

patient guide



JOHNS HOPKINS
NURSING

THE SIDNEY KIMMEL
COMPREHENSIVE CANCER
CENTER

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Welcome



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

Original Date
7/00
Oncology
Revised/ Reviewed
9/17

Visiting the Outpatient Department

Where do I go to register for the first time?

Go to the Welcome Center on the first floor of the Weinberg Building. You will fill out paperwork and be given an orange card with a bar code on the back.

How do I register on future visits?

You will scan the bar code at one of the kiosks in front of the Welcome Center to:

- 1) check yourself in
- 2) let the doctors, nurses, and pharmacists know you are here
- 3) print information about your appointments

Sometimes you will get a message to go into the Welcome Center if you need to do paperwork. Please ask one of the staff if you are not sure where to go next.



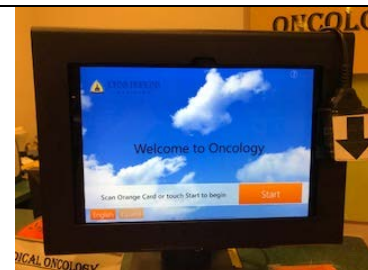
What do I do after I register?

1. If your printout says to go to the Lab in the 1st floor waiting area, you will need to go to **Phlebotomy** in the back of **Outpatient Services** to have your blood drawn. Scan the bar code upon arriving.

2. If your printout says to go to the Main Waiting Area, go to **Outpatient Services** and scan the barcode upon arriving. A staff member will call you when it is time to meet with your health care provider. If you are waiting longer than 20 minutes, please go to the reception desk to talk to a staff member.

3. If your schedule says to go to the Lower Level, take the elevator to L2. In this area, the scanner is to the left of the reception desk. Please scan in and take a seat. A staff member will call you for your appointment.

4. If your printout says to go to Infusion take the elevator to the second floor and turn right. The **Outpatient Treatment** area will be on your left. Scan the barcode and have a seat in the waiting area.





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Original Date
7/00
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Visiting the Outpatient Department

- We will weigh you and take your vital signs, and give you an armband. If this is your first visit, we will measure your height. If you had blood work done, it may take up to 2 to 4 hours for results. Based on the results of your blood work, your nurse will decide if you are ready for your treatment and then notify the pharmacist and/or your physician.
- Once you are “approved” to begin treatment, the pharmacists prepare your medications. Two pharmacists check your medications before they are sent to the treatment area.
- Once the medications arrive in the treatment area, two registered nurses will check them for accuracy.
- **Each step is important for your safety.**

What can I do while I am waiting?

It may take a while before your chemotherapy is given to you, so we encourage you to bring snacks, books, crossword puzzles, magazines, laptop, tablet, e-reader or portable DVD player (with head phones) to pass the time while you wait. There is guest WIFI.

Is there anything I can do to make my visit smoother?

- Your appointments are made for your specific treatment and you may be scheduled to see more than one health care provider during your visit.
- It is important that you arrive by the time requested on your new patient letter or My Chart, so that we can provide you with prompt service. Ask your nurse if you are not sure when you need to be here. At the end of your visit, please see the scheduler for your follow up appointment(s).
- Ask your doctor, nurse practitioner or physician assistant about getting your labs done in advance of your appointment either locally (Quest, LabCorp, physician office), or at one of our Johns Hopkins labs.
- One of our Advanced Clinical Evaluation (ACE) nurses may call you to ask you a few healthcare questions that may enable us to make your medications in advance. Please call them back if they have left you a message.
- Please ask a staff member if you have any questions about your visit or appointments. We are committed to providing you complete and efficient service.



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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9/00
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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 – 7pm

Fax line:
410-502-1511

Saturday – Sunday: 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.

3/15



The Johns Hopkins Hospital Patient Information

Physical Medicine and Rehabilitation Department

*Physical Therapy, Occupational Therapy, and
Speech Language Pathology Services*

Original Date
5/00

Oncology
Reviewed/Revised
5/17

What services does the Physical Medicine and Rehabilitation Department provide?

The Physical Medicine and Rehabilitation Department offers both inpatient and outpatient Physical, Occupational, and Speech Therapy services. Our therapists have a special interest and training in oncology. Therapists will suggest home equipment and follow-up therapy to help you improve your daily function and quality of life when you go home.

For inpatients, an exercise room on Weinberg 5A has a treadmill and stationary bicycle and an exercise room on Weinberg 5D has a reclined stepper- NuStep®. Ask your nurse or doctor about using the equipment. If you are on isolation precautions, you may not use these rooms.

Exercise offers lots of enjoyable and important benefits, such as:

- Strengthening your heart, lungs, bones, and muscles
- Giving you more energy and strength
- Helping you handle stress
- Helping you sleep better
- Helping you look good
- Making you feel upbeat



General Guidelines:

- Wear loose comfortable clothing and shoes with good support
- Keep a record of your progress
- Try to exercise at least once a day
- Have fun!!

Platelet Precautions:

1. When your platelets are **less than 20,000**, DO NOT use any weights, resistance bands or tubing, or lift any heavy objects.
2. When your platelets are **between 10,000 and 20,000**, you may perform light exercises, including walking, using a treadmill, and/or riding a stationary bike without resistance.
3. When your platelets are **less than 10,000** you may need to limit yourself to activities of daily living (bathing, dressing, etc.), range of motion of your arms and legs, and limited walking.

Reference: <http://c.ymcdn.com/sites/www.acutept.org/resource/resmgr/imported/labvalues.pdf>



The Johns Hopkins Hospital Patient Information

**Physical Medicine and Rehabilitation
Department**

*Physical Therapy, Occupational Therapy, and
Speech Language Pathology Services*

Original Date
5/00

Oncology
Reviewed/Revised
5/17

**Physical
Therapist**

Your physical therapist (PT) will work with you to set up a treatment plan to improve your strength and mobility, increase your activity, and help you to function safely when you go home.

**Occupational
Therapist**

Your occupational therapist (OT) will work with you to regain your ability to do things that are meaningful to you, such as bathing, dressing and homemaking, and can suggest equipment for home, such as a shower chair or bedside commode, to make those things easier to do. Therapy may also increase your upper body strength and use of your hands. We will also teach you ways to cope with fatigue, vision loss and memory or concentration problems if needed.

**Speech-Language
Pathologist**

Speech-language pathologists assess and treat patients with speech, language, thinking and swallowing problems. We will help you improve your communication and swallowing, as well as planning, problem solving and memory to do activities that are meaningful to you and your family.

**How can I find an
outpatient
therapist?**

- Johns Hopkins Cancer Rehabilitation Program
 - Meyer 1-130. 600 N. Wolfe Street, Baltimore, MD. 21287
 - Phone: 410-614-3234
 - http://www.hopkinsmedicine.org/physical_medicine_rehabilitation/

- Use 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.

JOHNS HOPKINS PHLEBOTOMY SITES



JOHNS HOPKINS OUTPATIENT CENTER – EXPRESS TESTING

601 N. CAROLINE STREET
BALTIMORE, MARYLAND 21287
PHONE: 410-955-1681 FAX: 410-614-1331
MONDAY-FRIDAY: 7:00AM-5:45PM
(NO WEEKENDS OR HOLIDAYS)

JOHNS HOPKINS LAB AT THE 550 BUILDING

550 N. BROADWAY
BALTIMORE, MARYLAND 21287
PHONE: 410-502-4276 FAX: 410-502-4280
MONDAY-FRIDAY: 8:30AM-4:30PM
(NO WEEKENDS OR HOLIDAYS)

EAST BALTIMORE MEDICAL CENTER

1000 EAST EAGER STREET, SUITE 1001
BALTIMORE, MARYLAND 21202
PHONE: 410-502-8368 FAX: 410-522-5124
MONDAY-FRIDAY: 8:00AM -5:30PM
(NO WEEKENDS OR HOLIDAYS)

NOTE: LAB CLOSES AT 4PM EVERY THIRD FRIDAY OF THE MONTH

WYMAN PARK MEDICAL CENTER

3100 WYMAN PARK DRIVE, SUITE 170A
BALTIMORE, MARYLAND 21211
PHONE: 410-338-3232 FAX: 410-338-3278
MONDAY-FRIDAY: 7:30 AM -4:50 PM
(NO WEEKENDS OR HOLIDAYS)

NOTE: LAB CLOSES AT 4PM EVERY THIRD FRIDAY OF THE MONTH

JOHNS HOPKINS MEDICAL LABORATORY GREEN SPRING STATION

10753 FALLS ROAD, PAVILION II, SUITE 105
LUTHERVILLE, MARYLAND 21093
PHONE: 410-583-2677 FAX: 410-583-2681
MONDAY-FRIDAY: 7:00AM-6:00PM
(NO WEEKENDS OR HOLIDAYS)

JOHNS HOPKINS BAYVIEW MEDICAL CENTER

4940 EASTERN AVENUE
BMO BUILDING, ROOM 01.1060
BALTIMORE, MARYLAND 21224
PHONE: 410-550-5797 FAX: 410-550-8044
MONDAY-FRIDAY: 7:30AM-5:00 PM
(NO WEEKENDS OR HOLIDAYS)

JOHNS HOPKINS VASCULITIS CENTER @ BAYVIEW

THE ASTHMA & ALLERGY CENTER / VASCULITIS
5501 BAYVIEW CIRCLE, SUITE 1B.59A
BALTIMORE, MARYLAND 21224
PHONE: 410-550-6823 FAX: 410-550-4332
MONDAY-THURSDAY: 7:00AM-5:30PM (NO WEEKENDS OR HOLIDAYS)

JOHNS HOPKINS MEDICAL LABORATORY WHITE MARSH

4924 CAMPBELL BLVD. SUITE 115
NOTTINGHAM, MARYLAND 21236
PHONE: 443-442-2100 FAX: 443-442-2102
MONDAY-FRIDAY: 8:00AM-6:00PM
SATURDAY: 8:00AM-12:00PM
(NO HOLIDAYS)

NOTE: LAB CLOSSES AT 4PM EVERY THIRD FRIDAY OF THE MONTH.

JOHNS HOPKINS MEDICAL LABORATORY ODENTON

1106 ANNAPOLIS ROAD, SUITE 270
ODENTON, MARYLAND 21113
PHONE: 410-874-1435 FAX: 410-874-1540
MONDAY-FRIDAY: 7:30AM-5:00PM
(NO WEEKENDS OR HOLIDAYS)

JOHNS HOPKINS MEDICAL LABORATORY HOWARD COUNTY

THE MEDICAL PAVILION AT HOWARD COUNTY
10710 CHARTER DRIVE, SUITE G040
COLUMBIA, MARYLAND 21044
PHONE: 443-546-1110 FAX: 443-546-1112
MONDAY-FRIDAY: 8:00AM-6:00PM
(NO WEEKENDS OR HOLIDAYS)

HOWARD COUNTY GENERAL HOSPITAL

5755 CEDAR LANE
COLUMBIA, MARYLAND 21044
BALTIMORE, MARYLAND 21287
PHONE: 410-740-7655 (MAIN LAB) FAX: 410-884-4689 (MAIN LAB)
MONDAY-FRIDAY: 7:00AM-7:00PM
(WEEKENDS: 7:00AM-7:00PM: STAT ORDERS ONLY)

SUBURBAN HOSPITAL OUTPATIENT STATION-CHEVY CHASE

5530 WISCONSIN AVENUE, SUITE 1150
CHEVY CHASE, MARYLAND 20815
PHONE: 301-951-3603 FAX: 301-951-6156
MONDAY-FRIDAY: 8:30AM-4:30PM
(NO WEEKENDS OR HOLIDAYS)

SUBURBAN HOSPITAL OUTPATIENT STATION-BETHESDA

6410 ROCKLEDGE DRIVE, SUITE 150
BETHESDA, MARYLAND 20817
PHONE: 301-896-6740 FAX: 301-530-0919
MONDAY-FRIDAY: 6:30AM-5:30PM
(NO WEEKENDS OR HOLIDAYS)

SIBLEY MEMORIAL HOSPITAL

5255 LOUGHBORO ROAD NW
WASHINGTON, DC 20016
PRE-SURGICAL TESTING CENTER (OUTPATIENT PHLEBOTOMY)
PHONE: 202-537-4437 FAX: 202-364-7639
MONDAY-FRIDAY: 8:00AM-4:30 PM
MAIN LAB
PHONE: 202-5374651 FAX: 202-537-4459



The Johns Hopkins Hospital Patient Information

Original Date
8/00

Oncology
Revised/ Reviewed
12/15

Understanding Your Bills

<p>Will my insurance cover my treatment?</p>	<p>Most of the time, insurance will cover this cost. You may need to get a referral from your primary care doctor to come to Johns Hopkins. You may also need to have blood work and x-rays done outside of Johns Hopkins. You should always check with your insurance company in advance about coverage and to get permission for care.</p>			
<p>If I receive a bill that shows a balance, does this mean my insurance company is not going to pay it?</p>	<p>Usually a “balance due” amount on a bill is the amount you need to pay after the insurance company has reviewed the claim. Sometimes the “balance” amount on a claim only means that your company has received the bill and is reviewing it before they decide how much of the bill you need to pay. If you have questions about what this balance means, please call the Billing Office at 443-997-0100 for hospital bills and 410-933-1200 for university bills. If additional assistance is needed, please call one of our financial counselors.</p>			
<p>What happens if I cannot pay my bills? Will my treatment be stopped?</p>	<p>Your treatment will not be stopped if you cannot pay the balance you owe. You should call one of our financial counselors to discuss payment options for the amount you owe after insurance.</p>			
<p>How do I contact a Financial Counselor?</p>	<table border="0"> <tr> <td style="vertical-align: top;"> <p><u>Medical Oncology</u> Telephone: 410 502-1304 410 955-8995 Fax: 443 287-3666</p> </td> <td style="vertical-align: top; text-align: center;"> <p>or</p> </td> <td style="vertical-align: top;"> <p><u>Radiation Oncology</u> Telephone: 410 955-6981 410 502-1643 Fax: 410 502-1637</p> </td> </tr> </table>	<p><u>Medical Oncology</u> Telephone: 410 502-1304 410 955-8995 Fax: 443 287-3666</p>	<p>or</p>	<p><u>Radiation Oncology</u> Telephone: 410 955-6981 410 502-1643 Fax: 410 502-1637</p>
<p><u>Medical Oncology</u> Telephone: 410 502-1304 410 955-8995 Fax: 443 287-3666</p>	<p>or</p>	<p><u>Radiation Oncology</u> Telephone: 410 955-6981 410 502-1643 Fax: 410 502-1637</p>		
<p>What does it mean when my insurance company denies payment on my claim?</p>	<p>Insurance companies provide a detailed summary (referred to as an explanation of benefits or “EOB”) about why a claim was paid or denied. Often, a company rejects a claim because it has incorrect information or an authorization/referral form is needed. Your health care provider may need to resend the claim with the requested information. Our billing office can help you with this. If services are not covered by your insurance company, you can call them and request a written explanation of your appeal rights.</p>			



The Johns Hopkins Hospital Patient Information

Original Date
8/00
Oncology
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12/15

Understanding Your Bills

Can I get financial assistance to help pay my medical bills?

You may be able to get assistance from Johns Hopkins or the State of Maryland Medical Assistance or other state programs. Again, our financial counselors can help you with this. Some drug companies also provide help with medicine costs.

Will my insurance company pay for services if I am in a clinical trial?

Ask your doctor or study nurse about what charges may be covered by the clinical trial. This information is also in the consent form you are required to sign. *Johns Hopkins Staff will check in advance what your insurance company may cover while you are in a clinical trial.*

Note: If you receive care at our Green Spring Station location, all of your services will appear on a physician's bill that comes from Johns Hopkins University.



The Johns Hopkins Hospital Patient Information

Original Date
January 25, 2013
Oncology
Revised/ Reviewed
2/16

Resources to Stop Smoking

<p>Why should I stop smoking now?</p>	<ul style="list-style-type: none"> • Our hospital is smoke free. Since you cannot smoke while you are here, it is a great time to quit. • You will be healthier while you are going through treatment, since your heart and lung function will improve and your body may heal quicker.
<p>How can I stop smoking now?</p>	<ul style="list-style-type: none"> • Your doctors and nurses would be very happy to help you quit if you are ready to try. • They can give you nicotine replacements such as gum or patches and information and support to help you quit.
<p>How can I stay quit?</p>	<ul style="list-style-type: none"> • Make sure you leave the hospital with your nicotine replacements or prescriptions. • Tell your family and friends you quit so they can help you stick with it. • It may take a couple of tries, before you quit for good. Set a new date if you relapse.
<p>Other Resources</p>	<p>There are many resources on the internet now which have coaches, plans and information to help you quit.</p> <p>Maryland Quitline: www.smokingstopshere.com or 1-800-784-8669</p> <p>American Cancer Society Quitline: www.cancer.org/healthy/stayawayfromtobacco/quit-for-life or 1-800-227-2345</p> <p>National Cancer Institute Quitline: www.smokefree.gov or 1-877-448-7848</p> <p>Asian Smokers' Quitline: http://www.asiansmokersquitline.org/</p>



My Personal Pages



My Cancer History

Primary Care Physician _____

Allergies _____

Advance Directive or Living Will? yes no

MOLST? yes no

Name of Cancer _____

Date of Diagnosis _____

Stage of Cancer _____

Surgery

Date of Surgery _____

Type of Surgery _____

Surgeon's Name _____

Any Problems _____

Chemotherapy

Dates of Chemotherapy _____

Names of Drugs _____

Number of Doses _____

How Given _____

Oncologist's Name _____

Any Problems_____

Radiation Therapy

Dates of Radiation_____

Number of Doses_____

Area of Body Treated_____

Radiation Oncologist's Name_____

Any Problems_____

Blood or Marrow Transplant

Date of Transplant_____

Type of Transplant_____

Any Problems_____

Blood Transfusions_____



My Appointment Notes

Date and Time: _____

Health Care staff I met
with: _____

Questions I
Have: _____

Answers I
Received: _____

(You may want to make additional copies of this page.)



My Treatment Plan



Monthly Treatment Calendar

Month:

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



The Johns Hopkins Hospital Patient Information

Original date:
January 12, 2012

Your Department:
Regulatory Affairs

Revised/ Reviewed:
April 9, 2015

A Guide for the Patient in Managing the Home Medication List

Why is it important to keep a current medication list?

- To provide safe and proper care, your healthcare provider needs to know what medications you are taking at home.
- A list of your home medications is helpful even when no medications are being ordered during your current visit.

What types of medications should I include on my medication list?

Include all you are currently taking OR stopped taking within the last 2 weeks:

- Prescription medications
- Over-the-counter medications
- Herbal products
- Vitamins
- Dietary supplements
- Natural remedies

What information should I include on my medication list?

- Name of medication, herb, vitamin, or supplement
- Dose
- How you take the medication (for example; by mouth, with food, injection)
- How often you take the medication (for example; once a day, twice a day, at bedtime)
- Allergy information

How often should I update my home medication list?

- Update your medication list whenever medications are stopped, doses are changed, or new medications are started

Who can help you in preparing your medication list?

- Healthcare provider (physician, nurse or pharmacist)
- Family member
- Friend

Where should I keep my current medication list?

- Keep your medication list with you at all times in case of emergency situations.
- Examples of ways to keep your medication list with you at all times include a wallet card, paper list, health vault, or mobile application)
- Give an updated list to your primary care provider.



Managing Side Effects



The Johns Hopkins Hospital Patient Information

Original Date
6/06
Oncology
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9/17

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 medication 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 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

Chemotherapy and You



Important Phone Numbers

Emergency _____

Clinic _____

Nurse _____

Doctor _____

Other _____

For More Information

This is only one of many free books for people with cancer. Here are some others you may find useful:

- *Biological Therapy*
- *Radiation Therapy and You: Support for People With Cancer*
- *Eating Hints: Before, During, and After Cancer Treatment*
- *Taking Part in Cancer Treatment Research Studies*
- *Thinking About Complementary & Alternative Medicine: A Guide for People With Cancer*
- *Pain Control: A Guide for People With Cancer*
- *When Cancer Returns*
- *Taking Time: Support for People with Cancer*

These books are available from NCI (the National Cancer Institute). NCI is a federal agency that is part of the National Institutes of Health. Call 1-800-4-CANCER (1-800-422-6237) or visit <http://www.cancer.gov>. (See page 59 for more information.)

*For information about your specific type of cancer, see the PDQ® database. You can also find the database at <http://www.cancer.gov>.

Product or brand names that appear in this book are for example only. The U.S. Government does not endorse any specific product or brand. If products or brands are not mentioned, it does not mean or imply that they are not satisfactory.

About This Book

Chemotherapy and You is written for you—someone who is about to receive or is now receiving **chemotherapy** for cancer. Your family, friends, and others close to you may also want to read this book.

This book is a guide you can refer to throughout your chemotherapy treatment. It includes facts about chemotherapy and its **side effects** and also highlights ways you can care for yourself before, during, and after treatment.

This book covers:

- **Questions and answers about chemotherapy.**

Answers common questions, such as what chemotherapy is and how it affects cancer cells.

- **Side effects and ways to manage them.**

Explains side effects and other problems that may result from chemotherapy. This section also has ways that you and your doctor or nurse can manage these side effects.

- **Tips for meeting with your doctor or nurse.**

Includes questions for you to think about and discuss with your doctor, nurse, and others involved in your cancer care.

- **Ways to learn more.**

Lists ways to get more information about chemotherapy and other topics discussed in this book—in print, online, and by telephone.

- **Words to know.**

A dictionary that clearly explains all the words that are in bold in this book.

Talk with your doctor or nurse about what you can expect during chemotherapy. He or she may suggest that you read certain sections of this book or try some of the ways to manage side effects.

Rather than read this book from beginning to end—look at only those sections you need now. Later, you can always read more.



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Rather than read this book from beginning to end—look at only those sections you need now. Later, you can always read more.

Questions and Answers About Chemotherapy

What is chemotherapy?

Chemotherapy (also called chemo) is a type of cancer treatment that uses drugs to destroy cancer cells.

How does chemotherapy work?

Chemotherapy works by stopping or slowing the growth of cancer cells, which grow and divide quickly. But it can also harm **healthy cells** that divide quickly, such as those that line your mouth and intestines or cause your hair to grow. Damage to healthy cells may cause side effects. Often, side effects get better or go away after chemotherapy is over.

What does chemotherapy do?

Depending on your type of cancer and how advanced it is, chemotherapy can:

- **Cure cancer**—when chemotherapy destroys cancer cells to the point that your doctor can no longer detect them in your body and they will not grow back.
 - **Control cancer**—when chemotherapy keeps cancer from spreading, slows its growth, or destroys cancer cells that have spread to other parts of your body.
 - **Ease cancer symptoms** (also called **palliative care**)—when chemotherapy shrinks tumors that are causing pain or pressure.
-

How is chemotherapy used?

Sometimes, chemotherapy is used as the only cancer treatment. But more often, you will get chemotherapy along with surgery, **radiation therapy**, or **biological therapy**. Chemotherapy can:

- Make a tumor smaller before surgery or radiation therapy. This is called **neo-adjuvant chemotherapy**.
 - Destroy cancer cells that may remain after surgery or radiation therapy. This is called **adjuvant chemotherapy**.
 - Help radiation therapy and biological therapy work better.
 - Destroy cancer cells that have come back (**recurrent cancer**) or spread to other parts of your body (**metastatic cancer**).
-

How does my doctor decide which chemotherapy drugs to use?

This choice depends on:

- The type of cancer you have. Some types of chemotherapy drugs are used for many types of cancer. Other drugs are used for just one or two types of cancer.
- Whether you have had chemotherapy before.
- Whether you have other health problems, such as diabetes or heart disease.

Where do I go for chemotherapy?

You may receive chemotherapy during a hospital stay, at home, or in a doctor's office, clinic, or **outpatient** unit in a hospital (which means you do not have to stay overnight). No matter where you go for chemotherapy, your doctor and nurse will watch for side effects and make any needed drug changes.

How often will I receive chemotherapy?

Treatment schedules for chemotherapy vary widely. How often and how long you get chemotherapy depends on:

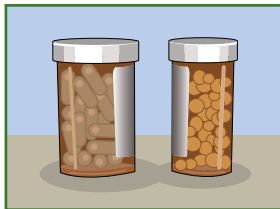
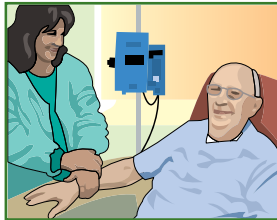
- Your type of cancer and how advanced it is
- The goals of treatment (whether chemotherapy is used to cure your cancer, control its growth, or ease the symptoms)
- The type of chemotherapy
- How your body reacts to chemotherapy

You may receive chemotherapy in cycles. A cycle is a period of chemotherapy treatment followed by a period of rest. For instance, you might receive 1 week of chemotherapy followed by 3 weeks of rest. These 4 weeks make up one cycle. The rest period gives your body a chance to build new healthy cells.

Can I miss a dose of chemotherapy?

It is not good to skip a chemotherapy treatment. But sometimes your doctor or nurse may change your chemotherapy schedule. This can be due to side effects you are having. If this happens, your doctor or nurse will explain what to do and when to start treatment again.

How is chemotherapy given?



Chemotherapy may be given in many ways.

- **Injection.** The chemotherapy is given by a shot in a muscle in your arm, thigh, or hip, or right under the skin in the fatty part of your arm, leg, or belly.
- **Intra-arterial (IA).** The chemotherapy goes directly into the artery that is feeding the cancer.
- **Intraperitoneal (IP).** The chemotherapy goes directly into the **peritoneal cavity** (the area that contains organs such as your intestines, stomach, liver, and ovaries).
- **Intravenous (IV).** The chemotherapy goes directly into a vein.
- **Topical.** The chemotherapy comes in a cream that you rub onto your skin.
- **Oral.** The chemotherapy comes in pills, capsules, or liquids that you swallow.

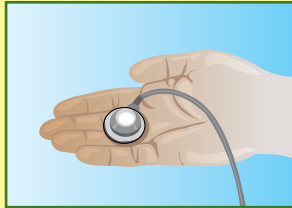
Things to know about getting chemotherapy through an IV

Chemotherapy is often given through a thin needle that is placed in a vein on your hand or lower arm. Your nurse will put the needle in at the start of each treatment and remove it when treatment is over. Let your doctor or nurse know right away if you feel pain or burning while you are getting IV chemotherapy.

IV chemotherapy is often given through **catheters** or **ports**, sometimes with the help of a **pump**.

- **Catheters.** A catheter is a soft, thin tube. A surgeon places one end of the catheter in a large vein, often in your chest area. The other end of the catheter stays outside your body. Most catheters stay in place until all your chemotherapy treatments are done. Catheters can also be used for drugs other than chemotherapy and to draw blood. Be sure to watch for signs of infection around your catheter. For more information on infection, see page 30.

- **Ports.** A port is a small, round disc made of plastic or metal that is placed under your skin. A catheter connects the port to a large vein, most often in your chest.



Your nurse can insert a needle into your port to give you chemotherapy or draw blood. This needle can be left in place for chemotherapy treatments that are given for more than 1 day. Be sure to watch for signs of infection around your port. For more information on infection, see page 30.

- **Pumps.** Pumps are often attached to catheters or ports. They control how much and how fast chemotherapy goes into a catheter or port. Pumps can be internal or external. External pumps remain outside your body. Most people can carry these pumps with them. Internal pumps are placed under your skin during surgery.



How will I feel during chemotherapy?



Chemotherapy affects people in different ways. How you feel depends on how healthy you are before treatment, your type of cancer, how advanced it is, the kind of chemotherapy you are getting, and the dose. Doctors and nurses cannot know for certain how you will feel during chemotherapy.

Some people do not feel well right after chemotherapy. The most common side effect is **fatigue**, feeling exhausted and worn out. You can prepare for fatigue by:

- Asking someone to drive you to and from chemotherapy
- Planning time to rest on the day of and day after chemotherapy
- Getting help with meals and childcare the day of and at least 1 day after chemotherapy

There are many ways you can help manage chemotherapy side effects. For more information, see the Side Effects At-A-Glance section starting on page 15.

Can I work during chemotherapy?

Many people can work during chemotherapy, as long as they match their schedule to how they feel. Whether or not you can work may depend on what kind of work you do. If your job allows, you may want to see if you can work part-time or work from home on days you do not feel well.

Many employers are required by law to change your work schedule to meet your needs during cancer treatment. Talk with your employer about ways to adjust your work during chemotherapy. You can learn more about these laws by talking with a social worker.

Can I take over-the-counter and prescription drugs while I get chemotherapy?



This depends on the type of chemotherapy you get and the other types of drugs you plan to take. Take only drugs that are approved by your doctor or nurse. Tell your doctor or nurse about all the over-the-counter and prescription drugs you take, including laxatives, allergy medicines, cold medicines, pain relievers, aspirin, and ibuprofen.

One way to let your doctor or nurse know about these drugs is by bringing in all your pill bottles. Your doctor or nurse needs to know:

- The name of each drug
- The reason you take it
- How much you take
- How often you take it

Talk to your doctor or nurse before you take any over-the-counter or prescription drugs, vitamins, minerals, dietary supplements, or herbs.

Can I take vitamins, minerals, dietary supplements, or herbs while I get chemotherapy?

Some of these products can change how chemotherapy works. For this reason, it is important to tell your doctor or nurse about all the vitamins, minerals, dietary supplements, and herbs that you take before you start chemotherapy. During chemotherapy, talk with your doctor before you take any of these products.

How will I know if my chemotherapy is working?

Your doctor will give you physical exams and medical tests (such as blood tests and x-rays). He or she will also ask you how you feel.

You cannot tell if chemotherapy is working based on its side effects. Some people think that severe side effects mean that chemotherapy is working well, or that no side effects mean that chemotherapy is not working. The truth is that side effects have nothing to do with how well chemotherapy is fighting your cancer.

How much does chemotherapy cost?

It is hard to say how much chemotherapy will cost. It depends on:

- The types and doses of chemotherapy used
- How long and how often chemotherapy is given
- Whether you get chemotherapy at home, in a clinic or office, or during a hospital stay
- The part of the country where you live

Does my health insurance pay for chemotherapy?

Talk with your health insurance company about what costs it will pay for. Questions to ask include:

- What will my insurance pay for?
- Do I need to call my insurance company before each treatment for it to be covered? Or, does my doctor's office need to call?
- What do I have to pay for?
- Can I see any doctor I want or do I need to choose from a list of preferred providers?
- Do I need a written referral to see a specialist?
- Is there a co-pay (money I have to pay) each time I have an appointment?
- Is there a deductible (certain amount I need to pay) before my insurance pays?
- Where should I get my prescription drugs?
- Does my insurance pay for all my tests and treatments, whether I am an inpatient or outpatient?



How can I best work with my insurance plan?

- Read your insurance policy before treatment starts to find out what your plan will and will not pay for.
- Keep records of all your treatment costs and insurance claims.
- Send your insurance company all the paperwork it asks for. This may include receipts from doctors' visits, prescriptions, and lab work. Be sure to also keep copies for your own records.
- As needed, ask for help with the insurance paperwork. You can ask a friend, family member, social worker, or local group such as a senior center.
- If your insurance does not pay for something you think it should, find out why the plan refused to pay. Then talk with your doctor or nurse about what to do next. He or she may suggest ways to appeal the decision or other actions to take.

What are clinical trials and are they an option for me?

Cancer clinical trials (also called cancer treatment studies or research studies) test new treatments for people with cancer. These can be studies of new types of chemotherapy, other types of treatment, or new ways to combine treatments. The goal of all these clinical trials is to find better ways to help people with cancer.

Your doctor or nurse may suggest you take part in a clinical trial. You can also suggest the idea. Before you agree to be in a clinical trial, learn about:

- **Benefits.** All clinical trials offer quality cancer care. Ask how this clinical trial could help you or others. For instance, you may be one of the first people to get a new treatment or drug.
- **Risks.** New treatments are not always better or even as good as **standard treatments**. And even if this new treatment is good, it may not work well for you.
- **Payment.** Your insurance company may or may not pay for treatment that is part of a clinical trial. Before you agree to be in a trial, check with your insurance company to make sure it will pay for this treatment.

Contact the NCI's Cancer Information Service if you are interested in learning more about clinical trials. See Ways To Learn More on page 59 for ways to contact them.



Tips for Meeting With Your Doctor or Nurse

- **Make a list of your questions before each appointment.**

Some people keep a “running list” and write down new questions as they think of them. Make sure to have space on this list to write down the answers from your doctor or nurse.



- **Bring a family member or trusted friend to your medical visits.**

This person can help you understand what the doctor or nurse says and talk with you about it after the visit is over.

- **Ask all your questions.** There is no such thing as a stupid question. If you do not understand an answer, keep asking until you do.

- **Take notes.** You can write them down or use a tape recorder. Later, you can review your notes and remember what was said.

- **Ask for printed information about your type of cancer and chemotherapy.**

- **Let your doctor or nurse know how much information you want to know, when you want to learn it, and when you have learned enough.** Some people want to learn everything they can about cancer and its treatment. Others only want a little information. The choice is yours.

- **Find out how to contact your doctor or nurse in an emergency.** This includes who to call and where to go. Write important phone numbers in the spaces provided on the inside front cover of this book.

Questions To Ask

About My Cancer

- What kind of cancer do I have? _____

- What is the stage of my cancer? _____

About Chemotherapy

- Why do I need chemotherapy? _____

- What is the goal of this chemotherapy? _____

- What are the benefits of chemotherapy? _____

- What are the risks of chemotherapy? _____

About My Treatment

- Are there other ways to treat my type of cancer? _____

- What is the standard care for my type of cancer? _____

- Are there any clinical trials for my type of cancer? _____

- How many cycles of chemotherapy will I get? How long is each treatment? How long between treatments? _____

- What types of chemotherapy will I get? _____

- How will these drugs be given? _____

- Where do I go for this treatment? _____

- How long does each treatment last? _____

- Should someone drive me to and from treatments? _____

About Side Effects

- What side effects can I expect right away? _____

- What side effects can I expect later? _____

- How serious are these side effects? _____

- How long will these side effects last? _____

- Will all the side effects go away when treatment is over? _____

- What can I do to manage or ease these side effects? _____

- What can my doctor or nurse do to manage or ease side effects? _____

- When should I call my doctor or nurse about these side effects? _____

Your Feelings During Chemotherapy

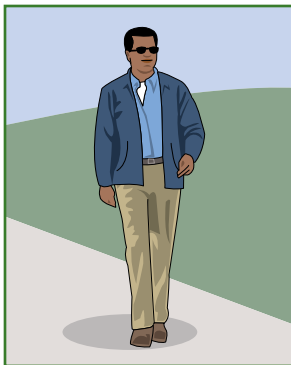


At some point during chemotherapy, you may feel:

- Anxious
- Depressed
- Afraid
- Angry
- Frustrated
- Helpless
- Lonely

It is normal to have a wide range of feelings while going through chemotherapy. After all, living with cancer and getting treatment can be stressful. You may also feel fatigue, which can make it harder to cope with your feelings.

How can I cope with my feelings during chemotherapy?



- **Relax.** Find some quiet time and think of yourself in a favorite place. Breathe slowly or listen to soothing music. This may help you feel calmer and less stressed.
- **Exercise.** Many people find that light exercise helps them feel better. There are many ways for you to exercise, such as walking, riding a bike, and doing yoga. Talk with your doctor or nurse about ways you can exercise.
- **Talk with others.** Talk about your feelings with someone you trust. Choose someone who can focus on you, such as a close friend, family member, chaplain, nurse, or social worker. You may also find it helpful to talk with someone else who is getting chemotherapy.
- **Join a support group.** Cancer support groups provide support for people with cancer. These groups allow you to meet others with the same problems. You will have a chance to talk about your feelings and listen to other people talk about theirs. You can find out how others cope with cancer, chemotherapy, and side effects. Your doctor, nurse, or social worker may know about support groups near where you live. Some support groups also meet online (over the Internet), which can be helpful if you cannot travel.



Talk to your doctor or nurse about things that worry or upset you. You may want to ask about seeing a counselor. Your doctor may also suggest that you take medication if you find it very hard to cope with your feelings.

It's normal to have a wide range of feelings during chemotherapy. After all, living with cancer and going through treatment can be stressful.

Ways to learn more

To learn more about coping with your feelings and relationships during cancer treatment, read *Taking Time: Support for People With Cancer*, a book from the National Cancer Institute. You can get a free copy at <http://www.cancer.gov/publications> or 1-800-4-CANCER (1-800-422-6237).

Cancer Support Community

Dedicated to providing support, education, and hope to people affected by cancer.

Call: 1-888-793-9355 or 202-659-9709

Visit: <http://www.cancersupportcommunity.org>

E-mail: help@cancersupportcommunity.org

CancerCare, Inc.

Offers free support, information, financial assistance, and practical help to people with cancer and their loved ones.

Call: 1-800-813-HOPE (1-800-813-4673)

Visit: <http://www.cancercare.org>

E-mail: info@cancercare.org

Side Effects and Ways To Manage Them

What are side effects?

Side effects are problems caused by cancer treatment. Some common side effects from chemotherapy are fatigue, **nausea**, **vomiting**, decreased **blood cell counts**, hair loss, mouth sores, and pain.

What causes side effects?

Chemotherapy is designed to kill fast-growing cancer cells. But it can also affect healthy cells that grow quickly. These include cells that line your mouth and intestines, cells in your **bone marrow** that make blood cells, and cells that make your hair grow. Chemotherapy causes side effects when it harms these healthy cells.

Will I get side effects from chemotherapy?

You may have a lot of side effects, some, or none at all. This depends on the type and amount of chemotherapy you get and how your body reacts. Before you start chemotherapy, talk with your doctor or nurse about which side effects to expect.

How long do side effects last?

How long side effects last depends on your health and the kind of chemotherapy you get. Most side effects go away after chemotherapy is over. But sometimes it can take months or even years for them to go away.

Sometimes, chemotherapy causes **long-term side effects** that do not go away. These may include damage to your heart, lungs, nerves, kidneys, or reproductive organs. Some types of chemotherapy may cause a second cancer years later. Ask your doctor or nurse about your chance of having long-term side effects.

What can be done about side effects?



Doctors have many ways to prevent or treat chemotherapy side effects and help you heal after each treatment session. Talk with your doctor or nurse about which ones to expect and what to do about them. Make sure to let your doctor or nurse know about any changes you notice—they may be signs of a side effect.

The chart on the next page tells you where in this book to look for more information about specific side effects.

Side Effects At-A-Glance

Below is a list of side effects that chemotherapy may cause.

Not everyone gets every side effect. Which ones you have will depend on the type and dose of your chemotherapy and whether you have other health problems, such as diabetes or heart disease.

You may have a lot of side effects, some, or none at all.

Talk with your doctor or nurse about the side effects on this list. Ask which ones may affect you. Mark the ones you may get and go to the pages listed to learn more.

Names of the chemotherapy that I am getting: _____, _____,
_____, _____, _____.

Side effects	Side effects that may affect you	Pages to learn more
Anemia		16
Appetite changes		18
Bleeding		20
Constipation		22
Diarrhea		24
Fatigue		26
Flu-like symptoms		51
Fluid retention		51
Hair loss		28
Infection		30
Infertility		33
Mouth and throat changes		35
Nausea and vomiting		38
Nervous system changes		40
Pain		42
Sexual changes		44
Skin and nail changes		47
Eye changes		51
Urinary, kidney, and bladder changes		50

Anemia

What it is and why it occurs

Red blood cells carry oxygen throughout your body. **Anemia** is when you have too few red blood cells to carry the oxygen your body needs. Your heart works harder when your body does not get enough oxygen. This can make it feel like your heart is pounding or beating very fast. Anemia can also make you feel short of breath, weak, dizzy, faint, or very tired.

Some types of chemotherapy cause anemia because they make it harder for bone marrow to produce new red blood cells.

Ways to manage

- **Get plenty of rest.** Try to sleep at least 8 hours each night. You might also want to take 1 to 2 short naps (1 hour or less) during the day.
- **Limit your activities.** This means doing only the activities that are most important to you. For example, you might go to work but not clean the house. Or you might order take-out food instead of cooking dinner.
- **Accept help.** When your family or friends offer to help, let them. They can help care for your children, pick up groceries, run errands, drive you to doctor's visits, or do other chores you feel too tired to do.
- **Eat a well-balanced diet.** Choose a diet that contains all the calories and protein your body needs. Calories will help keep your weight up, and extra protein can help repair tissues that have been harmed by cancer treatment. Talk to your doctor, nurse, or dietitian about the diet that is right for you. (To learn more, see *Appetite Changes* on page 18.)
- **Stand up slowly.** You may feel dizzy if you stand up too fast. When you get up from lying down, sit for a minute before you stand.



Normal number of red blood cells



Number of red blood cells when you have anemia



When you get up from lying down, sit for a moment before you stand.

Your doctor or nurse will check your blood cell count throughout your chemotherapy. You may need a blood transfusion if your red blood cell count falls too low. Your doctor may also prescribe a medicine to boost (speed up) the growth of red blood cells or suggest that you take iron or other vitamins.

Call your doctor or nurse if:

- Your level of fatigue changes or you are not able to do your usual activities
- You feel dizzy or like you are going to faint
- You feel short of breath
- It feels like your heart is pounding or beating very fast



For more information on how to manage fatigue that may be caused by anemia, see page 26.

Appetite Changes

What they are and why they occur

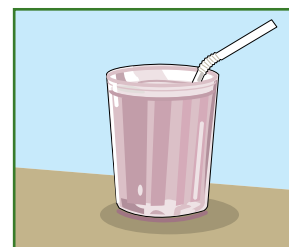
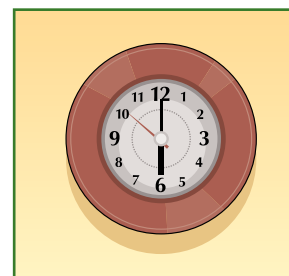
Chemotherapy can cause appetite changes. You may lose your appetite because of nausea (feeling like you are going to throw up), mouth and throat problems that make it painful to eat, or drugs that cause you to lose your taste for food. The changes can also come from feeling depressed or tired. Appetite loss may last for a day, a few weeks, or even months.

It is important to eat well, even when you have no appetite. This means eating and drinking foods that have plenty of protein, vitamins, and calories. Eating well helps your body fight infection and repair tissues that are damaged by chemotherapy. Not eating well can lead to weight loss, weakness, and fatigue.

Some cancer treatments cause weight gain or an increase in your appetite. Be sure to ask your doctor, nurse, or dietitian what types of appetite changes you might expect and how to manage them.

Ways to manage

- **Eat 5 to 6 small meals or snacks each day instead of 3 big meals.** Choose foods and drinks that are high in calories and protein. See page 54 for a list of these foods.
- **Set a daily schedule for eating your meals and snacks.** Eat when it is time to eat, rather than when you feel hungry. You may not feel hungry while you are on chemotherapy, but you still need to eat.
- **Drink milkshakes, smoothies, juice, or soup if you do not feel like eating solid foods.** Liquids like these can help provide the protein, vitamins, and calories your body needs. See page 53 for a list of liquid foods.
- **Use plastic forks and spoons.** Some types of chemo give you a metal taste in your mouth. Eating with plastic can help decrease the metal taste. Cooking in glass pots and pans can also help.



- **Increase your appetite by doing something active.** For instance, you might have more of an appetite if you take a short walk before lunch. Also, be careful not to decrease your appetite by drinking too much liquid before or during meals.
- **Change your routine.** This may mean eating in a different place, such as the dining room rather than the kitchen. It can also mean eating with other people instead of eating alone. If you eat alone, you may want to listen to the radio or watch TV. You may also want to vary your diet by trying new foods and recipes.
- **Talk with your doctor, nurse, or dietitian.** He or she may want you to take extra vitamins or nutrition supplements (such as high protein drinks). If you cannot eat for a long time and are losing weight, you may need to take drugs that increase your appetite or receive nutrition through an IV or feeding tube.

NCI's book "Eating Hints: Before, During, and After Cancer Treatment" provides more tips for making eating easier. You can get a free copy at <http://www.cancer.gov/publications> or 1-800-4-CANCER (1-800-422-6237).

Bleeding

What it is and why it occurs

Platelets are cells that make your blood clot when you bleed. Chemotherapy can lower the number of platelets because it affects your bone marrow's ability to make them. A low platelet count is called **thrombocytopenia**. This condition may cause bruises (even when you have not been hit or have not bumped into anything), bleeding from your nose or in your mouth, or a rash of tiny, red dots.

Ways to manage

Do:

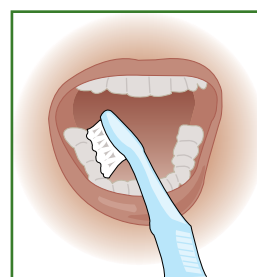
- Brush your teeth with a very soft toothbrush
- Soften the bristles of your toothbrush by running hot water over them before you brush
- Blow your nose gently
- Be careful when using scissors, knives, or other sharp objects
- Use an electric shaver instead of a razor
- Apply gentle but firm pressure to any cuts you get until the bleeding stops
- Wear shoes all the time, even inside the house or hospital

Do not:

- Use dental floss or toothpicks
- Play sports or do other activities during which you could get hurt
- Use tampons, enemas, suppositories, or rectal thermometers
- Wear clothes with tight collars, wrists, or waistbands

Check with your doctor or nurse before:

- Drinking beer, wine, or other types of alcohol
- Having sex
- Taking vitamins, herbs, minerals, dietary supplements, aspirin, or other over-the-counter medicines. Some of these products can change how chemotherapy works.



Check with your doctor or nurse before taking any vitamins, herbs, minerals, dietary supplements, aspirin, or other over-the-counter medicines.

Let your doctor know if you are constipated.

He or she may prescribe a stool softener to prevent straining and rectal bleeding when you go to the bathroom. For more information on **constipation**, see page 22.

Your doctor or nurse will check your platelet count often.

You may need medication, a platelet transfusion, or a delay in your chemotherapy treatment if your platelet count is too low.

Call your doctor or nurse if you have any of these symptoms:

- Bruises, especially if you did not bump into anything
- Small, red spots on your skin
- Red- or pink-colored urine
- Black or bloody bowel movements
- Bleeding from your gums or nose
- Heavy bleeding during your menstrual period or for a prolonged period
- Vaginal bleeding not caused by your period
- Headaches or changes in your vision
- A warm or hot feeling in your arm or leg
- Feeling very sleepy or confused



Constipation

What it is and why it occurs

Constipation is when bowel movements become less frequent and stools are hard, dry, and difficult to pass. You may have painful bowel movements and feel bloated or nauseous. You may belch, pass a lot of gas, and have stomach cramps or pressure in the rectum.

Drugs such as chemotherapy and pain medicine can cause constipation. It can also happen when people are not active and spend a lot of time sitting or lying down. Constipation can also be due to eating foods that are low in fiber or not drinking enough fluids.

Ways to manage

- **Keep a record of your bowel movements.** Show this record to your doctor or nurse and talk about what is normal for you. This makes it easier to figure out whether you have constipation.
- **Drink at least 8 cups of water or other fluids each day.** Many people find that drinking warm or hot fluids, such as coffee and tea, helps with constipation. Fruit juices, such as prune juice, may also be helpful.

When you eat more fiber, be sure to drink more fluids.



- **Be active every day.** You can be active by walking, riding a bike, or doing yoga. If you cannot walk, ask about exercises that you can do in a chair or bed. Talk with your doctor or nurse about ways you can be more active.



Check with your doctor or nurse before using fiber supplements, laxatives, stool softeners, or enemas.

- **Ask your doctor, nurse, or dietitian about foods that are high in fiber.** Eating high-fiber foods and drinking lots of fluids can help soften your stools. Good sources of fiber include whole-grain breads and cereals, dried beans and peas, raw vegetables, fresh and dried fruit, nuts, seeds, and popcorn. (To learn more, see the list of high-fiber foods on page 55.)
- **Let your doctor or nurse know if you have not had a bowel movement in 2 days.** Your doctor may suggest a fiber supplement, laxative, stool softener, or enema. Do not use these treatments without first checking with your doctor or nurse.



Diarrhea

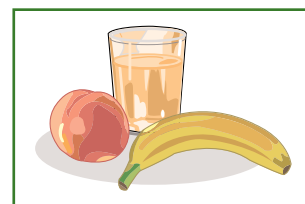
What it is and why it occurs

Diarrhea is frequent bowel movements that may be soft, loose, or watery. Chemotherapy can cause diarrhea because it harms healthy cells that line your large and small intestines. It may also speed up your bowels. Diarrhea can also be caused by infections or drugs used to treat constipation.

Ways to manage

- **Eat 5 or 6 small meals and snacks each day instead of 3 large meals.**

- **Ask your doctor or nurse about foods that are high in salts such as sodium and potassium.** Your body can lose these salts when you have diarrhea, and it is important to replace them. Foods that are high in sodium or potassium include bananas, oranges, peach and apricot nectar, and boiled or mashed potatoes.



- **Drink 8 to 12 cups of clear liquids each day.** These include water, clear broth, ginger ale, or sports drinks such as Gatorade® or Propel®. Drink slowly, and choose drinks that are at room temperature. Let carbonated drinks lose their fizz before you drink them. Add extra water if drinks make you thirsty or nauseous (feeling like you are going to throw up).

- **Eat low-fiber foods.** Foods that are high in fiber can make diarrhea worse. Low-fiber foods include bananas, white rice, white toast, and plain or vanilla yogurt. See page 56 for other low-fiber foods.

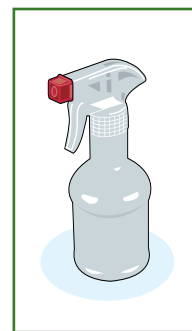
- **Let your doctor or nurse know if your diarrhea lasts for more than 24 hours or if you have pain and cramping along with diarrhea.** Your doctor may prescribe a medicine to control the diarrhea. You may also need IV fluids to replace the water and nutrients you lost. Do not take any medicine for diarrhea without first asking your doctor or nurse.



Ask your doctor or nurse before taking medicine for diarrhea.

■ **Be gentle when you wipe yourself after a bowel movement.**

Instead of toilet paper, use a baby wipe or squirt of water from a spray bottle to clean yourself after bowel movements. Let your doctor or nurse know if your rectal area is sore or bleeds or if you have hemorrhoids.



- **Ask your doctor if you should try a clear liquid diet.** This can give your bowels time to rest. Most people stay on this type of diet for 5 days or less. See page 52 for a list of clear liquids.



Stay away from:

- Drinks that are very hot or very cold
- Beer, wine, and other types of alcohol
- Milk or milk products, such as ice cream, milkshakes, sour cream, and cheese
- Spicy foods, such as hot sauce, salsa, chili, and curry dishes
- Greasy and fried foods, such as french fries and hamburgers
- Foods or drinks with caffeine, such as regular coffee, black tea, cola, and chocolate
- Foods or drinks that cause gas, such as cooked dried beans, cabbage, broccoli, and soy milk and other soy products
- Foods that are high in fiber, such as cooked dried beans, raw fruits and vegetables, nuts, and whole-wheat breads and cereals

To learn more about ways to manage diarrhea during cancer treatment read *Eating Hints: Before, During, and After Cancer Treatment*, a book from NCI. You can get a free copy at <http://www.cancer.gov/publications> or by calling 1-800-4-CANCER (1-800-422-6237).

Fatigue

What it is and why it occurs

Fatigue from chemotherapy can range from a mild to extreme feeling of being tired. Many people describe fatigue as feeling weak, weary, worn out, heavy, or slow. Resting does not always help.

Many people say they feel fatigue during chemotherapy and even for weeks or months after treatment is over. Fatigue can be caused by the type of chemotherapy, the effort of making frequent visits to the doctor, or feelings such as stress, anxiety, and depression. If you receive radiation therapy along with chemotherapy, your fatigue may be more severe.

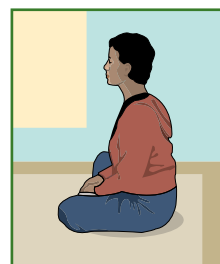
Fatigue can also be caused by:

- Anemia (see page 16)
- Pain (see page 42)
- Medications
- Appetite changes (see page 18)
- Trouble sleeping
- Lack of activity
- Trouble breathing
- Infection (see page 30)
- Doing too much at one time
- Other medical problems

Fatigue can happen all at once or little by little. People feel fatigue in different ways. You may feel more or less fatigue than someone else who gets the same type of chemotherapy.

Ways to manage

- **Relax.** You might want to try meditation, prayer, yoga, guided imagery, visualization, or other ways to relax and decrease stress.
- **Eat and drink well.** Often, this means 5 to 6 small meals and snacks rather than 3 large meals. Keep foods around that are easy to fix, such as canned soups, frozen meals, yogurt, and cottage cheese. Drink plenty of fluids each day—about 8 cups of water or juice.
- **Plan time to rest.** You may feel better when you rest or take a short nap during the day. Many people say that it helps to rest for just 10 to 15 minutes rather than nap for a long time. If you nap, try to sleep for less than 1 hour. Keeping naps short will help you sleep better at night.
- **Be active.** Research shows that exercise can ease fatigue and help you sleep better at night. Try going for a 15-minute walk, doing yoga, or riding an exercise bike. Plan to be active when you have the most energy. Talk with your doctor or nurse about ways you can be active while getting chemotherapy.



- **Try not to do too much.** With fatigue, you may not have enough energy to do all the things you want to do. Choose the activities you want to do and let someone else help with the others. Try quiet activities, such as reading, knitting, or learning a new language on tape.



- **Sleep at least 8 hours each night.** This may be more sleep than you needed before chemotherapy. You are likely to sleep better at night when you are active during the day. You may also find it helpful to relax before going to bed. For instance, you might read a book, work on a jigsaw puzzle, listen to music, or do other quiet hobbies.

- **Plan a work schedule that works for you.** Fatigue may affect the amount of energy you have for your job. You may feel well enough to work your full schedule. Or you may need to work less—maybe just a few hours a day or a few days each week. If your job allows, you may want to talk with your boss about ways to work from home. Or you may want to go on medical leave (stop working for a while) while getting chemotherapy.

- **Let others help.** Ask family members and friends to help when you feel fatigue. Perhaps they can help with household chores or drive you to and from doctor's visits. They might also help by shopping for food and cooking meals for you to eat now or freeze for later.



- **Learn from others who have cancer.** People who have cancer can help by sharing ways that they manage fatigue. One way to meet others is by joining a support group—either in person or online. Talk with your doctor or nurse to learn more.



- **Keep a diary of how you feel each day.** This will help you plan how to best use your time. Share your diary with your nurse. Let your doctor or nurse know if you notice changes in your energy level, whether you have lots of energy or are very tired.

- **Talk with your doctor or nurse.** Your doctor may prescribe medication that can help decrease fatigue, give you a sense of well-being, and increase your appetite. He or she may also suggest treatment if your fatigue is from anemia. (To learn more about anemia, see page 16.)



Hair Loss

What it is and why it occurs

Hair loss (also called **alopecia**) is when some or all of your hair falls out. This can happen anywhere on your body: your head, face, arms, legs, underarms, or the pubic area between your legs. Many people are upset by the loss of their hair and find it the most difficult part of chemotherapy.

Some types of chemotherapy damage the cells that cause hair growth. Hair loss often starts 2 to 3 weeks after chemotherapy begins. Your scalp may hurt at first. Then you may lose your hair, either a little at a time or in clumps. It takes about 1 week for all your hair to fall out. Almost always, your hair will grow back 2 to 3 months after chemotherapy is over. You may notice that your hair starts growing back even while you are getting chemotherapy.

Your hair will be very fine when it starts growing back. Also, your new hair may not look or feel the same as it did before. For instance, your hair may be thin instead of thick, curly instead of straight, and darker or lighter in color.

Hair often grows back 2 to 3 months after chemotherapy is over.

Ways to manage

Before hair loss:

- **Talk with your doctor or nurse.** He or she will know if you are likely to have hair loss.
- **Cut your hair short or shave your head.** You might feel more in control of hair loss if you first cut your hair or shave your head. This often makes hair loss easier to manage. If you shave your head, use an electric shaver instead of a razor.

If you plan to buy a wig, do so while you still have hair.

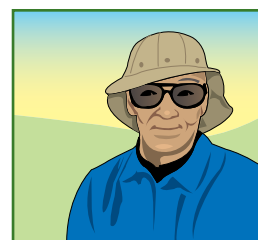
- **The best time to choose your wig is before chemotherapy starts.** This way, you can match the wig to the color and style of your hair. You might also take it to your hair dresser who can style the wig to look like your own hair. Make sure to choose a wig that feels comfortable and does not hurt your scalp.
- **Ask if your insurance company will pay for a wig.** If it will not, you can deduct the cost of your wig as a medical expense on your income tax. Some groups also have free “wig banks.” Your doctor, nurse, or social worker will know if there is a wig bank near you.



- **Be gentle when you wash your hair.** Use a mild shampoo, such as a baby shampoo. Dry your hair by patting (not rubbing) it with a soft towel.
- **Do not use items that can hurt your scalp.** These include:
 - Straightening or curling irons
 - Brush rollers or curlers
 - Electric hair dryers
 - Hair bands and clips
 - Hairsprays
 - Hair dyes
 - Products to perm or relax your hair

After hair loss:

- **Protect your scalp.** Your scalp may hurt during and after hair loss. Protect it by wearing a hat, turban, or scarf when you are outside. Try to avoid places that are very hot or very cold. This includes tanning beds and outside in the sun or cold air. And always apply sunscreen or sunblock to protect your scalp.



- **Stay warm.** You may feel colder once you lose your hair. Wear a hat, turban, scarf, or wig to help you stay warm.
- **Sleep on a satin pillow case.** Satin creates less friction than cotton when you sleep on it. Therefore, you may find satin pillow cases more comfortable.
- **Talk about your feelings.** Many people feel angry, depressed, or embarrassed about hair loss. If you are very worried or upset, you might want to talk about these feelings with a doctor, nurse, family member, close friend, or someone who has had hair loss caused by cancer treatment.



Ways to learn more

American Cancer Society

Offers a variety of services to people with cancer and their families, including referrals to low-cost wig banks.

Call: 1-800-ACS-2345 (1-800-227-2345)

TTY: 1-866-228-4327

Visit: <http://www.cancer.org>

Infection

What it is and why it occurs

Some types of chemotherapy make it harder for your bone marrow to produce new **white blood cells**. White blood cells help your body fight infection. Therefore, it is important to avoid infections, since chemotherapy decreases the number of your white blood cells.

There are many types of white blood cells. One type is called **neutrophil**. When your neutrophil count is low, it is called **neutropenia**. Your doctor or nurse may do blood tests to find out whether you have neutropenia.

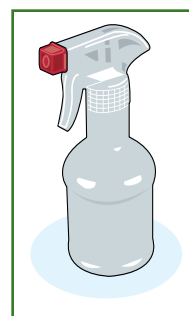
It is important to watch for signs of infection when you have neutropenia. Check for fever at least once a day, or as often as your doctor or nurse tells you to. You may find it best to use a digital thermometer. Call your doctor or nurse if your temperature is 100.5°F or higher.



Call your doctor or nurse right away if you have a fever of 100.5°F or higher.

Ways to manage

- **Your doctor or nurse will check your white blood cell count throughout your treatment.** If chemotherapy is likely to make your white blood cell count very low, you may get medicine to raise your white blood cell count and lower your risk of infection.
- **Wash your hands often with soap and water.** Be sure to wash your hands before cooking and eating, and after you use the bathroom, blow your nose, cough, sneeze, or touch animals. Carry hand sanitizer for times when you are not near soap and water.
- **Use sanitizing wipes to clean surfaces and items that you touch.** This includes public telephones, ATM machines, doorknobs, and other common items.
- **Be gentle and thorough when you wipe yourself after a bowel movement.** Instead of toilet paper, use a baby wipe or squirt of water from a spray bottle to clean yourself. Let your doctor or nurse know if your rectal area is sore or bleeds or if you have hemorrhoids.



- **Stay away from people who are sick.** This includes people with colds, flu, measles, or chicken pox. You also need to stay away from children who just had a “live virus” vaccine for chicken pox or polio. Call your doctor, nurse, or local health department if you have any questions.
- **Stay away from crowds.** Try not to be around a lot of people. For instance, plan to go shopping or to the movies when the stores and theaters are less crowded.
- **Be careful not to cut or nick yourself.** Do not cut or tear your nail cuticles. Use an electric shaver instead of a razor. And be extra careful when using scissors, needles, or knives.
- **Watch for signs of infection around your catheter.** Signs include drainage, redness, swelling, or soreness. Let your doctor or nurse know about any changes you notice near your catheter.
- **Maintain good mouth care.** Brush your teeth after meals and before you go to bed. Use a very soft toothbrush. You can make the bristles even softer by running hot water over them just before you brush. Use a mouth rinse that does not contain alcohol. Check with your doctor or nurse before going to the dentist. (For more about taking care of your mouth, see page 35.)
- **Take good care of your skin.** Do not squeeze or scratch pimples. Use lotion to soften and heal dry, cracked skin. Dry yourself after a bath or shower by gently patting (not rubbing) your skin. (For more information about taking care of your skin, see page 47.)
- **Clean cuts right away.** Use warm water, soap, and an antiseptic to clean your cuts. Do this every day until your cut has a scab over it.
- **Be careful around animals.** Do not clean your cat’s litter box, pick up dog waste, or clean bird cages or fish tanks. Be sure to wash your hands after touching pets and other animals.
- **Do not get a flu shot or other type of vaccine without first asking your doctor or nurse.** Some vaccines contain a live virus, which you should not be exposed to.
- **Keep hot foods hot and cold foods cold.** Do not leave leftovers sitting out. Put them in the refrigerator as soon as you are done eating.
- **Wash raw vegetables and fruits well before eating them.**
- **Do not eat raw or undercooked fish, seafood, meat, chicken, or eggs.** These may have bacteria that can cause infection.
- **Do not have food or drinks that are moldy, spoiled, or past the freshness date.**



Do not take drugs that reduce fever without first talking with your doctor or nurse.

■ **Call your doctor right away (even on the weekend or in the middle of the night) if you think you have an infection.** Be sure you know how to reach your doctor after office hours and on weekends. Call if you have a fever of 100.5°F or higher, or when you have chills or sweats. Do not take aspirin, acetaminophen (such as Tylenol®), ibuprofen products, or any other drugs that reduce fever without first talking with your doctor or nurse. Other signs of infection include:

- Redness
- Swelling
- Rash
- Chills
- Cough
- Earache
- Headache
- Stiff neck
- Bloody or cloudy urine
- Painful or frequent need to urinate
- Sinus pain or pressure



Be sure you know how to reach your doctor or nurse after office hours and on weekends.

Write the number to call in an emergency here:

Infertility

What it is and why it occurs

Some types of chemotherapy can cause **infertility**. For a woman, this means that you may not be able to get pregnant. For a man, this means you may not be able to get a woman pregnant.

In women, chemotherapy may damage the ovaries. This damage can lower the number of healthy eggs in the ovaries. It can also lower the **hormones** produced by them. The drop in hormones can lead to early menopause. Early menopause and fewer healthy eggs can cause infertility.

In men, chemotherapy may damage sperm cells, which grow and divide quickly. Infertility may occur because chemotherapy can lower the number of sperm, make sperm less able to move, or cause other types of damage.

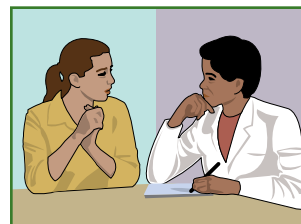
Whether or not you become infertile depends on the type of chemotherapy you get, your age, and whether you have other health problems. Infertility can last the rest of your life.

Before treatment starts, tell your doctor or nurse if you want to have children in the future.

Ways to manage

For WOMEN, talk with your doctor or nurse about:

- **Whether you want to have children.** Before you start chemotherapy, let your doctor or nurse know if you might want to get pregnant in the future. He or she may talk with you about ways to preserve your eggs to use after treatment ends or refer you to a fertility specialist.
- **Birth control. It is very important that you do not get pregnant while getting chemotherapy.** These drugs can hurt the fetus, especially in the first 3 months of pregnancy. If you have not yet gone through menopause, talk with your doctor or nurse about birth control and ways to keep from getting pregnant.
- **Pregnancy.** If you still have menstrual periods, your doctor or nurse may ask you to have a pregnancy test before you start chemotherapy. If you are pregnant, your doctor or nurse will talk with you about other treatment options.



Chemotherapy can cause birth defects. Do not get pregnant while you are getting treatment.

Talk with your doctor or nurse about saving your sperm before you start treatment, if you want to father children in the future.

For MEN, talk with your doctor or nurse about:

- **Whether you want to have children.** Before you start chemotherapy, let your doctor or nurse know if you might want to father children in the future. He or she may talk with you about ways to preserve your sperm to use in the future or refer you to a fertility specialist.
- **Birth control.** It is very important that your spouse or partner does not get pregnant while you are getting chemotherapy. Chemotherapy can damage your sperm and cause birth defects.



Chemotherapy may damage sperm and cause birth defects. Make sure that your spouse or partner does not get pregnant while you are in treatment.

Ways to learn more

American Cancer Society

Offers a variety of services to people with cancer and their families.

Call: 1-800-ACS-2345 (1-800-227-2345)

TTY: 1-866-228-4327

Visit: <http://www.cancer.org>

fertileHOPE

A LIVESTRONG initiative dedicated to providing reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

Call: 1-866-965-7205

Visit: <http://www.fertilehope.org>

Mouth and Throat Changes

What they are and why they occur

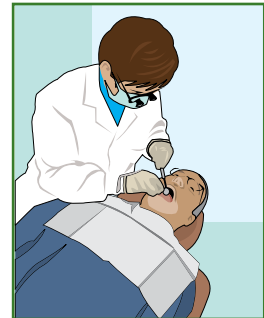
Some types of chemotherapy harm fast-growing cells, such as those that line your mouth, throat, and lips. This can affect your teeth, gums, the lining of your mouth, and the glands that make saliva. Most mouth problems go away a few days after chemotherapy is over.

Mouth and throat problems may include:

- Dry mouth (having little or no saliva)
- Changes in taste and smell (such as when food tastes like metal or chalk, has no taste, or does not taste or smell like it used to)
- Infections of your gums, teeth, or tongue
- Increased sensitivity to hot or cold foods
- Mouth sores
- Trouble eating when your mouth gets very sore

Ways to manage

- **Visit a dentist at least 2 weeks before starting chemotherapy.** It is important to have your mouth as healthy as possible. This means getting all your dental work done before chemotherapy starts. If you cannot go to the dentist before chemotherapy starts, ask your doctor or nurse when it is safe to go. Be sure to tell your dentist that you have cancer and about your treatment plan.
- **Check your mouth and tongue every day.** This way, you can see or feel problems (such as mouth sores, white spots, or infections) as soon as they start. Inform your doctor or nurse about these problems right away.



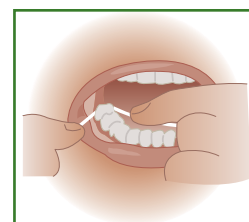
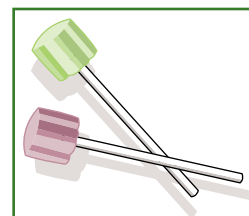
Visit your dentist at least 2 weeks before starting chemotherapy.

- **Keep your mouth moist.** You can keep your mouth moist by sipping water throughout the day, sucking on ice chips or sugar-free hard candy, or chewing sugar-free gum. Ask your doctor or nurse about saliva substitutes if your mouth is always dry.



■ Clean your mouth, teeth, gums, and tongue.

- Brush your teeth, gums, and tongue after each meal and at bedtime.
- Use an extra-soft toothbrush. You can make the bristles even softer by rinsing your toothbrush in hot water before you brush.
- If brushing is painful, try cleaning your teeth with cotton swabs or Toothettes®.
- Use a fluoride toothpaste or special fluoride gel that your dentist prescribes.
- Do not use mouthwash that has alcohol. Instead, rinse your mouth 3 to 4 times a day with a solution of 1/4 teaspoon baking soda and 1/8 teaspoon salt in 1 cup of warm water. Follow this with a plain water rinse.
- Gently floss your teeth every day. If your gums bleed or hurt, avoid those areas but floss your other teeth. Ask your doctor or nurse about flossing if your platelet count is low. (See the section called “Bleeding” on page 20 for more information on platelets.)
- If you wear dentures, make sure they fit well and keep them clean. Also, limit the length of time that you wear them.



■ Be careful what you eat when your mouth is sore.

- Choose foods that are moist, soft, and easy to chew or swallow. These include cooked cereals, mashed potatoes, and scrambled eggs.
- Use a blender to puree cooked foods so that they are easier to eat. To help avoid infection, be sure to wash all blender parts before and after using them. If possible, it is best to wash them in a dishwasher.
- Take small bites of food, chew slowly, and sip liquids while you eat.
- Soften food with gravy, sauces, broth, yogurt, or other liquids.
- Eat foods that are cool or at room temperature. You may find that warm and hot foods hurt your mouth or throat.
- Suck on ice chips or popsicles. These can relieve mouth pain.
- Ask your dietitian for ideas of foods that are easy to eat. For ideas of soft foods that are easy on a sore mouth, see page 57.

Call your doctor, nurse, or dentist if your mouth hurts a lot. Your doctor or dentist may prescribe medicine for pain or to keep your mouth moist. Make sure to give your dentist the phone number of your doctor and nurse.



■ **Stay away from things that can hurt, scrape, or burn your mouth, such as:**

- Sharp or crunchy foods, such as crackers and potato or corn chips
- Spicy foods, such as hot sauce, curry dishes, salsa, and chili
- Citrus fruits or juices such as orange, lemon, and grapefruit
- Food and drinks that have a lot of sugar, such as candy or soda
- Beer, wine, and other types of alcohol
- Toothpicks or other sharp objects
- Tobacco products, including cigarettes, pipes, cigars, and chewing tobacco

Do not use tobacco or drink alcohol if your mouth is sore.

Ways to learn more

National Oral Health Information Clearinghouse

A service of the National Institutes of Dental and Craniofacial Research that provides oral health information for special care patients.

- Call: 1-866-232-4528
- Visit: <http://www.nidcr.nih.gov>
- E-mail: nidcrinfo@mail.nih.gov

Smokefree.gov

Provides resources including information on quitlines, a step-by-step cessation guide, and publications to help you or someone you care about quit smoking.

- Call: 1-877-44U-QUIT (1-877-448-7848)
- Visit: <http://www.smokefree.gov>

Nausea and Vomiting

What they are and why they occur

Some types of chemotherapy can cause nausea, vomiting, or both. Nausea is when you feel sick to your stomach, like you are going to throw up. Vomiting is when you throw up. You may also have **dry heaves**, which is when your body tries to vomit even though your stomach is empty.

Nausea and vomiting can occur while you are getting chemotherapy, right after, or many hours or days later. You will most likely feel better on the days you do not get chemotherapy.

New drugs can help prevent nausea and vomiting. These are called **antiemetic** or **antinausea** drugs. You may need to take these drugs 1 hour before each chemotherapy treatment and for a few days after. How long you take them after chemotherapy will depend on the type of chemotherapy you are getting and how you react to it. If one antinausea drug does not work well for you, your doctor can prescribe a different one. You may need to take more than one type of drug to help with nausea. **Acupuncture** may also help. Talk with your doctor or nurse about treatments to control nausea and vomiting caused by chemotherapy.

Ways to manage

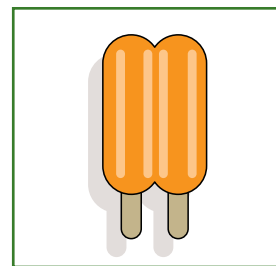
- **Prevent nausea.** One way to prevent vomiting is to prevent nausea. Try having bland, easy-to-digest foods and drinks that do not upset your stomach. These include plain crackers, toast, and gelatin. To learn more, see the list of foods and drinks that are easy on the stomach on page 58.
- **Plan when it's best for you to eat and drink.** Some people feel better when they eat a light meal or snack before chemotherapy. Others feel better when they have chemotherapy on an empty stomach (nothing to eat or drink for 2 to 3 hours before treatment). After treatment, wait at least 1 hour before you eat or drink.
- **Eat small meals and snacks.** Instead of 3 large meals each day, you might feel better if you eat 5 or 6 small meals and snacks. Do not drink a lot before or during meals. Also, do not lie down right after you eat.
- **Have foods and drinks that are warm or cool (not hot or cold).** Give hot foods and drinks time to cool down, or make them colder by adding ice. You can warm up cold foods by taking them out of the refrigerator 1 hour before you eat or warming them slightly in a microwave. Drink cola or ginger ale that is warm and has lost its fizz.

Eat 5 or 6 small meals and snacks each day instead of 3 large ones.

■ **Stay away from foods and drinks with strong smells.**

These include coffee, fish, onions, garlic, and foods that are cooking.

■ **Try small bites of popsicles or fruit ices.** You may also find sucking on ice chips helpful.



■ **Suck on sugar-free mints or tart candies.** But do not use tart candies if you have mouth or throat sores.



■ **Relax before treatment.** You may feel less nausea if you relax before each chemotherapy treatment. Meditate, do deep breathing exercises, or imagine scenes or experiences that make you feel peaceful. You can also do quiet hobbies such as reading, listening to music, or knitting.

■ **When you feel like vomiting, breathe deeply and slowly or get fresh air.** You might also distract yourself by chatting with friends or family, listening to music, or watching a movie or TV.



■ **Talk with your doctor or nurse.** Your doctor can give you drugs to help prevent nausea during and after chemotherapy. Be sure to take these drugs as ordered and let your doctor or nurse know if they do not work. You might also ask your doctor or nurse about acupuncture, which can help relieve nausea and vomiting caused by cancer treatment.



Tell your doctor or nurse if you vomit for more than 1 day or right after you drink.

Let your doctor or nurse know if your medicine for nausea is not working.

To learn more about dealing with nausea and vomiting during cancer treatment read *Eating Hints: Before, During, and After Cancer Treatment*, a book from NCI. You can get a free copy at <http://www.cancer.gov/publications> or by calling 1-800-4-CANCER (1-800-422-6237).

Nervous System Changes

What they are and why they occur

Chemotherapy can cause damage to your nervous system. Many nervous system problems get better within a year of when you finish chemotherapy, but some may last the rest of your life. Symptoms may include:

- Tingling, burning, weakness, or numbness in your hands or feet
- Feeling colder than normal
- Pain when walking
- Weak, sore, tired, or achy muscles
- Being clumsy and losing your balance
- Trouble picking up objects or buttoning your clothes
- Shaking or trembling
- Hearing loss
- Stomach pain, such as constipation or heartburn
- Fatigue
- Confusion and memory problems
- Dizziness
- Depression

Let your doctor or nurse know right away if you notice any nervous system changes. It is important to treat these problems as soon as possible.

Ways to manage

- **Let your doctor or nurse know right away if you notice any nervous system changes.** It is important to treat these problems as soon as possible.



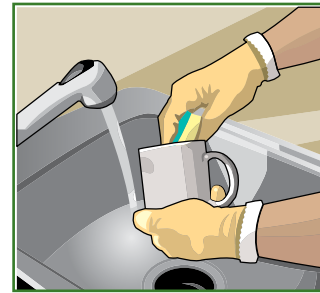
- **Be careful when handling knives, scissors, and other sharp or dangerous objects.**
- **Avoid falling.** Walk slowly, hold onto handrails when using the stairs, and put no-slip bath mats in your bathtub or shower. Make sure there are no area rugs or cords to trip over.

- **Always wear sneakers, tennis shoes, or other footwear with rubber soles.**



- **Check the temperature of your bath water with a thermometer.** This will keep you from getting burned by water that is too hot.

- **Be extra careful to avoid burning or cutting yourself while cooking.**



- **Wear gloves when working in the garden, cooking, or washing dishes.**

- **Rest when you need to.**

- **Steady yourself when you walk by using a cane or other device.**

- **Talk to your doctor or nurse if you notice memory problems, feel confused, or are depressed.**



- **Ask your doctor for pain medicine if you need it.**

Pain

What it is and why it occurs

Some types of chemotherapy cause painful side effects. These include burning, numbness, and tingling or shooting pains in your hands and feet. Mouth sores, headaches, muscle pains, and stomach pains can also occur.

Pain can be caused by the cancer itself or by chemotherapy. Doctors and nurses have ways to decrease or relieve your pain.



Be sure to tell your doctor or nurse if you have pain.

Ways to manage

■ **Talk about your pain with a doctor, nurse, or pharmacist. Be specific and describe:**

- Where you feel pain. Is it in one part of your body or all over?
- What the pain feels like. Is it sharp, dull, or throbbing? Does it come and go, or is it steady?
- How strong the pain is. Describe it on a scale of 0 to 10.
- How long the pain lasts. Does it last for a few minutes, an hour, or longer?
- What makes the pain better or worse. For instance, does an ice pack help? Or does the pain get worse if you move a certain way?
- Which medicines you take for pain. Do they help? How long do they last? How much do you take? How often?

■ **Let your family and friends know about your pain.** They need to know about your pain so they can help you. If you are very tired or in a lot of pain, they can call your doctor or nurse for you. Knowing about your pain can also help them understand why you may be acting differently.

■ Practice pain control

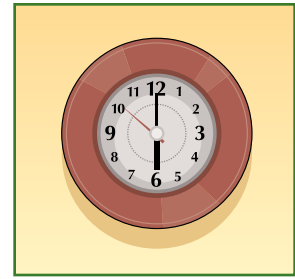
- Take your pain medicine on a regular schedule (by the clock) even when you are not in pain. This is very important when you have pain most of the time.
- Do not skip doses of your pain medicine. Pain is harder to control and manage if you wait until you are in a lot of pain before taking medicine.
- Try deep breathing, yoga, or other ways to relax. This can help reduce muscle tension, anxiety, and pain.

■ Ask to meet with a pain or palliative care specialist.

This can be an oncologist, anesthesiologist, neurologist, neurosurgeon, nurse, or pharmacist who will talk with you about ways to control your pain.

- ## ■ Let your doctor, nurse, or pain specialist know if your pain changes.
- Your pain can change over the course of your treatment. When this happens, your pain medications may need to be changed.

NCI's book, *Pain Control: Support for People With Cancer*, provides more tips about how to control pain from cancer and its treatment. You can get free copies at <http://www.cancer.gov/publications> or by calling 1-800-4-CANCER (1-800-422-6237).



Sexual Changes

What they are and why they occur

Some types of chemotherapy can cause sexual changes. These changes are different for women and men.

In women, chemotherapy may damage the ovaries, which can cause changes in hormone levels. Hormone changes can lead to problems like vaginal dryness and early menopause.

In men, chemotherapy can cause changes in hormone levels, decreased blood supply to the penis, or damage to the nerves that control the penis, all of which can lead to **impotence**.

Whether or not you have sexual changes during chemotherapy depends on if you have had these problems before, the type of chemotherapy you are getting, your age, and whether you have any other illnesses. Some problems, such as loss of interest in sex, are likely to improve once chemotherapy is over.

Problems for WOMEN include:

- Symptoms of menopause (for women not yet in menopause). These symptoms include:
 - Hot flashes
 - Vaginal dryness
 - Feeling irritable
 - Irregular or no menstrual periods
- Bladder or vaginal infections
- Vaginal discharge or itching
- Being too tired to have sex or not being interested in having sex
- Feeling too worried, stressed, or depressed to have sex

Problems for MEN include:

- Not being able to reach climax
- Impotence (not being able to get or keep an erection)
- Being too tired to have sex or not being interested in having sex
- Feeling too worried, stressed, or depressed to have sex

Ways to manage

For WOMEN:

■ Talk with your doctor or nurse about:

- **Sex.** Ask your doctor or nurse if it is okay for you to have sex during chemotherapy. Most women can have sex, but it is a good idea to ask.
- **Birth control.** It is very important that you not get pregnant while having chemotherapy. Chemotherapy may hurt the fetus, especially in the first 3 months of pregnancy. If you have not yet gone through menopause, talk with your doctor or nurse about birth control and ways to keep from getting pregnant.
- **Medications.** Talk with your doctor, nurse, or pharmacist about medications that help with sexual problems. These include products to relieve vaginal dryness or a vaginal cream or suppository to reduce the chance of infection.



Talk with your doctor or nurse about ways to relieve vaginal dryness and prevent infection.

■ Wear cotton underwear (cotton underpants and pantyhose with cotton linings).

■ Do not wear tight pants or shorts.

■ Use a water-based vaginal lubricant (such as K-Y Jelly® or Astroglide®) when you have sex.

■ If sex is still painful because of dryness, ask your doctor or nurse about medications to help restore moisture in your vagina.

■ Cope with hot flashes by:

- **Dressing in layers**, with an extra sweater or jacket that you can take off.
- **Being active.** This includes walking, riding a bike, or other types of exercise.
- **Reducing stress.** Try yoga, meditation, or other ways to relax.



For MEN:

■ Talk with your doctor or nurse about:

- **Sex.** Ask your doctor or nurse if it is okay for you to have sex during chemotherapy. Most men can have sex, but it is a good idea to ask. Also, ask if you should use a condom when you have sex, since traces of chemotherapy may be in your semen.
- **Birth control.** It is very important that your spouse or partner not get pregnant while you are getting chemotherapy. Chemotherapy can damage your sperm and cause birth defects.



If you are having sex less often, try activities that make you feel close to each other.

For men AND women:

■ Be open and honest with your spouse or partner.

Talk about your feelings and concerns.

- ### ■ Explore new ways to show love.
- You and your spouse or partner may want to show your love for each other in new ways while you go through chemotherapy. For instance, if you are having sex less often, you may want to hug and cuddle more, bathe together, give each other massages, or try other activities that make you feel close to each other.



- ### ■ Talk with a doctor, nurse, social worker, or counselor.
- If you and your spouse or partner are concerned about sexual problems, you may want to talk with someone who can help. This can be a psychiatrist, psychologist, social worker, marriage counselor, sex therapist, or clergy member.

Ways to learn more

American Cancer Society

Offers a variety of services to people with cancer and their families.

Call: 1-800-ACS-2345 (1-800-227-2345)

TTY: 1-866-228-4327

Visit: <http://www.cancer.org>

Skin and Nail Changes

What they are and why they occur

Some types of chemotherapy can damage the fast-growing cells in your skin and nails. While these changes may be painful and annoying, most are minor and do not require treatment. Many of them will get better once you have finished chemotherapy. However, major skin changes need to be treated right away because they can cause lifelong damage.

Minor skin changes may include:

- **Itching, dryness, redness, rashes, and peeling**
- **Darker veins.** Your veins may look darker when you get chemotherapy through an IV.
- **Sensitivity to the sun** (when you burn very quickly). This can happen even to people who have very dark skin color.
- **Nail problems.** This is when your nails become dark, turn yellow, or become brittle and cracked. Sometimes your nails will loosen and fall off, but new nails will grow back in.

Major skin changes need to be treated right away, because they can cause lifelong changes.

Major skin changes can be caused by:

- **Radiation recall.** Some chemotherapy causes skin in the area where you had radiation therapy to turn red (ranging from very light to bright red). Your skin may blister, peel, or be very painful.
- **Chemotherapy leaking from your IV.** You need to let your doctor or nurse know right away if you have burning or pain when you get IV chemotherapy.
- **Allergic reactions to chemotherapy.** Some skin changes mean that you are allergic to the chemotherapy. Let your doctor or nurse know right away if you have sudden and severe itching, rashes, or hives, along with wheezing or other trouble breathing.

Let your doctor or nurse know right away if you have burning or pain when you get IV chemotherapy.

Ways to manage

■ Itching, dryness, redness, rashes, and peeling

- Apply cornstarch, as you would dusting powder.
- Take quick showers or sponge baths instead of long, hot baths.
- Pat (do not rub) yourself dry after bathing.
- Wash with a mild, moisturizing soap.
- Put on cream or lotion while your skin is still damp after washing. Tell your doctor or nurse if this does not help.
- Do not use perfume, cologne, or aftershave lotion that has alcohol.
- Take a colloidal oatmeal bath (special powder you add to bath water) when your whole body itches.

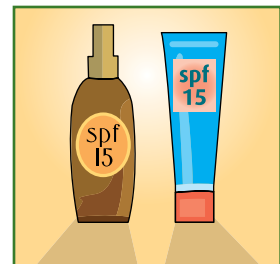
■ Acne

- Keep your face clean and dry.
- Ask your doctor or nurse if you can use medicated creams or soaps and which ones to use.



■ Sensitivity to the sun

- Avoid direct sunlight. This means not being in the sun from 10 a.m. until 4 p.m. It is the time when the sun is strongest.
- Use sunscreen lotion with an SPF (skin protection factor) of 15 or higher. Or use ointments that block the sun's rays, such as those with zinc oxide.
- Keep your lips moist with a lip balm that has an SPF of 15 or higher.
- Wear light-colored pants, long-sleeve cotton shirts, and hats with wide brims.
- Do not use tanning beds.



■ Nail problems

- Wear gloves when washing dishes, working in the garden, or cleaning the house.
- Use products to make your nails stronger. (Stop using these products if they hurt your nails or skin.)
- Let your doctor or nurse know if your cuticles are red and painful.



■ Radiation recall

- Protect the area of your skin that received radiation therapy from the sun.
- Do not use tanning beds.
- Place a cool, wet cloth where your skin hurts.
- Wear clothes that are made of cotton or other soft fabrics. This includes your underwear (bras, underpants, and t-shirts).
- Let your doctor or nurse know if you think you have radiation recall.



Urinary, Kidney, and Bladder Changes

What they are and why they occur

Some types of chemotherapy damage cells in the kidneys and bladder. Problems may include:

- Burning or pain when you begin to urinate or after you empty your bladder
- Frequent, more urgent need to urinate
- Not being able to urinate
- Not able to control the flow of urine from the bladder (**incontinence**)
- Blood in the urine
- Fever
- Chills
- Urine that is orange, red, green, or dark yellow or has a strong medicine odor

Some kidney and bladder problems will go away after you finish chemotherapy. Other problems can last for the rest of your life.

Drink plenty of fluids if you are getting chemotherapy that can damage the bladder and kidneys.

Ways to manage

- **Your doctor or nurse will take urine and blood samples to check how well your bladder and kidneys are working.**
- **Drink plenty of fluids.** Fluids will help flush the chemotherapy out of your bladder and kidneys. See the lists of clear liquids and liquid foods on pages 52 and 53.
- **Limit drinks that contain caffeine** (such as black tea, coffee, and some cola products).
- **Talk with your doctor or nurse if you have any of the problems listed above.**



Other Side Effects

Flu-like symptoms

Some types of chemotherapy can make you feel like you have the flu. This is more likely to happen if you get chemotherapy along with biological therapy.

Flu-like symptoms may include:

- Muscle and joint aches
- Headache
- Fatigue
- Nausea
- Fever
- Chills
- Appetite loss

These symptoms may last from 1 to 3 days. An infection or the cancer itself can also cause them. Let your doctor or nurse know if you have any of these symptoms.

Fluid retention

Fluid retention is a buildup of fluid caused by chemotherapy, hormone changes caused by treatment, or your cancer. It can cause your face, hands, feet, or stomach to feel swollen and puffy. Sometimes fluid builds up around your lungs and heart, causing coughing, shortness of breath, or an irregular heart beat. Fluid can also build up in the lower part of your belly, which can cause bloating.

You and your doctor or nurse can help manage fluid retention by:

- Weighing yourself at the same time each day, using the same scale. Let your doctor or nurse know if you gain weight quickly.
- Avoiding table salt or salty foods.
- Limiting the liquids you drink.
- If you retain a lot of fluid, your doctor may prescribe medicine to get rid of the extra fluid.

Eye changes

- **Trouble wearing contact lenses.** Some types of chemotherapy can bother your eyes and make wearing contact lenses painful. Ask your doctor or nurse if you can wear contact lenses while getting chemotherapy.
- **Blurry vision.** Some types of chemotherapy can clog your tear ducts, which can cause blurry vision.
- **Watery eyes.** Sometimes, chemotherapy can seep out in your tears, which can cause your eyes to water more than usual.

If your vision gets blurry or your eyes water more than usual, tell your doctor or nurse.

Foods To Help With Side Effects

Clear Liquids

This list may help if you have:

- Diarrhea (see pages 24 and 25)
- Urinary, kidney, or bladder changes (see page 50)

Type	Examples
Soups	Bouillon Clear, fat-free broth Consommé
Drinks	Clear apple juice Clear carbonated beverages Fruit-flavored drinks Fruit juice, such as cranberry or grape Fruit punch Sports drinks Water Weak tea with no caffeine
Sweets	Fruit ices made without fruit pieces or milk Gelatin Honey Jelly Popsicles

Liquid Foods

This list may help if you:

- Do not feel like eating solid foods (see Appetite Changes on pages 18 and 19)
- Have urinary, kidney, or bladder changes (see page 50)

Type	Examples														
Soups	Bouillon Broth Cheese soup Soup that has been strained or put through a blender Soup with pureed potatoes Tomato soup														
Drinks	<table> <tbody> <tr> <td>Carbonated beverages</td> <td>Milkshakes</td> </tr> <tr> <td>Coffee</td> <td>Smoothies</td> </tr> <tr> <td>Eggnog (pasteurized and alcohol free)</td> <td>Sports drinks</td> </tr> <tr> <td>Fruit drinks</td> <td>Tea</td> </tr> <tr> <td>Fruit juices</td> <td>Tomato juice</td> </tr> <tr> <td>Fruit punch</td> <td>Vegetable juice</td> </tr> <tr> <td>Milk (all types)</td> <td>Water</td> </tr> </tbody> </table>	Carbonated beverages	Milkshakes	Coffee	Smoothies	Eggnog (pasteurized and alcohol free)	Sports drinks	Fruit drinks	Tea	Fruit juices	Tomato juice	Fruit punch	Vegetable juice	Milk (all types)	Water
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Fruit drinks	Tea														
Fruit juices	Tomato juice														
Fruit punch	Vegetable juice														
Milk (all types)	Water														
Fats	Butter Cream Margarine Oil Sour cream														
Sweets	Custard (soft or baked) Frozen yogurt Fruit purees that are watered down Gelatin Honey Ice cream with no chunks (such as nuts or cookie pieces) Ice milk Jelly Pudding Syrup Yogurt (plain or vanilla)														
Replacements and supplements	Instant breakfast drinks Liquid meal replacements														

Foods and Drinks That Are High in Calories or Protein

This list may help if you do not feel like eating. See Appetite Changes on pages 18 and 19.

Type	Examples																
Soups	<p>Cream soups</p> <p>Soups with lentils, dried peas, or beans (such as pinto, black, red, or kidney)</p>																
Drinks	<p>Instant breakfast drinks</p> <p>Milkshakes</p> <p>Smoothies</p> <p>Whole milk</p>																
Main meals and other foods	<table> <tbody> <tr> <td>Beef</td> <td>Cream cheese</td> </tr> <tr> <td>Butter, margarine, or oil added to your food</td> <td>Croissants</td> </tr> <tr> <td>Cheese</td> <td>Deviled ham</td> </tr> <tr> <td>Chicken</td> <td>Eggs</td> </tr> <tr> <td>Cooked dried peas and beans (such as pinto, black, red, or kidney)</td> <td>Fish</td> </tr> <tr> <td>Cottage cheese</td> <td>Nuts, seeds, and wheat germ</td> </tr> <tr> <td></td> <td>Peanut butter</td> </tr> <tr> <td></td> <td>Sour cream</td> </tr> </tbody> </table>	Beef	Cream cheese	Butter, margarine, or oil added to your food	Croissants	Cheese	Deviled ham	Chicken	Eggs	Cooked dried peas and beans (such as pinto, black, red, or kidney)	Fish	Cottage cheese	Nuts, seeds, and wheat germ		Peanut butter		Sour cream
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Cottage cheese	Nuts, seeds, and wheat germ																
	Peanut butter																
	Sour cream																
Sweets	<p>Custards (soft or baked)</p> <p>Frozen yogurt</p> <p>Ice cream</p> <p>Muffins</p> <p>Pudding</p> <p>Yogurt (plain or vanilla)</p>																
Replacements and supplements	<p>Liquid meal replacements</p> <p>Powdered milk added to foods such as pudding, milkshakes, and scrambled eggs</p>																

High-Fiber Foods

This list may help if you have constipation. See pages 22 and 23.

Type	Examples
Main meals and other foods	Bran muffins Bran or whole-grain cereals Brown or wild rice Cooked dried peas and beans (such as pinto, black, red, or kidney) Whole-wheat bread Whole-wheat pastas
Fruits and vegetables	Dried fruit, such as apricots, dates, prunes, and raisins Fresh fruit, such as apples, blueberries, and grapes Raw or cooked vegetables, such as broccoli, corn, green beans, peas, and spinach
Snacks	Granola Nuts Popcorn Seeds, such as sunflower Trail mix

Low-Fiber Foods

This list may help if you have diarrhea. See pages 24 and 25.

Type	Examples
Main meals and other foods	Chicken or turkey (skinless) Cooked refined cereals Cottage cheese Eggs Fish Noodles Potatoes (baked or mashed without the skin) White bread White rice
Fruits and vegetables	Asparagus Bananas Canned fruit, such as peaches, pears, and applesauce Clear fruit juice Vegetable juice
Snacks	Angel food cake Gelatin Saltine crackers Sherbet or sorbet Yogurt (plain or vanilla)

Foods That Are Easy on a Sore Mouth

This list may help if your mouth or throat are sore. See pages 35 through 37.

Type	Examples
Main meals and other foods	Baby food Cooked refined cereals Cottage cheese Eggs (soft boiled or scrambled) Macaroni and cheese Mashed potatoes Pureed cooked foods Soups
Sweets	Custards Fruit (pureed or baby food) Gelatin Ice cream Milkshakes Puddings Smoothies Soft fruits (bananas and applesauce) Yogurt (plain or vanilla)

Foods and Drinks That Are Easy on the Stomach

This list may help if you have nausea and vomiting. See pages 38 and 39.

Type	Examples
Soups	Clear broth, such as chicken, vegetable, or beef
Drinks	Clear carbonated beverages that have lost their fizz Cranberry or grape juice Fruit-flavored drinks Fruit punch Sports drinks Tea Water
Main meals and other foods	Chicken (broiled or baked without its skin) Cream of rice Instant oatmeal Noodles Potatoes (boiled without skins) Pretzels Saltine crackers White rice White toast
Sweets	Angel food cake Canned fruit, such as applesauce, peaches, and pears Gelatin Popsicles Sherbet or sorbet Yogurt (plain or vanilla)

Ways To Learn More

For more resources, see National Organizations That Offer Cancer-Related Services at <http://www.cancer.gov>. In the search box, type in the words “national organizations.” Or call 1-800-4-CANCER (1-800-422-6237) for more help.

National Cancer Institute (NCI)

Find out more from these free NCI services.

Call: 1-800-4-CANCER (1-800-422-6237)
Visit: <http://www.cancer.gov>
Chat: <http://www.cancer.gov/livehelp>
E-mail: cancergovstaff@mail.nih.gov

American Cancer Society

Offers a variety of services to patients and their families. It also supports research, provides printed materials, and conducts educational programs.

Call: 1-800-ACS-2345 (1-800-227-2345)
Visit: <http://www.cancer.org>

Cancer Support Community

Dedicated to providing support, education, and hope to people affected by cancer.

Call: 1-888-793-9355 or 202-659-9709
Visit: <http://www.cancersupportcommunity.org>
E-mail: help@cancersupportcommunity.org

CancerCare, Inc.

Offers free support, information, financial assistance, and practical help to people with cancer and their loved ones.

Call: 1-800-813-HOPE (1-800-813-4673)
Visit: <http://www.cancercares.org>
E-mail: info@cancercares.org

fertileHOPE

A LIVESTRONG initiative dedicated to providing reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

Call: 1-866-965-7205
Visit: <http://www.fertilehope.org>

National Oral Health Information Clearinghouse

A service of the National Institute of Dental and Craniofacial Research that provides oral health information for special care patients.

Call: 1-866-232-4528
Visit: <http://www.nidcr.nih.gov>
E-mail: nidcrinfo@mail.nih.gov

Words To Know

Acupuncture (AK-yoo-PUNK-cher): The technique of inserting thin needles through the skin at specific points on the body to control nausea, vomiting, and other symptoms.

Adjuvant (AD-joo-vant) **chemotherapy**: Chemotherapy used to kill cancer cells after surgery or radiation therapy.

Alopecia (al-oh-PEE-shuh): The lack or loss of hair from areas of the body where hair is usually found. Alopecia can be a side effect of chemotherapy.

Anemia (a-NEE-mee-a): A problem in which the number of red blood cells is below normal.

Antiemetic (AN-tee-eh-MEH-tik): A drug that prevents or controls nausea and vomiting. Also called antinausea.

Antinausea: A drug that prevents or controls nausea and vomiting. Also called antiemetic.

Biological therapy (by-oh-LAH-jih-kul THAYR-uh-pee): Treatment to stimulate or restore the ability of the immune system to fight cancer, infections, and other diseases. Also used to lessen certain side effects that may be caused by some cancer treatments.

Blood cell count: The number of red blood cells, white blood cells, and platelets in a sample of blood. This is also called a complete blood count (CBC).

Bone marrow: The soft, sponge-like tissue in the center of most bones. It produces white blood cells, red blood cells, and platelets.

Cancer clinical trials: Type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Also called a clinical study or research study.

Catheter (KATH-i-ter): A flexible tube through which fluids enter or leave the body.

Chemotherapy (kee-moh-THAYR-uh-pee): Treatment with drugs that kill cancer cells.

Constipation: When bowel movements become less frequent and stools are hard, dry, and difficult to pass.

Diarrhea: Frequent bowel movements that may be soft, loose, or watery.

Dry heaves: When your body tries to vomit even though your stomach is empty.

Fatigue: A problem of extreme tiredness and inability to function due lack of energy.

Healthy cells: Noncancerous cells that function the way they should.

Hormones: Chemicals made by glands in the body. Hormones circulate in the bloodstream and control the actions of certain cells or organs.

Impotence: Not being able to get or keep an erection.

Incontinence: Not able to control the flow of urine from the bladder.

Infertility: For women, it means that you may not be able to get pregnant. For men, it means that you may not be able to get a woman pregnant.

Injection: Using a syringe and needle to push fluids or drugs into the body; often called a “shot.”

Intra-arterial (IN-truh-ar-TEER-ee-ul): Within an artery. Also called IA.

Intraperitoneal (IN-truh-PAYR-ih-toh-NEE-ul): Within the peritoneal cavity. Also called IP.

Intravenous (in-tra-VEE-nus): Within a blood vessel. Also called IV.

Long-term side effects: Problems from chemotherapy that do not go away.

Metastatic (MET-uh-STAT-ik): The spread of cancer from one part of the body to another.

Nausea: When you have an upset stomach or queasy feeling and feel like you are going to throw up.

Neo-adjuvant (NEE-o-AD-joo-vant) **chemotherapy:** When chemotherapy is used to shrink a tumor before surgery or radiation therapy.

Neutropenia: An abnormal decrease in the number of neutrophils, a type of white blood cell.

Neutrophil (NOO-tro-fil): A type of white blood cell.

Outpatient: A patient who visits a health care facility for diagnosis or treatment without spending the night.

Palliative (PAL-ee-yuh-tiv) **care:** Care given to improve the quality of life of patients with serious or life-threatening diseases.

Peritoneal (PAYR-ih-toh-NEE-ul) **cavity:** The space within the abdomen that contains the intestines, stomach, liver, ovaries, and other organs.

Platelet (PLATE-let): A type of blood cell that helps prevent bleeding by causing blood clots to form.

Port: An implanted device through which blood may be drawn and drugs may be given without repeated needle sticks.

Pump: A device that is used to deliver a precise amount of a drug at a specific rate.

Radiation therapy: The use of high-energy radiation to kill cancer cells and shrink tumors.

Recurrent: Cancer that returns after not being detected for a period of time.

Red blood cells: Cells that carry oxygen to all parts of the body. Also called RBC.

Side effect: A problem that occurs when treatment affects healthy tissues or organs.

Standard treatment: Treatment that experts agree is appropriate, accepted, and widely used.

Thrombocytopenia (THROM-boh-sy-toh-PEE-nee-uh): A decrease in the number of platelets in the blood that may result in easy bruising and excessive bleeding from wounds or bleeding in mucous membranes and other tissues.

Vomiting: When you throw up.

White blood cells: Cells that help the body fight infection and other diseases. Also called WBC.



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CANCER
INSTITUTE

NIH Publication No. 11-7156

Revised May 2007

Printed June 2011





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 Nutrition

The Johns Hopkins Hospital



The Johns Hopkins Hospital Patient
Information

January 2016
Oncology

Eating Well During Your Cancer Treatment

Why is good nutrition important during cancer treatment?	Maintaining good nutrition is a vital part of your treatment. Good nutrition means you are getting all the nutrients needed to maintain weight and strength, keep healthy body tissue, and fight infection.
Meet fluid needs	All caffeine and alcohol free fluids count towards your fluid needs. To calculate your fluid needs. Divide your body weight in pounds by 2. This is the ounces of fluid you need daily. Healthy fluids include: water, 100% fruit juice, vegetable juice, low-fat or non-fat milk, soups and broth.
Eat colorful vegetables and fruits	You should aim for 1 ½ to 2 cups of fruits and 2 ½ to 3 cups of vegetables a day.
Choose whole grains	Whole wheat bread, cereals, brown and wild rice, oats, quinoa, whole wheat pasta, corn and barley.
Include quality protein foods at each meal and snack.	Plant based proteins such as: nuts, beans, legumes, and seeds White meat poultry, fish, lean red meat, low fat or non-fat dairy and eggs.
Eat healthy fats.	Olive oil, canola oil, nuts and nut butters, fatty fish such as wild caught salmon, and avocados.
Resources	If you are having a difficult time maintaining your weight and or strength, one of our Oncology Dietitians can meet with you. The Dietitians' phone number is 410-955-8152.



Caregiving



The Johns Hopkins Hospital Patient Information

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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



CANCERcare®

800-813-HOPE (4673)
info@cancerCare.org
www.cancerCare.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.cancercares.org or call **800-813-HOPE (4673)**.

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

Twitter: @cancercares

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CANCERcare®

National Office • 275 Seventh Avenue • New York, NY 10001

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Care at Home



The Johns Hopkins Hospital Patient
Information

Original Date
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Oncology
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4/15

Home Care Services

Who arranges home care?

Home Care Coordinators at the Johns Hopkins Hospital will 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.

How do I pick a home care company?

Patients, families or caregivers may choose their Home Care Company, but often insurance policies will identify the preferred agency.

What types of services are included in home care?

The home care coordinators will arrange for skilled home nursing care, physical therapy, occupational therapy, speech therapy, home hospice care, medical social worker, home health aide, IV infusion, nutrition, and home medical equipment for patients being discharged from the hospital and through any of our outpatient centers or clinics.

How can I contact the home care coordinators?

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 Patient and Family Services office at 410-955-8934 or the Home Care Coordinators office at 410-955-1930.



The Johns Hopkins Hospital Patient Information

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9/10/15

Patient Safety: A Guide to Preventing Falls At Home

Why is it important to prevent falls?

Falls and the complications associated with falls are one of the most serious health problems facing the elderly. Preventing a fall is important to maintaining an active and independent lifestyle.

Who is at risk for falls?

Anyone can fall. Falls can occur in any age group; at any time and at any place.

Why do people fall?



An unsafe environment may cause falls. An illness or physical condition may affect your strength and balance, making you more likely to fall. Some environmental factors that may cause falls are:

- Wet floors
- Loose carpets, tiles and throw rugs
- Equipment in halls or walkways
- Poor lighting
- Waxed floors
- Poor fitting or inadequate footwear
- Inappropriate use of assistive devices, canes, walkers, and wheelchairs
- Any other object at the floor level that a person can trip or slip on

What illnesses or conditions make you unsteady on your feet or at risk for injury due to fall?

Illness or conditions that may make you unsteady on your feet are:

- Poor vision/hearing
- Poor gait/mobility
- Muscle weakness
- Incontinence
- Syncope (dizziness)
- Low blood pressure
- Low blood sugar
- Seizures
- Poor nutrition/dehydration
- Medication reactions
- At risk for bleeding
- At risk for fractures
- Advanced age (>80)



The Johns Hopkins Hospital Patient Information

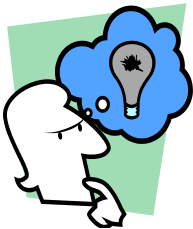
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9/10/15

Patient Safety: A Guide to Preventing Falls At Home

What should I tell my doctor?

- See your doctor as prescribed.
- See your eye doctor yearly.
- Tell your doctor if you have fallen and describe the circumstances of the fall(s).
- Tell your doctor if you use any walker aids, such as a cane or a walker.
- Tell your doctor about any vision problems and any other medical problems you may have.
- Tell you doctor if you have any side effects from your medications.
- Take good care of your feet.
- Let your doctor know if you are taking laxatives.

How can I make home safe?



- When getting out of bed, sit on the side of the bed before standing up.
- Place grab bars securely mounted in bathrooms around toilets, bath tubs, and shower areas.
- Place hand rails on both sides of stairwells.
- Make sure your home is well lit.
- Use night-lights in the bedroom, bathroom, hallways and stairways.
- Remove throw rugs, or fasten them to the floor carpet tape.
- Tack down carpet edges.
- Remove loose tiles.
- Remove electrical cords from pathways.

Be sure to tell your doctor about all medications you are taking.

Adapted from: Preventing Falls:
Instructions for Patients and Families;
Pittsburgh Healthcare System, June 2001
A Patient's Guide to Preventing Falls, The
American Geriatrics Society



The Johns Hopkins Hospital Patient Information

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7/17

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.



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Safety in the Home While on Hazardous Drugs

<p>What do I do if I splash myself with a hazardous drug or body waste?</p>	<ul style="list-style-type: none"> • 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.
<p>How can I prevent IV hazardous drug spills?</p>	<ul style="list-style-type: none"> • 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.
<p>What do I do if there is an IV hazardous drug spill?</p>	<ul style="list-style-type: none"> • 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.
<p>References</p>	<p>Chemotherapy and Biotherapy Guidelines and Recommendations for Practice, 4th Ed. Oncology Nursing Society, 2014</p> <p>National Take-Back Initiative for safe disposal of prescription drugs: www.deadiversion.usdoj.gov/drug_disposal/takeback/index</p>



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Care at Home for the Immunocompromised Patient



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
 - before and 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)

Do I need to wear a mask?

- Wear an N95 respirator mask when you travel to and from the hospital, when you are in the hospital, within two football fields of construction or digging, and in any public place.
- Close all car windows and turn on the re-circulate button of your ventilation system.
- Avoid crowds if possible. An area is crowded if you are within an arm's length of other people.
- Avoid closed spaces if possible.

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.



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Care at Home for the Immunocompromised Patient

<p>Are there any precautions I should follow about my personal care?</p>	<ul style="list-style-type: none"> • 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.
<p>Do I need to make any changes in my sex life?</p>	<ul style="list-style-type: none"> • 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.
<p>Can I still go swimming?</p>	<ul style="list-style-type: none"> • 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.
<p>How can I make sure my food and water are safe to eat and drink?</p>	<ul style="list-style-type: none"> • 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.



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Care at Home for the Immunocompromised Patient

	<ul style="list-style-type: none"> • 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?	<ul style="list-style-type: none"> • Do not work in the garden or dig in soil or mulch
Can I still take care of my pets?	<ul style="list-style-type: none"> • If you have a cat or dog, try to spend little time in contact with it and wash your hands immediately afterward. • 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?	<ul style="list-style-type: none"> • Do not smoke or use tobacco products. • Ask your doctor about nicotine replacement therapies. • No one should smoke in your house.
Can I travel?	<ul style="list-style-type: none"> • Check with your doctor about traveling abroad or using public transportation.



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Care at Home for the Immunocompromised Patient

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.



Surviving Cancer



The Johns Hopkins Hospital Patient Information

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Surviving Cancer

<p>What is a survivor?</p>	<p>“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.</p>
<p>How should I take care of myself after I am finished with treatment?</p>	<ul style="list-style-type: none"> • 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
<p>What can I do about changes in my appearance or my ability to do things?</p>	<ul style="list-style-type: none"> • Consider rehabilitation/home health services • Find out about cancer support organizations • The Image Recovery Center, located in the Cancer Center's first floor outpatient waiting area, offers a free consultation and can be contacted at 410-502-5623.
<p>How can I get help with my emotional health?</p>	<ul style="list-style-type: none"> • 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 think about?</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.



The Johns Hopkins Hospital Patient Information

Useful Websites for Cancer Information

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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



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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



Clinical Trials



The Johns Hopkins Hospital Patient Information

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3/16

Cancer Clinical Trials

<p>What are cancer clinical trials?</p>	<p>Cancer clinical trials are research studies, involving people, which are used to test new ways to prevent, detect, diagnose, and treat cancer.</p>
<p>What are the different types of research studies?</p>	<p><u>Treatment Studies</u>: 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”.</p> <p><u>Prevention Studies</u>: 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.</p> <p><u>Screening Studies</u>: Test new ways of finding cancer early.</p> <p><u>Quality of Life/Supportive Care Studies</u>: Studies that look at ways to improve the quality of life of cancer patients, care givers, and cancer survivors.</p>
<p>What are the “phases” of a research study?</p>	<p>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.</p> <p>Phase 1: Is the treatment safe?</p> <p>Phase 2: Does the treatment work?</p> <p>Phase 3: Does the new treatment work better than the current treatment?</p> <p>Phase 4: Is the treatment safe over time?</p>
<p>Who is eligible to participate in a research study?</p>	<p>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.</p> <p>Examples of eligibility criteria are:</p> <ul style="list-style-type: none"> • type of cancer you have • the stage of your cancer • your age



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- 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. However, you may ask other questions and you may continue to ask questions even after you decide to join the study.

- 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?



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Where can I get more information about our clinical trials?

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

Clinical Trials Recruitment Specialist
Phone: 443- 287-4272
E-mail: SKCCCTrials@jhmi.edu

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.

Other Resources

National Cancer Institute:
www.cancer.gov/clinicaltrials or **1-800-4-CANCER (1-800-422-6831)**

American Cancer Society: www.cancer.org or **1-800-ACS-2345 (1-800-227-2345)**

Coalition of National Cancer Cooperative Groups:
www.cancertrials-help.org or **1-877-520-4457**

The Center for Information & Study on Clinical Research Participation:
www.ciscrp.org or **1-877-MED HERO (1-877-633-4376)**

Reference

National Cancer Institute, 2012. Learn About Clinical Trials.
<http://www.cancer.gov/clinicaltrials/learningabout/>

National Institutes of Health, 2012. Clinical trials.gov, Learn About Clinical Trials.
<http://clinicaltrials.gov/ct2/about-studies/learn>

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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