

patient guide



JOHNS HOPKINS
NURSING

THE SIDNEY KIMMEL
COMPREHENSIVE CANCER
CENTER

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Welcome



JOHNS HOPKINS
M E D I C I N E

THE SIDNEY KIMMEL
COMPREHENSIVE CANCER
CENTER

Welcome to the Sidney Kimmel Comprehensive Cancer Center at the Johns Hopkins Hospital, where our mission is to provide the highest quality of care to individuals with cancer. This includes providing the best and latest cancer treatment and supportive care available.

We understand that a diagnosis of cancer may be stressful and overwhelming, which is why we created this Patient Guide to give you easy access to information about your care. Information about your disease, treatment, symptom management, support programs, care at home, hospital and internet resources are provided. You may find it helpful to bring your copy of the Guide with you for each visit.

While we believe that the Guide is a valuable resource for you and your family, it is not intended to replace one-on-one communication between you and your caregivers. If at any time you have questions or concerns about your treatment, support services, or other matters, we encourage you to discuss them with a member of your health care team.

Thank you for choosing the Sidney Kimmel Comprehensive Cancer Center. Please let us know if there is anything that we can do to enhance the quality of care and services that you receive.

Best Wishes,

William G. Nelson, MD, Ph.D.
Professor and Director

Sharon L. Krumm, PhD, RN
Administrator and Director of Nursing



The Johns Hopkins Hospital Patient Information

Your Health Care Team

Original Date
9/00

Oncology
Revised/ Reviewed
5/17

While a patient at the Kimmel Cancer Center, you will be cared for by a team of health care providers, most of who specialize in the treatment of cancer patients. All members of your health care team welcome any questions that you and your family may have during your care. If you are admitted to the hospital, our experienced team will continue to care for you. It is important to understand that your primary oncologist may not be treating you when you are hospitalized, but we will communicate with him or her. Once you are released from the hospital, your care will continue with your primary oncologist and outpatient team.

Attending Physician	As the leader of your health care team and the most senior-level doctor in charge of your care, an attending physician is in charge of planning your treatment and coordinating your care among all members of the team.
Oncology Fellow	A fellow is an experienced internal medicine physician and is completing specialty training in oncology. The fellow will see you while you are in the hospital and works with the attending physician to review all aspects of your care.
Medical Resident	A medical resident works with the attending and fellow in making daily decisions about your treatment plan while you are an inpatient. A resident has a medical degree and is completing training in internal medicine.
Physician Assistant (PA)	Physician assistants are licensed health professionals who practice medicine in a collaborative fashion with attending physician oversight. Physician assistants are trained and authorized to make medical decisions and provide highly skilled advanced care to patients in inpatient and outpatient settings.
Nurse Manager	The nurse manager oversees the staff on the nursing unit and is available to hear concerns about your care and safety. The nurse manager is an oncology nurse with an advanced degree.
Nurse Practitioner (NP)	The NP has an advanced degree in nursing. They work with physicians and other members of the team to develop and implement a treatment plan that meets the needs of individual patients and their families. They order medications, treatments, and diagnostic tests, and perform procedures. They provide highly skilled advanced care to patients in a variety of settings.
Clinical Nurse Specialist (CNS)	The CNS has an advanced degree in nursing to promote and maintain safe, optimal nursing practice during your stay. The CNS also helps patients and families to better understand their disease, treatment, and what to expect during and after their stay.
Oncology Nurse	The oncology nurse administers the treatment prescribed by your physicians, helps you to manage any side effects, and explains your care to you and your family. Your nurse will work with you to develop a plan of care for you in the hospital and for when you return home.
Clinical Technician	The clinical technicians are specially trained to do many nursing tasks and procedures like vital signs, blood drawing, dressing changes, helping with daily hygiene and EKGs. They assist your nurse with your care.
Unit Associate	The unit associates help with ordering and assisting with meals, taking you to tests and procedures, cleaning of certain equipment and changing the linens.



The Johns Hopkins Hospital Patient Information

Your Health Care Team

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EVC Staff	EVC staff cleans and disinfects your room.
Chaplain	Many patients find strength and comfort in the practice of their faith whether through prayer, meditation, religious counsel, worship or other rituals. The hospital chaplain is available to lend spiritual support, as well as help you and your family contact a local minister, rabbi, imam or other faith leader. The chaplain's job is always to help patients and their loved ones negotiate their own path no matter where it leads.
Dietitian	Cancer patients often have special dietary needs because of the effects of their therapy. A dietitian can advise you on how to manage problems such as loss of appetite, changes in your sense of taste, nausea, vomiting, weight gain or loss or any other nutrition concerns you may have.
Occupational Therapist (OT)	An OT can teach you how to perform skills and movements that are needed for daily living such as personal care, childcare or work duties. An OT can offer special training to use adapted aids or methods to safely and efficiently complete specific tasks. Therapy sessions may be held in your room or in the occupational therapy department.
Pharmacist	Oncology pharmacists are the medication experts. A team of pharmacists work together to make sure your medications are safe and the best for you. Pharmacists can also help educate you on the purpose and side effects of your medications.
Physical Therapist (PT)	Physical therapists help restore and improve your strength, flexibility and stamina. A PT can develop a treatment plan for your physical needs including exercise, massage and heat and cold applications. Therapy sessions may be held in your room, the exercise room, or in the physical therapy department.
Psychiatric Liaison Nurse	Psychiatric Liaison Nurses are available to talk with you, evaluate your concerns and make recommendations or provide treatment to improve your emotional well being, which may be stressed by a diagnosis of cancer and its treatment. Some of the emotional difficulties they can help with are anxiety and depression. There is no charge for these services.
Social Worker	The oncology social worker can help you and your family to cope with the changes and stresses in your life that often occur with a diagnosis of cancer. Your social worker can provide information about support groups, housing, transportation, financial issues and discharge planning. There is no charge for meeting with a social worker at the cancer center, and if you wish to speak with one, you should let your nurse or physician know.
Speech Therapist	Speech therapists help patients with speech and swallowing problems that happen as a result of cancer. They teach patients exercises and different ways to talk, like using an electro-larynx. Patients are also taught to use certain positions, kinds of foods, and exercises to swallow safely.
Volunteer	Volunteers support patients and staff in many ways, such as providing reading materials and snacks, running small errands, visiting patients and assisting in the patient education room and waiting areas.



Johns Hopkins Outpatient Pharmacy at Weinberg

Located on the 1st floor of the Weinberg building next to Outpatient Services

Main phone and Refill line:
410-955-5747

Hours:

Monday – Friday: 9am – 6pm

Fax line:
410-502-1511

Saturday: 10am-6pm

The Weinberg Pharmacists can answer your chemotherapy and insurance questions. We would like to invite first time patients to the cancer center to visit our pharmacy for a Consultation.

For this visit, please bring the following:

- All insurance cards (if available)
 - Medicare A & B
 - Medi-Gap
 - Medicaid
 - Private Insurance
- Home Address and/or local address (if different from home)
- Phone numbers
 - Including emergency numbers should the pharmacy need to reach the patient right away and the patient's local pharmacy phone number.
- Allergy Record
 - Any medicines or foods that cause the patient to have an allergic reaction such as hives.

Please note:

- To lessen your wait time, please call the Automated Refill Line (410-955-5747) 24 hours a day.
- If you would like your medicines delivered, please ask a pharmacy staff member.
- Not all insurance benefits are the same. They vary from plan to plan. Please check your pharmacy insurance benefits and call your plan's phone number if you have questions.



The Johns Hopkins Hospital
Patient Information

Original Date
8/00
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Understanding Your Bills

Will my insurance cover my treatment?	The Johns Hopkins Kimmel Cancer Center participates with most insurance plans including Medicare and State of Maryland Medicaid. Our Financial Counselor Office can answer specific questions related to your insurance plans. Your insurance company can also offer you information regarding your coverage.
How do I contact an Oncology Financial Counselor?	<p>Telephone: 410-502-1304 410-502-1306 410-955-8588</p> <p>Fax: 443-287-3666</p> <p>Hours of Operation: Monday – Friday (9 am – 5 pm)</p>
Whom do I call if I receive a bill from Johns Hopkins and have questions?	<p>If you have questions about your bill and the balance owed, please call 1-855-662-3071.</p> <p>If you need additional assistance, please call one of our Financial Counselors.</p>
Will my treatment be stopped if I cannot pay my bill on time?	<p>If you cannot pay your bill, your treatment will not be stopped.</p> <p>Please contact one of our Financial Counselors to discuss payment options.</p>
What does it mean when my insurance company denies payment on my claim?	Insurance companies provide an Explanation of Benefits or “EOB” which is a detailed summary about the payment or the denial of a claim. Sometimes, a claim will be denied because information is missing or an authorization/referral form was needed. Johns Hopkins will submit the requested documents and rebill the claim. You can call the Johns Hopkins Billing Office (see phone number above) to discuss the denial for payment.
Will my insurance company pay for services if I am in a clinical trial?	The Johns Hopkins staff will check your insurance in advance of your clinical trial appointment. Your doctor or study nurse will explain the clinical trial charges and your insurance coverage.



The Johns Hopkins Hospital Patient Information

Useful Websites for Cancer Information

Original Date
1/00
Oncology
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2/23/17

American Brain Tumor Association	www.abta.org	1-800-886-2282
American Cancer Society	www.cancer.org	1-800-227-2345
American Lung Association	www.lungusa.org	1-800-548-8252
Aplastic Anemia and MDS International Foundation	www.aamds.org	1-800-747-2820
Blood and Marrow Transplant Information Network	www.bmtinfonet.org	1-888-597-7674
Cancer Care, Inc.	www.cancercare.org	1-800-813-4673
Cancer Support Community	www.cancersupportcommunity.org	1-888-793-9355
American Childhood Cancer Organization	www.acco.org	1-855-858-2226
Colon Cancer Alliance	www.ccalliance.org	1-877-422-2030
Corporate Angel Network	www.corpangelnetwork.org	1-914-328-1313
Fertile Hope	www.fertilehope.org	1-855-220-7777
Healthfinder	healthfinder.gov	
International Myeloma Foundation	www.myeloma.org	1-800-452-2873
Johns Hopkins Breast Center	www.hopkinsbreastcenter.org	1-443-287-2778
Johns Hopkins Hospital	www.hopkinsmedicine.org	1-410-955-5000
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins	www.hopkinskimmeltcancercenter.org	1-410-955-5222
Kidney Cancer Association	www.nkca.org	1-800-850-9132
Kids Konected	www.kidskonected.org	1-800-899-2866
Susan G. Komen	ww5.komen.org	1-877-465-6636
Livestrong Foundation	www.livestrong.org	1-877-236-8820
Leukemia and Lymphoma Society	www.lls.org	1-800-955-4572
Lung Cancer Alliance	www.lungcanceralliance.org	1-800-298-2436
LUNGevity	www.lungevity.org	1-240-454-3100
Lymphoma Information Network	www.lymphomainfo.net	1-310-689-7531
Lymphoma Research Foundation	www.lymphoma.org	1-800-500-9976
Medicare	www.medicare.gov	1-800-633-4227
Medline Plus	medlineplus.gov	
Mothers Supporting Daughters with Breast Cancer	www.mothersdaughters.org	1-410-778-1982
National Bone Marrow Transplant Link	www.nbmtlink.org	1-800-546-5268
National Brain Tumor Society	www.braintumor.org	1-617-924-9997
Coalition of Cancer Cooperative Groups	www.cancertrials-help.org	1-215-789-3600
National Cancer Institute	www.cancer.gov	1-800-422-6237



The Johns Hopkins Hospital Patient Information

Useful Websites for Cancer Information

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National Center for Complementary and Alternative Medicine	www.nccam.nih.gov	1-888-644-6226
National Coalition for Cancer Survivorship	www.canceradvocacy.org	1-877-622-7937
National Comprehensive Cancer Network	www.nccn.org	1-215-690-0300
National Lymphedema Network	www.lymphnet.org	1-800-541-3259
National Marrow Donor Program	www.bethematch.org	1-888-999-6743
National Ovarian Cancer Coalition	www.ovarian.org	1-888-682-7426
Pancreatic Cancer Action Network	www.pancan.org	1-877-573-9971
Pregnant with Cancer	www.pregnantwithcancer.org	1-800-743-4471
Sarcoma Alliance	www.sarcomaalliance.org	1-415-381-7236
Social Security Administration	www.ssa.gov	1-800-772-1213
Support for People with Oral and Head and Neck Cancer	www.spohnc.org	1-800-377-0928
Teens Living with Cancer	www.teenslivingwithcancer.org	1-585-563-6221
ThyCa (thyroid cancer)	www.thyca.org	1-877-588-7904
Ulman Cancer Fund for Young Adults	www.ulmanfund.org	1-888-393-3863
United Ostomy Association	www.uoa.org	1-800-826-0826
University of Pennsylvania Cancer Center	www.oncolink.org	
US TOO (prostate cancer)	www.ustoo.com	1-800-808-7866



My Treatment Plan



Answers to Your Questions about High Dose Cyclophosphamide (Cytoxan®) and Mesna®

What is Cyclophosphamide?

- Cyclophosphamide is an anticancer or chemotherapy drug. Its generic name is Cytoxan.
- Cyclophosphamide kills fast growing cells in your body. Cancer cells, bone marrow cells, hair cells and cells lining the gastrointestinal tract are all fast growing cells.

Why am I getting Cyclophosphamide?

Cyclophosphamide is given for many reasons:

1. To kill your bone marrow cells to make room for new, transplanted bone marrow cells to grow.
2. To prevent graft versus host disease (GVHD).
3. To trick your body into making a lot of stem cells (bone marrow cells) so we can collect them for your transplant. This is called the mobilization phase. A growth factor medicine such as filgrastim (Neupogen®) will be given with it.
4. To decrease the number of leukemia cells.
5. To “reboot” the immune system in auto-immune diseases like lupus, autoimmune hemolytic anemia, aplastic anemia and many others.

How is Cyclophosphamide given?

- Cyclophosphamide will be given into your vein through your catheter.
- Cyclophosphamide is given over two hours.
- You may get one or more doses of Cyclophosphamide depending on your disease or treatment plan.
- If you get Cyclophosphamide after your transplant, it will be given on days three and four.
- During the mobilization phase you will only get 1 dose of Cyclophosphamide.

What is Mesna?

- Mesna is a drug often given along with Cyclophosphamide. It helps to protect the bladder wall from the side effects of Cyclophosphamide.

How is Mesna given?

- Mesna is given through your vein, also.
- For each dose of Cyclophosphamide that you get, you will also get four doses of Mesna. The first dose is given before you get Cyclophosphamide. You will receive three more doses at three hours, six hours and eight hours after receiving the Cyclophosphamide.

Does Cyclophosphamide have any side effects?

- Not everyone has side effects from Cyclophosphamide, but some people may.
- You may feel a burning or flushing sensation in your nose or sinuses while the Cyclophosphamide is going into your body.
- Cyclophosphamide may cause you to feel nauseated or throw up. We will give you anti-nausea medicines to help prevent nausea and make you feel better.
- Cyclophosphamide can hurt the wall of your bladder. Mesna will protect your bladder. You should also drink at least eight cups (sixty-four ounces) of fluids (water, juice, etc) the day before and during the day that you get Cyclophosphamide.

What do I do if it burns when I urinate or I see blood in my urine?

- You need to tell your nurse right away if you feel or see either of these symptoms.

What side effects can Cyclophosphamide cause later?

- One to two weeks after Cyclophosphamide, you may get mucositis. Mucositis is redness and sores or ulcers on your lips, mouth, or back of the throat. Mucositis can affect your rectum in the same way. We will give you medicine for any pain or discomfort that you may feel.
- Cyclophosphamide will lower your blood cells (red blood cells, white blood cells and platelets). You will be at risk for infection and bleeding.
- Very high doses of Cyclophosphamide can cause sterility and hair loss. Hair loss is temporary and hair usually grows back in a few months.
- Cyclophosphamide can cause an increased risk of cancers later in life.

Who can I talk to if I have other questions?

If you have any other questions about Cyclophosphamide, please feel free to ask any doctor, nurse, or pharmacist.

This information is not intended as a substitute for professional medical care. Always follow your health care provider's instructions.



Answers to your Questions about Total Body Irradiation

What is Total Body Irradiation?

- Total body irradiation (also known as TBI) is the treatment of the entire body with radiation using a machine called a linear accelerator.

What is the purpose of TBI?

- TBI kills cancer cells and also kills your bone marrow cells to make room for your new bone marrow to grow and to decrease the response of your immune system to the new stem cells.

Is there any preparation needed before beginning TBI?

- Before you begin your TBI treatments you will meet a Radiation Oncology Doctor who will examine you and talk to you about TBI. The doctor will take some simple body measurements with a special ruler. These measurements will be used to make sure that the radiation evenly covers your entire body.
- Some people may also have a material placed over their lungs or liver to take measurements using a light beam or regular X-rays. This is called "simulation" and may take about 30-60 minutes. The therapy team may then make a mold or "blocks" that will be used to cover your lungs or liver during your TBI treatments.

How is TBI given?

- The treatments are given in the Radiation Oncology department. You can wear lightweight clothing or your hospital pajamas during your treatment.
- You will be asked to lie on your side on a stretcher in the treatment room. The stretcher is placed next to the wall of the treatment room and the TBI machine will treat you from several feet away. Your position on the stretcher will be checked carefully by the radiation therapist. Rice bags placed against your body and special tape will be used to hold you exactly in the correct position on your side. The lights in the room will be dimmed and the door closed.
- You will be alone in the treatment room but the radiation therapist can always see you on a TV monitor outside the room. Also, there is an intercom in the treatment room so everything you say can be heard at all times.
- You should not wear makeup, lotion, creams, ointments, deodorant, jewelry or metal objects, such as rings or hairpins during TBI.

What will I feel while I am getting my TBI treatments?

- You won't feel anything during the treatment.
- When the treatment starts you will hear a clicking sound followed by a humming noise when the machine is turned on. The machine does not move or ever touch your body.

How long does it take to receive a TBI treatment?

- After about 20 minutes of treatment on your side, the machine will stop. The therapist will then come into the room and turn you on the other side, or turn the stretcher around. You will then get another 20 minutes of treatment.
- You may want to go to the bathroom or ask for any medications you need before your treatment begins. If there is ever something you need during the treatments, tell the therapist and the machine can be turned off and the therapist or nurse will enter the room to help you.
- You can expect to spend about one hour in the treatment room for each TBI session.

What can I do to pass the time while receiving the TBI?

- Some people like to listen to music (no headphones may be used). The therapist can play music into the room during your treatment. Other people take a nap during treatment. Some people bring a favorite picture that can be hung on the wall so they can look at it during treatment.

Will TBI make me radioactive?

- TBI will not make you, your clothing, or anything in the treatment room with you radioactive.

What immediate side effects can TBI cause and what can I do about them?

- Not everyone has side effects from TBI, but the risk side effects can increase with each dose.
- The most common side effects include: headache, nausea and vomiting, diarrhea, fatigue, and skin reactions. You will receive anti-nausea medicines before your treatments. Your skin might become dry, you may use unscented, uncolored moisturizing lotions after your radiation treatment.
- Some patients develop a mild reddening of the skin during the first few days of treatment.
- People having TBI can feel very emotional during the course or several weeks after therapy. This kind of depression is usually short term but can be difficult to cope with. It is important to know that there is help available if needed.

What longer term side effects can TBI cause?

- There are a number of side effects you may get during the days and weeks after your TBI including: hair loss, discomfort in the mouth and throat, change in taste, mouth sores, nausea and vomiting, diarrhea, and bone marrow suppression (low blood counts). These will go away over time.
- TBI can cause longer-term side effects that can occur months or years after your transplant. These include sterility, cataracts, second malignancies or new cancers, inflammation of the lungs, inflammation of the sac that surrounds the heart, and low thyroid hormone levels.

****If you have any other questions or concerns about TBI please feel free to ask any of the bone marrow transplant doctors.**

This information is not intended as a substitute for professional medical care. Always follow your health care provider's instructions.



Blood and Marrow Stem Cell Infusion

What is a blood and marrow stem cell transplant?

- A blood and marrow stem cell transplant is often used to treat cancers affecting the blood and other blood disorders after receiving chemotherapy. The new stem cells will grow into a new immune system.
- There are two types of blood and marrow transplants.
 - Autologous Transplant: the patient donates their own stem cells.
 - Allogeneic Transplant: stem cells are collected from a donor. The donor could be a family member or an unrelated donor.
- Stem cells can be collected from several different sources, including peripheral blood, bone marrow and cord blood.

What happens the day of infusion?

- The infusion will take place in your hospital room or in your IPOP space.
- You may receive pre-medications of acetaminophen (Tylenol®) and/or diphenhydramine (Benadryl®) depending on what type of transplant you are having.
- You may receive hydration before and after your transplant.
- You may receive intravenous furosemide before your transplant if the volume is greater than 1 liter.
- Autologous stem cells will arrive frozen and will be thawed at the bedside by a cellular therapeutics technician.
- Allogenic stem cells are not frozen. They will arrive ready to infuse.
- The stem cells will be infused by gravity using your central venous catheter. The infusion can take anywhere from 5 minutes to multiple hours depending on the volume of your products.
- During the infusion you will be monitored closely by your nurse for any signs of an infusion reaction. Your vital signs will be checked before, during and after the infusion.
- If your infusion takes place in IPOP, you will be monitored for 1-2 hours post infusion before being discharged for the day.

What are the signs and symptoms of an infusion reaction?

- Fever
- Chills
- Shortness of breath
- High blood pressure
- Low blood pressure
- Low heart rate
- Rash
- Hives/itching
- Chest and/or lower back pain

What happens if I have a reaction?

- Notify your nurse immediately.
- The infusion will be stopped and your provider will be notified.
- Based on your symptoms, we may give you medications to stop the reaction.
- Once your symptoms have resolved, we will restart the transplant usually at a slower rate.
- If your infusion takes place in IPOP, you may need to be admitted to the inpatient unit for observation.

This information is not intended as a substitute for professional medical care.

Always follow your health care provider's instructions.

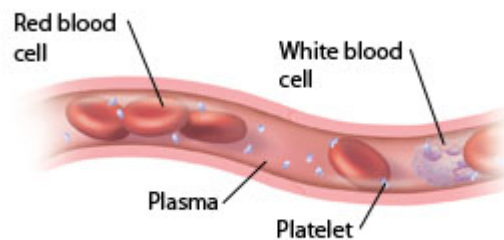
Blood and Blood Product Transfusions for Cancer

A blood transfusion is when whole blood or more often, parts of the blood are given to a person through an IV (intravenous) line placed in a vein. Whole blood or the parts of the blood used for transfusion are called blood products. The blood usually comes from another person. This person is called the donor.

Understanding blood and blood parts

Blood is a fluid that flows throughout the body. It is made up of different parts that have specific roles.

- Red blood cells (RBCs) carry oxygen throughout the body.
- White blood cells (WBCs) are part of the body's immune system. Their main job is to help fight infections and diseases.
- Platelets are fragments of blood cells that help with clotting. When you have a cut or bruise, platelets come together to form a clot or "plug." This helps to control bleeding, so you don't lose too much blood.
- Plasma is the liquid portion of blood. It carries the different types of blood cells to all the parts of the body. Plasma also carries proteins called clotting factors. Clotting factors help platelets with the clotting process.



Blood is divided into 4 types: A, B, AB, and O. Blood also has Rh types: positive (+) and negative (-). Any blood products you receive during a transfusion must match with your blood type.

Why a transfusion may be done

Cancer can cause problems that may need treatment with transfusions. For example:

- Cancer can affect the bone marrow. This is the soft, spongy part inside the bones where most of the body's blood cells are made. When the bone marrow is damaged or destroyed, the body can't make enough blood cells. Without enough blood cells, the body can't work normally.
- Cancer can cause anemia. This condition happens when there are too few red blood cells in the body. Without enough red blood cells, the body's tissues and organs don't receive enough oxygen. Anemia can make you feel tired or short of breath.
- Occasionally, certain cancers can cause internal bleeding. This can lead to blood loss that can threaten your health.

Certain treatments for cancer can lower the number of healthy blood cells in the body. A transfusion can help increase the number of healthy cells. These treatments include:

- Chemotherapy (chemo) uses strong medicines to help kill cancer cells. However, these medicines can also damage healthy cells, including cells in the bone marrow. This can lower your blood cell counts.
- Radiation uses strong X-rays to help kill cancer cells. As with chemo, this treatment can also damage healthy cells in the bone marrow. This can lower your blood cell counts.
- Surgery may be needed to remove a group of cancerous cells, called a tumor, in the body. The surgery can cause blood loss the need for transfusions.

Types of transfusions

Depending on what you need, your healthcare provider may suggest one or more of the blood products listed below as part of your treatment plan. He or she will explain to you how the transfusions will be given and how often they may be needed. Before receiving any blood products, you will need to have some blood drawn to identify your blood type. You will also need to sign a consent form that says that you understand the potential risks of receiving a transfusion.

RBC transfusions

These are most often used to treat severe anemia or blood loss. RBCs must be “typed” to match your blood type. Except in severe blood loss, people with cancer receive “packed” red blood cells without plasma. Each bag is called a unit. It takes about 2 hours to get 1 unit. During that time, nursing staff will be monitoring your temperature, pulse and blood pressure.

Platelet transfusions

These are used if your platelet count is too low. A low platelet count puts you at high risk of bleeding. Although platelets should be “typed” to match your blood type, it is not needed. Platelets can be obtained in different ways:

- From one donor (“apheresis product”)
- Combined from several bags of whole blood (“pooled product”)
- From a community donor who is specially matched (“matched product”)

It takes about 1 hour or less to get 1 unit of platelets. As with RBCs, nurses will monitor your temperature, pulse, and blood pressure.

Plasma (FFP) transfusions

These may be used to supply the blood with more clotting factors to help stop excess bleeding. FFP must be “typed” to match your blood type. One unit or bag of plasma is taken from a unit of whole blood and is then frozen at the blood bank. Plasma is thawed when it is needed. It usually takes 1 to 2 hours to get 1 unit of FFP.

WBC transfusions

Due to the severe risks involved, these transfusions are rarely used. If there is a problem with the WBCs, your healthcare provider may suggest other treatments to help encourage the growth of new WBCs.

Risks and possible complications of blood and blood product transfusions

These include the following:

- Fever and chills
- Allergic reaction (itchy skin or rash; redness, or flushing of the face)
- Chest pain
- Low blood pressure

In the rare event of receiving the wrong blood type:

- Back pain
- Fast heart rate
- Low blood pressure
- Nausea

Although extremely rare, some diseases can be transmitted through blood transfusions. They include:

- Hepatitis B
- Hepatitis C
- HIV
- Bacterial infections

Learning more about the safety of blood donation and blood transfusions

Strict measures are taken to make sure that donated blood and blood products are safe before they are given to you. To learn more about where donated blood comes from and the process of screening blood, these websites may help:

- American Cancer Society, Blood Donation and Transfusion, www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/BloodProductDonationandTransfusion/index



Managing Side Effects

A Patient's Guide to Chemotherapy



Johns Hopkins Kimmel Cancer Center
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Understanding Chemotherapy



Chemotherapy is often given in an outpatient setting.

Chemotherapy (“chemo”) is a treatment for cancer. Chemo can be a single medication. Or, it can be

a combination of medicines. When used alone or along with surgery or radiation therapy, it can often shrink a tumor or prevent its spread.

How chemotherapy works

Chemotherapy kills cells that grow quickly. Cancer cells can be fast growing cells; but many healthy cells grow fast, too. Fast growing cells of the mouth, stomach lining, bone marrow, skin and hair are able to grow back, but cancer cells that die, are not. That is why side effects such as hair loss, nausea, and low blood cell counts resolve with time. Usually, chemotherapy is given in "cycles" of treatment. A "cycle" is the time from one cancer treatment to the next. For example, if a treatment is given 2 weeks in a row, and then one week off, it is referred to as a 3 week cycle. If a treatment is given once every 3 week, it is referred to as a 3 week cycle, too. Time between treatments (during the cycle) is necessary to let normal cell recover before the next treatment.

The goals of chemotherapy

Chemo can kill cancer cells. As a result, it may do the following:

- Shrink cancer before surgery (neoadjuvent care)
- Rid the body of cancer cells that remain after surgery (adjuvent care)
- Reduce symptoms (such as pain) (palliative care)
- Control cancer for a period of time (palliative care)
- Cause remission (no evidence of the disease on medical testing)
- Cure cancer (no evidence of the disease years after treatment)

Side effects of chemotherapy

When healthy cells are damaged, side effects may develop including:

- Nausea and vomiting
- Hair loss
- Anemia (low red blood cell count)
- Infections
- Bleeding
- Mouth and throat sores
- Skin changes (dry skin, itching, acne)
- Lack of interest in sex
- Trouble remembering and concentrating
- Stress and depression

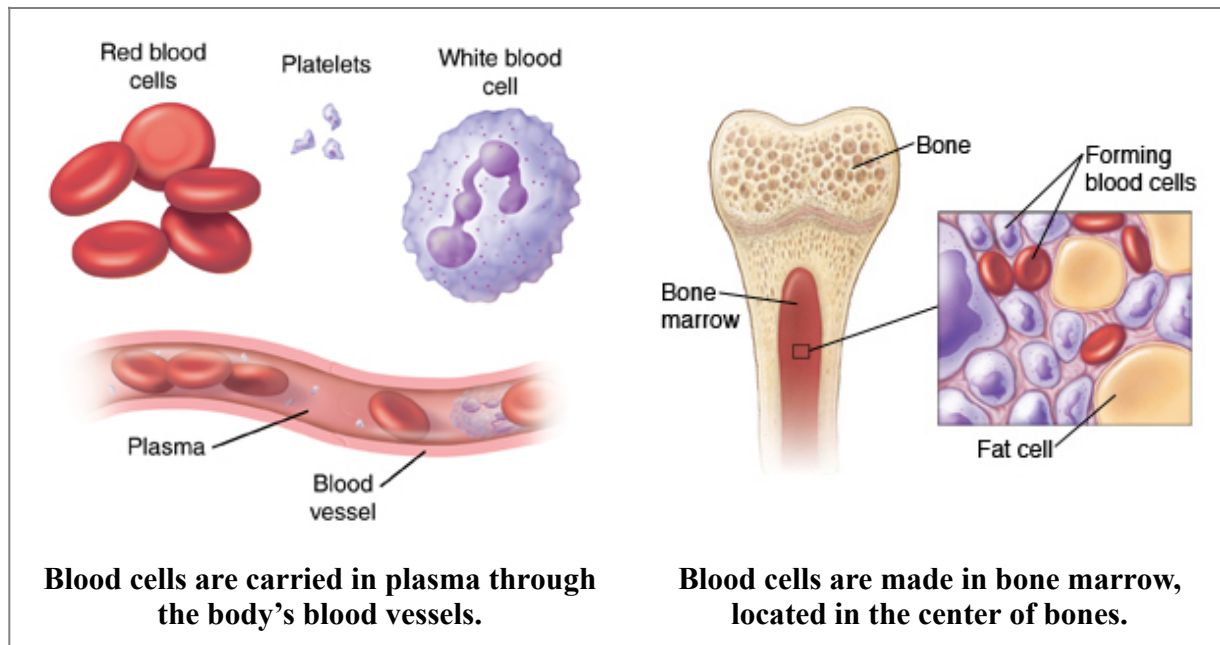
Long-term risks and complications

There are some long-term risks with chemo. But the benefits usually outweigh the risks. Risks depend on the type of chemo used. Some possible long-term risks include:

- Infertility
- Damage to certain organs, such as the heart, kidneys, liver, or lungs
- Lasting nerve damage
- Another cancer forming at a later time

Understanding Blood and Blood Components

Blood is a fluid that flows throughout the body in blood vessels. Blood is needed for life. Blood carries oxygen and nutrients to your organs and tissues and helps remove waste. Blood also helps you fight infections and heal from injuries. This sheet tells you more about blood and its important role in your body.



What are the components of blood?

Blood can be broken down into different parts (**components**). These components include red blood cells, white blood cells, platelets, and plasma.

- **Red blood cells (RBCs)** carry oxygen to the body. Each RBC lives for about 4 months. RBCs contain a protein called **hemoglobin**. Hemoglobin allows RBCs to pick up oxygen from the lungs. Iron is needed to make hemoglobin.
- **White blood cells (WBCs)** are part of the body's immune system. WBCs help fight infections and diseases. There are different types of WBCs. These include neutrophils, lymphocytes, monocytes, eosinophils, and basophils. WBCs live for days, months, or years depending on the specific type.
- **Platelets** are cells that help with clotting. When you have a cut or bruise, platelets come together to form a clot or "plug." This helps to control bleeding, so your body doesn't lose too much blood. Platelets live in the body for about 7 to 10 days.
- **Plasma** is the liquid portion of blood. It carries the different types of blood cells to all the parts of the body. Plasma also carries proteins called clotting factors. Clotting factors help platelets with the clotting process.

Where is blood made in the body?

Blood and plasma are made in the following ways:

- Blood cells are made in the **bone marrow**. The bone marrow is the soft, spongy part inside bones. New blood cells are made daily. They help replace the cells that die naturally or through

injury or illness.

- Plasma is made up mostly of water. Plasma is also made up of different proteins, fatty substances, salt, nutrients, vitamins, and hormones.

Oncology: Preventing Infections

Chemotherapy can make your body less able to fight off infection. This happens because treatment reduces the number of **white blood cells**. White blood cells fight infection in your body. To help prevent infections, follow the tips below.



Scrub your hands with soap and warm water for at least 15 seconds.

Know your nadir

The **nadir** is the time during your chemotherapy cycle when you have the fewest white blood cells. The length of your nadir and when it occurs depend on the medicines you are taking. Each medicine has its own nadir. Talk with your doctor or nurse about your nadir period. Then take extra precautions to prevent infection at that time.

Protect yourself

- **Keep your hands clean.** To reduce your risk of infection, bathe every day and wash your hands often throughout the day. For best results, lather them with soap for at least 15 seconds. Wash your hands before eating, after spending time in public places, and after using the bathroom.
- **Stay away from some foods.** Limit your risk. Don't eat uncooked or undercooked meat or fish. You may also be told not to eat raw vegetables or thin-skinned fruits during your nadir.
- **Reduce your risk for illness.** During this time your body is less able to fight off colds, measles, and other illnesses. Stay away from anyone who has a fever or an infection. Also stay away from large crowds during your nadir.
- **Wear gloves.** Make it harder for infection to enter your body. Wear gloves when you work around germs and dirt. Have someone else clean a pet's tank, cage, or litter box.
- **Try not to accidentally cut yourself.** Protect your feet from injury and germs by not walking barefoot.

How medicines can help

- **Prevent and treat infection.** Antibiotics work in this way by attacking and killing the germs that cause infection.
- **Trigger new cell growth.** These medicines cause your body to make new white blood cells. Neupogen is an example of such a medicine.

Talk with your doctor about the best medicines for you. In some cases, your doctor may tell you to not take acetaminophen or NSAIDs for pain relief because these medicines can “mask” a fever if you have neutropenia. Talk with your doctor about medicines for pain control if you need it during your nadir period.

When to seek medical advice

Contact your doctor right away if you have any of the following:

- Fever of 100.4°F (38°C) or higher, or as directed by your healthcare provider
- Burning when you urinate
- Severe coughing or sore throat
- Shortness of breath, sweating, or chills
- Pain, especially near an open wound or catheter site

Preventing Bleeding During Chemotherapy

Chemotherapy can make your blood less able to clot. This happens because the treatment reduces the number of **platelets** (clotting cells) in your blood. As a result, your risk of bruising and bleeding increases. To help prevent problem bleeding, use the tips on this handout.

Know what to expect

Some types of chemotherapy cause more bleeding problems than others. Often the risk of bleeding increases over the course of treatment. In any case, your risk is greatest during the **nadir** (the period in each treatment cycle when your platelet count is lowest). Talk with your doctor or nurse about your nadir period. Then take extra precautions to prevent bleeding at that time.

Avoid bleeding and bruising

- Use a soft toothbrush. If flossing or using a dental water jet causes bleeding, stop until your platelet count increases.
- Talk to your dentist about postponing teeth cleanings or dental work.
- Shave with an electric razor, not a straight razor.
- Ask your doctor which medications you should stop taking. Some, such as aspirin, make it harder for blood to clot.
- Eat a high-fiber diet to avoid constipation.
- Avoid contact sports or do activities likely to cause bruising.
- Do not use tampons or suppositories.

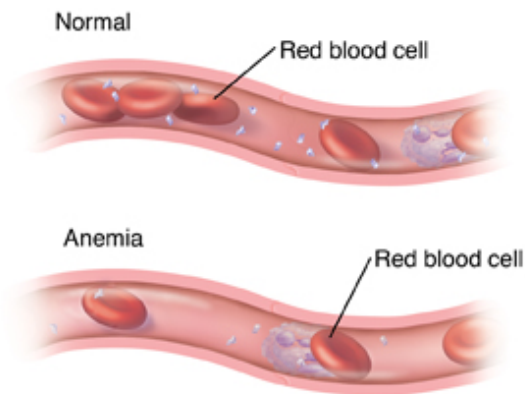
When to see your healthcare provider

Contact your doctor right away if you have:

- Blood in your urine or stool
- Easy bruising or small red spots under your skin
- Bleeding that won't stop (such as from gums or nose)

- Menstrual flow that is heavy or lasts longer than normal
- Vomiting, vision changes, frequent headaches

Anemia During Cancer



When levels of healthy red blood cells (RBCs) in the body drop to levels that are below normal, the condition is called anemia. Anemia can occur during cancer and its treatment for many reasons. Read below to learn more about anemia during cancer and how it's treated.

What is anemia?

RBCs are made in the bone marrow. Normal blood has about 35% to 50% RBCs. Anemic blood has less than 35% RBCs. RBCs carry oxygen around the body. If you have low levels of RBCs, not enough oxygen is delivered to your body. This may cause symptoms of dizziness, weakness, or tiredness. You may have trouble doing daily tasks. You may often feel cold. And you may be short of breath and have a rapid heartbeat. But some people with anemia have no symptoms.

Why anemia can occur with cancer

Anemia during cancer can have several **causes**. These include:

- Treatments that destroy bone marrow, such as chemotherapy and radiation therapy
- Blood loss during surgery
- Low levels of certain B vitamins or iron
- Kidney disease leading to low levels of EPO (erythropoietin), a substance the body needs to make RBCs
- Wasting (nutritional problems and weight loss) from cancer that lower the body's ability to make RBCs

Testing for anemia

A blood sample is taken from your arm and then tested. Several different types of tests may be done on this blood. Some count the numbers of blood cells. Others test for substances the body uses to make RBCs, such as vitamins and iron.

Treating anemia during cancer

Your treatment will depend on the cause of your anemia. It will also depend on how severe your symptoms are. Your doctor can tell you more about treatment options and their risks and benefits for you. Treatments include the following:

- **RBC transfusion.** A tube (cannula) is put into a vein in the hand or arm. RBCs from a donor are sent through the tube into the body. This increases the number of healthy RBCs in the body. This can reverse anemia very quickly. RBC transfusions are safe. However, there are some risks. Your doctor will discuss them with you. Be sure you understand these risks. You may need to sign a consent form before receiving treatment.
- **Erythropoiesis stimulating agent (ESA).** This is medicine that causes the body to make more RBCs. An ESA is given as a shot. It may be given along with iron (see below). An ESA takes several weeks or months to reverse anemia. There are special risks with ESA treatment. Your doctor will discuss them with you. Be sure you understand these risks. You may need to sign a consent form before receiving treatment.
- **Intravenous (IV) iron.** A liquid medicine containing iron is given by shots or IV line. Several treatments may be given. IV iron is usually used if you are being given an ESA. IV iron usually takes 1 to 4 weeks to reverse anemia.
- **Oral supplements.** Iron or vitamin B supplements may be given. These come in liquid or pill form, to take by mouth or they may be by injection. Oral supplements can take weeks or months to reverse anemia.

Checking your progress

During the course of your treatment, you'll likely have more blood tests. These are to check your blood levels and your response to the treatment.

Risks and complications

Each treatment has its own risks. Your healthcare provider will tell you what risks apply to you. These may include:

- Fever
- Hives or other allergic reactions
- Iron overload
- High or low blood pressure
- Nausea
- Liver inflammation
- Blood clots

Managing Fatigue



Family members can help with meals and chores around the house.

Fatigue is common. It can be caused by worry, lack of sleep, or poor appetite. Fatigue can also be a sign of **anemia**, a shortage of red blood cells. You might need medical treatment for anemia. The tips below can help you feel better.

Conserving energy

- Keep track of the times of day when you are most tired and plan around them. For instance, if you are more tired in the afternoon, try to get tasks done in the morning.
- Decide which tasks are most important. Do those first.
- Pass tasks along to others when you need to. Ask for help.
- Accept help when it's offered. Tell people what they can do to help. For instance, you may need someone to fix a meal, fold clothes, or put gas in your car.
- Plan rest times. You may want to take a nap each day. Just sitting quietly for a few minutes can make you feel more rested.

What you can do to feel better

- Relax before you try to sleep. Take a bath or read for a while.
- Form a sleep pattern. Go to bed at the same time each night and get up at the same time each morning.
- Eat well. Choose foods from all of the food groups each day.
- Exercise. Take a brisk walk to help increase your energy.
- Avoid caffeine and alcohol. Drink plenty of water or fruit juices instead.

Treating anemia

If you begin to feel more tired than normal, tell your doctor. Fatigue could be a sign of anemia. This problem is fairly common in cancer patients, especially during chemotherapy and radiation treatments. If your red blood cell count is too low, you may get a blood transfusion. In some cases, you may need medicine to increase the number of red blood cells your body makes.

When to call your healthcare provider

Call your healthcare provider if you have:

- Shortness of breath or chest pain
- A dizzy feeling when you get up from lying or sitting down

- Paler skin than normal
- Extreme tiredness that is not helped by sleep

Oncology: Controlling Nausea and Vomiting



Taken before meals, medicines can help ease nausea.

Nausea and vomiting are common side effects of chemotherapy and radiation therapy. Side effects happen when treatment changes some normal cells as well as cancer cells. In this case, the cells lining your stomach and the part of your brain that controls vomiting are affected.

Nausea is feeling that you need to throw up. Vomiting is when you actually do throw up. This is when your body forces food that is in your stomach out through your mouth.

Nausea and vomiting are common. They can be caused by many things. These include:

- Stomach flu (gastroenteritis)
- Food poisoning
- Stomach pain (gastritis)
- Blockages in the digestive system
- Constipation
- Infection

- Anxiety and stress

They can also be caused by a head injury, an infection in the brain or inside the ear, or migraines. Other common causes of nausea and vomiting include:

- Brain tumor
- Brain bruise or injury
- Motion sickness
- Alcohol, pain medicines such as morphine, and cancer medicines (chemotherapy)
- Certain medical treatments, such as radiation therapy
- Poisonous things (toxins) such as plants or liquids that are swallowed by accident
- Advanced types of cancer
- Movement problems (psychogenic problems)

Extra pressure in the fluid that surrounds the brain and spinal cord (elevated intracranial pressure)

Sometimes belly (abdominal) pain and cramps are experienced along with nausea and vomiting. The symptoms can be mild and go away by themselves. Other symptoms can be serious and must be treated.

When to seek medical advice

Nausea and vomiting can happen before, during, or after cancer treatments. But it can be controlled. Don't consider it a normal part of cancer and cancer treatment. If not managed, it can become serious. It can change the fluid and chemical balances in your body, and could even keep you from getting cancer treatment. Call your healthcare provider right away if any of the following occur:

- You have nausea or vomiting that lasts 24 hours or more
- You can't take your antiemetics, or they are not working
- You have trouble keeping fluids down
- You become dizzy, lightheaded, or confused
- You have very dark urine or you stop urinating

Talk to your healthcare provider about your treatment and the nausea and vomiting management plan that's best for you. Be sure you know how and when to use antiemetics and when to call your provider.

Medicines can help

Nausea or vomiting can often be prevented or controlled with medicines called antiemetics. Your provider may give you antiemetics before or after treatment if you are getting chemotherapy or other treatments that cause nausea or vomiting. You may have to try different medicines or different combinations of medicines to get relief. But in nearly all cases, nausea and vomiting can be relieved.

Eating tips

- If you have medicines to control nausea, take them before meals as directed.

- Avoid fatty or greasy foods while nauseated.
- Eat small meals slowly throughout the day.
- Ask someone to sit with you while you eat to keep you from thinking about feeling nauseated.
- Eat foods at room temperature or colder to avoid strong smells.
- Eat dry foods, such as toast, crackers, or pretzels. Also eat cool, light foods, such as applesauce, and bland foods, such as oatmeal or skinned chicken.
- Try to keep taking in clear fluids in small sips, or as ice chips, gelatin, or ice pops.

Other ways to feel better

- Get a little fresh air. Take a short walk.
- Talk to a friend, listen to music, or watch TV.
- Take a few deep, slow breaths.
- Eat by candlelight or in surroundings that you find relaxing.
- Use a method to help you relax, such as guided imagery. Imagine yourself in a beautiful, restful scene. Or daydream about the place you'd most like to be..

Mouth Care During Chemotherapy



Brush gently with an extra soft toothbrush and mild toothpaste.

Mouth sores (stomatitis) and dry mouth are common side effects of chemotherapy and radiation therapy. These side effects occur because these treatments affect normal cells as well as cancer cells. Using the tips on this handout may help you feel better.

Remedies that help

- Rinse with 1 teaspoon baking soda and 1 teaspoon salt mixed in 1 quart of warm water. Swish and spit. This helps keep your mouth free of germs.
- Use products that coat and protect the mouth and throat. Or use medicines that coat and soothe mouth sores themselves.
- Numb your mouth and throat with special sprays or lozenges to make eating easier.

Prevent mouth sores

- Buy an extra soft toothbrush and mild toothpaste.
- Gently brush your teeth and gums.
- Have your dentist treat any dental problems before your therapy begins.

Moisten a dry mouth

- Drink plenty of water. Take frequent sips or suck on ice chips.
- Suck on sugar-free candy and lozenges. Chew sugar-free gum.
- Use products that moisten the mouth if your doctor prescribes them.
- Apply lip balm to help prevent dry lips.
- Don't use mouthwash that contains alcohol.

Choose foods less likely to irritate

Try foods that are:

- Soft and go down smoothly, such as a milkshake or food puréed with a blender
- Served cold or at room temperature
- Cooked until tender and cut into small pieces

Don't eat foods that are:

- Sharp or crunchy
- Hot, salty, or spicy
- Acidic, such as citrus juices

When to seek medical advice

See your healthcare provider if:

- You develop mouth sores
- Mouth pain keeps you from eating or resting

Oncology: Coping With Hair Loss



A short haircut may make it seem as if you are losing less hair.

Hair loss is a common side effect of chemotherapy and radiation therapy. It occurs because these treatments affect normal cells as well as cancer cells. Not all types of chemotherapy and radiation therapy cause hair loss, but if it does happen, these tips can help.

Making hair loss easier

- Get a short haircut to make hair loss seem less sudden.
- Use soft brushes and mild shampoos.
- Towel dry your hair or set your hair dryer on low heat.
- Don't color or perm your hair. It is not dangerous to do so, but you may be disappointed with the results or durability.
- Have a wig made before hair loss occurs. Buy one or find out how you can borrow one. Your local American Cancer Society may be able to help. Also, if your health care provider writes a prescription for a wig, your insurance may help pay for it.
- Fill in missing patches of eyebrow with a makeup pencil.

When you've lost your hair

- Wear a hat, scarf, or turban. Doing so can protect your scalp as well as make hair loss less obvious.
- Have someone shave the remaining patches if your hair loss has been uneven.
- Expect that there may be changes in the color or texture of hair that grows back after treatment ends.

Taking care of your scalp

- Use sunscreen with an SPF of at least 15 on your scalp any time you go outside. Wear hats and scarves.
- Keep your scalp clean.
- See a skin doctor about any changes in skin color.
- Ask your doctor to suggest a mild shampoo and lotion.

- If you wear a wig, take it off for a while each day. This allows the skin on your head to breathe.

This information is not intended as a substitute for professional medical care.

Always follow your health care provider's instructions.



What Is Delirium?

Delirium is a sudden change in a person's mental state that varies over short periods of time. It can cause a person to have a hard time paying attention or have a conversation. Their thinking and speech may not make sense and be random. A person's mental state may change from being restless and alert to slow and sleepy. At times, the person can be confused, argue, and see or hear things that you don't.

Delirium is a medical emergency. If it is not diagnosed and treated, it can lead to lasting problems or death.

Who is at risk?

Delirium happens most often in older adults. It can happen when a person is in an unfamiliar place, such as a hospital. It's common after surgery or during a serious illness. Drug abuse withdrawal from drug or alcohol use can cause it. Some medicines can cause it. And toxins and infections can cause it. A disease that affects the kidneys or liver can cause toxins to build up in the body. This can cause delirium. Not enough oxygen due to lung disease can cause it.

In most cases, something triggers the delirium. Often it may be the first sign that a person has dementia. But dementia is a different condition. It is permanent and usually gets worse over months to years.

Delirium can be upsetting for family and friends to see. But steps can be taken to help manage it. These can help ensure your loved one's safety and comfort.

What are the signs of delirium?

The signs of delirium can come and go over hours or days. A person may:

- Seem sleepy and quiet
- Be confused*
- Have trouble paying attention and focusing*
- Not know where he or she is*
- See or hear things that others can't see or hear (hallucinations)
- Believe things that aren't known to be true (delusions)
- Think that people want to harm the person (paranoia)
- Have trouble remembering things that just happened*
- Change the subject too often while talking
- Talk about things that may not make sense*
- Seem restless and alert
- Become violent*
- Have less interest in eating*
- Appear to be depressed and not interested in doing things*
- Have quick emotional changes such as anxiety or sadness, or strong moods of joy and excitement (euphoria)
- Be unsteady while walking*
- Have twitching or stiff movement in the arms, legs, or neck*

*These symptoms can also happen with dementia and other health problems. Talk with a healthcare provider if a person has these.

If you think someone has delirium

Delirium is a medical emergency. If you think a person has delirium, get medical help right away. If the person is at home, call 911. If he or she is in the hospital, tell a healthcare provider right away.

Oncology: Controlling Diarrhea

A common side effect of cancer and cancer treatment is diarrhea. This is when you have loose, watery stools more often than usual. There are many things that can cause diarrhea, such as:

- Chemotherapy
- Radiation therapy to the belly or pelvis
- Medicines, such as antibiotics
- Infection
- Stress

Diarrhea can cause you to quickly become dehydrated. It can also change the balance of nutrients and minerals in your body. To help limit this problem, try the tips on this handout.



For breakfast, try eating toasted white bread and a banana.

Tips for controlling diarrhea

These steps can help you keep diarrhea from starting or getting worse:

- Limit the amount of fiber in your diet. Don't eat high-fiber foods such as whole-grain bread and brown rice. Instead, eat white bread and rice.
- Eat foods rich in potassium, such as bananas and oranges. This can help replace electrolytes lost due to diarrhea.
- Eat small, frequent meals.
- Drink plenty of fluids. Water, juice, sports drinks, and flat light sodas, such as ginger ale, are best. They can help replace fluids lost due to diarrhea.
- Stay away from coffee, tea, and alcohol.
- Don't eat foods that are fried, greasy, spicy, or sweet.
- Limit milk products and how much milk you drink.

Medicines can help

Ongoing diarrhea is not something you have to live with. And it can become harmful. Talk with your healthcare provider about:

- Your risk for diarrhea
- What you can do to try to prevent it
- What you should do if it starts

You may be given medicine to stop diarrhea or help keep it from starting. Your healthcare provider may also suggest these tips:

- Use an ointment to soothe irritation.
- Keep the anal area clean with a mild soap or baby wipes.

. Don't take any over-the-counter products without checking with your healthcare provider first.

When to call your healthcare provider

See your healthcare provider if any of these happen:

- The diarrhea lasts more than 24 to 48 hours.
- There is blood in your stool or when you wipe.
- You have pain in your belly.
- You become lightheaded or dizzy.
- Your urine turns very dark or you stop urinating.
- The medicine you were given to stop diarrhea is not working.

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Graft-versus-Host Disease (GVHD)

What is GVHD?

- Graft versus host disease (GVHD) is a possible risk of an allogeneic blood or marrow transplant (allo BMT).
- GVHD can last weeks or months. In some cases, GVHD can come and go.

What causes GVHD?

GVHD happens when some of the new white blood cells from the donor (graft) see you (the host) as foreign and attack your skin, liver, GI tract, and/or lungs.

What are the signs and symptoms of GVHD?

- Red rash (like sunburn) which may be itchy; often on the palms of the hands, soles of the feet, and ears. It can become a total body rash with blister formation
- Nausea that doesn't go away even with medicine
- Diarrhea (large amounts of watery, sometimes bloody, stools)
- Abdominal pain and cramping
- Yellowing of the skin
- Increase in liver blood values

The symptoms of acute GVHD can range from very mild (most common) to severe (rare). Please let your doctor or nurse know if you have any of these symptoms.

How is GVHD diagnosed?

A sample of the skin, liver or other organs involved may be taken for diagnosis.

Who is at risk for GVHD?

- All patients who receive an allogeneic blood or marrow transplant are at risk for GVHD.
- Patients who received peripheral blood stem cells are at higher risk than those who received stem cells from bone marrow.

What symptoms need to be reported to my doctor or nurse?

The symptoms of GVHD can range from very mild (most common) to severe (rare). Please let your doctor or nurse know if you have any of these symptoms.

- Skin: Red skin, red bumps on the skin, increased dryness, loss of hair, decreased ability to sweat, lightening or darkening of the skin, any other changes in the appearance of the skin.
- Mouth: Sores, white areas, sensitivity to foods (spicy foods, toothpaste, citrus, soft drinks), increased dryness.
- Eyes: Increased dryness or grittiness, pink eye, discharge, yellow appearance of white of the eyes and light sensitivity.
- GI: Diarrhea, nausea, stomach cramping, weight loss.
- Muscles: Loss of movement in the joints, increase in weakness, SEVERE cramping.
- Lungs: Shortness of breath, especially with exercise.

What are the treatments for GVHD?

- Allo BMT patients receive medicines to prevent GVHD (immunosuppressive drug therapy). The most common medicines are tacrolimus, sirolimus, mycophenolate mofetil and cyclophosphamide.
- GVHD can be treated with steroids to limit the immune response of donor cells against your body. Other treatments may be used as needed.

- If your GVHD is mild, it may not be treated.

What can I do to prevent GVHD?

- Don't get a sun burn. Wear a broad-spectrum sunscreen that contains zinc oxide or titanium (SPF>30) every day.
- Don't forget the top of your head and your ears! Wear a wide brim hat to protect your face and neck.
- Don't over heat. You may not be able to control your body temperature as well as you have in the past.
- Report symptoms early to your doctor or nurse.
- Take your medicines as ordered and let your doctor or nurse know if you cannot take them.

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Exercise after a Blood and Marrow Transplant

Why Exercise?

Exercise and being active may help you to:

- Maintain your strength and activity levels.
- Feel independent and improve your mood.
- Keep your lungs, bones, and muscles healthy.
- Decrease risk of infections or pneumonia.
- Lessen your risk of falling.
- Decrease the amount of time you have to stay in the hospital.
- Improve your appetite.
- Reduce your tiredness.

Is there anything I should do to get ready to exercise?

- You will be more likely to stick with your exercise program if you feel safe and comfortable while exercising.
- Wear loose fitting clothes.
- Always wear shoes that fit well that are designed for exercise.
- Wear a hat when it is cool outside to retain body heat.
- Wear a visor or hat and use sunscreen to protect your eyes and skin from the sun.
- Drink plenty of fluids before, during, or after exercise (unless you are on a water-restricted diet).
- Keep track of the times of day when you are most tired and plan around them. For example, if you are more tired in the afternoon, try to walk or exercise in the morning.
- Ask your health care provider if you have questions or would like to set an exercise goal.

How should I exercise?

- Spend as much time as you can out of bed and active.
- If you have been lying down, sit at the edge of the bed for a moment before standing.
- If you are in the hospital, check with your nurse before leaving the unit or clinic and wear an N95 mask. You can wear a paper mask while on the unit.
- Ask your nurse about our available exercise stretch bands, treadmills, reclining bike, and chair cycles in the hospital.

How much should I exercise?

- Exercise at a good level for you, not to keep up with family members or other patients.
- Adjust your exercise level based on your symptoms and level of fatigue.
- Perform the “talk test.” If you are unable to talk, you are exercising too hard. Slow down until you can talk comfortably while exercising.
- You might find it helpful to keep an exercise journal to record your exercise and how you felt doing it.

Stop exercising and call your doctor or nurse if you have any of these symptoms:

- **Chest pain, chest tightness, or light headedness.**
- **Unusual shortness of breath.**
- **Heart palpitations or irregular heart rate.**
- **Unusual or increased body pain.**

What else can I do to improve my energy?

- Plan rest times. You may want to take a nap each day. Just sitting quietly for a few minutes can also help make you feel more rested.
- Keep regular bedtime hours. Go to bed at the same time each night and get up at the same time each morning.

What team members may help me with exercise?

The Doctors, Nurse Practitioners and Physician Assistants may recommend therapy and suggest limits regarding exercise if needed.

The Nurses will help you to do general exercises like walking and using a bike, as well as assist you in following the plans of PT and OT.

A Physical Therapist (PT) may work with you to set up a treatment plan to improve your strength, balance, mobility and activity level. They may suggest equipment to assist with your walking, such as a cane or walker, to improve your safety.

An Occupational Therapist (OT) may work with you to improve your ability to complete activities of daily living, such as bathing, dressing, and grooming, and suggest equipment for home (ex: shower chair, bedside commode) to make those things easier to do. They may assist with upper body strength, hand coordination, fatigue, vision loss, and memory/concentration.

Are there any other resources that may be helpful?

- Johns Hopkins Cancer Rehabilitation Program
 - Meyer 1-130. 600 N. Wolfe Street, Baltimore, MD.
 - Phone: 410-614-3234
 - http://www.hopkinsmedicine.org/physical_medicine_rehabilitation/
- The American Physical Therapy Association Website
 - www.apta.org
 - Click “Find a PT” located at the very top of the web page.
 - Enter your information when asked.
 - Select “Cancer” when asked to search by practice area.
- Oncology Nursing Society “Get up and Moving Campaign” with videos
 - <https://www.ons.org/practice-resources/get-up-getmoving>

References

Some content adapted from KODI, The StayWell Company:
“Chemotherapy: Common Questions about Activity During Treatment,” “Exercising Safely,” “Cancer: Managing Fatigue”

This information is not intended as a substitute for professional medical care.

Always follow your health care provider's instructions.



Eating Well



Dear Patient,

The nutrition staff at the Sidney Kimmel Comprehensive Cancer Center is a team of Registered and Licensed Dietitians who specialize in Oncology. We can assist you with any nutrition concerns you may have; such as weight loss, eating difficulties, use of supplements and eating during treatment.

At some point in your treatment, a member of your health care team may suggest a nutrition consult. Cancer treatments can have side effects that interfere with how well you can nourish yourself. People who eat well are better able to deal with the side effects of cancer treatment.

It is helpful to see a Dietitian as soon as you start to have weight loss, loss of appetite, taste changes, swallowing problems, mouth sores, nausea, constipation or diarrhea.

To schedule an appointment with a Dietitian, please call 410-955-8152. When leaving a message, please provide your name and phone number. Most health insurance companies will cover this service, but you should check with them in advance about coverage and to obtain permission for care.

Sincerely,

The Department of Clinical Nutrition

The Johns Hopkins Hospital

9/2019

Nutrition During Chemotherapy

During chemotherapy, the energy provided by a healthy diet can help you rebuild normal cells. It can also help you keep up your strength and fight infection. As a result, you may feel better and be more able to cope with side effects. Ask your doctor about your nutrition needs.

Drink plenty of fluids

- Fluids help the body produce urine and decrease constipation. They help prevent kidney and bladder problems. They also help replace fluids lost from vomiting and diarrhea.
- Try water, unsweetened juices, and other flavored drinks without caffeine. They flush toxins from the body.



Drink plenty of liquids, such as water.

Get enough calories

- Calories are fuel. The body uses this fuel to perform all of its functions, including healing.
- It's OK to be lean, but be sure you are not underweight. If you are, try eating more calories.
- Eat calorie-dense foods such as avocados, peanut butter, eggs, and ice cream.
- If you need extra calories, add butter, gravy, and sauces to foods (if tolerated).
- If you don't need the extra calories, try to limit foods that are fried, greasy, or high in fat or added sugar.

Eat protein, fruits, and vegetables

- Protein builds muscle, bone, skin, and blood. It helps your body heal and fight infection. It also helps boost your energy level.

- Good protein choices include yogurt, eggs, chicken, lean meats, beans, and peanut butter.
- Fruits and vegetables are full of important vitamins, minerals, and fiber to help your body function properly.
- Try to eat a variety of vegetables, fruits, whole grains, and beans.
- Ask your doctor about instant protein powder or other supplements.

Eating right during treatment

Side effects may make it a little harder to eat well on some days. The following tips will help you continue to get the nutrition you need:

- Be open to new foods and recipes.
- Eat small portions often and slowly.
- Have a healthy snack instead of a meal if you are not very hungry.
- Try eating in a new setting.
- Physical activity, such as walking, can help increase your appetite. Try to be active for at least 30 minutes each day.
- Boost your diet by getting the vitamins and minerals you need from fruits, vegetables, and whole grains.
- If you live alone and are not up to cooking, ask your healthcare provider about Meals on Wheels or other outreach programs.
- Sometimes, it is best to follow your appetite. Eat when you are hungry, but when you are not, forcing yourself to eat can make you feel bad, nauseated, or even cause you to vomit.

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The Johns Hopkins Hospital Patient Information

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Hydration and Fluid Needs

<p>Why is hydration important?</p>	<p>Hydration, or getting enough fluids, is important to prevent dehydration, prevent constipation and to clean your kidneys after certain chemotherapy and medications.</p>
<p>What are some signs that I am not getting enough fluids?</p>	<p>Some signs that you are not getting enough fluids are:</p> <ul style="list-style-type: none"> • dry mouth and skin • dizziness (especially when you stand up) • dark yellow urine • fatigue
<p>What counts as a fluid?</p>	<p>Fruit juices Baked custard/Puddings Broth/Strained and blended cream soups Caffeine-free coffee and teas Caffeine-free soft drinks/sodas Fruit-flavored drinks/Sports drinks Gelatins Ice milk/sherbet/sorbet/smooth ice cream Liquid meal replacements Italian ice/Popsicles Water and ice Milk/soy/rice milkshakes Pasteurized eggnog Strained lemonade/limeade Thin fruit purees</p>
<p>Are there any other tips I should know about?</p>	<ul style="list-style-type: none"> • If you are thirsty, you are already dehydrated, so drink <u>before</u> you are thirsty! • Caffeinated and alcoholic drinks do not count toward daily fluid goals. • Add foods to your diet that contain a lot of fluid (popsicles, gelatins). • Sip fluids throughout the day, using a straw may help.
<p>Other Resources</p>	<p>For additional information, contact Oncology Nutrition Service at 410-955-8152.</p>



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Foods For Sore Mouth and Sore Throat

<p>What can cause a sore mouth and throat?</p>	<p>Sore mouth and sore throat (also called mucositis or esophagitis) are side effects of chemotherapy and radiation therapy. They can make it hard to chew and swallow your food. Often they will limit your food intake so that you can't eat and drink enough.</p>
<p>What foods can I try?</p>	<ul style="list-style-type: none"> • Choose soft, creamy foods such as mashed potatoes, custard, pudding, eggs, casseroles, macaroni and cheese, and milkshakes with ice cream. • Select lukewarm or cool foods that soothe the throat. Very hot or very cold foods can be painful. Melons, canned fruit, fruit nectars, warm or cold cream soups, cottage cheese, and yogurt work well. • Make solid foods easier to swallow by adding gravy, sauces, salad dressing, mayonnaise, or margarine. • Take 1- 2 high protein, high calorie shakes or supplements every day. Shakes between meals can boost calories and help prevent weight loss.
<p>What foods should I avoid?</p>	<ul style="list-style-type: none"> • Don't eat crunchy, crispy foods like grainy cereals and breads, dry toast, crackers, pretzels, potato chips, popcorn, nuts, raw fruits and vegetables. • Stay away from sour, salty, and acidic food or drinks such as: <ol style="list-style-type: none"> 1. Citrus fruits and juices (like orange, grapefruit, and lemon) 2. Pickled and vinegary foods (like relishes and pickles) 3. Tomato-based food and drinks (like spaghetti, pizza, tacos, salsa, and tomato juice) • Spices like pepper, curry, cumin, chili powder, paprika, cloves, nutmeg, cinnamon, and horseradish used in cooking can irritate the mouth and throat. Peppermint and spearmint can also inflame sensitive areas. • Avoid alcohol and caffeine (like chocolate, colas, coffee, and tea.) Decaffeinated colas, coffee and tea are okay.
<p>Other Tips</p>	<ul style="list-style-type: none"> • Drink through a straw to avoid the mouth when it hurts. • Keep your teeth and gums clean to reduce the bacteria in your mouth. • You may need medicines to control pain or infection. Be sure to take them on time as prescribed by your oncologist or dentist. • Nicotine can increase mucous and acid production, so avoid tobacco. • Drink plenty of fluids. Your fluid needs are ____ ounces (____ cups). If juices or electrolyte beverages (such as Gatorade®) are uncomfortable to drink, try an unflavored oral rehydration solution (such as unflavored Pedialyte®).



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How to Increase Calories

Nuts and Seeds	<p>Eat as a snack.</p> <ul style="list-style-type: none"> -Add to pancakes, muffins, waffles, cakes. -Use as a topping for salads, cereals, fruit, ice cream, pudding, yogurt or baked goods.
Nut Butters	<ul style="list-style-type: none"> -Spread on bread, crackers, bagels, fruits. -Add to cookies, brownies and milkshakes.
Granola	<ul style="list-style-type: none"> -Mix with dry fruits and nuts for a snack. -Sprinkle on yogurt, ice cream, custard, pudding, cereal, pancakes, waffles, and fruit. -Use in cookie, muffin, and bread batters. -Layer with fruits and bake.
Dried Fruit	<ul style="list-style-type: none"> -Add to muffins, pies, cakes, breads, cookies, pancakes, stuffing, rice and grain dishes, chicken or tuna salad. -Use as a topping for cereal, yogurt, pudding, ice cream. - Combine with nuts and granola for a snack. -Combine with cooked vegetables such as carrots, sweet potatoes, and squash.
Bean Dip and Hummus	<p>Use as a topping for chips, crackers, bread, baked potatoes, tortillas, bagels, pita bread.</p>
Cheese and Cheese Sauce	<ul style="list-style-type: none"> -Add to sandwiches, scrambled eggs or omelets, casseroles, mashed potatoes, soups. -Use as a topping for salads, cooked vegetables, pasta, crackers, bagels, bread, tortilla chips.
Milk and Cream	<ul style="list-style-type: none"> -Use whole milk instead of low fat. -Use cream instead of milk. -Add powdered milk to foods. -Use for milkshakes and hot chocolate. -Use in mashed potatoes, cream soups, chowders, casseroles, pudding, and custard. -Put on hot or cold cereal. -Use as a binder for hamburgers or meatloaf.
Cream Cheese	<ul style="list-style-type: none"> -Spread on bread, muffins, bagels, toast, crackers. -Use as a dip for fresh fruit or vegetables. -Stir into tomato sauces. -Add to sandwiches.



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How to Increase Calories

Sour Cream	<ul style="list-style-type: none"> -Add to mashed potatoes, casseroles, stews, cream soups, macaroni and cheese, au gratin potatoes, sauces, and salad dressings. -Use as a topping for baked potatoes, beans, chili, baked meat and fish. -Use as a topping for cakes, fruit, gelatin desserts, breads, and muffins. -Use as a dip for fresh vegetables.
Oils	<ul style="list-style-type: none"> -Use to stir fry vegetables, chicken, fish, eggs. -Use as a dip for breads. -Drizzle over pasta or salads. -Add to milkshakes.
Avocado	<ul style="list-style-type: none"> -Add to sandwiches or salads. -Use for guacamole dip.
Butter and Margarine	<ul style="list-style-type: none"> -Spread on bread, crackers, bagels, muffins, pancakes, and waffles. -Add to mashed potatoes, baked potatoes, cooked vegetables, rice, pasta, hot cereals. -Stir into cream soups, sauces, and gravies. -Combine with herbs and seasonings and spread on cooked meats, fish, and poultry. -Use melted butter or margarine as a dip for raw vegetables, and seafood such as shrimp, scallops, crab, and lobster.
Gravy	<ul style="list-style-type: none"> -Use to top mashed potatoes, meats or poultry, rice, noodles.
Mayonnaise	<ul style="list-style-type: none"> -Add to sandwiches. -Use in tuna, chicken, egg, vegetable or pasta salads. -Add to vegetable dips.



Caregiving



CANCERcare®

800-813-HOPE (4673)
info@cancercaare.org
www.cancercaare.org

fact sheet

CARING ADVICE FOR CAREGIVERS: HOW CAN YOU HELP YOURSELF?

Caregivers are individuals who provide emotional and physical care for a person with cancer. Being a caregiver can be a full-time job, and caregivers often put their own needs or feelings aside while caring for their loved one. Taking good care of yourself is an important part of being a caregiver. This can improve your quality of life and help you to be better equipped to handle your caregiving responsibilities.



HERE ARE SOME TIPS FOR TAKING CARE OF YOURSELF WHEN YOU'RE A CAREGIVER:

Organize help.

Decide which of your loved one's needs you can or would like to meet on your own, and which ones you need help with. Then, ask family members, friends, neighbors, co-workers or professionals to share the care. Ideally, many people will want to help. Realistically, only one or two people may be available. Still, these individuals can make a big difference. Check with community agencies, religious institutions or a hospital social worker for information on volunteer and respite care programs.

Join a support group for caregivers.

Support groups help many caregivers feel less alone. They provide a safe, supportive environment for sharing feelings and discussing the challenges and rewards of being a caregiver. Group members provide a listening ear and share tips and resources they've learned along the way. CancerCare offers free, professionally led, face-to-face, telephone and online support groups for caregivers.

Become informed.

Learn about your loved one's diagnosis and treatment so you have a sense of what to expect. With your loved one's permission, you may want to speak to the doctor or nurse if you have any concerns. He or she can recommend resources for learning more and getting support. Find out who else on the health care team (such as an oncology social worker, oncology nurse or pharmacist) is available to help you if you have any questions.

Understand your rights.

Under the Family and Medical Leave Act, most employers are required to provide up to 12 weeks of unpaid, job-protected leave for family members who need time off to care for a loved one. For help with insurance rules and regulations, contact your insurance company. Many insurance companies will assign a case manager to address concerns, clarify benefits and suggest ways to obtain additional health-related services.

(over)



Keep up with your own check-ups, screenings and medications.

Your health is very valuable. Stay on top of your doctor appointments, and find a good system for remembering to take any medicines you need to stay healthy.

Get individual help.

As a caregiver, you may sometimes feel overwhelmed and need more than friends or family members to talk to. Speaking with a counselor or social worker can help you cope with some of the emotions or concerns you may be facing. CancerCare provides free individual counseling from oncology social workers who specialize in helping people with cancer and their loved ones and caregivers.

Do something good for yourself.

Take a few moments for yourself each day to do something enjoyable or relaxing, even if it's just taking a walk around the block. Give yourself credit for all you do as a caregiver, and find ways to reward yourself for your hard work.

CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers.

To learn more, visit www.cancercare.org or call **800-813-HOPE (4673)**.

Facebook: [facebook.com/cancercare](https://www.facebook.com/cancercare)

Twitter: @cancercare

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Caregiver Resources

Programs and Support Groups

Caregiver Café-Are you taking care of or supporting someone with cancer? You are invited to our Caregiver Café to relax, meet other caregivers and ask your questions. Just stop by on Thursdays from 11-12 in the Weinberg 5th floor waiting area across from the visitor elevators. No reservations needed. All caregivers welcome.

Ask the Expert- Caregiver Skills. A place to ask your questions about taking care of your loved one (mouth care, nutrition, catheters, dressings, etc.) and yourself.

More information about these programs and others are available on the Living with Cancer Calendar which can be found in the Patient Education Room on the 2nd floor, the 1st floor waiting area and at this website:

http://www.hopkinsmedicine.org/kimmel_cancer_center/patient_information/resource_programs.html

Walking on Eggshells Videos cover a wide range of topics, such as communicating with healthcare providers and children, taking care of yourself, finances:

http://www.hopkinsmedicine.org/kimmel_cancer_center/patient_information/videos/caregivers.html

Fine Print of Cancer, Caregiving Video shares what it is like to be a caregiver:

http://www.hopkinsmedicine.org/kimmel_cancer_center/patient_information/videos/fineprint.html

If you would like to speak to a **Social Worker**, please call:
1-410-955-8934

Medical Care for Yourself

If you need medical care, you can call Johns Hopkins USA at 410-464-6555 or 855-695-4872 or email husa@jhmi.edu. The website is www.hopkinsmedicine.org/usa/. Our social workers can also make the referral for you.

Websites

www.cancercare.org
www.caringbridge.org

Resources

“Caring for Your Loved One with Cancer,”
http://www.cancercare.org/publications/1-caregiving_for_your_loved_one_with_cancer, Cancer Care.

“Young Adults as Caregivers”
http://www.cancercare.org/publications/141-young_adults_as_caregivers



Care at Home



Welcome to IPOP/HIPOP

What is IPOP/HIPOP?

- IPOP/HIPOP Is a clinic on the 5th floor of the Weinberg building. IPOP stands for Inpatient-Outpatient, and HIPOP stands for Hematological Inpatient-Outpatient.
- The IPOP part of the clinic is between the inpatient units 5A and 5B. The HIPOP part is between 5C and 5D. You might be seen in either clinic space.
- IPOP/HIPOP is a special clinic for patients who don't need inpatient care, but need close monitoring and treatments such as blood transfusions, chemotherapy, antibiotics, pain and symptom management, catheter care and daily blood count checks.
- The clinic is open 7:00 AM to 7:00 PM, seven days a week, including holidays.
- The phone number is 410-614-4501.

Are there any special requirements to be an IPOP/HIPOP patient?

There are two things you need to be a patient in IPOP/HIPOP to keep you safe while your blood counts are low.

- **24 hour caregiver:** You need a responsible adult with a car who will be with you around the clock at home. This does not have to be one person, but multiple people can help cover the 24 hours. Your caregiver does not have to stay when you come for your clinic visit as long as he or she comes up to the clinic to check in with the nurse, but some patients need extra help while in the clinic and having your caregiver with you can be very helpful.
- **Housing within 1 hour drive of the hospital:** Some patients live far away from the hospital, and will need to find a local place to stay. Our Housing Coordinator can help you find one. The phone number is 410-614-6527.

Where can I park when I come to the clinic?

- Parking is available under the Weinberg building for a fee. Valet parking service is available in the circular drive in front of the Weinberg building from 7am to 4pm. The valet fee may be reduced by validating your ticket in the 1st floor Welcome Center.
- You can also get a "Weinberg Appointment" sign for your windshield from the PSC to give you priority parking in the Weinberg building.
- If the Weinberg lot is full, you will be directed to another parking facility or you can use the valet service.
- Discount parking coupons may be bought at the self-service kiosk in front of the Welcome Center on the 1st floor.
- Ask your social worker about a possible refund from the Leukemia and Lymphoma Society if you need one.
- Parking is free at Hope Lodge for residents.
- There is a small parking fee at the Hackerman-Patz House.
- For more parking information, call 410-955-5333.

What do I do when I arrive for an appointment?

- You will need an orange card to register. If you don't have an orange card, please go to the Welcome Center on the 1st floor. You may need to go into the Center to pay co-pays or sign forms, but please do not wait in a long line. Come to IPOP first and have your blood drawn, so your visit will not be delayed.
- If you have an orange card, swipe it at the kiosk on the 5th floor. This lets our staff know that you are here. If you have issues checking in at the kiosk, see the Patient Service Coordinator (PSC) at the desk when you enter 5A.
- Next, take a seat in the waiting area behind the kiosk on the 5th floor and wait to be called by a Clinical Technician (Clin Tech) to have your vital signs checked and blood drawn in room

5010.

- Please let us know if you are not feeling well and need to lie down right away.
- Arrive at your appointment on time. Please call if you are running very late or are unable to come. Please do not come early. We schedule to provide safe care for all.
- If you have a concern or question about your appointment time, the IPOP charge nurse would be happy to listen. She is the one who coordinates times with the scheduler.

What can I expect on the day of my appointment?

- The average clinic visit is 4 hours, but can last anywhere from 3 to 12 hours. For example, blood counts can take 1 hour; blood chemistries can take 2-3 hours; blood bank typing can take 2-4 hours.
- You should expect to be seen in IPOP daily for the first week or 2. Your appointment time may move to the afternoon as you move through therapy and need less care.
- If you had a BMT, you will be followed in IPOP for a minimum of 20-60 days after BMT day zero depending on what type of transplant you received.
- You will see a nurse at all your visits. You will also be seen in IPOP at least once a week by an oncology fellow or attending doctor, nurse practitioner (NP) or physician's assistant (PA).
- You will have lab draws and other tests or procedures done during your visits depending on your treatment plan and medical condition. Your IPOP nurse will explain these procedures and answer any questions you may have.
- You may spend some long days in IPOP. Please bring lunch or snacks, books, magazines, headphones or laptop. WIFI is available in the building.
- Regular meal service is not provided; however, you can order a hospital meal tray ahead of time for a fee. There are also many eateries throughout the hospital, including Ground Rounds in the first floor Weinberg Lobby. You can keep your food in the 5A, 5B, 5C or 5D pantries. There is also water, ice, juice, soda, milk, crackers and soup for our patients in the pantries. **If you become sick and need to stay on the inpatient units, you will not be able to go into the pantries if you are on isolation.**
- If you would like a locker, the PSC can assist you.
- Please bring **all** medicines that you are currently taking in their original containers, including over the counter medications and supplements to **each** IPOP visit. Keep an updated list of all of your medicines. Do not take any medicine without talking to your provider. This includes vitamins, supplements and over the counter medicines.
- The clinic can get very crowded; so we ask that you only bring one person with you. It would also be helpful if you do not bring oversize coats or bags or more than one bag into the clinic treatment space.
- At the end of **every** visit, check with your nurse for the date and time of your next visit.

How do I get the supplies I need for home?

The social worker will give you the name and phone number of the home care company that will send you your catheter supplies. The home care company chosen will depend on your health insurance plan. You can reorder from the company when your supplies are getting low. They can be delivered to IPOP or wherever you are staying.

Other Resources

- The dietitian can assist you with nutrition questions.
- The social worker can continue to meet with you while you are in IPOP. He or she can inform you of resources and provide supportive counseling if needed.
- The Cancer Counseling Center is available to provide long and short term counseling for issues related to cancer, marriage, family, substance abuse or other areas of mental health. For an appointment call 410-955-1010.

What symptoms do I need to tell my doctor, nurse or physician's assistant about on my next visit?

- Headache, dizziness, blurring and vision changes or stiff neck

- Mouth dryness, soreness, bleeding, white or red patches or ulcers in the mouth or throat
- Increase or decrease in urination or feeling of urgency, vaginal or penile discharge or lower back pain
- Redness, swelling itching, bruising, or and new rashes, blisters, sores or tender areas of the skin
- Any tenderness, swelling, dryness or discharge of eyes
- Any pain or swelling of joints, muscle cramps or aches.
- It is helpful to keep a journal of your symptoms so you don't forget what to tell them.
- Please follow the Symptoms to Report and IPOP/HIPOP Emergency Phone Numbers handouts for urgent concerns!

This information is not intended as a substitute for professional medical care.

Always follow your health care provider's instructions.



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Symptoms to Report

Why is it important to report certain symptoms to my doctor or nurse right away?

Many cancers and cancer treatments lower the number of blood cells, making you at greater risk for infection and bleeding.

If you have chest pain or trouble breathing, call 911. You will be taken to the nearest emergency room.

Otherwise, please follow the guidelines below.

What symptoms should I immediately call my clinic doctor or nurse for?

1. Temperature of 100.5 ° F or greater
2. Shaking or chills
3. New cough or shortness of breath
4. Nausea or vomiting that is not controlled by medications or you are unable to keep medications or fluids down for longer than 24 hours
5. Constipation lasting 2 or more days
6. Diarrhea of 4 or more loose stools a day
7. New or worsening pain not controlled by pain medicine.
8. Pain or burning with urination or inability to urinate
9. Redness, pain, swelling, drainage from catheter site or any incision or wound site
10. Any unusual bruising or bleeding that does not stop after 10 minutes of pressure
11. Dizzy or light-headed
12. Any falls or fainting
13. Confusion
14. Extreme weakness and fatigue (tiredness)
15. New or worsening rash
16. Yellowing of skin or eyes
17. New sore throat
18. Blood in your urine or tea-colored urine
19. Bright red blood in your stools or black stools
20. **Any new or unusual symptoms**

What should I tell the doctor or nurse when they call me back?

- Symptoms or concerns you are having
- Name of your clinic or nurse
- The day of your last treatment or visit to the clinic



Emergency Information for IPOP and HIPOP Patients

Call 911 if you have an emergency that CANNOT WAIT or your medical condition has changed quickly and is serious enough that you cannot wait for a return call.

(If the ambulance cannot take you to the Johns Hopkins Hospital Emergency Room, ask the emergency room staff where you go to call 410-955-4331 number and ask for the Attending IPOP doctor. We will have you brought back to the Johns Hopkins Kimmel Cancer Center when it is safe to move you.)

If you have a new medical problem or your current problem becomes worse, between 7AM – 7PM (7 days a week, including holidays) call 410-614-4501.

- The IPOP/HIPOP Patient Service Coordinator will answer. Tell her that you have a medical problem and need to speak with (name of your provider). She will page your provider who should call you back within 20 minutes.
- Tell her if you need an interpreter or speak a language other than English. She will call an interpreter. Do not hang up your phone while she makes the call.
- Please remove any call blocking features on your phone and always have your cell phone charged and turned on.

If you do not get a call back within 20 minutes:

- Call **410-614-4501** again.
- Ask to speak with the IPOP/HIPOP charge nurse (or any IPOP nurse if the charge nurse is not available) and explain your problem.
- The nurse will contact your provider. Your provider or the nurse will call you back within 20 minutes and give you instructions.

****** If you have a fever, it is important that you speak with an IPOP provider within 30 minutes ******

If you are having a new medical problem or your current problem becomes worse between 7 PM and 7 AM, call 410-955-4331.

- A paging operator will answer. Tell the operator that you are an IPOP patient, and need to speak with the “_____ (medical team color) doctor”.
- Tell the operator if you need an interpreter or speak a language other than English. He or she will call an interpreter.
- Do not hang up your phone while he or she calls the doctor (and interpreter if needed).

****** If you have a fever, it is important that you speak with an IPOP provider within 30 minutes ******

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Infection Prevention Guidelines for Blood and Marrow Transplant Patients

What is the immune system?

We all have “germs” in our body. Our immune system helps keep “germs” under control and keeps them from growing in numbers. White blood cells control the growth of the germs but sometimes antibiotics may need to be given to help get rid of an infection.

Why do I need to be concerned about my immune system?

Your immune system has been weakened by your treatment. You are more likely to get an infection. Some infections are caused by germs that are found in our bodies every day. Others can be passed on from people around us who are sick. There are certain times of the year, like flu season, when the risk of infections is greater.

How can my caregiver and I prevent infections?

You and your caregiver(s) should follow these precautions the entire time you are with us.

- Wash your hands often, especially after using the bathroom or if leaving the clinic and traveling to other areas in the hospital.
- Wear a mask in the hospital, in crowded spaces or near construction.
- You do not need to wear your mask when you are in your own clinic space or when you are in your own home.
- Caregivers should wear a mask if they feel they are getting sick.
- Caregivers who become ill should not enter the IPOP clinic and may need to step out of their caregiving role until they are well.
- Caregivers must also report any changes in their medical condition to their doctor. It is important to treat symptoms early.
- Avoid being near anyone who is sick.
- Patients and caregivers should limit their exposure to children.
- One person should come with you to your appointment. Limit the number of people who come to the clinic.
- It is very important that everyone do their part in preventing the spread of infections & communicable diseases.

What questions should I ask my visitors?

You should ask your visitors if they have been sick recently (especially children). If the answer to any of the following questions is **YES**, then they should not visit you.

- Has the visitor received any live vaccines in the past 28 days?
- Has the visitor been exposed to chicken pox in the past 28 days?
- Has the visitor had nausea, vomiting, or diarrhea in the past week?
- Has the visitor had a runny nose, cough, or cold in the past week?
- Has the visitor had a fever (>100°F) in the past week?
- Has the visitor had any cold sores or fever blisters in the past week?
- Has the visitor had any type of skin rash in the past week?
- Has the visitor had any sign or symptom of illness in the past week?

Do I need to take any precautions if I have flu-like symptoms?

- Yes, if you are a patient or caregiver, and you have flu-like symptoms such as **new cough, aches, chills, fever or new rash** or have **recently been exposed to someone who is ill**.
- **Do not wait in the IPOP waiting area.**

- Keep your mask on and ask a nurse where you should wait.

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Always follow your health care provider's instructions.



Care at Home for the Immunocompromised Patient

What does immunocompromised mean?

- Immunocompromised means your immune system is weaker than normal, probably from your disease and/or treatment. It is important to prevent infection during this time.

What can I do to prevent infection?

Hand washing is the **best way** to prevent infection.

- Carry hand sanitizer with you at all times.
- Wash with soap and water or hand sanitizer
 - after you use the bathroom
 - before and after preparing or eating food
 - after touching pets or animals
 - after contact with someone who has an infection such as a cold or the flu
 - after touching surfaces in public areas (such as elevator buttons, handrails and gas pumps)
- Avoid crowds if possible. An area is crowded if you are within an arm's length of other people.

When do I wear a mask?

- Wear a mask when you travel to and from the hospital, when you are in the hospital and in any public place. Also, close all car windows and turn on the recirculate button of your ventilation system.

Can I have visitors?

- Tell friends and family who are sick not to visit.
- It may be a good idea to have visitors call you first.

Are there any precautions I should follow about my medicine?

- Do not take aspirin or aspirin-like products (such as Advil™, Motrin™ or Excedrin™) unless told by your doctor.
- You should wear a medical alert bracelet that identifies you as a cancer patient or bone marrow transplant patient at risk for bleeding or infection.
- **Keep a current medication list with you at all times.**
- Do not take any herbal products.
- Avoid grapefruit juice, which interacts with many medications.

Are there any precautions I should follow about my personal care?

- Do not schedule any dental procedures (including cleaning and minor surgery) without your oncologist's permission.
- Do not use tampons or douche.
- Do not use enemas or suppositories
- Do not apply artificial fingernails, overlays or nail tips.
- Do not have manicures or pedicures.
- Gently file and care for cuticles.
- Do not share personal items, such as nail polish, nail file or makeup, with anyone.
- Only use electric razors to shave.

Do I need to make any changes in my sex life?

- Check with your oncologist before having intercourse if your platelets or white blood cells are low.

- Clean your genital area very well.
- Urinate after intercourse to reduce bladder infections.
- Male patients and male partners of patients should use condoms to prevent infection and chemotherapy exposure.
- Female patients should use lubrication to minimize vaginal irritation.
- Avoid sexual practices in which oral exposure to feces may occur.

Can I still go swimming?

- Do not swim in water that may be contaminated, such as oceans, ponds, lakes, rivers and public pools.
- Do not sit in hot tubs or whirlpools.
- If you have a catheter or tube, do not swim or let it go under the water.

How can I make sure my food and water are safe to eat and drink?

- Wash hands with warm soapy water before and after preparing food and before eating.
- Clean the areas where you prepare food. Use a separate cutting board for raw meat.
- Throw out all prepared foods after 72 hours in the refrigerator that have been opened, used or are left over.
- Refrigerate leftovers within 2 hours of cooking time in small shallow containers. Throw leftovers away that have been at room temperature more than 2 hours.
- Meat, fish and shellfish should be cooked well done.
- Eggs and foods containing eggs must be fully cooked.
- Always check the “sell by” and “use by” dates. Do not buy or use products that are out of date.
- Avoid salad bars, delicatessens, and buffets.
- Raw fruits and vegetables should be washed and or peeled.
- Use only **pasteurized** dairy, eggs, juice, honey and beer products.
- Never eat anything that has mold on it.
- Do not use herbal supplements.
- Patients with blood cancers should not use probiotics.
- Patients with other types of cancer should check with their doctor before using probiotics.
- Do not drink well water unless tested yearly and found to be safe.

Is it okay to garden?

- Do not work in the garden or dig in soil or mulch.

Can I still take care of my pets?

- Wash your hands after playing with your pets.
- You **should not** have any contact with birds, fish, rodents, reptiles or farm animals.
- If your pet develops diarrhea, remove it from your living area until a veterinarian has seen it.
- You may not clean up pet urine or feces, including litter boxes, birdcages or aquariums.
- Avoid exposure to any cat which is not declawed.

Can I still smoke?

- Do not smoke or use tobacco products.
- Ask your doctor about nicotine replacement therapies.
- No one should smoke in your house.

Can I travel?

- Check with your doctor about traveling abroad or using public transportation.

What should I call my doctor or nurse about?

You should call your doctor or nurse right away if you have:

- a fever greater than 100.5°
- chills or shaking
- soreness, swelling, redness or pus from a wound, central line or other IV
- new cough
- sinus pain or drainage
- white patches in the mouth
- frequency, urgency or burning when urinating
- sore throat
- new, hard lumps
- exposure to an infectious disease, contaminated food or water, or pets mentioned previously.

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The Johns Hopkins Hospital Patient Information

Taking and Recording Your Temperature

Original Date
5/01
Oncology
Date
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Why do I need to take my temperature?

- When your white blood cell (WBC) count is less than 1000 you are at a higher risk for getting an infection.
- A fever is usually a sign that you have an infection.

When should I take my temperature?

When your white blood cell count is less than 1000 you should:

- Take your temperature at least 3 times a day, once in the morning, once in the afternoon and once in the evening.
- Take your temperature any time you feel chilly, unusually cold, have shaking chills, or if you are not feeling well.

How should I take my temperature?

- Take your temperature at about the same time each day. Your “normal” body temperature changes by as much as 1 degree depending on the time of day it is taken.
- Normal body temperature is different from person to person but the normal average oral temperature is 98.6°F (37°C).
- Wait ½ hour after eating or drinking before taking your temperature.
- The thermometer probe should be placed under your tongue with the tip resting as far back under your tongue as possible, against either side of your mouth.
- Be sure your mouth is closed tightly and there are no “air gaps” which could cause lower temperature readings.
- Use a digital thermometer.
- Avoid the use of ear probe thermometers and mercury thermometers. The readings can be less accurate.
- Don’t use aspirin or aspirin-like products, such as acetaminophen (Tylenol®) or ibuprofen (Advil®), or medicine containing them, such as (Percocet®) unless you ask your doctor or nurse.
- If your temperature is **100.5° F or higher**, you have a fever and should contact your doctor immediately.



The Johns Hopkins Hospital Patient Information

**Taking and Recording Your
Temperature**

Original Date
5/01
Oncology
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	C	F	C	F
CONVERSIONS	36.0	96.8	38.0	100.5
(From Celsius to Fahrenheit)	36.1	97.0	38.1	100.6
	36.2	97.2	38.2	100.8
	36.3	97.3	38.3	100.9
	36.4	97.5	38.4	101.1
	36.5	97.7	38.5	101.3
	36.6	97.9	38.6	101.5
	36.7	98.1	38.7	101.7
	36.8	98.2	38.8	101.8
	36.9	98.4	38.9	102.0
	37.0	98.6	39.0	102.2
	37.1	98.8	39.1	102.4
	37.2	99.0	39.2	102.6
	37.3	99.1	39.3	102.7
	37.4	99.3	39.4	102.9
	37.5	99.5	39.5	103.1
	37.6	99.7	39.6	103.3
	37.7	99.9	39.7	103.5
	37.8	100.0	39.8	103.6
	37.9	100.2	39.9	103.8
			40.0	104.0



Safety in the Home while on Hazardous Drugs

Why do some drugs need special precautions?

- The drug you are taking is important for your treatment, but may cause harm to others. Your body wastes and fluids (including urine, stool, vomit, blood, sweat, semen and vaginal fluids) may also contain some of the drug.
- Your loved ones should follow special precautions for their protection when handling hazardous drugs, body wastes and fluids while you are on treatment and for 48 hours after you have finished treatment.

What special precautions are always needed for hazardous drugs?

- Keep drugs where your children and pets cannot reach them.
- Pregnant women, children and pets should never touch the drug, body wastes and fluids or contaminated items.
- You and your loved ones should always wear gloves when touching the drug. Wash hands after taking gloves off. Never use gloves more than once.
- If your drug is a tablet, do not crush it. Your pharmacy should crush tablets if needed.
- Place any leftover drug in the hazardous drug container provided to you by your infusion company. Do not throw it in the trash or flush down the toilet. If you do not have a container, ask your doctor, nurse or pharmacist where to put it.

What special precautions are needed for 48 hours after you receive hazardous drugs?

- Your loved ones should wear gloves when touching body wastes and fluids or contaminated items, such as linens, bedpans or urinals, and items they are throwing away. They should wash their hands after taking gloves off. Never use gloves more than once.
- Always double bag with two plastic bags any contaminated items you are throwing away, such as diapers, ostomy bags, absorbent pads and gloves.
- You can use the toilet as usual, but always close the lid and flush 2 times. Wash your hands.
- Wash reusable containers, such as a urinal or bedpan, with liquid soap or dish detergent and warm water and rinse well. Be careful not to splash yourself or others.
- You can wash all linens and clothes normally unless they are soiled with hazardous drugs or body wastes. If they are, use gloves to handle and wash them separately.
- Ask your doctor or nurse about precautions for sexual activity.

What do I do if I splash myself with a hazardous drug or body waste?

- If hazardous drugs, body wastes or fluids get on the skin, wash it well with soap and water. Call your doctor or nurse if redness or irritation develops.
- If the drug or body waste splashes into the eye, rinse the eye with running water for 10-15 minutes. Call your doctor, nurse or clinic to tell them and get further instructions.

How can I prevent IV hazardous drug spills?

- Check all IV lines and tubing every day for cracks, tears or leaks. Call your home care nurse if you find any.
- Keep sharp things away from supplies.
- Prevent IV tubing from being pulled or tugged.
- Make sure all connections are tight.

What do I do if there is an IV hazardous drug spill?

- Clean the spill right away using your spill kit and its directions.
- Pregnant women and children should not clean a spill.
- If the spill is on clothing, remove the clothes immediately. Wash the items in the washer with warm water and detergent. Wash the skin where the spill was with soap and warm water.
- If the spill is on a piece of furniture, clean up the spill per directions in the spill kit, then scrub the area with soap and water while wearing gloves.
- Remove your gloves. Wash hands very well with soap and water.
- Call your home infusion company and ask them what to do with the materials. Do not throw out with your trash!
- A spill kit should be in the home at all times. If you require a replacement, please contact your home infusion company.

References -

- Chemotherapy and Biotherapy Guidelines and Recommendations for Practice, 4th Ed. Oncology Nursing Society, 2014
- National Take-Back Initiative for safe disposal of prescription drugs: www.deadiversion.usdoj.gov/drug_disposal/takeback/index

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Always follow your health care provider's instructions.

Safe Storage & Disposal of Pain Medications

Why do doctors prescribe pain medication(s)?

People diagnosed with cancer often experience pain, either from the cancer itself or as a side effect of treatment. As a result, managing and treating pain is an important part of a person's overall cancer treatment plan. Treatment may involve the use of pain relief medications called analgesics. For some people with moderate to severe pain, the doctor may prescribe opioids, also known as narcotics.

Why is it important to know how to store my pain medication(s)?

Although opioids are very effective at managing and relieving cancer pain, they are dangerous if a family member or pet accidentally swallows them. Fentanyl skin patches (see below) can stick to the hands and feet of kids and pets, who can absorb the drug, even if the patch has already been used. In addition, people who use drugs may seek them out. Therefore, it is important to take additional steps to safely and securely store your prescription pain medication.



What steps should I take to safely store my pain medication(s)?

It is important to store your pain medication in a bottle that has a child-resistant lid. You should also keep all of your opioid medication in a location where a pet, child, teenager, or stranger would not easily see it or get to it. Consider storing your pain medication in a secure lockbox that only you and your caregiver can open. Some people have safes to secure cash, documents, or firearms, and those can be used, as well. Do not store your pain medication in many different places around the house or leave it sitting out. Finally, only share details about your prescription(s) with your caregiver or others who need to know.

How should I get rid of any old or unused medication?

The U.S. Food and Drug Administration (FDA) recommends that some opioid medications be flushed down the toilet. However, some communities have rules and restrictions against this. Another option is to take any unused or expired drugs to a prescription medication take-back program collection site. If you can't take your medication to a collection site or flush it, you may need to put it in the trash. To do this safely, take all of the medication out of its container and put it in a sealable plastic bag or coffee can. Then mix the medication with an undesirable substance such as cat litter or coffee grounds. Finally, seal the container and be sure to put it in the trash, not the recycling.

How should I dispose of used pain-relief skin patches?

If you have been prescribed a fentanyl skin patch, make sure used patches are kept away from others. According to the FDA, too much fentanyl can cause severe breathing problems and even death in babies, children, pets, and adults, especially those who have not been prescribed the drug. After using a patch, fold it in half so the sticky parts are sealed together and flush it down the toilet or use another of the disposal methods listed above.

Questions to ask the health care team

Regular communication is important in making informed decisions about your health care. Consider asking your health care team the following questions:

- Would you explain the options for managing my pain with medication?
- Why is it important for me to safely store and dispose of my pain medication?
- Where is the best place for me to keep my medication?
- Should I lock up my pain medication? If so, where would you recommend?
- What should I do if a pet or family member accidentally swallows or comes in contact with my medication?
- What should I do if some or all of my medication goes missing?
- What should I do with any leftover medication if my prescription changes or if I don't need to take it any more?
- Is it safe for me to flush any old or unused pain medication down the toilet?
- Are there any drug take-back programs in my area? Or should I return left over medication to a member of my health care team?
- Whom should I call if I have any questions or problems?

Find more information about how to safely store and dispose of cancer medications at www.cancer.net/safestorage. Download the free Cancer.Net mobile app to get more questions and track your prescriptions at www.cancer.net/app.

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WORDS TO KNOW

Analgesic:

A medication that relieves pain

Breakthrough pain:

Pain that occurs between regularly scheduled doses of pain medication

Drug disposal:

Getting rid of or destroying unused medication

Neuropathic pain:

Burning, shooting, or numbing pain from nerve damage

Opioid:

A medication that requires a prescription and provides strong pain relief

Pain threshold:

The point at which pain is noticeable

Pain tolerance level:

The peak amount of pain that a person can endure

Prescription medication:

A medication that is only available from a pharmacy with written instructions from a doctor, nurse practitioner, or physician assistant

Rescue medicine:

A medication used to control breakthrough pain

Take-back program:

National or local initiatives to collect unused prescription medications so they can be disposed of in a safe, legal, and environmentally friendly way

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How to Dispose of Unused Medicines

Is your medicine cabinet filled with expired drugs or medications you no longer use? How should you dispose of them?

Most drugs can be thrown in the household trash, but consumers should take certain precautions before tossing them out, according to the Food and Drug Administration (FDA). A few drugs should be flushed down the toilet. And a growing number of community-based “take-back” programs offer another safe disposal alternative.

Guidelines for Drug Disposal

FDA worked with the White House Office of National Drug Control Policy (ONDCP) to develop the first consumer guidance for proper disposal of prescription drugs. Issued by ONDCP in February 2007 and updated in October 2009, the federal guidelines are summarized here:

- Follow any specific disposal instructions on the drug label or patient information that accompanies the medication. Do not flush prescription drugs down the toilet unless this information specifically instructs you to do so.
- Take advantage of community drug take-back programs that allow the public to bring unused drugs to a central location for proper disposal. Call your city or county government’s household trash and recycling service (see blue pages in phone book) to see if a take-back program is available in your community. The Drug Enforcement Administration, working with state and local law enforcement agencies, is sponsoring National Prescription Drug Take Back Days (www.deadiversion.usdoj.gov) throughout the United States.
- If no instructions are given on the drug label and no



Take drugs out of their original containers and mix them with an undesirable substance, such as used coffee grounds ...

take-back program is available in your area, throw the drugs in the household trash, but first:

- Take them out of their original containers and mix them with an undesirable substance, such as used coffee grounds or kitty litter. The medication will be less appealing to children and pets, and unrecognizable to people who may intentionally go through your trash.
- Put them in a sealable bag, empty can, or other container to prevent the medication from leaking or breaking out of a garbage bag.

FDA's Deputy Director of the Office of Compliance Ilisa Bernstein, Pharm.D., J.D., offers some additional tips:

- Before throwing out a medicine container, scratch out all identifying information on the prescription label to make it unreadable. This will help protect your identity and the privacy of your personal health information.
- Do not give medications to friends. Doctors prescribe drugs based on a person's specific symptoms and medical history. A drug that works for you could be dangerous for someone else.
- When in doubt about proper disposal, talk to your pharmacist.

Bernstein says the same disposal methods for prescription drugs could apply to over-the-counter drugs as well.

Why the Precautions?

Disposal instructions on the label are part of FDA's "risk mitigation" strategy, says Capt. Jim Hunter, R.Ph., M.P.H., senior program manager on FDA's Controlled Substance Staff. When a drug contains instructions to flush it down the toilet, he says, it's because FDA, working with the manufacturer, has determined this method to be the most appropriate route of disposal that presents the least risk to safety.

Drugs such as powerful narcotic pain relievers and other controlled substances carry instructions for flushing to reduce the danger of unintentional use or overdose and illegal abuse.

For example, the fentanyl patch, an adhesive patch that delivers a potent pain medicine through the skin, comes with instructions to flush used or left-over patches. Too much fentanyl can cause severe breathing problems and lead to death in babies, children, pets, and even adults, especially those who have not been prescribed the drug. "Even after a patch is used, a lot of the drug remains in the patch," says Hunter, "so you wouldn't want to throw something in the trash that contains a powerful and potentially dangerous narcotic that could harm others."

Environmental Concerns

Despite the safety reasons for flushing drugs, some people are questioning the practice because of concerns about trace levels of drug residues found in surface water, such as rivers and lakes, and in some community drinking water supplies. However, the main way drug residues enter water systems is by people taking medications and then naturally passing them through their bodies, says Raanan Bloom, Ph.D., an environmental assessment expert in FDA's Center for Drug Evaluation and Research. "Most drugs are not completely absorbed or metabolized by the body, and enter the environment after passing through waste water treatment plants."


A company that wants FDA to approve its drug must submit an application package to the agency. FDA requires, as part of the application package, an assessment of how the drug's use would affect the environment. Some drug applications are excluded from the assessment requirement, says Bloom, based on previous agency actions.

"For those drugs for which environmental assessments have been required, there has been no indication of environmental effects due to


flushing," says Bloom. In addition, according to the Environmental Protection Agency, scientists to date have found no evidence of adverse human health effects from pharmaceutical residues in the environment.

Nonetheless, FDA does not want to add drug residues into water systems unnecessarily, says Hunter. The agency reviewed its drug labels to identify products with disposal directions recommending flushing or disposal down the sink. This continuously revised listing can be found at FDA's Web page on Disposal of Unused Medicines (www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/ucm186187.htm).

Another environmental concern lies with inhalers used by people who have asthma or other breathing problems, such as chronic obstructive pulmonary disease. Traditionally, many inhalers have contained chlorofluorocarbons (CFC's), a propellant that damages the protective ozone layer. The CFC inhalers are being phased out and replaced with more environmentally friendly inhalers.

Depending on the type of product and where you live, inhalers and aerosol products may be thrown into household trash or recyclables, or may be considered hazardous waste and require special handling. Read the handling instructions on the label, as some inhalers should not be punctured or thrown into a fire or incinerator. To ensure safe disposal, contact your local trash and recycling facility. 

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Home Care Services

<p>Who arranges home care?</p>	<p>Home Care Coordinators at the Johns Hopkins Hospital may arrange skilled home care services for patients, based on their needs. Our coordinators are experienced nurses who work directly with the patient and their family, physicians, nurse practitioners, social workers, and staff nurses to develop a safe home care plan.</p>
<p>How do I pick a home care company?</p>	<p>Patients, families or caregivers may choose their Home Care Company, but often insurance policies will identify the preferred agency.</p>
<p>What types of services are included in home care?</p>	<p>The home care coordinators can arrange services for patients being discharged from the hospital, outpatient center or clinic:</p> <ul style="list-style-type: none"> • skilled nursing • physical therapy, occupational therapy, speech therapy • home hospice care • social worker • home health aide • IV infusion and nutrition support • home medical equipment
<p>How can I contact the home care coordinators?</p>	<p>The home care coordinators are available to answer questions or meet with the patient and family. Ask a member of your health care team to contact the home care coordinator or social worker. You may also directly call the Home Care Coordinators office at 410-955-1930.</p>



Surviving Cancer



The Johns Hopkins Hospital Patient
Information

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Surviving Cancer

What is a survivor?

“Survivor... a word that represents the strength, courage, and determination to face your worst fears and to move forward.”
(National Coalition for Cancer Survivorship)
You are a cancer survivor from the moment you are diagnosed. The fact that you have had cancer will change your life, but cancer does not have to define you.

How should I take care of myself after I am finished with treatment?

- Get copies of your medical records
- Continue to see your family doctor and oncologist
- Get regular check ups and be alert to any signs of possible cancer return or treatment side effects
- Ask your doctor about any concerns such as pain or fatigue
- Adopt good health habits: eat right, do not smoke and get enough sleep and exercise to help you feel better
- Do things you enjoy, even if you don't feel up to par

What can I do about changes in my appearance or my ability to do things?

- Consider rehabilitation/home health services
- Find out about cancer support organizations
- The Image Recovery Centers, located on the first floors of the Weinberg (410-502-5623) and Viragh (410-502-7767) buildings offer free consultations.

How can I get help with my emotional health?

- Talk to a social worker, psychiatric liaison nurse, therapist or a clergyperson
- Consider joining a cancer survivors' support group
- Focus on the positive
- Talk with friends and family
- Talk about your feelings



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Surviving Cancer

<p>What insurance issues do I need to consider?</p>	<ul style="list-style-type: none"> • Get copies of your insurance policies • Keep careful records of all expenses and conversations with insurance representatives • File claims for all covered costs. If claim is turned down, file again • Take all Federal income tax deductions for health care costs that you are allowed • Participation in clinical trials may be covered by your health insurance • Call your private insurance carrier for any questions related to your specific coverage • If you have any questions about Medicare coverage, call <ul style="list-style-type: none"> ▪ 1-800-medicare or www.medicare.gov • For any general insurance questions, call the Hopkins Cancer Center's Financial Counselors at 410-955-8995
<p>What can I do about easing my return to work?</p>	<ul style="list-style-type: none"> • The Americans with Disabilities Act bans discrimination against qualified workers who have disabilities • You can get a letter from your doctor to explain your health condition and physical limitations to your employer • Maintain contact with your employer and coworkers during your treatment and recovery • Join (or form) a workplace support group for cancer survivors
<p>Other Resources</p>	<ul style="list-style-type: none"> • National Cancer Institute's Cancer Information Service 1-800-4-CANCER, www.cancer.gov • American Cancer Society 1-800-ACS-2345, www.cancer.org • National Coalition for Cancer Survivors 1-877-622-7937 • Cancer Legal Resource Center 1-866-843-2572 or www.cancerlegalresourcecenter.org • Publications, including <i>Facing Forward: Life After Cancer Treatment</i> are available in the Patient Education Room on the 2nd floor and the Patient and Family Services Suite 1210.



Clinical Trials



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Cancer Clinical Trials

What are cancer clinical trials?

Cancer clinical trials are research studies which are used to test new ways to prevent, detect, diagnose, and treat cancer.

What are the different types of research studies?

Treatment Studies: Test new treatments or new ways of using current treatments such as new drugs, vaccines, techniques in surgery or radiation, or combinations of treatments. These studies are done in a stepwise fashion called “phases”.

Prevention Studies: Test new ways to avoid cancer in people who have never had it or stop it from coming back in people who have. These studies may include medications, vaccines, vitamins or lifestyle changes.

Screening Studies: Test new ways of finding cancer early.

Quality of Life/Supportive Care Studies: Studies that look at ways to improve the quality of life of cancer patients, care givers, and cancer survivors.

What are the “phases” of a research study?

Each phase of a treatment research study is used to answer a different question about a drug or a treatment to determine if it is safe and effective.

Phase 1: Is the treatment safe?

Phase 2: Does the treatment work?

Phase 3: Does the new treatment work better than the current treatment?

Phase 4: Is the treatment safe over time?

Who is eligible to participate in a research study?

Every trial has a list of rules, called eligibility criteria, for who can and cannot take part in the trial. These rules keep people in the study safe and make sure the study results are reliable.

Examples of eligibility criteria are:

- type of cancer you have
- the stage of your cancer
- your age



The Johns Hopkins Hospital Patient Information

Cancer Clinical Trials

Original Date
7/04
Oncology
Revised/ Reviewed
3/19

- what other treatments you are receiving or have received in the past

Is a research study right for me?

You may be asked to take part in a research study at any time during your care with us. Before you are given the choice to take part in a research study, your doctor and the research study team will talk to you about the possible benefits and risks of the study; what your other treatment options are; and be sure that you have all the information you need to make the right decision for you.


Questions to ask about taking part in a research study

Below are just some of the questions you may ask your doctor or the research study team.

- Why is the study being done?
- What treatment will I receive?
- Have other patients received the treatment?
- Do all patients in the study receive the same treatment?
- If patients receive different treatments, how is it determined which treatment I receive?
- What tests or procedures are involved?
- Will I have to stay in the hospital?
- How often will I have to visit the hospital or clinic?
- How long is the study?
- What if the study ends, but the treatment is working for me?

Where can I get more information

For more information about clinical trials at the Sidney Kimmel Comprehensive Cancer Center you may contact:

	<p>The Johns Hopkins Hospital Patient Information</p>	<p>Original Date 7/04 Oncology Revised/ Reviewed 3/19</p>
<p>about our clinical trials?</p>	<p style="text-align: center;">Cancer Clinical Trials</p> <p>Clinical Trials Recruitment Specialist Phone: 443- 287-4272 E-mail: SKCCCTrials@jhmi.edu</p> <p>Our website may be accessed at: www.hopkinskimmelcancercenter.org You will find all currently available Hopkins Kimmel Cancer Center clinical trials listed with a brief description of the trial and the criteria to participate.</p>	
<p>Other Resources</p>	<p>National Cancer Institute: www.cancer.gov/clinicaltrials or 1-800-4-CANCER (1-800-422-6831)</p> <p>American Cancer Society: www.cancer.org or 1-800-ACS-2345 (1-800-227-2345)</p> <p>The Center for Information & Study on Clinical Research Participation: www.ciscrp.org or 1-877-MED HERO (1-877-633-4376)</p>	
<p>Reference</p>	<p>National Cancer Institute, 2019. Learn About Clinical Trials. http://www.cancer.gov/clinicaltrials/learningabout/</p> <p>National Institutes of Health, 2019. Clinical trials.gov, Learn About Clinical Trials. http://clinicaltrials.gov/ct2/about-studies/learn</p>	

Patient Guide Feedback Form

We created this guide to help you during your cancer journey. We would appreciate your feedback so we can improve it as needed. Thank you!

How often do you use your guide?

Daily Weekly Monthly I don't use the guide

Overall, how helpful do you find the guide?

Very helpful Somewhat helpful Not very helpful

What parts of the guide do you like the best?

What parts of the guide do you like the least?

Do you have any suggestions for anything we can change to make the guide better?

If you would like us to call you to discuss your comments, please provide your name and phone number.

Please return this form to the Patient Education Room or mail to:
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401 N. Broadway
Baltimore, MD 21231