MASSEY
CANCER CENTER
VCU

CELLULAR IMMUNOTHERAPIES AND TRANSPLANT PROGRAM

Patient and Caregiver Manual

Allogeneic Transplant Guide to Care

Welcome to the Cellular Immunotherapies and Transplant (CIT) Program at the Massey Cancer Center VCU Health. This patient education manual has been prepared to help guide you through all stages of your transplant. We recognize this may be a stressful time for you and your family. Our transplant team will be with you every step of the way.

June 2021

VCU Health Cellular Immunotherapies and Transplant Program

Bone Marrow Transplant Clinic Hours of Operation

Monday through Friday 7:30AM – 5:00PM
Saturday and Sunday 8:30AM – 4:00PM
Main Telephone Number # 804-828-4360
Appointment Scheduling Telephone # 804-628-4463

North 10 Floor –Inpatient Telephone # 804-628-2371

After Hours Answering Service Telephone # 804-628-4145

Pre-Transplant Nurse Coordinators

Dana Broadway, RN	Telephone # 804-828-3554	Fax # 804-828-0128
Angela Buskey, RN	Telephone # 804-828-3478	Fax # 804-828-0128
Judy Davis, RN	Telephone # 804-628-2079	Fax # 804-828-0128
Linda Mayhew, RN	Telephone # 804-628-8273	Fax # 804-828-0128

Post-Transplant Coordinators

Yvonne Allen, RN	Telephone # 804-628-0264	Fax # 804-628-3863
Michelle Sherwood, RN	Telephone # 804-628-9956	Fax # 804-628-3863
Kristina Folks, RN	Telephone # 804-628-5287	Fax # 804-628-3863

Financial Transplant Coordinator

Denna Chaber, RN	Telephone # 804-828-4372	Fax # 804-628-2268

Medication Prior Authorizations

Chavia Martin	Telephone # 804-628-9791	Fax # 804-628-5955

Scheduling

Patient Service Rep	Telephone # 804-628-4463	Fax # 804-828-7825
Sharon Stampley	Telephone # 804-628-1168	Fax # 804-628-1566

New Patient Coordinator

Jennifer Warden	Telephone # 804-628-2749	Fax # 804-828-7825

Patient Records	Telephone # 804-628-1174	Fax # 804-828-7825

Social Workers

Jennifer Blosser, LCSW	Telephone # 804-828-5451	Fax # 804-828-7825
Karen Mullin, MSW	Telephone # 804-628-3861	Fax # 804-828-7825

Care Coordination

Amy Spradlin, RN	Telephone 804-628-6228	Fax 804-628-4752

Dietician

Brett Bowie	Telephone # 804-201-5755

Discharge Nurse

Lynn Hoffman, RN	Telephone # 804-628-4694	Fax # 804-628-4752

VCU Patient Portal	**vcuhealth.org/myvcuhealth**

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PRE-TRANSPLANT PLANNING & PREPARATION

CELLULAR IMMUNOTHERAPIES & TRANSPLANT (CIT) PROGRAM OVERVIEW

- Established in 1988
- First transplant in 1988
- Inpatient beds 21
- Allogeneic, Autologous, CAR T therapies for Adult and Pediatric Patients
- Program includes services to harvest and store bone marrow and stem cells
- Outpatient clinic that provides care before and after transplant
- Accredited by the National Marrow Donor Program
- Accredited by the Foundation for Accreditation of Cellular Therapy (FACT)
- Interdisciplinary team which includes transplant physicians, advanced practice providers, transplant coordinators, clinical research assistants, nurse managers, registered nurses, patient care partners, dietitians, social workers, financial coordinators, pharmacists, administrative support staff, and physical and occupational therapist.

WHEN STEM CELL TRANSPLANTS ARE NEEDED

- A disease that affects the bone marrow, such as leukemia and myelodysplastic syndrome.
- There is a failure of the bone marrow to produce sufficient number of blood-forming cells or to produce adequately functioning cells for the immune system.

TYPES OF TRANSPLANTS

- **Autologous Transplant:** When a person receives their own stem cells
- **Allogeneic Transplant:** When a person receives stem cells from another person, either a relative or someone unrelated
- **Syngeneic Transplant:** When a person receives stem cells from an identical twin
- **Cord Blood Stem Cell Transplant**: When a person receives stem cells from umbilical cord blood

COLLECTION SOURCES FOR TRANSPLANT

Bone marrow is the tissue inside our bones. It has a spongy texture and is rich in stem cells. Stem cells grow and divide into white blood cells, red blood cells and platelets. Each of these cells have a very important role in our bodies. They are collected from the following sources:

- **Bone Marrow:** Marrow is collected from the iliac crest (hipbone). This is a bone marrow transplant
- **Blood Stream:** Growth factors stimulate stem cell production. Apheresis is the process of collecting stem cells from the circulating blood. Peripheral blood stem cell transplant is the infusion of these cells.
- **Umbilical Cord:** The umbilical cord of newborn babies contain a rich source of stem cells. This is an umbilical cord blood transplant.

FIRST CONSULT

- Meet the CIT Team *You will be assigned a Pre-Transplant Coordinator
- History and Physical
- Discussion of recommendations, transplant process, current research and clinical trials. * Referring physician will receive a consultation note with recommendations and potential plan.

INSURANCE COVERAGE FOR TRANSPLANT

- Provide your insurance information and referral, if required on your first visit.
- Financial coordinator will review your insurance information to determine coverage for your transplant. This includes deductible, inpatient stay, copays and out of pocket maximum.
- Financial coordinator will contact insurance company to obtain approval for the transplant. This may take up to several weeks.
- Some insurers will assign a case manager, who will work with our financial coordinator during all phases of the transplant process.
- If there are problems meeting financial obligations, the CIT Social Worker can provide resources and assistance.

DONOR SEARCH AND HLA TYPING

- Each human has a set of proteins on the surface of cells called Human Leukocyte Antigens (HLA). These markers are used when trying to find a donor that is matched to your DNA.
- You inherit half of your DNA from each parent. A sister or a brother has a 25% chance of matching. Parents and children can be used in cases where there is not a fully matched donor. Extended family, such as grandparents and cousins, are not likely to match. Your Pre-Transplant Coordinator will discuss how a swab kit, which is mailed to the potential donor, is used.
- Unrelated donors may be an HLA compatible match. The National Marrow Donor Program provides potential unrelated donor options, such as adult peripheral stem cells or cord blood.
- Prior to donation of cells, donors go through an evaluation. This is required to ensure the donor is healthy enough to donate cells. Tests for infectious diseases, chest x-ray, EKG and blood work are included, in addition to a physical exam. Female donors will have a pregnancy test, if they are of childbearing potential.

PRE-TRANSPLANT EVALUATION

When you and the team have decided to proceed with transplant, a clinical evaluation is ordered. This evaluation includes tests, that serve as a baseline and to determine of you are able to tolerate the transplant. Your Pre-Transplant coordinator will provide you a schedule. The goal is to have all the testing in one to two days.

SMOKING, ALCOHOL AND DRUGS

Because of the increased risk of severe complications in transplant patients who actively smoke, drink or use recreational drugs, we ask that you stop using these substances.

- Active smoking and exposure to second hand smoke may cause lung infections, pneumonia or fungal infections. It has also been associated with permanent and often fatal lung damage during transplant.
- People, who live with you, cannot smoke in the house.
- Alcohol and drugs increase the risk of damage to the heart, lungs, brain and kidneys.
- The risks associated with smoking, alcohol and recreational drugs will remain higher through your lifetime. This is secondary to the high dose chemotherapy and/or radiation therapy used in peripheral blood stem cell transplant. The CIT Team will work with you to help abstain from smoking, alcohol and recreational drugs.

SECOND CONSULT

- Transplant process detailed for you and your caregiver.
- Consents are signed.
- You must have a caregiver that will be responsible for transportation, food preparation and activities of daily living. They must be available to you 24 hours a day, 7 days a week after transplant. You can have more than one caregiver and they can share this role. If you do not have a caregiver or plan, transplant cannot proceed. Some patients have hired outside agencies to help with caregiver responsibilities. Your assigned social worker can help with finding an agency.
- You are given the link to caregiver and patient education.

CIT SOCIAL WORK & RESOURCES

CIT has social workers dedicated exclusively to the program. They provide the following services:

- Psychosocial assessment for CIT, high risk screening, ongoing psychosocial evaluation
- Continuous screening for adjustment to impact of treatment
- Counseling for adjustment to illness, depression, anxiety, survivorship, grief and loss and end of life
- Pain and symptom management, i.e.: guided imagery and relaxation techniques
- Discharge and transitional care planning
- Psychoeducation and linkage with resources, i.e., support groups and financial assistance
- Advocacy and system navigation
- Evidence-based program development and evaluation
- Help patients and families identify a 24/7 caregiver plan
- Relocate and establish temporary housing near the transplant center

Financial Resources

Grants are available primarily based on income and sometimes on assets and diagnosis. You can apply for these through the transplant social worker.

Leukemia and Lymphoma Society – helps with mileage reimbursement. One-time grants and urgent needs fund for those under age 40 or in a clinical trial. Co-pay Assistance Program covers drug, insurance premiums and MD visit co-pays. Application available (LLS-CO PA) online, but social worker needs to assist. 1-877-557-2672

National Marrow Donor Program – Be the Match – www.marrow.org. Post-transplant grant covers those whose UNRELATED donors have been obtained through the NMDP. Grant Transplant Assistance available for patients with chronic GVHD, for crises, and for patients needing help to travel to clinical trials.

Peer Connect program (Be the Match) - connects patients and caregivers within peer support.
1-888-999-6743

The Lymphoma Research Foundation – 1-800-500-9976

The Bone Marrow and Cancer Foundation - Helps pay non-medical bills up to $500 and $1,000, depending on monies available. www.bonemarrow.org

Cancer Care – 1-800-813 HOPE. Helps pay bills associated with treatment such as transportation, childcare, chemotherapy, etc. www.cancercare.org

Health Well Foundation – Helps with treatment related bills. Covers only certain diagnosis and medicines. Apply on their site online. www.healthwellfoundation.org. 1-800-675-8416

Patient Advocate Foundation – 1-800-532-5274, a case management organization in the Tidewater area (Hampton) that can help connect you with resources.

Patient Services, Inc., 1-800-366-7741. Co-pay assistance for some diagnoses.

Patient Access Network Foundation – Co-pay assistance. https://panfoundation.org

Good Days Foundation- Co-pay assistance. https://mygooddays.org.

BMT Infonet – Information, support, and a small grant is available for financial needs (covers autologous, related donor allogeneic, and CAR-T cell patients). www.bmtinfonet.org. 1-888-597-7674

Most of the grant programs offer help once a year or one time only. . There may be other resources available. Most of the above can be located online.

Frequently Asked Questions on Financial Aid

Q: What is the difference between Medicare and Medicaid?
A: Medicare is insurance provided at retirement age when one has had a job paying Medicare tax, or when one has received Social Security Disability payments for 24 months. It includes parts A, B, and D. A is hospitalization, B is outpatient benefits and D is the drug program. There is extra help available for low-income beneficiaries for drug co-pays through Social Security. Call them and ask about the Extra Help or Low-Income Beneficiary program. There are now Medicare Advantage plans run by private managed care organizations (MCOs) available. VCU is in network with many of these plans. You should check with your insurer to see if VCU is in network for cellular transplant services (formerly called bone marrow transplant).

Medicaid is for people with very low income (and for some assets are considered in the determination) and is obtained through the local Department of Social Services or through Cover VA (www.coverva.org). As of January 2019, Medicaid was expanded in Virginia to cover adults who are non-disabled and have low income.

Q: Can I have both Medicaid and Medicare?
A: Yes, if you meet the requirements for both.

Q: What is the donut hole?
A: That is the period during which a Medicare covered person needs to pay 25% of the costs of their medicine before Medicare kicks back in to cover them. There are some options with co-pay assistance programs and prescription assistance programs through drug companies. For each year, the total out of pocket drug cost to start the coverage gap and end it change. For 2020, the gap starts at $4020 and ends at $6350. Expenditures that do not count towards your ending the coverage gap are as follows: monthly insurance premiums, non-covered drugs, drugs obtained at out of network pharmacies, and the 75% generic discount.

Q: What is “dual eligible”?
A: This person has both Medicare D and Medicaid. These people do not have a coverage gap in their Medicare Part D and Medicaid should pay the premiums for their Medicare. Contact 1-800-633-4227 and your local Department of Social Services to help you. There are different levels of Medicaid coverage for low-income Medicare beneficiaries and not all receive the same type of coverage.

Q: the Social Security Disability and Social Security Income application processes confuse me. What are the steps?

A: Generally, you must have stopped working. You can call 1-800-772-1213 to schedule a phone interview to start your application, you can apply online for Disability at www.ssa.gov or you can visit your local office. They will give you many papers to fill out (or online pages) asking you questions about your illness and treatment, your job duties, your work history, your everyday function and what keeps you from working. It helps if you have your doctor and hospital information with you (names, addresses, phone, and medical record number). Important things to mote are if pain or other physical problems hinder your ability to work. For CIT patients, immune suppression is one of the major reasons why work is not possible. You will sign consent forms so they can ask your doctor for information. The application goes from your local office to the area Disability Determination Office where they make the medical decision. Then it goes back to your local office where they determine if you have enough work history to qualify. They notify you in the mail of the decision. You can appeal a denial decision. If an appeal is denied, you can then ask for a reconsideration that is done by one of their administrative law judges (this can take a long time). Getting medical information to them at any part of this process is very important.

Q: Why didn't I get money right away, but some people do?
A: Congress decided when they made this program that there would be a mandatory 6 month waiting period (you are "eligible" in 5 months) from the date, you are seen as disabled until you get your first check. There are a couple of diagnoses for which the waiting period does not apply. Some people, depending on income, can get SSI checks in that 6-month period. Some people get a date of disability that is retroactive (in the past) enough months that they get their checks sooner. Remember, the checks come 6 months after the date they say you were disabled, not from when you hear about their decision.

Q: Are there resources for caregivers in the community? Is there anything that pays for caregivers?
A: In most cases, the answer is no. Transplant requires patients have a caregiver due to the medical risks to the patient. Patients are restricted from doing many of the daily activities associated with infection risk (not basic self-care). Most private insurance has no benefit for this. Caregivers, such as an aide or sitter, can be hired privately, but this is an out of pocket to you. Local home health agencies can quote you their rates. The exception of the above is for Medicaid recipients who meet the medical and physical dependency criteria for a waiver program, so a reliable care-giving situation is necessary. The Medicaid program that covers aide care (personal care) requires dependency in basic self-care, basic activities of daily living, a medical need beyond medicine administration, and that a person have a primary caregiver. This is the level of function consistent with a person requiring custodial nursing facility care. Transplant restricts only instrumental activities of daily living (IADLs) with risks of infection like cooking and cleaning. Requiring help with these alone is NOT enough to qualify for the personal care services under Medicaid.

LINC – Legal Information Network for Cancer – 804-272-5462 or www.CancerLinc.org
They assist with information about many aspects of cancer relate legal issues. The LINC can refer you to free or reduced cost legal services.

Medical Legal Partnership – They are a cooperative effort between VCU, LINC, Legal Justice and Legal Aid. There is a rep onsite. See your CIT social worker for a referral.

Patient Advocate Foundation – 1-800-532-5274, a case management organization in the Tidewater area (Hampton) that can help connect you with resources.

Community Resources

Department of Social Services – Administered by each county or city. You must go to the one in your area of residence. If you have temporarily relocated to Richmond due to a transplant, the local office may be able to serve you. You can apply for a specific program or meet with Eligibility and Service workers to determine your need. They have income support programs such as SNAP for families with children, heating and cooling assistance, general relief (temporary income for non-disabled adults – not all localities have this), State and Local Hospitalization Funds (for acute care hospital stays for those with no insurance), and Medicaid. They also provide access to day care – occasionally subsidized – and health care sponsored through the Medicaid Waiver programs.

Social Security – 1-800-772-1213. www.ssa.gov. Apply here for disability benefits you may have based on your work history and current medical condition. You may also be eligible for Supplemental Security Income. Application for Disability will also potentially lead to getting Medicare. Your local Area Agency on Aging Ombudsman can help you with understanding some of these programs as they work with the elderly (who often need these services). Check your phone directory for this office.

www.needymeds.org is a site that directs you to your drug company's indigent programs to help pay for medicines. You must meet income and asset requirements and particular insurance requirements of each program.

The Partnership for Prescription Assistance - 1–888-4PP-ANOW, offers information to link you to manufacturer's assistance programs. www.pparx.org

American Cancer Society - Information and referral line that may help you with other community programs. 1-800-ACS-2345

National Foundation for Transplants – www.transplant.org Helps organize fundraising.

Help Hope Live – https://helphopelive.org helps organize fund raising

nbmt link – www.nbmtlink.org Support for patients and caregivers.

Check with your insurance company to explore what benefits or programs they may have. If you have a case manager, this is a good person to call. Some companies pay for or reimburse travel, lodging and meal expenses related to transplant.

Employment Resources

FMLA – Family Medical Leave Act. – www.dol.gov Check with your HR department or the Department of Labor website.

COBRA – Consolidated Omnibus Budget Reconciliation Act – This act created the privacy rules that contained the regulations allowing you to take you employer's health insurance with you after separating from a job. This involves your payment of the whole premium (without employer subsidy) to a third-party administrating agency. There are specific steps to take to get the benefit extended after the standard 18-month allowance. Speak with your HR office or go to the Department of Labor website at www.dol.gov.

National Coalition for Cancer Survivorship – www.canceradvocacy.org Information and advocacy on job discrimination.

Cancer and Careers – www.cancerandcareers.org Information and assistance for woman cancer survivors and work issues.

NOTES:

HOUSING FOR TRANSPLANT PATIENTS AFTER DISCHARGE FROM CIT UNIT

- If you live more than 30 minutes from VCU Health, you will be required to stay locally.
- The duration of your stay will vary depending on your type of transplant.
- Contact your insurance company regarding benefits for food, lodging allowance and reimbursement.
- **The Doorways**: 612 E. Marshall St is about seven blocks from the hospital. Shuttle services are available to from the hospital. The Doorways is a charitable organization and they ask for a donation, but this is not mandatory. Your social worker or transplant coordinator can provide more information.
- **Extended Stay Hotels**: Prices vary and some offer discounts for VCU patients.
- **Apartments**: Some in the area allow for short-term lease. An apartment locator guide, real estate agent or internet search can assist you.
- **Transplant Apartments**: There are two apartments reserved for patients having allogeneic transplants. Talk with your social worker if interested.

ONLINE CIT CAREGIVER AND PATIENT EDUCATION

- masseycancercenter.org
- Hover over Cancer Types & Treatments
- Select Cancer Treatments
- Select Cellular Immunotherapies and Transplantation Program
- Select Resource Tab *scroll down and you will see videos
  Each new speaker will start when previous speaker has finished

MOBILIZATION FOR RELATED DONORS

- Stem cells are from two sources, bone marrow and peripheral blood.
- Growth factor stimulates stem cells to move out of the bone marrow into the blood stream. Stem cells are then collected using apheresis.
- A temporary catheter may be placed in the donor's chest if unable to use the arm veins.
- The Pre transplant coordinator will schedule the apheresis.
- The operating room is where bone marrow is collected. The donor will require anesthesia and possible overnight stay.

PREPARING FOR ADMISSION

- Your pre-transplant coordinator will schedule you to have a central line catheter placed in your chest.
- Determine where you will stay, if you are not in the 30-minute radius of the hospital.
- Finalize your caregiver list and provide them link to the caregiver and patient education on line site.
- Review the CIT Visitor Rules and provide them to family and friends.
- Address for mail and packages on CIT
  Name
  C/o VCU Health
  Bone Marrow Transplant Program
  1300 E. Marshall St
  North Hospital, 10th Floor
  P.O. Box 980157
  Richmond, VA 23298-0157
- You are allowed to receive cards, balloons, stuffed animals, silk flowers, books, magazines, puzzles, CD's, DVD's etc. No fresh or dried flowers or fresh fruit.

WHAT TO BRING TO CIT North 10

- Pack light, as there is limited storage space on North 10. Bring enough for several days. There is no washer or dryer on North 10, so your caregiver will need to bring you fresh clothes and pick up the dirty clothes to launder.
- Pajamas and comfortable clothes such as sweat pants and shorts. Tops with an opening in the front for easy access to your central lines. You will receive continuous IV fluids. To prevent infection, we will not disconnect your IV lines for clothing changes, baths etc.
- Eyeglasses. Leave contact lenses at home, due to risk of infection.
- Socks and underwear
- Hat, scarf or wig
- Slippers or comfortable shoes for walking in the halls. We will provide you with nonslip socks, if you do not have slippers or slip resistant shoes.
- New unused foam pillow, if you desire. No feather or down pillows.
- Magazine, books, puzzles, etc.
- Journal or diary, stationary and pens
- Hobby work (no needles, sharp objects, glues or solvents with harsh odors)
- Pictures of family and friends
- Posters or drawings. No tape is allowed on the walls in your room.
- Phone card, cell phone
- Laptop computer(wireless access available)
- Unopened personal hygiene products: tissues, antibacterial soap, toothpaste, lip balm, electric razor
- No appliances in the room. This includes refrigerators, microwaves and Keurigs.

Please be aware the room you are admitted to is not your permanent room. You may have to move rooms or units depending on your clinical needs. Your family may need to take your belongings, until you are returned to North 10.

MEDICATIONS, PHARMACY AND EQUIPMENT

- A clinical pharmacist is part of the CIT Team on North 10 and in the Ancillary Clinic.
- A pharmacy reimbursement specialist assists with prescription coverage issues such as prior authorizations and insurance coverage.
- Social Workers can assist with financial issues regarding medication.
- Bring all medications with you to the hospital day of admission, including any devices you are currently using, such as a glucometer, walker or cane.
- Bring your prescription and insurance cards.
- Bring the settings for your C-Pap machine. The CIT Team will order a C-Pap for you to use in the hospital, as our respiratory therapy team will clean and maintain that equipment, while you are here.
- Your pharmacy will receive discharge prescriptions, closer to discharge. The Nurse Patient Family Educator on North 10 will help you find a pharmacy if you will be staying in the Richmond area and are not local.

CIT GUIDELINES FOR VISITOR AND PATIENT SAFETY

- Visitors with a cold, sore throat or the flu should not come onto the unit. All visitors who had exposure to chickenpox or any live or attenuated virus vaccinations within the last three weeks cannot visit. All visitors will wear a mask on the unit, including in the patient room.
- **No fresh flowers or live plants.** This includes dried or artificial flower arrangements that use real moss in the base.
- **No outside food allowed.** * Any food brought from home must be approved by the CIT Team.
- Only staff allowed in the food galley. Please ask for assistance.
- Staff will remove food trays from your room. Do not throw away leftover food or food trays in your trashcan. Please do not set on floor outside of your room.
- **Visitors must wash hands or use foam cleanser before entering and leaving the room.** They must rewash if they touch their face, mouth or anything that is on the floor.

- **Visitors cannot use the bathroom facilities in the patient room, the phone, or bed.** Visitor restrooms are located in the hall by the elevator.
- **We do not recommend caregivers bring food for themselves into the patient room.** If you would like to eat in the room with the patient, please ask a member of our team. You will be asked to follow the following guidelines. Eat 6 feet away from the patient and replace mask as soon as you are done. Do not throw food items in the trash that are freshly prepared (example: chicken). Empty drink containers, snack bags, etc. are appropriate to discard in the room. Do not bring foods with strong odors or items the patient cannot eat without discussing with the patient and/or the nurse first. You may have a drink that is covered.
- **Smoking** is not allowed on VCU Health Hospital property.
- **Visitation guidelines change frequently due to current infectious disease guidelines.** Please reference the most up to date visitor guidelines provided by our team. This includes visitation guidelines for children.
- A mask is required at all times by our visitors, including in the patient room.
- Visitors should avoid kissing the patient. Hugs and holding hands permitted.
- Parking validation not provided for valet parking for visitors. Free parking provided, when the patient is an outpatient in the Ancillary Clinic.
- Visitors should check in at our main nursing stations desk prior to proceeding to the patient's room.
- In order to obtain information about a patient, the visitor/caller must have a dedicated code number. The patient receives this code on admission. The patient gives the number to their support team.
- **Recently immunized visitors must be cleared to visit by transplant staff.**
    - Oral Polio-wait one month before visiting
    - Chicken Pox/Varicella Live Vaccine-wait six weeks before visiting
    - MMR-wait two weeks before visiting
    - H1N1 and Influenza Inhalation form-wait two weeks before visiting

ADMISSION DAY

- A member of the team will review your medical history, including medications and allergies. They will obtain a current height and weight.
- Vital signs (Temperature, Pulse, Respirations and Blood Pressure) obtained in addition to blood work, physical exam, EKG, urine sample and cultures. Blood for labs, is obtained from the central lines. A two RN skin check will be obtained to check skin integrity; this allows us to provide appropriate skin care and prevent skin injury during your hospital stay.
- After the team reviews your medications, have your caregiver take them home. You cannot keep them in your room. The medications are stored in our pharmacy, if they cannot take them.
- You will receive the **Cellular Immunotherapies & Transplant Unit Guidelines.** This contains information about a typical day on the unit. When vital signs, labs, weights obtained, how to order food, and patient expectations.
- You will receive a patient code number. This is your dedicated code and you can give to the support people you would like personal health information shared with during your stay. If they would like to call the unit to inquire about your care, they will need to give this code in order to receive any information. We ask that you designate only one point of contact to speak to the nursing staff and then they can share information with other members of your support team.
- You will receive our Fall Safety Guidelines.
- You will receive information about your protocol that prepares your marrow to receive the stem cells. This may involve chemotherapy, total body irradiation or a combination of both.
- You will meet the inpatient team on CIT North 10, which includes Care Coordination Nurse, Nurse Patient Family Educator and Discharge Coordinator, Dietician, Physical Therapy in addition to the CIT Medical and Nursing Team.

TYPICAL DAY ON CIT North 10

- Change of shift occurs at 7AM and 7PM daily. Your nurse will handoff to the oncoming nurse at your bedside. During this time, your nurse will discuss elements of your hospital stay, as well as complete several safety checks at the bedside.
- Vital Signs are every 4 hours and more often if needed.
- Weights are least once daily in the morning.
- Daily CHG Bath. You will be required to shower or bathe daily with chlorhexidine (CHG) wipes. Linens are changed daily. Research has shown that this significantly decreases your risk of infection.
- Call your nurse when you are ready to shower, so we can change your bed and bring you supplies. DO NOT get back in a dirty bed after you have showered.
- Oral hygiene is required at least twice a day. We will provide CHG rinses in the morning and evenings, in addition to saline to rinse your mouth as needed. When your platelet count drops below 50,000, we will provide you with foam sponges to continue with your daily mouth care. NO flossing during this time.
- Electric razors only. You can use a regular safety razor, once your platelets recover.
- Your meals will be prepared in an onsite kitchen. We will provide you with a menu. You and your family can call the number to the kitchen and place your order. Throughout your stay, your dietary needs and requirements may change. Your menu is updated, as needed.
- Rounds are daily by the CIT Team in the morning. They will keep you updated on your treatment plan.
- Central line dressings are changed every 7 days, unless they become dirty, wet or loose. Port-a-Cath needles changed every 7 days. IV lines changed every 4 days. You will use an Aqua guard, when showering to protect the dressing.
- Intake and Output (I&O). We will be recording all intake (what you eat and drink) as well as all output (urine, stool, vomit) starting the day you arrive. We provide urinals, etc. The nursing staff will empty these and record the information for accuracy.

- Daily labs. Frequency and times may vary. Your nurse cannot print you a copy of your labs results, but you can access the results on your VCU My Patient Portal.
- Medications are given throughout your stay in various forms. Some are by mouth and others through your central line. Your IV pump will deliver the IV medications. For your safety, never touch or manipulate the buttons on your IV pump. If your machine is beeping, let your nurse fix the issue.
- Please ask about your medications. Our team will provide information about side effects and purpose. Listed below are some of the categories of medications, which you may receive.
    - Antibiotics-Used to prevent or treat bacterial infections
    - Antivirals-Used to prevent or treat viral infections
    - Antifungals-Used to prevent or treat fungal and yeast infections
    - Antiemetics-Used to prevent or treat nausea and vomiting
    - Immunosuppression-Used to prevent rejection or graft versus host disease
    - Chemotherapy-Used to kill cancer cells
    - Electrolytes-Salts and minerals found in the blood which are necessary for proper cell and organ function
- Blood and Platelet Transfusions are as needed. This is a normal expectation, as your bone marrow recovers.
- Heart (Cardiac) Monitoring may be required during your hospital stay to monitor your heart function.
- Exercise daily. We encourage you to walk the halls and sit up in the chair for meals. This is a self- directed activity, but it is important in your recovery. A physical therapist will meet with to assess your needs and establish achievable exercise goals.

White boards in your room reflect your CIT Team for that day, diet, activity, recent lab values, progress toward discharge and estimated date of discharge. Your team updates white boards daily.

CONDITIONING: GETTING YOUR BODY READY FOR TRANSPLANT

- Chemotherapy drugs are given to get your body ready for transplant. This is called a conditioning regimen.
- These drugs are used to eradicate malignant (cancer) cells and suppress the immune system to prevent graft rejection.
- Chemotherapy is a single drug or a combination of two or more drugs.
- Side effects of this chemotherapy include but are not limited to:
    - Nausea and vomiting
    - Loss of appetite
    - Taste changes
    - Diarrhea
    - Blood in urine
    - Fluid retention
    - Mouth sores
    - Hair loss
    - Muscle spasms
    - Confusion (less common)

  Long-term side effect may include:

    - Possible sterility, making you unable to have children
    - Possible damage to the liver, heart, kidneys or lungs
    - Numbness and tingling in hands and feet

- Total Body Irradiation is administered in some conditioning protocols. It is given in one or more sessions. The major side effect is nausea. You are given nausea medications prior to treatment, if this is part of your protocol.

- ATG (Antithymocyte globulin) is a polyclonal antibody that is directed against circulating T cells. It is a part of the conditioning regimen to prevent graft versus host disease (GVHD) in some protocols.

All protocols are unique to each patient and disease. Your CIT Team will decide which protocol is best for you.

TRANSPLANT DAY

- Infusion of stem cells takes place after your conditioning regimen is complete. You may have 1-2 rest days. Your CIT Team will tell you the date
- The infusion takes place in your room.
- Pre-infusion medications of Benadryl, Tylenol and occasionally steroids.
- The cells are infused into your central IV line. Vital signs are taken frequently. Several members of our CIT Team are with you monitoring the infusion.
- If a preservative was added to your cells, you may taste an oyster-like flavor. Sour or bitter hard candies during the infusion to help reduce this taste.
- The preservative may give off a distinct odor, as it is eliminated from your body.
- Urine color may change from clear yellow to a pink or red color. The red blood cells in the stem cells cause this color change. You will receive a large amount of fluids to flush any preservative or red cells from your kidney after transplant.
- Signs of reactions include flushing of the skin, tightness or a heavy feeling in the chest, nausea, vomiting, diarrhea and difficulty breathing. Reactions require immediate intervention.

WHAT TO EXPECT AFTER TRANSPLANT

- Mucositis
  - Swelling or inflammation of the lining of your mouth
  - Change in color of the inside of your mouth
  - A coating on the inside of your mouth or tongue
  - Sores on the inside of your mouth
  - Pain with swallowing, talking or opening of mouth
  - Thick saliva
  - Nausea and vomiting
  - Diarrhea
  - Gastric reflux
  - Loss of appetite and altered taste

These changes will start to improve with engraftment (recovery of bone marrow function).

The following interventions will help you take care of your mouth

- ○ Rinsing with saline solution at least 4 times a day, after meals and at bedtime. Your nurse will provide this solution.
- ○ Use your CHG mouthwash twice a day. If you experience a burning sensation, let the CIT Team know.
- ○ If you are unable to swallow and your saliva is thick, your nurse will instruct you how to use a suction device.
- ○ No flossing of your teeth. Soft sponges, to brush your teeth, twice a day, are provided.
- ○ Remove dentures, to prevent sores and to allow the rinses to bathe the gums.
- ○ Lip Balm

You will receive medications to help with the nausea, vomiting and diarrhea. Diet is adjusted, as needed. You may receive nutritional supplementation through your IV fluids.

- Skin Changes can occur due to medications or possibly GVHD. Report the follow symptoms to your team
    - Redness
    - Itching
    - Burning or tingling of hands and feet
    - Bumps or sores
    - Rashes or hives
    - Excessive dryness

The following interventions will help you take care of your skin

- Electric razors, only
- Mild soaps and shampoos, use your CHG wipes daily, as directed (never on your face)
- Non-scented moisturizer
- Do not use any skin products with antiaging products
- No cosmetics or cologne

- Hair Loss (Alopecia)
    - Your hair will start to thin during chemotherapy and will gradually fall out following treatment. This may include your eyelashes and brows.
    - We recommend shaving your head to maintain a clean and healthy environment. You may choose to shave your head before admission to the hospital. If you choose to shave your head after your hair starts to fall out, you can have a caregiver bring in an electric razor to shave your head. VCUHS does not allow employees to assist patients in shaving their heads.
    - Use a mild shampoo, if needed.
    - You may choose to wear a wig, hat or scarf.

- Fatigue
    - You may feel tired and exhausted.
    - It is important you maintain your exercise routine.
    - Short naps during the day may help with your fatigue.

- Neutropenia (Low White Blood Cell Count)
    - Your immune system is your first line of defense against infection. When your white blood cell count is low, you are more susceptible to infections.
    - Symptoms of infection include:
        - Fever or chills
        - Redness, pain or swelling at the IV site, skin, or central line
        - Cough, nasal drainage, shortness of breath
    - If you develop a fever of 100.4 or greater, your team will draw blood from all IV access ports to test for bacteria, viruses and fungi. You will get a chest x-ray and will need to give a urine sample. IV antibiotics will be started as a precaution until culture results come back.

- Thrombocytopenia (Low Platelet Count)
    - Platelets help your blood to clot.
    - Platelet counts are included, with your daily labs.
    - You will receive platelet transfusions to keep your counts above a certain level.

- During the time your platelet counts are low
    - Do not use sharp objects (razors, fingernail clippers or scissors)
    - Do not blow your nose
    - Wear slippers when out of bed
    - Use mouth swabs to brush your teeth
    - Report any nosebleeds, menstrual bleeding, blurred vision, headaches, blurred vision and blood in vomit, urine or stool.

- Anemia (Low Red Blood Cell Count)
    - Anemia occurs when you have a low red blood cell count.
    - Your red blood cells carry oxygen to your organs and tissues.
    - If your red blood cells get low, you will need a blood transfusion.
    - Symptoms of anemia are shortness of breath, low energy, weakness and pale skin.

- Fluid and Electrolyte Imbalance
    - Your electrolytes will be checked daily with labs
    - If they are low, IV electrolytes will be given to replenish them
    - Swelling and fluid retention sometime occurs in the feet, ankles and legs. Medications help you get rid of the extra fluid.
    - Daily weights and monitoring intake and output help us monitor the balance of fluid in your body.

- Emotions
    - It is normal to feel like your emotions are on a “roller coaster”. If it begins to interfere with your activities of daily living, let your team know.

Engraftment

- Engraftment starts when the stem cells from your transplant start to grow and produce new blood cells.
- After transplant, the stem cells travel to the bone marrow.
- It takes about 10-20 days to make enough new cells that are measurable.
- During the engraftment process, you will be at increased risk for bleeding, infections and fatigue.
- Some patients enjoy tracking their counts. Your labs will be available in the patient portal.

PREPARING FOR DISCHARGE

- You will be ready for discharge when you meet the following criteria:
    - Absolute Neutrophil Count is greater than 1500
    - No fever for 24 hours
    - Taking in 1000 calories per day
    - Drinking 1 quart of fluid per day
    - Medications switched from IV to pill form
    - Up out of bed 75% of the time
- When you meet the above criteria, you and your doctor will decide it is time to leave the inpatient unit. You will be followed in our clinic.
- Our patient family educator on North 10 will schedule a time to discuss guidelines for care at home. This is usually 3 days prior to discharge.
- Our Care Coordination RN will set up any durable medical equipment if needed. He or she will coordinate any IV home infusion, home nursing, and home physical therapy if needed.
- Discharge prescriptions are sent to your preferred pharmacy. All medications must be picked up and brought to the unit day of discharge. Our pharmacist will meet with you and review all medications. A current medication list will be provided.
- Social Workers will meet with you and help with any concerns.

GUIDELINES FOR CARE AFTER DISCHARGE

- Activity
    - No public health clubs of gyms.
    - Walking is the best form of exercise. Start out slow and gradually increase speed and distance.
    - Check with your doctor before swimming or using a hot tub.
    - Alternate periods of activity with rest.
    - Avoid areas that the soil is being disturbed, lawn mowing or new construction. These areas increase your exposure to molds and fungus.
    - Avoid vigorous activity and heavy lifting until instructed otherwise by your medical team.
    - No driving until approved by your medical team.
    - Do not return to work until approved by your team.

- Reducing the Risk of Infection
    - Handwashing by you and your caregiver. Frequent and often, especially before meals, after going to the bathroom, when preparing meals, after visitors, handling money and when returning home from errands.
    - Wear a mask when you are outside or in public to avoid respiratory infections. Change them daily and if they become soiled or moist due to activity.
    - Your home should be cleaned before you are discharged home
        - Vacuumed, dusted, mopped, bed linens and towels washed and bathrooms disinfected
        - Once a week, have your home cleaned. You cannot do the cleaning. You cannot be in the room, when cleaning is happening.
        - Bathrooms and eating areas require more frequent cleaning.
        - Disinfectant cleaners with bleach make clean up easier.
        - Bed Linens laundered twice a week.
        - No humidifiers. Air purifiers are permitted

    - Gas burning fireplaces are fine, but no wood burning fires or wood stoves.
    - Have someone change the air filters in your furnace regularly.
- Personal Hygiene
    - You may use a soft toothbrush and lightly floss, once your platelets are greater than 50,000. Brush your teeth at least twice a day.
    - Use an alcohol-free mouthwash.
    - Daily shower with a mild soap.
    - Fresh towel and washcloth daily
    - Continue to use an electric razor until your platelet count is greater than 50,000.
    - Contact lens wearing can resume, only when you CIT Team approves.
    - Makeup must be new without antiaging ingredients. No eye makeup until team advises you that it is safe to do so.
    - Wear a sunblock and hat if you plan to be out in the sun. Some of your medications will make you more sensitive to the sun.
- Do not work in the yard or garden. Avoid being around or working with houseplants. Place them in a less frequently used room and let someone else care for them.
- Do not share cell phones. Clean landline phones in between other household users.
- Clean computer keyboards often.
- Follow our guidelines in the “Safe Pet Ownership after Transplant”. Wash your hands after touching your pet.
- Plan trips to a mall, restaurant or theater at non-peak times to avoid crowds.

  - Sexual intercourse allowed when your platelet count is over 50,000. Use condoms and water-soluble lubricants to increase comfort, prevent infection and prevent bleeding. Oral genital sex is permitted, if there are no oral or genital lesions. You should avoid anal sex. If you have any concerns or questions about sexual activity, ask your nurse or doctor.

SIGNS AND SYMPTOMS OF INFECTIONS **Notify CIT Clinic Immediately or Call Afterhours Answering Service

Bone Marrow Transplant Clinic Hours of Operation
Monday through Friday 7:30AM – 5:00PM
Saturday and Sunday 8:30AM – 4:00PM
Main Telephone Number # 804-828-4360 Select Option 2 for Triage Nurse

After Hours Answering Service Telephone # 804-628-4145

- Fever or chills
  - Temperature at or above 100.4 degrees F or 38 degree C
  - Shaking chills with or without fever
  - Temperature should be taken once a day with an oral or tympanic thermometer or if patient is symptomatic
- Diarrhea
  - Consistent or uncontrolled
  - Abdominal cramping with stool
  - Bloody, burgundy or black stool
  - New onset diarrhea
  - More than 5 diarrhea stools a day*
  - Passing whole pills or undigested food in stool*
  - Weakness or dizziness with diarrhea
- Urinary Symptoms
  - Unable to void (pass your water) for more than 8 hours
  - Blood in urine
  - Painful urination

- Rash
    - Sudden new rash
    - Change in skin rash*
- Nausea and Vomiting
    - Uncontrolled vomiting
    - Bloody or “coffee ground” appearing vomitus
    - Unable to keep medicine down
    - Nausea persists despite medication*
    - Weakness of dizziness with nausea or vomiting
- Confusion or decreased alertness
    - New or increased confusion
    - Change is level of alertness
    - Vision changes
    - Falling or change in balance
    - New numbness or tingling
    - Unable to move arms or legs
    - Difficulty walking*
    - Mood swings or behavior changes*
- Bleeding
    - New or increased bleeding
    - Nosebleed
    - Blood in vomitus, stool, urine or sputum
    - Heavy vaginal bleeding (More than 1 pad per hour)
    - Small purple or red spots in the skin *
- Severe Fatigue (Tiredness)
    - Inactive*
    - Dizziness
    - Too tired to walk or go to the bathroom
- Cold or Cough
    - Shortness of breath
    - Trouble breathing when lying flat
    - Wheezing
    - Uncontrolled cough
    - Cold or flu like symptoms

  - Coughing up bloody, yellow or green sputum
  - New onset of shortness of breath with daily activities*
  - New or persistent cough*
- Pain
  - Severe headaches
  - Abdominal pain
  - Mouth pain not controlled*
  - Difficulty in swallowing
- Swelling
  - Changes in central line site with redness, tenderness, or drainage*
  - New onset of swelling in legs, feet or hands with or without pain*
- Circulatory
  - Lightheadedness
  - Increased pulse, or feeling like your heart is racing
  - Chest pain. Call 911 immediately

*Call the CIT Clinic within 24 hours of onset

CALL 911 FOR ANY LIFE THREATENING SYMPTOMS

- **UNCONSCIOUS**
- **SEIZURE**
- **DIFFICULT TO AROUSE**
- **UNCONTROLLED AND PERSISTENT BLEEDING**
- **NOT BREATHING**
- **CHOKING**
- **CHEST PAIN**
- **STROKE**

WHAT TO EXPECT ON CLINIC VISITS

- Once you are discharged from the inpatient unit, you will return to the clinic for lab work and provider appointments. This may include weekends and holidays.
- You will receive your first appointment time from the discharge nurse on North 10. The clinic staff will make subsequent appointments.
- Caregivers not allowed in clinic, except during a provider visit. You will see a doctor or advanced practice provider once a week.
- You caregivers can wait in the waiting rooms on North Ground, Main 1 or Gateway Building.
- Cell phones are a good way of communicating with your caregivers, so they know when to come get you.
- When checking in, please report if you or caregivers have new upper respiratory symptoms, fever, or GI symptoms. You may need to be isolated in a private room for these conditions. Do not walk around the clinic and expose other patients.
- Upon arrival to the clinic, weight and vital signs obtained. Blood drawn for testing.
- Depending on your lab test results, you may need blood products, fluids or electrolyte replacement. The length of time you will spend in the clinic varies. It can be between 2-6 hours.
- Bring food and drink to clinic.
- Bring your medications that you will need in clinic. This includes your scheduled medications and your “as needed” medications.
    - On your first clinic visit, you will need to bring all your discharge medications and Medication Sheet with you. The pharmacist in the clinic and the nurse will need to see them
- Wear comfortable clothing. Bring a sweater if you are subject to being cold.
- You may want to bring a book, magazine, laptop or other form of entertainment to help pass the time.
- Make a list of questions that may come up at home and bring them with you to discuss with the nurses or doctors.

- The Discharge Nurse on North 10 will give you at discharge an informational sheet, “Tips for Your Clinic Visits”.

MEDICATIONS AFTER TRANSPLANT

Pharmacy team members

A clinical pharmacist is part of the team caring for you during your inpatient stay and while in the clinic.

- Inpatient pharmacist: Contact through inpatient North 10 unit (phone: 804-628-2371)
- Clinic pharmacist: Contact through clinic North 7 (phone: 804-828-4360)

A pharmacy reimbursement specialist is also available to assist with prescription coverage issues including prior authorizations and questions about your insurance formulary (please note this resource is NOT for refill assistance or refill requests).

- Chavia Martin, contact through patient portal or by phone: 804-628-9791

Medications commonly prescribed following stem cell transplant

Medications to prevent increased risk of infections: Patients’ white blood cells, produced by the bone marrow, are responsible for fighting infection. After bone marrow transplant, white blood cells and other important immune system cells are low increasing the risk for developing an infection. Depending on the type of transplant you receive, medications will be prescribed to prevent bacterial, viral, and fungal infections.

Medications to prevent graft-versus-host disease: Graft versus host disease (GVHD) is a condition that is experienced by patients receiving stem cells from another person (allogeneic transplant) and is a reaction of the donor cells to the patient. GVHD can cause a red skin rash, nausea, vomiting, abdominal cramping, and diarrhea. Notify the clinic immediately if these symptoms occur. Medications such as tacrolimus, cyclosporine, sirolimus, and mycophenolate are used to prevent GVHD. It is very important to take these medications as you are instructed, and these medications must be filled before discharge. The dose of tacrolimus, cyclosporine, and sirolimus is adjusted based on the amount of drug measured in the blood. Patients should not take their morning dose of these medications on the days of clinic visits when a blood level is drawn. See the medication sheet for instructions and ask your nurse when your next blood level is due. Sunscreen (SPF30, hypoallergenic), long-sleeves and pants, and hats should be worn to avoid sun exposure while on these medications.

Medications to prevent nausea, upset stomach, and vomiting: Many patients experience nausea, vomiting, and upset stomach after hospital discharge as the gastrointestinal (GI) tract continues to recover from the chemotherapy given before transplant. All patients are given anti-nausea medications to take at home to prevent and treat nausea as needed. Patients will also receive an anti-acid medication to take for at least the first month after transplant. To decrease the risk of nausea and upset stomach, avoid taking medications on an empty stomach unless instructed specifically to do so.

Home medications: Frequently patients' home medications before transplant are stopped during the inpatient stay due to drug interactions and potential side effects. If you are not sure whether to start these medications at discharge, ask your provider or pharmacist before beginning home medications. Please bring all your home medications and supplies (e.g., glucose meter) to Richmond to be kept by your caregiver (not in the hospital). These can be reviewed when preparing for discharge to determine what new prescriptions are needed.

Medications to avoid after transplant

- If a medication you were taking at home before transplant is not on your medication sheet, ask your doctor or pharmacist before taking. Home medications may be on hold during and after transplant due to side effects or drug interactions.
- Ask your doctor or pharmacist before taking herbal medications, supplements, or vitamins. These medications may have important drug interactions or side effects.
- Non-steroidal anti-inflammatory drugs (NSAIDs) and aspirin may decrease the body's ability to clot blood and increase the risk of bleeding. Common NSAIDs include Ibuprofen (Motrin®, Advil®) and Naproxen (Aleve®). Patients should not take these medications until told it is safe by a doctor. Acetaminophen (Tylenol®) does not affect blood-clotting ability. It is safe to take if you need something for mild pain relief.

Notes:

Preparing for discharge

- Three to four days before discharge prescriptions will be sent to the pharmacy. Please have the most recent copy of your prescription drug insurance card with you for our discharge coordinator.
- Pharmacy options for your discharge prescriptions:

Pharmacy	**Contact**	**Notes**
Richmond has most chain and grocery store pharmacies	We will help you find the closest one to where you are staying	Staying with your same pharmacy allows for smooth communication between your home and local Richmond pharmacy
VCU Discharge & Ambulatory Care Center (ACC) Pharmacies	Discharge Pharmacy: Coordinated by inpatient unit ACC Pharmacy: Located on the ground floor of the ACC building (phone: 804-828-0756)	The VCU Discharge Pharmacy will fill your prescriptions one time (at discharge only). Refills and new prescriptions can be filled through the ACC Pharmacy.
Buford Road Pharmacy	Address: 2608 Buford Rd, Richmond, VA Phone: 804-272-1423	Independent pharmacy on Richmond’s Southside. Free delivery within ~10 miles (includes Doorways)
Westbury Apothecary	Address: 8903 Three Chopt Rd, Henrico, VA Phone: 804-285-3428	Independent pharmacy on Richmond’s Westside. Free delivery within ~10 miles (includes Doorways)

At least two days before discharge, a caregiver should pick up all medications. Ensuring all medications were filled correctly is necessary for a safe discharge. Please have a plan to pick up additional prescriptions the day of discharge in case last minute medication changes are made.

- Bringing your prescriptions to the hospital for review is a **requirement** for discharge.
- The day before or day of discharge, a pharmacist will counsel you and your caregiver on your medications and provide you with a medication sheet.
- Plan for organizing your medications. Many patients find pillboxes, timers, and cell phone alarms useful.

What to expect in the stem cell transplant clinic

Bring your medication sheet and any medications you may need to take during the time you will be in clinic with you to your appointments.

- Changes to your medications are made frequently. This is normal, expected after transplant, and does not mean you are not doing well. Make sure to get a new medication sheet when changes are made.
- If an IV medication is needed during your time in the clinic, a home health company will deliver the medication to your home and teach you how to administer it.

Medication safety at home

- Keep medications in a cool, dry place, away from children and pets.
- To safely dispose of medications, watch the news for “Take Back Days” or throw the drugs in the household trash, but first:
- Take medications out of their original containers and mix them with an undesirable substance, such as used coffee grounds or garbage.
- Put them in a sealable bag, empty can, or other container to prevent the medication from leaking or breaking out of a garbage bag.

DIET GUIDELINES FOR IMMUNOSUPPRESSED PATIENTS

Follow diet for 1 year post-transplant or as doctor orders. No Restaurant or Takeout food until approved by CIT Team

Food Groups	Allowed	Not Allowed
Dairy	All pasteurized milk and milk products Commercially packaged cheese and cheese products made with pasteurized milk (e.g., mild and medium cheddar, mozzarella, parmesan, swiss, etc.) Pasteurized yogurt Dry, refrigerated, and frozen pasteurized whipped topping Ice cream, frozen yogurt, sherbet, ice cream bars, homemade milkshakes Commercial nutritional supplements and baby formulas, liquid and powder Commercial pasteurized eggnog	Unpasteurized or raw milk, cheese, yogurt, and other milk products Cheeses from delicatessens Cheeses containing chili peppers or other uncooked vegetables Cheeses with molds (e.g., blue, stilton, Roquefort, gorgonzola, etc.) Sharp cheddar, brie, camembert, feta cheese, farmer’s cheese Soft serve ice cream or yogurt

Food Groups	Allowed	Not Allowed
Meat and Meat Substitutes 160° F cooked eggs 145° F cooked fish, shellfish 160° F Beef, pork, lamb 165° F poultry 165° F reheated food Cold food below 40° F	All well-cooked or canned meats (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs) Well cooked eggs Well-cooked pasteurized egg substitutes (e.g., Egg Beaters) Commercially packaged salami, bologna, and other luncheon meats need to be heated in the microwave until steaming prior to using Canned and commercially packaged hard-smoked fish; refrigerated after opening	Raw or undercooked meat, poultry, fish, game, tofu Raw or undercooked eggs and egg substitutes Meats and cold cuts from delicatessens Hard cured salami in natural wrap Cold smoked salmon (fish); lox Pickled fish

Food Groups	Allowed	Not Allowed
Fruits and Nuts	Canned and frozen fruit and fruit juices Well washed raw fruit; foods containing well washed raw fruits Dried fruits Canned or bottled roasted nuts Nuts in baked products Commercially packaged peanut butter	Unwashed raw fruits Unroasted raw nuts Roasted nuts in the shell Unpasteurized fruit and vegetable juices
Vegetables	All cooked frozen, canned, or fresh vegetables and potatoes Well washed raw vegetables Fresh, well washed herbs and dried herbs and spices (added to raw or cooked foods)	Unwashed raw vegetables or herbs All raw vegetable sprouts (alfalfa, radish, cauliflower, broccoli, mung bean, all others) Salads from delicatessens Raw Mushrooms

Food Groups	**Allowed**	**Not Allowed**
Beverages	**Tap water and ice made from tap water** **Commercial bottled distilled, spring, and natural waters** **All canned, bottled, powdered beverages** **Instant and brewed coffee, tea; cold brewed tea made with boiling water** **Non-Caffeinated beverages** **Brewed herbal teas using commercially packaged tea bags** **Commercial nutritional supplements, liquid and powdered must be approved by a BMT team member prior to use**	**Well water (unless tested frequently and found to be free of coliforms; please discuss with doctors or dietitian)** **Unpasteurized commercial fruit and vegetable juices** **Caffeinated beverages** **Mate tea** **Alcohol**

Food Groups	Allowed	Not Allowed
Desserts	Refrigerated commercial and homemade cakes, pies, pastries, and pudding Refrigerated, cream filled pastries Homemade and commercial cookies Shelf stable cream filled cupcakes (e.g., Twinkies®, Ding Dongs®, etc.), fruit pies (e.g., Pop Tarts®, Hostess Fruit Pies®), and canned pudding Ices, popsicle-like products	Unrefrigerated, cream filled pastry products (not shelf stable)
Bread, Grain, and Cereal Products	All breads, bagels, rolls, muffins, pancakes, sweet rolls, waffles, French toast Potato chips, corn chips, tortilla chips, pretzels, popcorn Cooked pasta, rice, and other grains All cereals, cooked and ready-to-eat	Raw grain products
Fats	Oil, shortening Refrigerated lard, margarine, butter Cooked gravy and sauces Commercial, shelf stable mayonnaise and salad dressings (including cheese based salad dressings; refrigerated after opening)	Fresh salad dressings containing aged cheese (e.g., blue, Roquefort) or raw eggs, stored in refrigerated cases Homemade Caesar dressing (contains raw product)

Food Groups	Allowed	Not Allowed
Other	Salt, sugar, brown sugar Jam, jelly syrups; refrigerated after opening Commercial (heat treated and/or pasteurized) honey Catsup, mustard, barbeque sauce, soy sauce, other condiments (refrigerated after opening) Pickles, pickle relish, olives (refrigerated after opening) Candy, gum	Raw or non-heat treated honey; honey in the comb Herbal and nutrient supplement preparations Brewer's yeast, if eaten uncooked Pepper added to food after cooking Any raw uncooked spices such as cinnamon, ginger, nutmeg, etc.

Leftovers: discard any food left out at room temperature for more than 2 hours. Use most cooked leftovers within 2 days

NOTES:

GASTROINTESTINAL – DIET 1

SUGGESTION TO TRY FIRST:

Beverages	CEREALS	STARCHES
Water Gatorade or G2 Juice (avoid grapefruit) Crystal light Decaffeinated beverages (soda, tea, coffee) Lactose milk Soy milk Almond milk	Hot (all made with water): Cream of rice Cream of wheat Oatmeal Grits Cold cereal: no bran cereal or high fiber cereal such as (Mini Wheats, Fiber One etc.)	White bread, plain bagel, roll, or English muffin Pasta Potato (no skin), baked or mashed Rice, white Saltines, Ritz, club crackers Pretzels

FRUITS	OTHER
Applesauce, plain Banana Canned fruit (peaches, pears, apples, fruit cocktail)	Hard candy Broth, beef or chicken Popsicle. Italian ice

MISCELLANEOUS: Sugar (white or brown), sugar substitute, salt, jams, jelly, syrup, margarine, oils

IF TOLERATED TRY:

Protein Sources **(Allowed with 1 tsp. margarine or mayonnaise)**	**Other**
Well cooked chicken or turkey breast (no skin), Baked, broiled, or boiled Ham, lean Egg, well cooked Fish, baked or poached Tuna, packed in water Ensure plus, Boost High Protein, Premier protein Ensure clear	Chicken rice, chicken noodle soup (broth based soups) Sandwiches made with low-fat mayonnaise on white bread: egg salad, tuna salad, chicken, turkey, or lean ham Vanilla wafers, graham crackers Animal crackers Angel food cake Carrots, well cooked Green beans, well cooked Sweet potatoes (no skin), baked or mashed

Gastrointestinal – Diet 2

For Patients without G.I. Problems

This portion of the gastrointestinal diet is for the immunosuppressed patient whose GI symptoms are controlled and that can begin to progress their diet. All foods must be selected and prepared according to the Diet Guidelines for Immunosuppressed Patients.

Daily Food Allowances

Food Recommended	Foods To Avoid
Dairy and Supplements: 3 or more cups per day	
Lactose-free 2%, 1% or skim milk Soy milk Rice milk Ensure®, Ensure Plus® Resource®, Fruit Beverage Resource®, Resource Plus® Boost® Scandishake®, lactose-free, made with lactose free low fat milk Note: chocolate flavored beverages are allowed Take with lactose enzyme tablet as needed (discuss with dietician) Instant breakfast, made with low-lactose milk Buttermilk Regular 2%, 1%, or skim milk Low fat yogurt (6-8oz) Low fat cottage cheese (non-fat or 1%) Low fat cheeses (cheddar, Monterey Jack, Swiss (1oz) American cheese (1oz) Cheddar cheese (1oz) Jack cheese (1oz) Mozzarella cheese, part skim (1oz) Parmesan cheese: grated or canned (1oz) Ricotta cheese, part skim (1/4 cup) Ricotta cheese, fat free String cheese (part-skim mozzarella) (1oz) Swiss cheese (1oz)	Any milk or milk-based product not pre-treated or not taken with lactase enzyme

***Foods Recommended	Foods to Avoid
Meat or Meat Substitutes: 3 or more 3oz. Servings per day (or suggested portion size)	
Well-cooked, lean cut of broiled, baked or roasted fish, beef, skinless poultry, ham Crab and imitation crab Canned, water-packed tuna and seafood Casseroles prepared with allowed foods Eggs, well cooked Cooked tofu Lean luncheon meat (such as turkey, chicken, ham) Low fat hot dogs Turkey bacon	High fat luncheon meat (Spam®, potted meat) Hot doge Corned beef Pepperoni Pickled or cured meats/fish Fried meats or fish Beans and legumes
Fruit and Fruit Juices: 2 or more ½ cup servings per day	
Juices: cranberry, cran-raspberry, nectars ½ strength juices: apple, grape (mix equal parts of water and juice) Fresh Fruit (peeled): apricots, bananas, melons, pears, papaya, mango, nectarine Apples, baked and peeled Canned Fruit: peaches, pears, plums, apricots Other: applesauce (plain) and canned cranberry Jelly or sauce	Juices: citrus, prune, V-8®, V-8 Splash®, tomato, Pineapple All raw fruits except those specifically allowed Canned or Fresh: berries, figs, oranges, lemons, limes, grapes, pineapple, prunes, rhubarb, cherries Dried Fruit: raisins, Craisins®, dates, apricots, pineapple, prunes, bananas
Vegetables: 2 or more ½ cup servings per day	
Well cooked, tender vegetables, as tolerated: Asparagus tips, beets, carrots, green beans, lettuce, mushrooms, pumpkin, sweet potatoes, yams (without skin), winter squash, skinless potatoes (baked, broiled, boiled, mashed) Frozen potatoes: Low fat French fries and hash browns (less than 4 gm fat per 3oz)	Raw or undercooked vegetables; also the following cooked vegetables: artichokes, baked beans, bamboo shoots, bean dishes, bean sprouts, beets, greens, broccoli, celery, Brussel sprouts, chives, cabbage, corn, cucumbers, peas, eggplant, bell peppers, leeks, legumes, lentils, lima beans, mustard greens, parsley, rutabagas, tomatoes, sauerkraut, summer squash, turnips, spinach, collard greens, Swiss chard and all other similar foods
Soups: As desired	
Broth-based soups made with allowed meats and vegetables (*in moderation): beef broth, beef noodle, chicken broth, chicken noodle, chicken with rice, turkey noodle, vegetable, etc. ramen soups, without flavor packet, Homemade milk and cream – based soups and chowders (made with low fat, lactose-free milk	Highly seasoned soups Tomato based soups Ready-to-eat cream soups Soups with more than 2 gm of fiber per serving: Bean with bacon, beef noodle with vegetables, chili, green pea, Manhattan clam chowder, onion, split pea, minestrone

***Recommended if having GI issues such as diarrhea

*** Foods Recommended	Foods to Avoid
Bread and cereal products: 4 or more servings per day	
Bagels (plain) Breads, enriched and refined (corn, white, pita, sourdough) Cereals with less than 2 gm of fiber per serving: Cheerios®, Corn Chex, corn flakes, cream of rice, cream of wheat, Fruit Loops®, Kix®, Rice Chex®, Rice Krispies®, Special K, Sugar Pops®, Sugar Smacks®, Trix®, puffed rice, Captain Crunch®, Cocoa Krispies®, instant oatmeal, instant grits Cornmeal, corn starch Crackers: animal, graham, saltines, low fat English muffins: white or sourdough Noodles, Polenta, pretzels Rice cakes: plain Rolls: white Tortillas: corn or flour White flour White rice, couscous Zwieback Low fat baked tortilla chips or baked potato chips pancakes, waffles: frozen, mix or home recipe using allowed ingredients	Whole grain bagels, breads, English muffins, or rolls (cracked wheat, rye, whole wheat, pumpernickel) Breads and cereals with raisins, nuts or seeds, brown or wild rice, bulger cereals with more than 2 gm of fiber per serving: Bran, cracked wheat, granola, Grapenuts®, Nutrigrain®(all varieties), puffed wheat, Shredded Wheat®, Wheaties®, regular oatmeal Whole grain macaroni and noodles Whole wheat tortillas Wheat germ Crackers with more than 2 gm of fiber per serving **Note: Avoid products with Olestra®, Olean®**
Desserts: As desired (read ingredients list)	
Cake (plain, without frosting) Custard made with lactose-free milk Jell-O Homemade fruit cobbler made with allowed fruits Pastries and pie made with allowed fillings (omit spices): apple, peach, pear, cherry (use commercial filling), pumpkin, sweet potato (use evaporated milk treated with lactase0 Popsicles Puddings, made with lactose-free milk Plain cookies (such as vanilla wafers, graham crackers, ginger snaps) Rice Krispie Treats Angel food cake Low fat, non-dairy ice cream	Cake with raisins, nuts, coconut, other omitted foods and spices Pastries and desserts with dried or candied fruit, coconut, nuts, raisins, seeds High fat cream-filled cakes and pastries Premium high fat ice creams Sugar cookies, wafer crèmes and other cookies not recommended

***Foods Recommended	Foods to Avoid
Take with lactase enzyme tablet as needed **Discuss with dietitian:** Canned puddings Sherbet (check label for milk in package) Sorbet (check label for milk in package Low fat hard-pack ice cream and frozen yogurt (less than 3 gm fat per serving) Smoothies made with allowed ingredients	
Beverages: As desired	
Non-cola caffeine-free carbonated beverages (check labels on carbonated beverages and choose sodas without caffeine) Chocolate milk or Strawberry Quik® made with lactose free milk Fruit-ades: Hawaiian Punch®, Hi-C®, Tang®, Gatorade®, PowerAde®, Kool-Aid® Tea, weak decaffeinated and herb teas, in moderation (except peppermint) ************************************ **Take with lactase enzyme tablet as needed** **Discuss with dietitian**: Cocoa	Alcoholic beverages Coffee: regular or decaffeinated Tea, including regular or strong decaffeinated carbonated beverages containing caffeine cola type carbonated beverages Peppermint tea
Fats	
Low fat or nonfat choices – No restrictions on portion size: Low calorie margarine Fat free mayonnaise Fat free non-dairy creamers Low fat gravies and sauces made with lactose free milk or broth Low fat salad dressing	
Fats with limited portion size: Avocado (1/8 each) Bacon, lean crisp (1 slice) Butter (1 tsp) Cooking oil (1 tsp) Cool Whip® (1 tbsp.) Margarine (1 tbsp.) Mayonnaise (1 tbsp.) Peanut butter, creamy (2 tsp) Gravies and sauces made with lactose free milk (1/4 cup) Take with lactase enzyme tablet as needed Discuss with dietitian Cream cheese (1 tbsp.) Sour Cream (2 tbsp.) Whipping cream (2 tbsp.) Half-and-half (2 tbsp.)	

***Foods Recommended	Foods to Avoid
Gum drops, jelly beans, hard candy, gummi bears Herbs and spices for seasoning: basil, bay leaf. Oregano, rosemary, thyme, cinnamon Honey Jelly Marshmallows Fruit roll-ups Ripe olives Salt Sugar (any type) Soy sauce Syrups Vinegar	Friend snack foods: corn chips, Doritos®, Cheetos®, Potato chips Jams with seeds or skin Nuts, seeds, dried fruit, coconut: alone or in any food product Pickles Popcorn Spices: cayenne, chili powder, garlic (fresh, salt powder), mustard, onion (powder, salt), pepper, paprika Condiments: catsup, chili sauce, jalapeno, relish, horseradish, peppers, prepared mustard, steak sauce, barbecue sauces Salsa Tabasco

NOTES:

POST-TRANSPLANT CARE

- You will meet with your post- transplant nurse coordinator to review your long-term care follow up plan.
- The CIT Team will be doing intermittent testing to check for late transplant effects and complications. Testing will depend on your physical condition before transplant, your diagnosis, chemotherapy, type of transplant and your current medical condition.
- The long-term follow up phase may occur for up to 5-10 years.
- Post- Transplant testing may include:
    - Bone marrow Biopsy
    - Pulmonary Function Test
    - Chest CT Scan
    - Liver Function Test
    - Thyroid Screening
    - Bone Density Scan
    - Cardiovascular Risk Assessment
- Complications of Transplant
    - Renal (kidney) problems
    - Veno-occlusive disease (liver)
    - Secondary Cancers
        - Rare side effect
        - CIT Team will assess your risk and will recommend a screening plan.
        - Dermatologist yearly, for a full body exam
        - Female patients should have annual mammograms and pap testing if applicable.
        - Men should have regular prostate monitoring.
        - Regular dental visits every six months. Check with your team if you need prophylactic antibiotics prior to visit.
        - Colonoscopy as recommended
    - Sexual Dysfunction
        - Talk with your CIT Team if you have any concerns

    - Graft-Versus Host Disease (GVHD)
        - Most people who had an allogeneic transplant will experience some symptoms of chronic GVHD
        - You will be provided with information pre and post-transplant about GVHD. This information goes over in detail early warning signs and prevention. Your CIT Team will discuss this with you, pre and post-transplant.
        - You can lower your risk by:
            - Taking your medications as directed
            - Protecting yourself from the sun
            - Watching for early warning signs and symptoms and reporting them immediately to the CIT Team
- Re-immunization
    - The CIT Team will let you know when you can begin the immunization process.
    - Immunizations require intermittent injections to fully protect you. They may include Hepatitis B, DTaP, HiB, Pneumococcal, Influenza, MMR and Polio.
    - Each vaccination has its own potential side effects. Your clinic nurse will give you information about each vaccine and side effects prior to the vaccine.
    - Discuss any concerns you have with your CIT Team before the vaccination.