions, if the doctor determines that it is necessary.

Usually, discharge takes place that same evening. Because of the anesthesia, your donor will not be able to drive, and must have a ride home. Your donor may not drive until the clinical team says it is safe.

# PRE-ADMISSION

## PRE-ADMISSION VISIT FOR YOUR BMT

The day before your admission, or the Friday before your weekend admission, you will be scheduled for your pre-admission appointment in the BMT Center. Go to Patient Access (Registration) in the lobby, then to the Phlebotomy Lab to get your blood drawn. Both are located on the ground floor of the hospital. Next, go to the BMT Center. We will take your history and give you a physical exam, including your height and weight, and then you will be seen by a BMT physician. Your chemotherapy orders will be completed by the team. We will send you to Interventional Radiology to have your central venous line placed (see below). When all of this is done, you may go home or to local lodging.

## PEDIATRIC PRE-ADMISSION VISIT FOR YOUR BMT

The day before your child's admission, or the Friday before your child's weekend admission, please go to Pediatric Clinic for your Pre-Admission appointment. We will take your child's history and give him or her a physical exam, including height and weight. Your child will be seen by an NP and/or pediatric BMT physician. Your child's chemotherapy orders will be completed by the team. Your child may be sent to Interventional Radiology for a line placement, depending on whether he or she needs a new central venous line for the transplant. When all of this is done, your child may go home or to local lodging.

## GETTING A CENTRAL VENOUS LINE

A central venous line is a thin, flexible tube that is placed into a vein in the neck or chest area. Placement is usually done in Interventional Radiology Center. One end of the catheter rests in the vein, near the heart, and the other end of the catheter is brought through the skin. Central venous lines are an effective way to give IV fluids and medications that need to be placed directly into a vein, give blood transfusions, take blood samples, and deliver chemotherapy. Consistent access to a central vein preserves the veins in your arms and limits the amount of needle sticks.

The catheter will remain in place for the duration of your transplant and possibly after discharge. Your caregiver will be taught how to care for your central venous line.

## THE DAY OF ADMISSION

Please go to the Patient Access (Registration) area unless you were asked to go directly to the BMT unit. When you arrive on the unit, the staff will meet you and take you to your room. Your admitting nurse will do a nursing assessment. A nurse practitioner, physician assistant, or a medical oncology fellow will do a physical assessment. Remember, the nursing staff is always ready to answer questions or find answers for you.

Your treatment regimen will be ordered by your physician based on your disease, remission status, age, and prior treatment. It is sometimes called a conditioning or preparative regimen. It may consist of chemotherapy alone or in combination with total body irradiation (TBI). You will be told what days you will receive chemotherapy and/or TBI.

# ROSWELL PARK'S TRANSPLANT UNIT

Our Blood and Marrow Transplantation Unit is located on the 5th floor for adult patients and on 6 North for pediatric patients. All patient rooms are private, and all rooms and hallways are High Efficiency Particulate Free Air (HEPA)-filtered, giving you the freedom to leave your room and walk within the unit.

Each room has a viewing window and all rooms have a camera to enable the nursing staff to monitor your situation more closely, if needed. Isolation rooms are available if necessary to protect you or other patients.

A solarium and restroom facilities for your family and visitors are located next to the inpatient unit, on the 5th floor. The solarium is comfortably furnished and has a refrigerator, microwave oven, television, washer and dryer, and a telephone. Food is allowed in the solarium, but we ask family and visitors to remember that this is a shared area.

## GUIDELINES FOR EATING/DRINKING IN PATIENT ROOMS

- Family members are allowed to eat in the patient rooms.
- Patients must strictly follow the low microbial diet at all times (brochures available).
- Please throw away food leftovers when you are outside patient rooms.
- Please clean up immediately when finished eating.
- VERY IMPORTANT: Please do not leave or store food in patient rooms.
- Please do not leave dirty dishes in patient's room or nutrition room – these will be discarded.

- Do not share food or drinks with patients.
- Please be aware that patients are very sensitive to smells/odors.
- If a patient is NPO (nothing by mouth) please do not bring food into the room. We will let you know when you may resume eating/drinking in the patient's room.
- Children can visit if they have an adult with them, but the child must not be sick.

Meals are provided by the Food and Nutrition Department. You will be on a **low microbial** diet, which is designed to do two things:

- reduce your exposure to bacteria
- prevent infection and food-borne illnesses

When you are admitted to the hospital, you will get a Room Service menu to make your meal selections. A registered dietitian nutritionist (RDN) reviews your meal selections, monitors how well you tolerate foods and beverages, and can guide your meal choices, if needed.

Food from home is okay as long as items are selected and prepared within the guidelines of the low microbial diet. Please refer to the booklet "Low Microbial Diet" for specific guidelines and recommendations. Food should be kept in a safe temperature zone during transport. Prepared food should be eaten within 72 hours of being prepared. Food should be labeled with name and date, and then placed in the Nutrition Room refrigerator.

# PATIENT GUIDELINES

## (SEE VISITOR RULES AND GUIDELINES SECTION)

You may find it comforting to surround yourself with personal items. Converting your hospital room into your own “space” will help to alleviate some of the stress of a long stay. Pictures of family members, posters, a special bedspread or comforter, a CD or DVD player with your favorite music, books, videos, or even a pillow can often help.

- Do not wear contact lenses. Make sure to bring your glasses with you.
- Pierced earrings are allowed. Please wear metal that does not irritate your skin.
- Please remove acrylic nails or nail polish; it can interfere with the oxygen equipment.
- Please do not wear expensive jewelry such as heirlooms, they may have to be removed and may get lost, especially rings. Your hands may become swollen during this time and your rings may need to be cut off. These items are much safer if they are left at home!
- Pillows and comforters must not contain down or feathers; they must be new or freshly laundered. Stuffed animals should also be new or laundered to minimize the risk of infection.
- Feel free to bring your own clothes. Be sure they are loose fitting so that you are comfortable and the BMT team can easily access your catheter. Please leave all expensive jewelry, credit cards, medications, and large amounts of money at home.

- Mail will be delivered daily. New magazines, newspapers, and other unused reading material are acceptable. The unit secretary will open all your mail before you get it. (This lowers the risk of getting a paper cut, which could cause infection while your white blood cell and platelet counts are low.)
- As of August 1, 2015, there is no charge for TV and phone.
- You may bring a laptop or tablet from home and access the Internet using Roswell Park’s public wireless network. Inpatients may also get a laptop on loan from the Resource Center for Patients and Family on the first floor, in the Sunflower Cafe. Family members may go get it for you, or you can ask the nurse on your unit to call the Resource Center at X 1729. There is no charge.
- Do NOT keep money or valuables in your room.
- Your door must be closed at all times so the special air-filter system works to its fullest potential.
- Fresh or dried flowers, plants, and animals are not allowed on the unit. Artificial flowers are okay. Be sure that artificial arrangements do not contain dried moss. Cards and balloons are fine.



# VISITOR RULES AND GUIDELINES

## VISITING

- The BMT unit has an open visiting policy, which means that family members or friends can visit at any time. However, you should check with your doctor and charge nurse before children visit.
- Children under the age of 16 are allowed to visit in the patient rooms, but must be accompanied by a responsible adult other than the patient at all times while on the unit.
- Children will go directly to the patient's room, remain in the room for the duration of their visit, and exit the unit directly on leaving the patient's room.
- Children may not visit a patient in strict respiratory isolation. For patients on contact isolation, children may visit and be closely monitored by an adult other than the patient.
- Only 2 visitors in the room at a time. A patient may request to limit or restrict visitors at any time. Only 1 person over age 18 is allowed to stay in the room overnight.

## GUIDELINES

- These rules and guidelines are designed to create a pleasant, healthy environment for everyone and to decrease the risk of infections for our patients. Please respect them.
- Family members should make sure that the nursing station has multiple and correct phone numbers for emergency contacts. Including home number, cell phone number, caregiver home number, caregiver cell phone number, caregiver work number, etc.
- Visitors should recognize that a good night's sleep is very important to recovery. Should you have a problem, family members returning to their home or hotel for the night will be notified of any change in your status.
- Smoking is not allowed. Roswell Park is dedicated to the overall mission of curing cancer. Cigarette smoking is known to be a leading cause of cancer. Therefore, Roswell Park has a strict *No Smoking* policy throughout the unit and all Roswell Park buildings and outside grounds. No e-cigarettes, no vaporizing of tobacco or other products (vaping) and no aerosolization of oils, because they are all irritating to the lungs. Your clinical team can prescribe medications to help you quit smoking.
- **Hand washing with antimicrobial soap is the single most effective way to prevent infection.**
- Before entering a patient's room, all visitors must wash their hands thoroughly. Hand sanitizer dispensers are also located outside every patient room. You may also use sanitizer unless otherwise specified.
- Adults and children with a fever, cold, contagious infection such as chicken pox or flu, or recent exposure to a contagious infection within the past 2 weeks may not visit.
- Visitors who have been recently immunized with flu mist should not visit for 7 days.
- Visitors may not use the patient's bathroom. This is to prevent cross-contamination. Restroom facilities are located off the unit.
- Family members, as well as patients, are not to visit other patients in their rooms. This helps to prevent the spread of infection.
- Diapers are **not** to be changed within the BMT unit. There are public restrooms located on the ground, 1st, 2nd, and 3rd floors of the atrium area that are equipped with diaper changing stations.

# BLOOD AND PLATELET DONATIONS

Blood is an important, life-saving resource. Almost all patients going through BMT will require blood and/or platelet transfusions. Often, family and friends will ask if they can help in any way. A wonderful opportunity exists for them to give not only to the patient but to the whole cancer community. Donation may only take 45 minutes for red blood cells or 90 minutes to donate platelets. Those who are interested should talk to the clinical team about donating blood and platelets for your family member.

Family and friends may donate blood and platelets directly at Roswell Park by scheduling an appointment through the Donor Center at **716-845-8275**.

# INJECTIONS

You may receive 2 types of injections: growth factors to help your blood counts recover, and a blood thinner enoxaparin (Lovenox®) to prevent clots. These injections cannot be given in your central venous line. You can have a subcutaneous port placed for these injections and other medications like insulin. Almost all of our patients leave the hospital without requiring hormone growth factors.

# PREVENTING INFECTION WHILE YOU ARE HOSPITALIZED

To help avoid infection while your immune system is recovering, please follow these guidelines.

- Wash your hands with soap and water before eating or performing any oral (mouth) care, and after using the bathroom. If you use only a hand sanitizer, such as Purell®, it is important to wash your hands again, especially if your hands are soiled with urine or stool.
- Contact lenses should not be worn during your hospital stay to decrease the risk of infection.
- It is important that your prescription be updated and glasses are worn.
- Please remove artificial nails and use only clear nail polish.
- No new body piercings.
- Use Chlorhexidine Gluconate (CHG) wipes with or without showering every day. **Your skin is your first line of defense against infection.** Compromised skin can create doorways for infections to enter your body.
- Put on clean clothing every day.
- Follow your prescribed low microbial diet. A copy of the diet will be given to you and your family. The dietary department will also assist you when ordering meals.

- Perform daily oral care with a sponge toothette or an extra-soft bristled toothbrush, depending on your platelet count. Use recommended toothpaste or oral rinses as prescribed by your clinical team. While your platelet count is low, you should not floss because of the risks of bleeding and infection.
- Avoid contact with people who are sick. Friends and family who have a fever, cold, flu, or other contagious diseases must not visit. If someone has been recently exposed to an individual who is sick, he or she should not visit you.
- Anyone who has received the flu mist vaccine (nasal spray) should not visit the patient for 7 days.
- No plants, fresh flowers, fresh fruit, or fruit baskets in your room.
- Take all of your medication on time as instructed by your nursing team. If you are having trouble taking your medication, let the clinical team know.
- A mask must be worn if you are being transported off the unit for a test or procedure. The only reason for leaving the protective environment is for a test or procedure.
- Don't wear your shoes or slippers in bed because it will transfer germs from the floor to your bed.
- Avoid contaminating your bedside table (keep urinals separate from that area).

If you develop an infection during your recovery, your antibiotics may be changed. It is crucial to tell your doctor and nurses how you are feeling. Symptoms of infection include:

- fever
- chills/sweating
- shortness of breath, difficulty breathing
- cough: dry, persistent, or with sputum
- sore throat or pain with swallowing
- sores or white patches in your mouth or on your tongue
- sinus drainage, nasal congestion, facial tenderness, headache
- redness, tenderness or drainage at the site of your central venous line
- difficulty urinating or pain with urination
- cloudy or foul-smelling urine
- diarrhea
- vaginal itching or unusual discharge
- rectal pain or tenderness
- fatigue and dizziness
- pain

# CHEMOTHERAPY

The chemotherapy you will receive has been carefully planned and is part of a protocol or non-protocol treatment. Your treatment timetable was designed by experts in the field of blood and marrow transplant.

Chemotherapy, often called chemo for short, is an important part of your treatment and will include one or more medications. It will be given on a special schedule that is thought to be best for killing your cancer while reducing harm to your body's normal cells, as much as possible. You will be told what days you will receive chemo and how you should expect to feel. Chemotherapy drugs will be given orally or through an IV.

The doses of chemotherapy used in a transplant are usually different than those you may have received in the past. You may have different side effects than before. You are likely to have profound fatigue while in the hospital and after you are discharged home, so physical therapy (PT) is very important to your recovery.

Chemotherapy usually kills other cells in addition to cancer cells; this is why people receiving chemo often have side effects. It can damage normal, fast-growing cells such as those in your mouth, throat, bowels, skin, hair, and bone marrow. You may experience mouth or throat sores, nausea and vomiting, diarrhea, a skin rash, changes in skin color, and hair loss. Your blood counts may become very low.

You will receive medications to minimize nausea and vomiting. Pain medications will be given if you develop pain or sores in your mouth or throat. An oral hygiene program will begin once you are admitted to the hospital. It is very important that you do oral care to prevent side effects. Medications also will be given if you develop diarrhea or constipation. A pharmacist will review your medications to make sure you do not receive a severe reaction.

You may lose your hair during treatment. This is usually temporary and your hair should grow back within 3-6 months. Because body heat is lost through the head, you may feel colder after the loss of your hair. You are encouraged to wear a cap, scarf or wig. The Resource Center for Patients & Families, located on the first floor in the Sunflower Café (cafeteria) offers one new wig per year at no cost to those who have hair loss due to treatment. A second wig may be purchased at cost.

The Center also has various types of caps, scarves, and other head coverings.

Chemotherapy may affect other organs of your body such as your kidneys, liver, heart, or lungs. Although severe side effects are rare, they can progress and cause complications such as liver disease, kidney failure, congestive heart failure, or scarring/stiffening of the lungs. We cannot predict who will experience these rare side effects. You will be given information on these potential side effects, as well as explanations of each chemotherapeutic medication and its potential side effects. We will monitor you daily for signs and symptoms of possible side effects.

# RADIATION

Radiation therapy (also called irradiation) is part of some transplant conditioning regimens. The type of radiation you may receive is called total body irradiation (TBI) because it is given to your entire body. During treatment, a machine sends x-rays of high energy into your body. The cells in your body are prevented from growing and multiplying when they are exposed to these high- energy rays.

**What to Expect:** First, you will meet with the radiation oncologist, who will review the procedure and ask you to sign a separate informed consent form. TBI treatments are usually given once or twice a day – once in the morning and once in the afternoon. The number of treatments depends upon your treatment plan or clinical trial.

Before going for TBI, you may be given medication to prevent nausea. You should have a light breakfast before going. Do not wear any jewelry. You will need to wear a hospital gown; you should not wear any clothing with metal on it such as zippers, snaps, etc. The treatment usually takes 1 hour. You will not feel anything while receiving the treatment. During this time, you will be asked to remain lying in a bed. You will be alone in the treatment room, but you will be monitored on 2 TV screens and a microphone. The technologist will be able to see and hear you. One screen will be focused on you and the other will be focused on a machine that monitors your blood pressure and pulse. If you are having any problems, you can visually signal or speak any concerns to your technologist who will do everything possible to make you comfortable.

Like chemotherapy, radiation affects both cancer cells and normal cells. The side effects that may occur are due to the effects on normal cells. Initially, you may experience nausea, vomiting, and diarrhea. You will be given medications to prevent and treat these side effects.

After you complete the treatments, you may develop some other side effects. These may include: red, dry skin, dry mouth (from the effects of the radiation on your salivary glands), parotitis (swelling of the parotid glands in front of your ears), infertility, lung changes, or cataracts. Your doctors and nurses watch very closely for any of these side effects. Some are easily treated, while others may require long-term follow-up. If you have any questions regarding your treatment, please ask any member of the transplant team or your radiation therapist/oncologist.

# STEM CELL TRANSPLANT DAY (DAY “0”)

The donor’s collected hematopoietic cells are given to you by infusion through your central venous line. It looks very much like a blood transfusion. An experienced nurse performs the BMT infusion at the bedside. This will be done in your room on the BMT unit. Once thawed, the nurse will return the cells to you via your central venous line. We will monitor you very closely for side effects.

Your vital signs – blood pressure, heart rate, respirations, temperature, and oxygen saturation – will be monitored throughout the infusion, and afterwards, for at least one hour. We monitor you because you could have a rare reaction.



# BLOOD CELL TYPES

There are 3 main types of blood cells – red blood cells, white blood cells, and platelets. Each has a specific job to do, and each may be affected by chemo and/or radiation in a different way. To ensure you have enough of each type of blood cell, your blood will be monitored regularly, and transfusions will be given as necessary.

## RED BLOOD CELLS (erythrocytes or RBCs)

RBCs, which give blood its red color, carry an iron-rich protein known as hemoglobin, which picks up oxygen from your lungs and carries it to all the cells in your body. When your hemoglobin level is low (anemia), you may feel weak or dizzy, lack energy, be short of breath, have headaches, and/or become irritable. If you become too anemic, there are standard orders written by the clinical team so your nurses will give you a red blood cell transfusion. You will receive one or more bags of packed red blood cells, as needed, to boost your hemoglobin level. Each bag will be transfused over 2-3 hours. To lessen the chance of a reaction, the blood is typed and cross-matched to confirm that you and the donor have the same blood type. If you have a transfusion reaction, the symptoms may include chills, hives, itching, and/or breathing problems. If you have any of these symptoms, please notify your nurse immediately. Because RBCs have a longer lifespan than platelets, you will not usually need RBC transfusions as often as platelet transfusions.

## PLATELETS (thrombocytes)

Platelets are the smallest components in blood; they play a crucial role in blood clotting and preventing bleeding. Without enough platelets (a condition called thrombocytopenia), spontaneous bleeding or excessive bruising may occur. Normal platelet values are between 150,000 and 300,000 per microliter of blood. To help prevent bleeding, you may be given transfusions of platelets if your count is less than 10,000 (sometimes the term used is 'less than 10'). Platelets may be transfused more frequently if there is active bleeding or before any invasive procedures. Transfusions may be given until your bone marrow begins to produce its own platelets. If your platelets are low you may develop petechiae (rash of

pinpoint-sized reddish- purple spots) or an ecchymosis (large bruise) near the area(s) where you had injections.

## WHITE BLOOD CELLS (leukocytes, WBCs)

WBCs defend your body against disease-producing bacteria, viruses, parasites, fungi, foreign substances, and tumor cells. There are 3 main types.

- **Neutrophils** (granulocytes) are the body's first line of defense against infection. The bone marrow can quickly speed up production of these cells whenever they are needed. They combat infection by rapidly moving into the bloodstream where they respond to the presence of bacteria or foreign substances. When the infection is controlled, their production returns to normal.
- **Lymphocytes** patrol the bloodstream and all parts of your body.
- **Monocytes** defend the body against bacterial and fungal infections.

A normal total WBC count ranges between 5,000 and 10,000 cells per microliter of blood. Another numerical term you may hear is 5 to 10 cells per microliter, which is an abbreviated way of saying 5,000 to 10,000. Neutrophils account for approximately 50 percent to 80 percent of the total number of WBCs. You have neutropenia when your neutrophil count is low. Your risk of infection increases if your count is below 1,000. The risk increases dramatically if your count is below 500, and you will be given antibiotics. Your WBC and absolute neutrophil count (ANC) will be monitored daily. Generally, as the overall number of WBCs increases, so too, does the number of circulating neutrophils. Your neutrophil count may decrease after you stop growth factor injections.

All blood products are carefully tested for infections such as hepatitis, HIV, and syphilis, according to federal regulations. Cytomegalovirus (CMV) testing will be done if your doctor decides it is needed. All blood products are irradiated and filtered to help eliminate the chance of reactions from white blood cells and transmission of infectious viruses such as CMV.

# ENGRAFTMENT AND COUNT RECOVERY

The cells you receive during your transplant are often referred to as a graft.

Engraftment is the process in which your transplanted cells migrate from your bloodstream to the center of your large bones, where bone marrow is located. Once these cells have found their way, they can begin to produce new blood cells. This process can take 2-4 weeks. During this time period, all of your blood counts will be low and you will be susceptible to infection and bleeding. You will receive antibiotics to prevent infection. You will also receive blood products, such as red blood cells and platelets, until you are able to produce these cells on your own.

When your white blood cell, red blood cell, and platelet counts begin to rise, we know that engraftment has begun. It is at this time that your need for red blood cell and platelet transfusions will decrease. Your antibiotic treatment may be changed in anticipation of discharge.

Graft failure or poor count recovery is a very rare complication that occurs when cells are not accepted by the body. With graft failure, the new cells do not repopulate the bone marrow.

When this happens, patients are susceptible to infection and other complications. Sometimes graft failure is life-long, even life threatening, but it is a very rare complication. You may need transfusions of red blood cells and platelets for support. Additional treatment may include injections that stimulate the production of red or white blood cells such as erythropoietin/Procrit®/Epogen®, filgrastim/Neupogen®, or sargramostim/Leukine®. Your transplant team will discuss this with you, if applicable.

# POTENTIAL SIDE EFFECTS AND COMPLICATIONS

A transplant can be a potentially life-saving procedure and it comes with the possibility of complications. These complications can be very serious and even life threatening.

Side effects and complications may happen quickly or develop over time and persist for long periods. Please report any symptom(s) you have to your nurse or doctor, so that we can address the problem and start treatment.

## **Possible Side Effects of Conditioning Therapy**

- Low blood counts
- Fever and Infection
- Fatigue
- Bleeding
- Nausea, vomiting and diarrhea
- Mouth sores
- Decreased appetite
- Skin rash and/or skin changes
- Difficulty eating
- Loss of appetite
- Diarrhea
- Hair loss

High-dose chemotherapy and total body irradiation are harmful not only to diseased cells, but also to normal tissues and organs. When normal cells are affected, side effects develop. These side effects can include nausea, vomiting, difficulty eating, loss of appetite, diarrhea, hair loss, and skin changes.

The healthcare team will be managing these side effects with medications, blood transfusions, IV fluids, and interventions as appropriate. Every day, we will check your Complete Blood Count (CBC). After conditioning therapy, the CBC values will drop below normal. The neutrophil count will fall close to zero, and can remain low for several weeks. During that time, you are at high risk for infections. That is also the time when you will feel the sickest. When the neutrophils start to recover, during the period of engraftment, you will begin to feel better.

## **DIFFICULTY EATING**

There are many reasons you may have difficulty eating during and after your transplant. Chemotherapy and/or radiation can cause nausea and/or vomiting, mouth or throat sores, and diarrhea. In addition, your saliva may thicken and make chewing and swallowing food difficult. Rinsing your mouth often and drinking fluids will help. You can ask for a suction catheter (like the kind in a dentist's office) to help rinse your mouth.

Mouth dryness may last for several months after your transplant. Taste changes, either the inability to taste foods or a change in normal taste, may last for 30 to 60 days or longer after chemo or radiation. It is very important to eat small frequent meals even if you experience taste changes. It is also important not to eat greasy or fatty foods. You may receive nutrition in your central venous line called TPN (total parenteral nutrition).

## **NAUSEA AND VOMITING**

Nausea and/or vomiting are common during and after all conditioning regimens, but can usually be controlled with medications. Medications and infections may also cause nausea or vomiting. Drugs called anti-emetics are used to treat nausea. (Emesis means vomiting, so anti-emetics are drugs that prevent or control vomiting).

Even if you are feeling a little bit nauseous, please tell your nurse right away. The dose and frequency of the anti-nausea medications may have to be adjusted. Anti-nausea medications will be given to you through your central venous line on a regular schedule and on an as-needed basis. You can also get an anti-nausea skin patch. It is very important not to let nausea and vomiting get out of control.

## **DIARRHEA**

Getting diarrhea after your conditioning regimen is common. Infection can also cause diarrhea. Your stool will be tested for an infection called *Clostridium difficile* or C. diff. If a C. diff infection is suspected, you may be started on an oral or IV antibiotic. Antidiarrheal drugs will not be given until we are sure you do not have an infection. Keeping the rectal area clean and dry is important to prevent infection and skin breakdown. You will be provided with wipes to help keep yourself clean. If your rectal area becomes irritated, please tell your nurse and creams will be provided to relieve your discomfort. You may develop hemorrhoids. If you do, it is important to keep them clean. Another complication is rectal fissure (tear), thus rectal exam and care are important to be done daily. It is important to change your underwear or disposable briefs (such as Depends®) every day.

## **HAIR LOSS (ALOPECIA)**

Hair loss may occur after the conditioning regimen. You may also experience thinning or loss of eyelashes, eyebrows, and body hair. This usually occurs within 3-4 weeks of receiving chemotherapy. Some patients prefer to shave their heads or cut their hair very short before hair loss begins. Scarves, caps, hats or wigs can be worn until your hair grows back. Wigs and other headgear are available at Roswell Park's Resource Center for Patients and Families. (One wig and one head covering are free and you can purchase one more of each at cost.) You may wish to consider stopping by the Resource Center before you lose your hair. Hair normally grows back within 3-6 months after transplant. You may notice changes in the color, thickness, texture, or curl of your hair.

## **SKIN CHANGES**

Depending on the chemo and/or radiation you have, you may get a skin rash, peeling and/or reddened skin, or changes in the shade of your skin. This is temporary, and you will receive creams to relieve any discomfort. The nurse will give you further instructions about your specific skin care. Less often, hyperpigmentation (dark spots on the skin) occurs. This usually fades over a period of 1-2 months.

## **URINE**

It is important to use the stool and urine collection hats from the toilet so the team can keep track of your output. Your urine will be tested to make sure you do not have an infection that requires treatment.

## FATIGUE

Until your red blood cell counts recover, you may suffer from anemia. Symptoms may include:

- shortness of breath
- chest pain
- easily fatigued/weakness/dizziness
- headache
- difficulty concentrating
- rapid heartbeat: usually associated with exercise; irregular heartbeat that may require medication (see *atrial fibrillation*)
- leg cramps

Until your red blood cell count recovers, you may require blood transfusions to treat your anemia. To help with the side effects, rest between activities, change position slowly to avoid dizziness and always call for assistance if you aren't feeling well.

## SINUSOIDAL OBSTRUCTION SYNDROME (SOS)/VENO-OCCLUSIVE DISEASE (VOD)

SOS/VOD is a rare but potentially serious condition caused by the high doses of chemo and/or radiation received before BMT. With SOS/VOD, the blood vessels that carry blood through the liver swell and become blocked.

This condition interferes with the liver's ability to remove waste products from the bloodstream. Pressure and fluid buildup in the liver makes it swell and become tender. Other symptoms include rapid weight gain (from fluid retention), swelling in the arms, legs or abdomen, and an increase in bilirubin. Fluid in the abdomen may cause pressure on the lungs making breathing difficult. Also, toxins that the liver is unable to remove may affect how the brain functions, resulting in confusion.

Blood thinners including enoxaparin/Lovenox® (daily injections) and ursodiol/Actigall® pills will help prevent you from developing SOS/VOD.

If SOS/VOD is suspected, your BMT team will attempt to prevent more serious complications by:

- minimizing or eliminating certain medications
- prescribing diuretics to increase urine output and relieve fluid retention in the body
- carefully monitoring the volume of fluids in the body
- transfusing packed red blood cells to keep the circulating blood volume high until the SOS/VOD runs its course

## LUNGS AND HEART

It is possible that your heart and lungs may be affected by high doses of chemo, radiation, fluids, or infections, decreasing their ability to function. For this reason, we will test you before, during, and after your transplant to monitor your heart and lungs.

You can play a vital and active role in preventing lung complications. If you smoke, you must stop before your admission for transplant. Smoking is not permitted while you are in the hospital. This includes electronic cigarettes. Resuming smoking after transplant greatly increases your risk of serious lung complications and death. Information to help you stop smoking is available. You may visit the Resource Center for Patients and Families for material or visit [www.nysmokefree.com](http://www.nysmokefree.com).

You may also call New York State Smokers' Quitline at 1-866-NY-QUITS (1-866-697-8487).

You may get an EKG, chest x-ray, CT scan (computerized tomography scan) or cardiac echocardiogram to evaluate your heart function. Some patients are at risk for irregular and fast heart beats. We may use a monitor to watch and evaluate your heart rate. We may also draw blood to check that your heart is working properly.

You can develop lung problems up to several months after your BMT. You may have pulmonary function tests (PFTs) to check your lung function. If you feel short of breath, can't catch your breath, or are having trouble walking, let your nurse know. We will check the oxygen level while you are at rest, and maybe while you are walking. If it is abnormal, you may have a chest X-ray or CT scan done. Your team will treat any lung infection or inflammation, if it occurs.

Your health care providers will teach you how you can help maintain healthy lung function while you are hospitalized. Your nurses and doctors will evaluate your lungs daily. If necessary, your physician may prescribe an aerosol medication, chest physiotherapy, or oxygen. If you feel short of breath or have difficulty breathing at any time, please alert your nurse or doctor immediately.

## KIDNEYS AND BLADDER

Your kidneys and/or bladder may be harmed by chemotherapy and other medications. We closely monitor how well your kidneys are working while you are in the hospital. You will be weighed every morning and blood will be drawn daily; or more often if needed. Intravenous and oral fluids will be measured carefully and recorded. **All urine, stool, and emesis will be measured and recorded.** This is referred to as Intake & Output. If urine is not properly collected, the clinical team may not know if you need a diuretic to remove extra fluid from your body. Always let your health care providers know what fluids you drink and if you are vomiting. As mentioned previously, it is very important to use the collection hat and urinal.

Sometimes the large amount of intravenous fluids that you receive can cause fluid retention. If this occurs, you may be given a diuretic medication to increase your urine output. In some cases, you may have difficulty emptying your bladder completely. If fluid or urine retention becomes a problem, a Foley catheter may be inserted into the bladder via the urethra. This flexible and soft tube allows the urine to flow freely into a collection bag. The catheter is temporary. If you develop lower abdomen and bladder discomfort, you may ask your nurse for a bladder scan.

Occasionally, despite close monitoring and aggressive therapy, kidney failure can occur. In these cases, dialysis may be necessary to help the kidneys heal and to remove toxins that build up in the body. The need for dialysis may be temporary until normal kidney function returns. In rare cases, the need for dialysis is permanent.

## DENTAL

Conditioning regimens that include radiation can cause complications of the mouth and the mucus membranes. Dry mucosal membranes can cause you to make less saliva, which leads to dental cavities. Frequent oral hygiene is vital, and must be continued after discharge.

You may brush your teeth with a regular toothbrush if your platelet count is above 50,000. Otherwise, use a sponge swab called a toothette or an extra soft toothbrush. We will provide these for you. Oral rinses will be prescribed.



## CATARACTS

Radiation and steroid therapy may increase the risk of cataracts. Blurriness and changes in vision are common symptoms. Other symptoms include dry eyes, a feeling of grittiness, burning, itching and sensitivity to light. Protective sunglasses and artificial tears (eye drops) can reduce the discomfort. Medical follow-up and surgical intervention may be required if cataracts develop. This can occur months or years after exposure.

## THYROID CHANGES

Thyroid problems may result if radiation is included in your conditioning regimen. Report symptoms such as lack of energy, sluggishness, depression, sleep disturbances, swelling, weight gain, and sparse or thinning hair. We will draw blood and test it to see how well your thyroid is working. If needed, we can prescribe medication to replace thyroid hormones.

## BONE LOSS

### **Complications of Steroids – Avascular Necrosis, Osteopenia/Osteoporosis, and Steroid Myopathy**

Steroids are frequently used to control side effects during BMT but sometimes, they can cause serious side effects that cause problems with bone and muscle tissue.

**Avascular necrosis** is the death of bone tissue due to a loss of the blood supply to that bone. The condition most commonly affects the ends of long bones such as the femur (thigh bone), the head of the humerus (arm bone), and knees. Early symptoms include a dull, aching sensation within the hip that becomes worse with weight bearing or extreme hip motion. Any hip or shoulder pain or discomfort, limited range of motion, or joint stiffness should be reported to your doctor. Surgery may be needed.

A more frequent complication from steroid medication is a loss of bone density. **Osteopenia and osteoporosis** are related conditions caused by a loss of bone density. Osteoporosis is the more serious condition. Loss of bone density can lead to broken bones (fractures). We can minimize the bone loss caused by steroid medications with exercise and medication before and after your transplant. This would include calcium, vitamin D, and bone strengthening exercises.

In addition, you may be given medications called bisphosphonates, along with calcium and vitamin D, to prevent or reverse bone loss. Bisphosphonates can cause a rare complication called osteonecrosis of the jaw or ONJ. This condition causes the jaw bone to weaken and die. It is important to have your teeth monitored by a dentist to prevent tooth complications.

**Steroid myopathy** is damage to the muscle fibers.

Using steroid medications causes a decrease in muscle mass/size (muscle atrophy) and weakness. This condition may make it difficult to climb stairs or rise from a seated position. Lifting objects may be difficult. Other symptoms include a dull, aching sensation in the hip or shoulder area or limited range of motion. Muscle strength usually returns over time, however, in some cases, the muscle has too much damage and full recovery is not possible. **It is critically important to maintain physical activity before, during, and after the transplant process.**

## SECONDARY MALIGNANCY

Sometimes, people who have had chemo and/or radiation may develop a second, new type of cancer. The risk of a second cancer is outweighed by the benefits of a transplant.

When your doctor makes the recommendation to use chemotherapy and/or radiation, it is because he or she believes that the risk of not treating your first cancer is worse than the risk of possible side effects (including a new cancer) that may occur in the future.

A secondary cancer can occur any time after chemotherapy and radiation – at any point in a patient's life. The medical team sees post-transplant patients every 1-2 years for life to screen for this possible complication. Some of the most common secondary malignancies are mouth (oral) cancers, bladder cancers, acute myeloid leukemia (AML), myelodysplastic syndromes (MDS), skin cancer, and other solid tumors such as lung cancer. Talk to your health care providers regarding your risk. In addition, you should continue the usual cancer screening such as mammograms, pap smears, and colonoscopies.

## GRAFT VERSUS HOST DISEASE (GVHD)

**You may develop Graft versus Host Disease.** You may be offered the chance to receive a protocol/trial to decrease the chances of developing GvHD or to treat it.

Except for identical twins, there is some degree of incompatibility (mismatch) between all donor and recipient pairs, even if they have matching HLA antigens. GvHD is a common complication following allogeneic BMT. The disease can range from mild to life-threatening, with short-term or long-term symptoms.

GvHD occurs when T-cells from the donor's immune system recognize proteins (antigens) on the recipient's cells as foreign. GvHD may have a beneficial effect – the donor cells help wipe out the recipients' severe underlying cancer, even if it has been resistant to chemo. But too much GvHD may cause severe problems, even death.

The incidence and severity of GvHD varies depending upon the degree and types of differences between the donor and recipient: If HLA antigens tested are compatible, the incidence of GvHD is less. But not all people are able to find a donor who matches them completely. Certain antigen mismatches cause more serious problems than others. Depending on the HLA matching and the type of transplant, GvHD may be more or less severe. Different complications may arise with older patients requiring different transplant approaches. Newer treatments are improving the control of GvHD.

Patients who develop symptoms of GvHD may need a skin biopsy, upper or lower endoscopy, liver biopsy, endoscopic lung biopsy, or lavage to determine if there is GvHD or some other medical complication.

GvHD can also occur from a blood transfusion if the blood is not properly prepared because the white blood cells in the product can react against the recipient. To help prevent transfusion-associated GvHD, all Roswell Park blood products (plasma, red cells, and platelets) are irradiated before transfusion. Not all hospitals routinely use this practice. Discuss blood product transfusion with your clinical team. You will receive a bracelet that states all blood products that you receive should be filtered and irradiated. (Radiation inactivates all donor white blood cells but not the red cells or platelets.)

- GvHD can be acute or chronic. Patients may experience none, one, or both types.
- Acute GvHD usually occurs within the first 100 days of an allogeneic BMT.
- Chronic GvHD usually occurs after the first 100 days and up to several years after transplant.

Some form of GvHD prevention (prophylaxis) is started during your allogeneic BMT. It is critical that you take your anti-GvHD medications and notify your doctor, nurse practitioner, physician assistant, or nurse if you are having any problems. Anti-GvHD medications are frequently adjusted after your transplant.

The most common agents used to prevent GvHD are tacrolimus (FK-506/ Prograf®/Tacro™), cyclosporine A (CsA), methotrexate (MTX), and mycophenolic acid (MMF/mycophenolate mofetil/CellCept®). Some of these medications require monitoring. For half-matched (haplo-identical) transplants, we can either:

- give you cyclophosphamide (done after the donor cells are infused) – OR –
- screen out the donor T-cells most likely to cause an intense reaction (done before the donor cells are infused).

You may be offered a clinical trial that looks at new approaches to managing GvHD. The members of the transplant team are here to help you cope with all transplant challenges.

## ACUTE GVHD (AGVHD)

- Acute GvHD usually affects the skin (rash), GI tract (nausea, vomiting, diarrhea), and liver (yellowing skin, dark urine).
- Symptoms may range from mild to serious, occur alone or together, or last a long time.
- Gastrointestinal (GI) irritations can make it difficult to properly absorb nutrients and can lead to problems with swallowing or eating, heartburn, stomach pain, weight loss, and loss of appetite. In severe cases, permanent disability or death may occur. Fortunately, severe problems do not happen often, but it is very important to promptly report all symptoms you are having.
- Fortunately, most patients recover without significant long-term side effects. Researchers at Roswell Park and all over the world continue to investigate ways to reduce the complications of GvHD.

## CHRONIC GVHD (CGVHD)

The symptoms of chronic GvHD are often different than acute GvHD. Chronic GvHD (cGvHD) can weaken the immune system, as can the immunosuppressive drugs used to treat it. Coping with this condition can be very challenging and you and your family may feel very frustrated. Chronic GvHD does have an anti-tumor effect and keeps the underlying disease from recurring. There may be a cGvHD study for you that will treat the cGvHD and help us understand its causes.

### Chronic GvHD can cause:

- more infections: GVHD weakens your natural barriers such as skin and mucous membranes, to infection. Good personal hygiene practices are very important!
- liver problems: yellow skin, dark urine, and change in how you break down medicines
- skin problems: rash, itching, changes in skin color, premature graying, hair loss (Severe problems include blistering, peeling, and scarring)
- eye problems: dryness, burning, grittiness, irritation, and extreme sensitivity to light
- mouth problems: dry or burning mouth and mouth sores
- GI problems: difficulty swallowing, feeling full, loss of appetite, and diarrhea
- vision problems
- tightening of the tendons in joints that can make arm and leg movement difficult
- lung complications: Pulmonary Function Testing (PFTs) should be performed regularly after your transplant to assess your lung function. Identifying lung problems early can prevent long term lung damage
- medication side effects: steroids may cause diabetes (which may require insulin or oral medications), mood swings, depression, and anxiety

### Medications/Treatments used to treat chronic GvHD:

- acitretin (Soriatane®)
- alemtuzumab (Campath®)
- antilymphocyte Globulin (equine) (ATG/ATGAM®)
- beclomethasone (BDP): BDP +/- Budesonide EC (Entocort EC®)
- hydroxychloroquine (Plaquenil®)
- imatinib (Gleevec®)
- interleukin-2 (Proleukin®)
- infliximab (Remicade®)
- methylprednisolone (Medrol®)
- pentostatin (Nipent®)
- photopheresis
- rituximab (Rituxan®)
- sirolimus (Rapamune®)
- tocilizumab (Acemra®)
- vedolizumab (Entyvio®)

Some of these medications/treatments require **prior authorization** from your insurance company.

## INFECTIONS

While waiting for your new cells to engraft (before your blood count recovery) your white blood cell counts will be low. This means you are at a high risk for developing infections. At this point in time, infection can be critical and even life-threatening.

Infections can be caused by bacteria, viruses, or fungi. You will receive medication to prevent infection.

# TYPES OF INFECTIONS

## BACTERIAL INFECTIONS

Your body is host to thousands of types of bacteria that are important in keeping you healthy. Most bacterial infections are caused by organisms that are already present on your body. When your immune system is weak, your ability to fight bacterial infections is changed in several ways. The skin and mucous membrane barriers that normally prevent bacteria from entering the body are damaged. White blood cells that are responsible for fighting bacteria are not present.

## FUNGAL INFECTIONS

Candida and Aspergillus infections are the most common fungal infections after transplant. Candida fungi and bacteria live all over your body including the mouth and vagina. Taking antibiotics can affect the bacteria that normally regulate Candida growth. This can lead to Candida overgrowth and a fungal infection. Aspergillus is a fungus found in the environment (soil, air). It can cause infection in the lungs and sinus cavities. Fungal infections can be difficult to treat and life-threatening. You will be given antifungal medications to prevent infection.

## VIRAL INFECTIONS

Viral infections after transplant can occur as a result of being exposed to a new virus or reactivation of an old virus that is dormant (sleeping) in your body. Viral infections are also difficult to treat and are most common during the first 12 months following BMT. The most common infections are caused by herpes simplex virus (cold sores), cytomegalovirus (CMV) and varicella zoster virus (chicken pox, shingles). You will be given anti-viral medications to help prevent infection.

# BLEEDING PRECAUTIONS

After transplant, you are at an increased risk for bleeding because your platelet count is low. Your platelets will begin to rise as your bone marrow recovers. Platelets usually take a few days longer to grow back than white blood cells.

## Symptoms of a low platelet count

- Nose bleeds
- Bleeding gums
- Bruising
- Bleeding from any body cavity or injury
- Bleeding longer than usual from a procedure
- Blood in the urine or stool (which may not be detectable by sight)

# TRANSFUSIONS

Once your platelet counts are below 10,000 (sometimes called less than 10), you may have bleeding when there has not been an injury, and you will receive platelet transfusions. This bleeding may be very serious if it occurs in the brain or other parts of the body. These guidelines will help you prevent bleeding.

- Take good care of your skin and lips. Moisturize daily and as needed. Dry or cracked skin and lips are prone to bleeding, as well as infection.
- Use only an electric razor.
- Use a nail file or emery board to keep finger and toenails groomed. Avoid use of nail clippers, which may lead to unintended injury or infection.
- Wear shoes or slippers at all times when you are not in bed and remove them before getting back into bed.
- Avoid blowing your nose forcefully.
- Avoid high impact exercise or any activity that has a potential for injury.
- Avoid straining with bowel movements. If you are constipated, tell your doctor or nurse.
- Prevent injury to your mouth. Do not use toothpicks or dental floss. Cleanse with a sponge toothette or extra-soft toothbrush, depending on your platelet count.
- Avoid extremely high temperature foods or sharp utensils.
- Do not use a rectal thermometer, suppository, enema, tampon, or douche.
- Report a headache or lightheadedness to a nurse immediately.
- Remember to save all urine and stool in the collection hat so we can inspect and test for blood and infection.



# ADVANCE DIRECTIVES

Sometimes a patient's cancer proves to be resistant to all therapies we have to offer. No matter how hard the patient, family, and transplant team try, occasionally the BMT does not work, or insurmountable complications arise and death results.

Having a potentially fatal illness, and undergoing high-dose chemotherapy and/or radiation only point out how fragile life may be. At Roswell Park, we believe that patients should discuss their end of life wishes with their family, loved ones and medical providers to make sure their wishes are honored. All Roswell Park patients are asked to complete Advance Directives, Health Care Proxy, Do Not Resuscitate orders, and the Medical Order for Life-Sustaining Treatment (MOLST) form. Please speak to your transplant team about the purpose of each of the forms, and how to complete them so your wishes will be followed if you become unable to make decisions.

# LIFE AFTER TRANSPLANT

Maintaining your health insurance is critical to your long term care and recovery after discharge. All insurance changes should be reported to Patient Registration. Please direct any questions or concerns to your social worker.

## INFERTILITY

While infertility can be a side effect of high-dose chemotherapy and/or radiation, not all BMT patients will experience this side effect. Please let your BMT physician know if you have any concerns about fertility.

## RELAPSE

Occasionally a transplant does not achieve its goal, and the patient's disease doesn't go into remission or reoccurs. This can be devastating to a patient and his or her family.

If this happens, there are other treatment options such as new therapies and clinical trials, (studies that are evaluating promising new treatments). Additional cellular therapy or a second transplant may be offered.

At times, after considerable discussion with the patient, family, and the clinical team, a consult is requested for palliative care services or hospice services may be offered. This path is meant to provide support to the patient and family to optimize the remainder of life.

## YOUR DISCHARGE

Discharge planning begins on the day of admission. Several days before your discharge, a check list will be placed on your door. Everyone from the BMT team will need to see you and mark in their appropriate sections. Pharmacy will need to see you either the day before or the day of discharge, in the presence of your caregiver, to go over all medications with both of you. On the day of discharge, your nurse will review the medications again along with any other specific instructions. Discharge time should be no later than 11:00 am.

After your discharge, you will be cared for as an outpatient. The outpatient BMT Center is open every day. Monday through Friday, the center is open from 7:00 am until 5:00 pm. Hours vary on weekends and holidays. If any problems occur, please call us at **716-845-1444**. For concerns after hours, please call Roswell Park at **716-845-2300** and ask for the BMT physician on call. **If you have not received a response within 10 -15 minutes, please repeat the call.**

At your first clinic visit, you should bring your pillbox and all your medications, your schedule of medications, and your primary caregiver. Before leaving the BMT Center, please set up your next clinic appointment time along with any additional tests or procedures you need.

If you live more than 45 minutes away from Roswell Park, you will be expected to stay locally up to day +100 or longer, based upon your medical condition and at your BMT physician's discretion. Our social work department will work with you to secure lodging at one of the local facilities approved for post BMT living.

## YOUR OUTPATIENT VISITS

You will be seen in the BMT Center the day after discharge. The frequency of clinic visits depends on variables such as transfusion needs, electrolyte replacement, hydration, nutrition status, and medication management. We encourage caregivers to accompany you on your visits to the clinic so they can ask questions, and stay involved in your care.

Blood will usually be drawn in the phlebotomy department before most clinic visits. If your lab results indicate a red blood cell or platelet transfusion is necessary, you will require treatment while you are in clinic.

As a post-transplant patient you may be able to return to your regular hematologists/ oncologists for interim care approximately day +100 after clearance by the BMT physician. Your Day 100 workup will be performed at Roswell Park.

It is crucial that you keep your BMT clinicians informed about any problems that arise.

**Please contact the Outpatient BMT Center if you have any of these symptoms.**

- Temperature of 100.4° F (38.0° C) or above
- Sudden onset of cough, shortness of breath, difficulty breathing
- Worsening fatigue
- Changes in skin appearance
- Feeling dizzy, lightheaded, or falling
- Nausea or vomiting not controlled with medication
- Difficulty urinating
- Increase in diarrhea, diarrhea not controlled with medication, or constipation
- Increase or change in pain
- Altered mental status
- Bleeding

We ask you to have a caregiver with you so you have help if you are feeling sick.

This is a time of recovery and recuperation but you may feel weak or fatigued, and may not have much appetite. Everyone's recovery time is different and some people take more time than others. Do not get discouraged if your body takes longer to recover; give it the time and rest it needs. Physical therapy (PT) and exercise speeds your recovery. Your post discharge progress will be monitored closely in the BMT Center and the BMT team will be able to answer your questions and keep you informed of your plan of care. If you think of questions or concerns after your visit, please call the BMT Center at **716-845-1444**.

## **LIFE AFTER DISCHARGE**

Your living space, whether it is your home or temporary housing, should be cleaned in preparation for your arrival. **You should not do the cleaning!** Your caregiver should be responsible for maintaining a clean living space because you should not be exposed to any dusts, molds, or any other bugs. Most infections you get are a result of an overgrowth of the organisms that naturally exist in your body. Although your immune system is slowly building itself back up, you are not yet ready to fight off infections. Please check with your team about when it is OK to start doing house hold chores again.

The best way to prevent the spread of infection – and to keep you from getting sick – is good hand washing! Your family and anyone who comes to visit you should be washing their hands frequently.

### **Other ways to protect yourself from infections**

- When you come to the Center or go out in public, wear the mask the BMT team gave you. You do not need to wear a mask while in the car or at home around healthy family members or if you're out in the yard (unless you live around a construction area). Discourage people who do not feel well from visiting you.
- Avoid large crowds until you have been cleared by your physician. This includes movie theatres, grocery stores, restaurants, places of worship, and outdoor functions such as football games, fairs, etc. If you are unsure please ask a member of the BMT team.
- If other members of your household become sick with a cold or flu, inform your BMT team. Avoid close contact with them and wash your hands frequently and thoroughly. Flu shots are recommended for all caregivers and close family members. You should wear a mask if you need to be in close contact with the individual or ask the individual to wear a mask around you until recovered.

- Contact with pets is safe as long as they have remained in the home, do not live outdoors, and all their immunizations are up to date. It is very important to avoid litter boxes, feces, birds, and reptiles. Do not clean fish, turtle, or reptile tanks, gerbil/hamster cages, litter boxes, or clean up after a dog. Birds should not be kept in your house. They carry infections that may be harmful to you.
- You should not work in the yard or garden or dig in the soil as there are organisms that can cause infections to your weakened immune system.
- If you have a central venous line or are neutropenic, do not go swimming in pools, oceans, lakes, or hot tubs.

Maintaining a clean home is extremely important to preventing you from getting any infections. The patient should not do the cleaning. Here are some guidelines for your caregiver to properly clean to help you stay healthy:

- Dust, mold and fungus should be minimized
- Bathrooms and eating areas should be cleaned daily
- Dirty sponges should be cleaned at least every 3 days either in a dishwasher or washing machine
- Use cleaners with disinfectant properties such as Lysol or Clorox
- When dusting, use a damp cloth or a Swiffer Wet Jet or disposable duster
- Make sure air filters are cleaned or replaced frequently
- Patients should avoid pesticides, solvents and fertilizers
- Patients should also avoid outside areas where there is freshly mowed grass, hay, disturbed earth, and construction areas

Do not have any dental work done, even cleaning, until your physician has said it is safe to do so. Extra measures may need to be taken to prevent an infection or bleeding.

We will review your medications at every visit following discharge. It is very important that you take your medications as prescribed and not miss any doses. Keep track of any medications that need to be refilled and alert the provider if you do not have any refills, or let the BMT nurse know at your clinic visit. Please call at least 3 days in advance for refills.

Protect your skin from direct sun exposure. Some medications cause skin sensitivity when exposed to sunlight. Avoid direct sunlight between 10:00 a.m. and 5:00 p.m. because that is when the sun is at its peak. If you must be outside during this time, be sure to wear a hat, sunglasses and a long sleeve shirt and pants. It is recommended that you reapply sunscreen with an SPF of 30 or higher every 30 minutes. Use a sunscreen that is PABA free to reduce the chance of skin irritation.

## NUTRITION

Adequate nutrition is very important after your transplant. Proper intake of calories, protein, vitamins, and minerals are needed to promote healing and reduce side effects. Some common side effects of treatment – poor appetite, taste changes, sensitivity to smells, mouth sores, nausea and vomiting, diarrhea and constipation – may interfere with your nutritional intake. When you are discharged, you must continue to follow the low microbial diet. You must remain on this diet until you are off of all immunosuppression drugs. Your medical team will also consider if:

- You are at least **6 months past Day Zero** (the day you had your transplant).
- You are on a tapering schedule of tacrolimus, your therapeutic levels for tacrolimus are no longer being monitored, **OR** you have been on low-dose steroids\* for **the past 30 days**. (\*such as a methylprednisone dose of less than 0.1 milligram per kilogram of body weight per day)
- You have not received any other systemic agents to control Graft vs. Host Disease (GvHD) such as rituximab, infliximab, ruxolitinib, tocilizumab) **within the past 6 months**.

**Please note:** You may need to continue or restart a low microbial diet if you are readmitted to the hospital for illness, have a flare-up of GvHD, or if it is in your best interest according to your doctor's judgement.

### **Tips to help meet your nutritional goals**

- You may need to eat 5-6 smaller meals rather than 2-3 larger meals a day.
- To increase calories and protein, nourishing snacks or liquid supplements such as Carnation® Instant Breakfast, Boost®, Ensure®, Isopure®, or homemade shakes made with protein powder such as Gold Standard® Protein Powder may be added between or with meals.
- You can increase calories by adding these foods when cooking: butter, margarine or oil, whipped cream, high fat dairy products, cheeses, salad dressings or other dips and spreads, nuts and nut butters, and honey or jams. Also, add bread, rice, and pasta to meat and vegetables dishes.
- Exercising for 10-15 minutes before you eat will help stimulate your appetite.
- A pleasant atmosphere or meals enjoyed with friends or family can also help stimulate the appetite.

### **TASTE CHANGES/SMELL SENSITIVITY**

- Adjust the seasonings and flavorings in your food to accommodate taste changes.
- If cooking smells are unpleasant, try cool or chilled foods.
- Avoid very spicy foods and beverages such as hot sauce, and those with an overpowering aroma.

#### **If you have mouth sores**

- Experiment with different textures of foods.
- Pureed and soft foods may be easier to eat. Moisten your foods by adding extra gravy, butter, margarine, sauces, soups, or broth.

- Avoid highly fibrous, coarse, and rough foods such as raw fruits, vegetables, and bran products.
- Avoid very dry foods such as crackers and toast unless consumed with large amounts of liquid.
- Acidic foods such as tomatoes and citrus fruits and juices (such as orange juice or cranberry juice) may cause discomfort.

### **NAUSEA/VOMITING**

- Try clear liquids, carbohydrates (crackers, toast if you do not have mouth sores, rice, cereal and pasta) and cold foods.
- Foods more likely to cause nausea are greasy/fried foods, spicy or acidic foods.
- Avoid foods with strong or unpleasant odors (including during cooking).

### **CONSTIPATION**

- Increase fluid and fiber intake by eating more fruits, vegetables, whole grain products, beans, nuts, and dried fruit such as raisins and prunes.

### **DIARRHEA**

- Avoid high fiber, high-fat desserts and snacks, spicy foods, and fried foods.
- Be sure to replace the fluid lost with diarrhea by consuming adequate fluids throughout the day.
- Milk contains lactose, a sugar in milk. It may be a factor in aggravating the diarrhea. You may ask for medication to help tolerate lactose.
- Lactose-free milk and dairy free alternatives (such as soy or almond milk) are widely available. You may need to use lactose-free milk or increase intake of yogurt, with active cultures, until the diarrhea significantly decreases.
- Talk to your clinical team about medications that may help relieve these symptoms.
- Never smoke, chew tobacco, or use vapor products.
- Avoid all alcoholic beverages.

## **PHYSICAL ACTIVITY AND RECREATION TO MAINTAIN STRENGTH AND IMPROVE RECOVERY**

You may find that once you are discharged home, you are more fatigued than you thought you would be. This is normal. How quickly you recuperate depends on a number of factors including your blood counts, nutrition, and activity level. Regular activity will help you regain your strength more quickly, even if you begin with a short walk or a flight of stairs.

Independent functioning is a key factor in regaining endurance. It may be difficult to immediately resume all of your normal activities when you get home. It is important to do what you can for yourself in order to regain your strength and independence. It is also important to realize any limits you may have and ask for assistance as needed. Remember, though, to pace yourself. This simply means planning your daily schedule with the most demanding activities early in the day and allowing for breaks as needed. Space your activities throughout the day and week. Exercise is the most important thing and you need to limit computer/TV screen time to 2 hours a day.

Most patients are not physically strong enough to return to the workplace for several weeks or even months. This usually means that you may have an increased amount of free time. Take the opportunity to do something you enjoy. Maybe it is time to get back to a hobby, read a good book, visit with friends or family, or do whatever it is you like to do. Getting involved in recreation and leisure activities is an excellent way to increase strength and endurance. These activities are also a great way to reduce stress. Do not hesitate to ask your provider for guidance about your activities.

## **SEXUALITY (PLEASE DISCUSS ANY QUESTIONS YOU MAY HAVE WITH YOUR CLINICAL TEAM)**

Intimacy is an important part of a healthy relationship, but some patients may be embarrassed to ask when they can resume sexual activities after BMT. The decision is based on many individualized factors including recovery of your neutrophil and platelet count. In general, you may have sexual intercourse when you no longer need a transfusion to maintain your platelet count greater than 50,000. Additionally, the absolute neutrophil count (ANC) must be greater than 1,000 without growth factor support. Even if this criteria is met, it is important to wear condoms to protect yourself against Human Immunodeficiency Virus (HIV), Herpes Simplex Virus (HSV), Human papillomavirus (HPV) or any other viruses or sexually transmitted diseases (such as chlamydia, gonorrhea, syphilis) that could be transmitted through vaginal or seminal fluid.

Good communication with your partner is needed, as many men and women experience a decrease in their desire and find they do not have the same interest in sex that they did before their transplant. These are common feelings that can relate to your illness, recovery time, medication side effects, and general health. If these problems continue longer than you expect or are causing significant stress on your relationship, please discuss them with your BMT clinician.

Many women experience early menopause, which can cause the vagina to become dry and less flexible. The decrease in vaginal secretions can make intercourse painful. There are over the counter water-based lubricants that can help relieve these symptoms such as KY Jelly® or Astroglide®. If the discomfort continues despite using these products, please talk to your BMT clinician for further evaluation. Their recommendation may depend on your specific diagnosis, history, and associated treatment.



Men may experience difficulty either getting or maintaining an erection. This issue may be caused by a variety of factors including hormonal levels, supportive medications, chemotherapy, or radiation. We recommend discussing this issue with your BMT clinician for further evaluation or a referral to a specialist.

## IMMUNIZATIONS AND VACCINES

After having a blood or marrow transplant, you will have some changes, at least temporarily, to your body's immune system. Adult patients who have had a blood or marrow transplant may have only a short-term immune system deficiency. You will need to have your immunizations repeated beginning 6 months after treatment.

## ANNUAL BMT CLINIC

In order to maintain our continued commitment to your successful recovery, the BMT program has established an annual clinic to provide follow-up care and information about how to protect your health over the long term. It is open to anyone who has undergone a blood stem cell or marrow transplant (BMT), even if the transplant did not take place at Roswell Park.

The clinic does not replace your regular follow-up clinic visits. It adds an extra level of care, monitoring you for health issues that can arise long after a transplant. It provides you, and the medical professionals who care for you, with important information to keep you healthy as a survivor after a cancer diagnosis.

## YOUR CAREGIVERS

A caregiver is the person who will be responsible for taking care of you after you leave the hospital. Your caregiver must make sure that all of your needs are met. Being a caregiver is an important responsibility and you will need to choose this person very carefully. This person must be able to help you in many different ways while taking care of themselves too. It can be an adjustment for everyone and requires understanding and patience. Choose a primary and a secondary caregiver. **At least 1 caregiver (the main one) must attend the required caregiver class before you are admitted.**

### Caregiver's responsibilities:

- Providing transportation to and from the BMT Outpatient Center and tracking appointments
- Observing changes in your condition and reporting them to the clinic
- Calling for medical care, if needed
- Monitoring medication schedules
- Assisting with meal preparation and diet restrictions
- Assisting you with personal hygiene needs
- Assisting with medical planning
- Serving as a communication link and advocate
- Being physically present with you
- Giving encouragement
- Reporting temperatures of 100.4° F (38.0 C) or above

## TAKING CARE OF THE CAREGIVER

Caregivers do so much for you that they will need to take care of themselves too, especially if they are your spouse, parent, or child. Caregivers must remember to exercise, eat a proper diet, and get adequate sleep in order to help you the most. Your caregiver might experience a mix of emotions about taking on this new role. Supporting your caregiver is essential during this time of adjustment. While you are in the hospital, we do not recommend your caregiver stay every night – this may lead to exhaustion.

### The caregiver should:

- take care of their own personal health
- take a break when they can
- know their limits and ask for help
- form a caregiver team to provide backup
- join a support group (information provided at the caregiver orientation)
- seek relaxation

## HELPFUL HINTS FOR THE CAREGIVER

- Develop a schedule for the week and include clinic appointments, medications, physical exercise, and central venous line care.
- Maintain a log of what the patient has had to eat or drink.
- Keep a list of questions to bring with you to the next clinic appointment.
- Develop a telephone-calling tree to get information to family and friends.
- Use email or a web site to keep friends and family posted.

If you are in need of handicap parking, please ask our social worker for the Department of Motor Vehicles Handicap Form. Our BMT clinicians will fill it out and you will then need to return it to the Department of Motor Vehicles (DMV).

## PATIENT/DONOR CONFIDENTIALITY

Blood & Marrow Transplant patients and donors are ALWAYS anonymous to one another for a minimum of 1 year after transplant. In some cases, you are allowed to send anonymous correspondence before one year. Rules about contact vary by country. Please speak with your BMT Coordinator for more information about donor contact.

The identity of cord blood donors is confidential. The units are listed by number and cord blood bank. There is never any personally identifying information available. You will be told the gender of the baby and their blood type.

# VISITOR INFORMATION

## PARKING

- The parking ramp at Roswell Park is located at the corner of Michigan Avenue and Carlton Street. The patient/visitor entrance is on Carlton Street. The parking ramp is open 24 hours a day, seven days a week. You may use the enclosed walkway on the third floor of the parking ramp to go directly into the hospital or simply cross Carlton Street at the crosswalk.
- Parking ramp office hours are from 7:00 am to 5:00 pm, Monday through Friday. The office is located on the ground floor of the ramp.
- You can get a Reduced Rate Stamp on your parking ticket at the information desk located in the lobby on the ground floor of the main hospital or on an inpatient unit. (see below)
- Handicapped parking spots are available on the first (ground) floor of the ramp and near the elevators on the second floor.
- Metered on street parking is also available. Roswell Park cannot assume responsibility for parking tickets, personal items, or damage to vehicles.
- Escort service is available 24 hours a day through the division of public safety, located just inside the hospital entrance on the left. This service is recommended when leaving to obtain your vehicle if not using the valet service.
- Valet parking service is also available from 7:00 am to 6:00 pm, Monday through Friday. The rate is the time parked plus a \$1.00 service fee. Valet parking is not available on weekends.

## REDUCED RATE STAMPS FOR PARKING

A Reduced Rate stamp allows a patient or the driver of a patient to pay a reduced rate for each 24- hour period they are parked. New patients may bring their tickets to Registration for a Reduced Rate Stamp. Patients and drivers of patients may obtain a stamp at the Information Desk. If there is no one at the Information Desk, they may get a stamp from Public Safety.

### ***Who Should Get a Reduced Rate Stamp?***

- An outpatient or the designated driver on the day of an appointment
- An inpatient or designated driver on the day of admission or discharge

### ***How Much Will I Save With the Reduced Rate Stamp?***

Please understand that this is not a validation. This stamp gives you a reduced rate per each 24 hours you are parked in the ramp. As of August 2015, the reduced rate is \$4.00/24 hours; the full rate is \$9.00/24 hours. Rates are subject to change.

## REDUCED RATE STAMP FOR INPATIENTS

Upon request, an inpatient may receive a stamp on his/her ticket by whichever floor they are on. This stamp works like a Reduced Rate Stamp but it will not read in the Pay Station in the middle lane of the Roswell Park parking ramp. The driver can redeem it at the parking ramp cashier booth or with a valet.

## DONOR CENTER VALIDATIONS

Visitors who are donating blood or platelets will be given validations, and do not pay for parking. The green validation sticker will not read in the Pay Station in the middle lane of the Roswell Park parking ramp. The driver can redeem it either at the parking ramp cashier booth or with valet.

## MULTIPLE VISITS IN A DAY

There are times when a patient or the driver of a patient must leave and return to Roswell Park more than once in a day. We try to accommodate our patients and visitors.

**Receipts** – Whether parking in the Roswell Park parking ramp or using valet service, the driver should get a receipt. The first time the driver leaves, he or she will pay and be given a receipt. Each time thereafter, the driver will obtain a new ticket. He or she should get another Reduced Rate Stamp on the ticket. Upon exiting, the driver will give the ticket and the receipt to the cashier (or valet driver) to be exempted from paying again. As long as the entry date is the same as the exit date, the driver will not have to pay again for parking.

## PAYMENT METHODS

- Parking ramp cashier booth accepts cash and credit cards (except for American Express).
- Parking ramp pay station machine (middle lane) accepts only electronic stamps. Please note: No manual stamps (inpatient or advance blood draw stamps), nor validation stickers (given to blood/platelet donors), or separate vouchers (given in Chemoinfusion Center) can be read in the pay station.
- Valet parking accepts cash only.
- The Transportation and Parking Office accepts cash, checks, money orders, and credit cards (except for American Express).

# LODGING

## DOWNTOWN BUFFALO

NAME	ADDRESS	PHONE	COST	AMENITIES
<b>Kevin Guest House<sup>*^</sup></b>	782 Ellicott St. Buffalo, NY 14203	716-882-1818	\$25/night, per person  \$50/night BMT apartments	<ul style="list-style-type: none"> <li>• Free Parking</li> <li>• Shuttle Available</li> <li>• STAIRS ONLY</li> <li>• Continental Breakfast</li> <li>• Laundry Facility</li> <li>• Free Wi-Fi</li> <li>• Air Conditioning</li> <li>• BMT Apts with private bathroom</li> </ul>
<b>Ronald McDonald House<sup>*</sup></b>	780 W. Ferry St. Buffalo, NY 14222	716-883-1177	\$15/night	<ul style="list-style-type: none"> <li>• <b>**PEDIATRIC PATIENTS ONLY**</b></li> <li>• Shuttle Available</li> <li>• Laundry Facility</li> <li>• Wi-Fi</li> <li>• Toy Room</li> </ul>
<b>Wyndham Gardens<sup>^</sup></b>	125 High St. Buffalo, NY 14203	716-845-0112	\$105-135/night	Connected to Roswell Park by Skywalk <ul style="list-style-type: none"> <li>• Shuttle available</li> <li>• Wi-Fi</li> <li>• Air Conditioning</li> <li>• In-Room microwave &amp; fridge</li> <li>• Laundry Facility</li> <li>• Wheelchair Accessible</li> </ul>
<b>Hyatt Regency</b>	2 Fountain Plaza Buffalo, NY 14202	716-856-1234	\$97/night	<ul style="list-style-type: none"> <li>• Shuttle Available</li> <li>• Internet Access</li> <li>• Refrigerator</li> <li>• Air Conditioning</li> <li>• iHome Stereo with iPod docking system</li> <li>• Rooftop indoor pool</li> <li>• Full service Spa</li> <li>• Wheelchair Accessible</li> </ul>
<b>Adam's Mark Hotel<sup>^</sup></b>	120 Church St. Buffalo, NY 14202	716-845-5100	\$79-89/night	<ul style="list-style-type: none"> <li>• Shuttle Available</li> <li>• Free parking</li> <li>• Free breakfast</li> <li>• Internet Access</li> <li>• ATM</li> <li>• Wheelchair Accessible</li> <li>• In-Room mini fridge &amp; microwave</li> <li>• Laundry Facility</li> <li>• Air Conditioning</li> <li>• Indoor Pool</li> </ul>

## SOUTH BUFFALO

NAME	ADDRESS	PHONE	COST	AMENITIES
<b>Staybridge Suites^ Buffalo South</b>	164 Slade Ave. West Seneca, NY 14224	716-939-3100	1-6 day stay \$90-100/night 7-30 day stay \$75-85/night 30+ day stay \$69-79/night	<ul style="list-style-type: none"> <li>• Off Street Parking</li> <li>• Free Breakfast</li> <li>• Free Dinner Mon-Thurs</li> <li>• Full Kitchen</li> <li>• Pet Friendly</li> <li>• Handicapped Rooms Available</li> <li>• Pet Friendly</li> <li>• Free Laundry Facility</li> </ul>

## AMHERST/AIRPORT

NAME	ADDRESS	PHONE	COST	AMENITIES
<b>Candlewood Suites^</b>	20 Flint Road Amherst, NY 14226	716-688-2100	\$69/night	<ul style="list-style-type: none"> <li>• Free Parking</li> <li>• Shuttle Available within 5 miles</li> <li>• Internet Access</li> <li>• Air Conditioning</li> <li>• Laundry Facility</li> <li>• Wheelchair Accessible</li> </ul>
<b>Holiday Inn Express Buffalo Airport</b>	131 Buell Ave. Cheektowaga, NY 14226	716-631-8700	\$79/night Sun-Thurs \$99/night Fri-Sat	<ul style="list-style-type: none"> <li>• Free Parking</li> <li>• Shuttle available within 5 miles</li> <li>• Free breakfast bar</li> <li>• Internet Access</li> <li>• Air Conditioning</li> <li>• In-Room mini fridge &amp; microwave</li> <li>• Heated pool</li> <li>• Wheelchair Accessible</li> </ul>

\* Indicates Guest House, which includes a private room, and shared common areas with other guests such as bathroom, kitchen, etc.

^ Highlighted hotels are approved for stays after a Bone Marrow Transplant

For reservations, please contact the hotel directly and indicate your stay is related to a Roswell Park visit. Roswell Park will be contacted to verify, or you can contact Roswell Social Work Department at **716-845-8022** for further assistance

For questions regarding accommodations, please contact the hotel directly

For questions regarding financial assistance, please contact the Social Work Department at Roswell Park at **716-845-8022** Monday thru Friday excluding holidays, or the operator at **716-845-2300**



# MEDICATIONS

Here are the typical medications that allogeneic BMT patients may receive when discharged. Side effects will also be discussed at discharge.

## Antivirals – prevent/treat viral infections

- acyclovir/Zovirax®
- valacyclovir/Valtrex®
- famciclovir/Famvir®

## Antifungals – prevent/treat fungal infections

- voriconazole (Vfend®)
- posaconazole (Noxafil®)
- micafungin (Micamine®)

## Antibacterials – prevent/treat bacterial infections

- penicillin VK (PenVK®)
- azithromycin (Zithromax®)

## Antibiotic for fever

- levofloxacin (Levaquin®) Call Roswell for instructions before you take this medication

## Prevent (PCP/PJP) pneumonia

- sulfamethoxazole 800 mg/trimethoprim 160 mg/ Bactrim®, Septra®
- pentamidine /Pentam® 300 mg via inhalation monthly in clinic
- dapsone (need G6PD blood level before starting)
- atovaquone/Mepron®

## Immunosuppression

- tacrolimus (Prograf®)/ (FK506)
- cyclosporine (Sandimmune®, Neoral®)
- mycophenolate mofetil (MMF) (Cellcept®) (to stop after Day + 60 doses)
- sirolimus (Rapamune®)

## GVHD medications (immunosuppressants)

- beclomethasone 2 mg
- budesonide EC (Entocort EC®)
- methylprednisolone (Medrol™)

## Supplements

- folic acid (Vitamin B9)
- multivitamin (without iron)
- magnesium+ protein (magnesium sulfate IV if oral supplements are not adequate)
- cholecalciferol/calcium citrate (Vitamin D)

## Anti-anxiety (lessen stress)

- lorazepam /Ativan® (also used for nausea)
- clonazepam/Klonopin®
- alprazolam /Xanax® (not preferred)

## Help with sleep problems

Preferred	Alternatives
mirtazapine /Remeron®	zolpidem/Ambien®
quietapine/Seroquel®	temazepam/Restoril®
trazodone /Desyrel®	diphenhydramine/Benadryl®
doxepin/Silenor®	

## For gastrointestinal reflux (GERD) and ulcers (Required if on steroid medication)

- famotidine/Pepcid®
- omeprazole/Prilosec®
- pantoprazole/Protonix®
- ranitidine/Zantac®

## For other GI problems

- metoclopramide/Reglan® – for delayed gastric emptying or nausea
- erythromycin/Emycin® – for delayed gastric emptying
- ursodiol/Actigall® – for gall bladder/increase liver enzymes

**Anti-diarrhea**

- loperamide/Imodium®
- atropine & diphenoxylate/Lomotil®

**Laxatives**

- docusate/Colace®
- senna & docusate/Senokot-S®

**Anti-nausea**

- lorazepam/Ativan®
- prochlorperazine/Compazine®
- ondansetron/Zofran®
- scopolamine/Transderm Scop®
- metoclopramide/Reglan® – for delayed gastric emptying or nausea

**Relieve pain**

- oxycodone/Roxicodone®
- hydromorphone/Dilaudid®
- fentanyl patch/ Duragesic®
- methadone
- tramadol/Ultram®

# GLOSSARY OF TERMS AND ABBREVIATIONS

**24 Hour Urine Collection** – All urine during a 24- hour period is collected and tested to determine how well your kidneys are working

**ablation** – The administration of high-dose chemotherapy and/or radiation before hematopoietic stem cell transplantation. Its purpose is to destroy diseased or malignant cells and to empty the bone marrow of cells to make room for new cells. Also referred to as a conditioning or preparative regimen

**absolute neutrophil count (ANC)** – The total number of neutrophils present in the blood. Neutropenia is an ANC less than 1500/per milliliter or (1.5 per microliter). Severe neutropenia is an IANC less than 500/per milliliter or (0.5 per microliter). Engraftment for adults and children is defined as the point at which a patient has a sustained ANC of greater than 500/per milliliter for 3 days or more

**acute** – characterized by sharpness or severity (acute pain) or, (2) having a sudden onset, sharp rise, and short course (acute disease)

**alkaline phosphatase (ALP)** – An enzyme produced by the liver and bone. An elevated level in the blood may indicate a liver or bone problem

**ALL** – acute lymphoblastic leukemia (also called acute lymphocytic leukemia)

**allogeneic hematopoietic stem cell transplant** – A transplant in which the hematopoietic (stem) cells come from a different person

**alopecia** – loss of hair

**AML** – acute myeloblastic leukemia (also called acute myelocytic leukemia)

**anaphylaxis** – An acute allergic reaction with symptoms of shortness of breath, rash, wheezing, and drop in blood pressure. Treated with medication and may be easily reversed

**anemia** – A condition in which there is a decreased number of red blood cells. Symptoms include fatigue, weakness, pallor, shortness of breath and a fast heartbeat. Anemia in men and women is defined as a hemoglobin level below 12 g/dL (grams per deciliter)

**antibiotics** – Medications are used to prevent and treat infections. They can be given by mouth (pills, capsules or liquids) or intravenously (through your long-term IV central venous line)

**antibodies** – Proteins made by the immune system that are capable of recognizing a specific substance or marker on a cell. Antibodies are also made in response to vaccinations, which helps protect you from certain infections

**anticoagulant** – A drug used to prevent blood from clotting

**anti-emetic** – A drug used to control nausea or vomiting

**antigen** – Chemical structures in cells that can be recognized by a person's body as foreign and then cause a reaction (immune response of creating/ releasing antibodies). Vaccines may contain antibodies that are meant to cause an immune response

**antiviral** – An agent that kills a virus or that suppresses its ability to reproduce

**apheresis (pheresis)** – A process in which blood is taken from a donor, a blood component is separated out, and the remaining blood components are returned to the donor. In the case of peripheral blood stem cell collection, the white blood cell component, which contains the hematopoietic cells, is separated out

**apheresis (pheresis) machine** – A machine used to perform apheresis (pheresis) (separating out certain types of blood cells from the blood); also known as a cell separator

**aplastic anemia** – Non-cancerous blood disorder in which the bone marrow is not functioning and the patient is not making enough red blood cells, white blood cells and platelets

**arterial blood gas (ABG)** – Blood test to check the level of oxygen in the blood. The sample is drawn from an artery (generally in the wrist)

**arterial catheter** – Catheter inserted into an artery for continuous monitoring of the pressure inside the artery and to obtain serial arterial blood samples with minimal discomfort to the patient. This is always placed in the Intensive Care Unit (ICU)

**autologous hematopoietic stem cell transplant** – A transplant in which the hematopoietic cells are taken from the patient, preserved and frozen, and later returned to the patient

**bacteria** – Microscopic organisms that may cause infection. Some bacteria are good for you, such as those found in yogurt, and are helpful in your GI (digestive) tract

**baseline test** – A test to measure an organ's normal level of function. The result is compared against tests done after treatment to see if the treatment caused any changes in organ function

**bilirubin** – A substance, made by the liver when RBCs are broken down, which is one of the components of bile. When the liver is not working properly, bilirubin levels build up and may cause a yellowing of the skin and eyes. It may cause darkening of the urine as well

**biopsy** – The removal of a small piece of tissue for laboratory examination

**BK virus** – A virus that normally lives in the body but that may sometimes cause blood in the urine. It may be treated with antibiotics

**blast cell** – an immature cell

**blast crisis** – An advanced stage of relapsed leukemia when the patient has a large number of circulating blast cells. This can be seen in CML patients blood and marrow transplant (BMT), also called hematopoietic stem cell transplant – A type of hematopoietic stem cell transplant in which the hematopoietic cells are obtained from the bone marrow. The term “bone marrow transplant” may be used to indicate either a peripheral blood or bone marrow hematopoietic stem cell transplant

**blood tests** – Taking a sample of someone's blood and running tests for quality, biochemistry, and microscopy of that blood

**blood typing/cross matching** – Blood cells have factors that are not the same in all people. Before a transfusion, blood samples from the donor and the patient are typed, or classified, (type A, AB, B or O) to match them. Once typed, the samples are cross-matched to confirm that they are compatible

**bone marrow (BM)** – The soft spongy material in the center of bones that produces all of the body's blood cells

**bone marrow aspiration and biopsy** – The removal of a small portion of bone marrow using a needle, followed by microscopic evaluation of the cells collected

**bronchoalveolar lavage (BAL)** – A medical procedure in which a bronchoscope is passed through the mouth or nose into the lungs and fluid is squirted into a small part of the lung and then collected for examination

**bronchoscopy** – A medical procedure, performed under anesthesia, in which a bronchoscope is passed through the mouth or nose into the lungs so the pulmonologist can look into the airways and take samples

**C. diff (Clostridium difficile colitis)** – A type of bacterial infection that can cause severe digestive problems, usually diarrhea and stomach cramping. Your stool will be tested for infection as needed. Infection can be treated with antibiotics

**candida** – A type of yeast that can cause infection in BMT patients

**cardiac** – pertaining to the heart

**catheter** – A flexible plastic tube inserted into the body to give or remove fluids. The most commonly used catheters go into your blood stream and bladder. Rarely a catheter may be inserted into the chest to drain fluid

**cell separator** – see apheresis machine

**central venous line** – a catheter placed in one of the large veins in your body to draw blood for testing. The line may be temporary, less than 1 week, or semi-permanent, more than a week. There are several different types of central venous lines (also called central venous catheter)

**chemotherapy** – Drugs used to destroy or slow the growth of abnormal (usually cancer) cells

**chest physiotherapy (cpt)** – Treatments generally performed by physical therapists and respiratory therapists to improve breathing by indirect removal of mucus from the breathing passages

**chest x-ray** – An x-ray that looks at your heart, lungs, bones, and chest

**chronic** – persisting for a long time

**clinical trial** – A research study designed to evaluate new and better treatments for disease

**CLL** – chronic lymphocytic leukemia

**CML** – chronic myelocytic leukemia

**CNS** – Stands for central nervous system, which includes your brain and spinal cord

**colitis** – Inflammation of the GI tract, particularly the colon, which can cause severe abdominal cramping and diarrhea

**colony stimulating factor (CSF)** – A substance that stimulates the growth and development of blood cells; also known as a hematopoietic growth factor. Certain CSFs are used to mobilize peripheral blood hematopoietic stem cells and may be given after the hematopoietic stem cell transplant to reduce the risk of infection

**complete blood count (CBC)** – A test that determines whether the proper number of red blood cells, white blood cells, and platelets are present in the patient's blood

**computerized tomography (CT or CAT) scan** – A type of imaging study that uses x-ray equipment and computers to make cross-sectional pictures of your body that are more detailed than an x-ray

**conditioning regimen** – See ablation

**conjunctivitis** – An inflammation of the conjunctiva, the thin clear tissue that lies over the white part of the eye and lines the inside of the eyelid

**cryopreservation** – The process of preserving and freezing cells

**culture** – Specimens taken of body fluids or tissues and then grown in the laboratory to identify the organisms responsible for an infection

**cytomegalovirus (CMV)** – A type of virus that is not usually harmful in healthy individuals, but that can cause problems, especially pneumonia, in people with low resistance to infection. The virus may be dormant and may reactivate. CMV is characterized by fever, pancytopenia (low counts of all three blood cell types), and inflammatory changes in multiple organs including the liver, lungs, and in the retina of the eye. Colitis is a frequent manifestation of this acute systemic illness

**deciliter** – A unit measuring volume; it equals one tenth of a liter

**dialysis** – A process by which a patient's blood is filtered outside of the body because the kidneys are not functioning properly

**dimethyl sulfoxide (DMSO)** – A chemical used in the cryopreservation (using very low temperatures to preserve structurally intact living cells and tissues) of various types of cells. Has a unique smell for 24 hours after the hematopoietic stem cells are thawed out and given to the patient

**Dual-energy X-ray Absorptiometry (DEXA) bone density scan** – A test to measure bone mineral density (BMD). BMD determines the strength of the bones. Lower than normal BMD is called osteopenia. If BMD is very low, the condition is called osteoporosis. Low BMD increases the risk of bone fractures

**echocardiogram** – A test that records the position and motion of the heart

**edema** – Swelling caused by the abnormal accumulation of fluid in body tissues  
**electrocardiogram (ECG, EKG)** – A test that measures the electrical activity of the heart

**electrolytes** – Electrically charged particles, such as sodium and potassium, found in the bloodstream. The correct level of each, and balances between them, is important for the overall body function

**emesis** – vomit

**engraftment** – The process in which transplanted tissue “takes” and begins to function normally. In the case of hematopoietic stem cell transplants, engraftment refers to the time when your body begins to make new blood cells

**engraftment syndrome** – a complication of transplant in which the lungs collect extra fluid and the skin becomes red and collects fluid. This is an unusual occurrence and is treated with steroids

**erythema** – redness of the skin  
**erythrocyte** – see red blood cell  
**febrile** – having a fever

**Foley catheter** – A soft, flexible plastic tube inserted into the bladder to allow urine to drain out continuously

**fungus** – Primitive life form(s) that can cause infection in the body. Candida and Aspergillus are fungi that sometimes cause infection in post-transplant patients

**gastrointestinal (GI) tract** – The digestive system, which extends from the mouth to the anus and is responsible for receiving food, breaking it down into nutrients (digestion), absorbing these nutrients into the bloodstream, and, finally, eliminating all the indigestible parts of the food from the body

**glucocorticoids** – immunosuppression steroids used to treat inflammation

**graft failure** – A complication of transplantation in which the transplanted cells do not function. In the case of a hematopoietic stem cell transplant, graft failure may be due to graft rejection or may result when the donated cells fail to make new cells. Treatment includes growth factor injections and, potentially, another transplant



**granulocyte** – A type of white blood cell; also called a neutrophil

**granulocyte-colony stimulating factor (G-CSF)**

– A glycoprotein that stimulates the bone marrow to produce granulocytes (white blood cells) and hematopoietic stem cells and release them into the bloodstream. Neupogen® (filgrastim) is one of the current G-CSF medications. There are generic forms of the G-CSF that will be used in the future

**hematocrit** – The percentage of total blood volume that consists of red blood cells. A low count can indicate anemia. Normal hematocrit levels average 38.0 to 52.0%

**hematopoiesis** – The formation of blood cells (hematopoietic – pertaining to hematopoiesis)

**hematopoietic growth factor** – See colony-stimulating factor

**hematopoietic progenitor cells (HPCs)** – A type of blood cell capable of self-renewal, repopulating damaged bone marrow, and restoring the production and development of blood cells

**hematopoietic stem cell harvest** – The process of using a needle and syringe to collect hematopoietic cells from the marrow in the center of the bones (usually from the pelvis), or from the peripheral blood (also known as bone marrow harvest)

**hematopoietic stem cell transplant** – The process by which the patient is treated with chemotherapy, radiation, or both. After the treatment, new hematopoietic cells from a donor or with the patient's own previously harvested hematopoietic cells are infused (also known as peripheral blood stem cell transplant)

**hemoglobin** – The part of red blood cells that carries oxygen to the tissues. Normal hemoglobin levels are 13.5-17.5g/dL. Results less than 8 or 9g/dL are likely to be treated with a transfusion

**hemorrhage** – excessive bleeding

**hemorrhagic cystitis** – inflammation of the bladder, with bleeding

**Herpes Simplex Virus (HSV)** – A type of virus that causes cold sores and other viral infections (see virus)

**Hickman catheter** – a type of central venous line

**High-Efficiency Free Air (HEPA) Filtration** – These air filtration systems can remove mold, dust, and other particles from the air

**HLA typing** – Human leukocyte antigen (HLA) typing is used to match you with a donor for your transplant. HLA is a protein (antigen) found on most cells in your body. Your immune system uses HLA markers to know which cells belong in your body and which do not (see tissue typing)

**Hodgkin Lymphoma** – A type of lymphoma, cancers of the lymphatic (immune) system

**Hohn catheter** – a type of central venous line

**hyperbilirubinemia** – A condition in which there is too much bilirubin in the blood. When red blood cells break down, a substance called bilirubin is formed (see jaundice)

**hyperpigmentation** – darkening of the skin  
hypertension – high blood pressure  
hypotension – low blood pressure

**iliac crest** – Part of the hip bone where a large quantity of bone marrow is concentrated and where a bone marrow biopsy is often performed

**immune system** – Consists of many white blood cells that defend against diseases and can assist in the treatment of cancer

**immunocompromised** – A condition in which the immune system is not working normally and the patient is at increased risk for infection

**immunosuppression** – A decrease in the ability of the immune system to fight infection. Immunosuppression can be caused by chemotherapy and radiation therapy

**interstitial pneumonitis (interstitial pneumonia)** – A nonbacterial, nonfungal inflammation of the lungs. It may be treated with antibiotics and may be diagnosed with a bronchoalveolar lavage (BAL)

**intravenous (IV)** – The administration of fluids or medications into a vein through a thin catheter

**jaundice** – A yellowing of the skin and whites of the eyes, usually the result of a liver abnormality. Less common causes are drug reactions or hemolysis, a blood disorder. It is a sign that the liver is not functioning properly. This may be confirmed with a blood test and may require a biopsy. This may require ursodiol (Actigall®) pills or suspension (also called hyperbilirubinemia)

**leukemia** – Cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood stream

**leukocytes** – A type of white blood cell that plays a major role in the body's immune system. Leukocytes are divided into three main subgroups: granulocytes, lymphocytes, and monocytes

**leukopenia** – A white blood cell count that is below an adult's normal range of 4,500 to 11,000 cells/per milliliter. (4.5-11 cells/per microliter)

**liter** – a unit for measuring the volume of a liquid or gas that is equal to 1.057 quarts

**liver function tests (LFTs)** – Laboratory tests performed on a blood sample that give information about how well the liver is working

**lymphocyte** – A type of white blood cell that helps protect the body against disease and infection

**lymphoma** – A group of cancers that affect the cells that play a role in the immune system, most of which are in the lymphatic system (lymph nodes) of the body

**magnetic resonance angiogram (MRA)** – A medical test that uses a powerful magnetic field, radio frequency pulses, and a computer to produce detailed pictures of blood vessels inside the body

**magnetic resonance imaging (MRI)** – A noninvasive medical test that uses a powerful magnetic field, radio frequency pulses, and a computer to produce detailed pictures of organs, soft tissues, bone and virtually all other structures in the body

**metastatic** – The spread of cancer from the organ or tissue where it began to another part of the body

**microliter** – equal to one-thousandth of a milliliter or one-hundred-thousandth of a liter

**mobilization** – The administration of colony-stimulating factors to cause hematopoietic cells to leave the bone marrow and enter the blood stream. Mobilization is used before peripheral blood hematopoietic stem cells are collected to boost the number available for collection

**monocyte/macrophage** – A type of white blood cell that surrounds and kills microorganisms, removes dead cells, and stimulates the action of other immune hematopoietic cells

**multigated acquisition scan (MUGA)** – A nuclear medicine test that uses a radioactive tracer and special camera to take pictures of the ventricles (the two lower chambers of the heart that hold blood) as your heart pumps blood. This test may be done in addition to an echocardiogram

**multiple myeloma** – Cancer that arises from plasma cells (a type of white blood cell that normally produces antibodies) in the bone marrow. Multiple myeloma can cause infections, bone weakness, kidney failure, and anemia

**neutropenia** – An abnormally low neutrophil count (less than 500 neutrophil cells/per milliliter of blood). A patient with neutropenia is at high risk for developing an infection. There are 3 levels of neutropenia, which are based on the absolute neutrophil count (ANC).

- Mild neutropenia (1000-1500 cells per milliliter) – mild risk of infection
- Moderate neutropenia (500-999 cells per milliliter) – moderate risk of infection
- Severe neutropenia (less than 500 cells per milliliter) – severe risk of infection

**neutrophil** – A type of white blood cell (granulocyte) that plays a major role in the body's defense against infection

**NPO** – Abbreviation for the Latin “nil per os” which means “nothing by mouth.” You may be NPO before a procedure because if you eat there is a risk that the contents of your stomach may come back up the esophagus and then be inhaled into your lungs and cause pneumonia

**orthostatic hypertension** – A drop in your blood pressure when you change position (usually changing from sitting to standing) that can cause dizziness, fainting, and falls

**peripheral blood stem cell (PBSC)** – Blood progenitor cells obtained from the peripheral blood of a patient or donor after mobilization

**physical exam** – The process when a clinician (MD, NP, RN) examines your body (listening to your heart and lungs and feeling your belly) to look for abnormalities

**PICC or PIC line** – A peripherally inserted central catheter is a form of intravenous (IV) access that can be used for a longer time than a standard IV. It is useful for long chemotherapy regimens, extended antibiotic therapy, or total parenteral nutrition

**platelets** – Small blood cell fragments that help prevent bleeding by causing blood to clot. Normal count is 150-450 x 10<sup>9</sup> per liter. If your count goes lower than this, you are at a much higher risk for bleeding. Invasive procedures may require a higher platelet count for patient safety (also called thrombocytes)

**plasma** – The fluid part of the blood that contains proteins. The blood cells float in the plasma

**positron emission tomography scan (PET)** – An imaging test that uses a radioactive substance called a tracer to look for cancer or inflammation in the body

**preparative regimen** – see ablation

**PRN** – Abbreviation for the Latin “pro re nata” which means “as needed.” If your healthcare provider orders a medication for you PRN – it will only be given when you need it or ask for it. This is in contrast to medication that is given to you on a set schedule, such as every 4 hours

**progenitor cell** – A cell that has a tendency to become a specific type of cell, but is already more specific than a stem cell and is pushed to differentiate into its “target” cell

**prognosis** – predicted or likely course of a disease; the chance of recovery or recurrence

**prophylaxis** – A preventative measure taken to maintain health and/or prevent the worsening of disease, such as giving medication to prevent infections

**pulmonary** – pertaining to the lungs

**pulmonary artery catheter** – A specialized catheter that is guided through veins and into the heart to measure the pressures. It is used to monitor various medical conditions such as fluid overload (hypervolemia), sepsis (bacteria or their toxins in the blood or tissues), renal failure (kidneys not able clear waste products from the body), or complex circulatory conditions (also called a Swan- Ganz catheter)

**pulmonary function tests (PFTs)** – Tests that measure how well your lungs are working. You may be placed inside a special chamber to measure the oxygen and carbon dioxide inside your lungs

**pulse oximeter** – A medical device that measures your oxygen saturation (the level of oxygen in your blood)

**Quinton catheter** – A type of central venous line used for the convenience of collecting hematopoietic stem cells. Also called a pheresis catheter

**radiation therapy** – A type of cancer treatment that uses high-energy rays (x-rays, gamma rays, neutrons, etc.) to damage or kill cancer cells. May be a local treatment, targeted to a specific area, or it may be given as total body irradiation (TBI)

**red blood cell (RBC)** – A type of blood cell that carries oxygen to all tissues in the body (also known as an erythrocyte)

**relapse** – A recurrence of disease after treatment

**remission** – The decrease or disappearance of all signs and symptoms of disease; no clinical or microscopic evidence of disease

**renal** – pertaining to kidneys

**sepsis** – The presence of bacteria or their toxins in the blood or tissues leading to severe illness

**sinusoidal obstruction syndrome (SOS)** – A condition in which some of the small veins in the liver are obstructed, which may lead to liver damage. We use enoxaparin/Lovenox® and ursodiol/Actigall® as preventative treatment for preventing this complication (also called Veno-Occlusive Hepatic Disease or VOD)

**skeletal survey** – A series of X-rays of all the bones in the body

**sperm banking** – The process of collecting, freezing, and storing sperm to be used at a later date

**stem cell** – An immature hematopoietic cell (pertains to the blood or marrow) in the blood or bone marrow that produces new bone marrow and blood cells

**stem cell harvest** – The process of collecting hematopoietic cells, including stem cells, from the marrow in the center of the bones (usually from the pelvis), or from the peripheral blood (also called hematopoietic stem cell transplant)

**steroid** – A type of medication commonly used to treat inflammation. Side effects may include high blood pressure, thinning of bones and muscles, weakness, mood alterations, and sleep alteration. It is critically important to discuss your side effects with your treating team (also called corticosteroids)

**stomatitis** – Inflammation of the mouth, with or without mouth sores (also called Mucositis)

**T lymphocyte** – A type of lymphocyte (white blood cell) that fights infection (also called a T cell)

**thrombocyte** – see platelet

**thrombocytopenia** – A lower than normal number of platelets in the blood, which can interfere with normal blood clotting and cause bruising and/or excessive bleeding

**tissue typing** – A blood test that identifies certain antigens on the surface of cells and tissues. Checking the antigens can tell if the donor tissue is safe to transplant to another person (see HLA typing)

**total body irradiation (TBI)** – Radiation treatment of the entire body to destroy malignant cells and bone marrow in preparation for a hematopoietic stem cell transplant (see radiation therapy)

**total parenteral nutrition (TPN)** – An intravenous (IV) solution with high nutritional content that is given in place of food when someone is unable to eat by mouth

**toxin** – poison

**tracheotomy** – A surgical procedure to create an opening through the neck into the trachea (windpipe). It allows the patient to breathe with the assistance of a breathing machine instead of having a tube down the throat

**transfusion** – The infusion of whole blood or specific kinds of blood cells that someone may need until the bone marrow starts producing its new blood cells

**typed & cross match** – Blood typing is a laboratory test done to determine a person's blood type. If a transfusion is needed, another test called crossmatching is done after the blood is typed to make sure the patient's body will accept the donor's blood

**veno-occlusive Disease (VOD)** – see Sinusoidal Obstruction Syndrome (SOS)

**virus** – A microorganism that can only reproduce inside a cell. Viruses cause the common cold and infections such as CMV pneumonia. Antibiotics are not effective against viral infections

**white blood cell (WBC)** – A type of blood cell that helps the body fight infection. WBCs include granulocytes, lymphocytes, and monocytes

# ABOUT ROSWELL PARK COMPREHENSIVE CANCER CENTER

## OUR MISSION

To eliminate cancer's grip on humanity by unlocking its secrets through personalized approaches and unleashing the healing power of hope.

## OUR VALUES

Core values reflect what is most true and important to us as an organization. These are values that have shaped us and will continue to do so. They do not change given circumstances or time but rather are consistent throughout our mission areas. Roswell Park is a special place to work and the staff and faculty who live these values have made it so. These values will guide and power our personal and collective actions and enable future successes on behalf of individuals and the world.

- **Innovation:** We are driven to provide care that cures and comforts, research that informs the world, and education that enlightens and enables future generations. We proudly stand on our rich history and use it as a platform from which to embrace discovery and change.
- **Integrity:** We are committed to making each decision, whether related to patient care, research, education, or administration, based on standards that are thoughtful, informed, honest, transparent when appropriate, and always respectful of privacy.
- **Teamwork:** We value and encourage the viewpoints and constructive opinions of all people and disciplines and recognize that all contributions strengthen the results we achieve, the value we provide, the actions we take, and the team we strive to be.

- **Commitment:** We are devoted to achieving extraordinary progress on behalf of those we serve; patients and families who come to us during times of great need, scientists and clinicians who wish to collaborate, students seeking education, the science of cancer that awaits our contributions, and the community that deserves strong stewardship and economic leadership.
- **Compassion and Respect:** We are enriched by the diverse cultures, needs, and expectations of our coworkers and of the communities we serve. It is our privilege and responsibility to appreciate these differences as we establish research goals, develop care plans, and interact with one another.

In 1898, Roswell Park opened as the nation's first cancer research, treatment, and education center. We are a public benefit corporation, internationally renowned, and a major affiliate of the University at Buffalo School of Medicine and Biomedical Sciences. We are the only upstate New York facility to hold the National Cancer Institute designation of "comprehensive cancer center", which means that our research, treatment, and educational programs have weathered extensive peer review, met rigorous national standards, and made fundamental contributions to reducing the cancer burden. Roswell Park also participates in a number of national quality and patient safety initiatives. Our website is [www.roswellpark.org](http://www.roswellpark.org)



## **NATIONAL COMPREHENSIVE CANCER NETWORK**

Roswell Park is a member of the National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of the world's leading cancer centers. Experts from NCCN Member Institutions diagnose and treat all cancers, particularly complex, aggressive or uncommon cancers and provide best practice guidelines and measurement tools. More than 160,000 new patients receive cancer care at NCCN Member Institutions each year. Thirty-eight Nobel Prize winners have served on the faculties of NCCN Member Institutions.

**[www.nccn.org](http://www.nccn.org)**

## **FOUNDATION FOR THE ACCREDITATION OF CELLULAR THERAPY**

The Foundation for the Accreditation of Cellular Therapy (FACT) has accredited Roswell Park since 2002. Accreditation means our program is in compliance with the current FACT Cellular Therapy Standards. Accredited programs have met rigorous standards as defined by leading experts; is based on the latest knowledge of cellular therapy product transplantation, and in compliance with governmental regulations.

**[www.factwebsite.org](http://www.factwebsite.org)**

## **COMMISSION ON CANCER (COC)**

Established by the American College of Surgeons (ACS) in 1922, the multidisciplinary Commission on Cancer establishes standards to ensure quality, multidisciplinary, and comprehensive cancer care delivery in health care settings. It conducts surveys in health care settings to assess compliance with those standards; collects standardized data from CoC-accredited health care settings to measure cancer care quality; uses data to monitor treatment patterns and outcomes, and develops effective educational interventions to improve cancer prevention, early detection, cancer care delivery, and outcomes in health care settings.

**[www.facs.org/quality-programs/cancer](http://www.facs.org/quality-programs/cancer)**

## **JOINT COMMISSION**

The Joint Commission provides meaningful information about the comparative performance of accredited organizations to the public, publishes organization-specific Performance Reports. To earn and maintain The Joint Commission's Gold Seal of Approval™, an organization must undergo an on-site survey by a Joint Commission survey team at least every three years. (Laboratories must be surveyed every two years.)

**[www.jointcommission.org](http://www.jointcommission.org)**

## **NATIONAL CANCER INSTITUTE (NCI)**

Since 1971, Roswell Park has been recognized by the NCI as an Accreditation Quality Report (AQR). It was the nation's first, and continues to serve as a national model. AQR-designated cancer centers are characterized by scientific excellence and the capability to integrate diverse research approaches to focus on the problem of cancer. They play a vital role in advancement towards our goal of reducing morbidity and mortality from cancer. Roswell Park is the only NCI hospital in upstate New York.

**[www.cancer.gov](http://www.cancer.gov)**

## **VOLUNTARY HOSPITAL ASSOCIATION, INC.**

Roswell is involved in the Transformation of the ICU (TICU) and Transformation of the Operating Room (TOR) clinical performance improvement projects. Intensive care units (ICUs) have the highest incidence of hospital acquired infections (HAIs). Participants in VHA's Transformation of the Intensive Care Unit (TICU) program have dramatically decreased their incidence of HAIs and changed the way they deliver care. The program provides participants with the tools and methodologies, training and guidance, and measurement necessary to transform their ICU care.

**[www.vha.com](http://www.vha.com)**

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## NOTES

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# NOTES



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A National Cancer Institute-Designated Comprehensive Cancer Center  
A National Comprehensive Cancer Network Member  
A Blue Distinction Center for Transplants®