

# patient guide



**JOHNS HOPKINS**  
NURSING

THE SIDNEY KIMMEL  
COMPREHENSIVE CANCER  
CENTER

## Table of Contents

1. Welcome
  - a. Director's Letter
  - b. Visiting the Outpatient Department
  - c. Your Health Care Team
  - d. Outpatient Pharmacy
  - e. Physical Medicine and Rehab Department
  - f. Phlebotomy Sites
  - g. Understanding Your Bills
  - h. Resources to Stop Smoking
  
2. My Personal Pages
  - a. My Cancer History
  - b. Appointment Notes
  - c. Symptom Diary
  
3. My Treatment Plan
  - a. Monthly Treatment Calendar
  - b. Home Medication List
  - c. Medication Wallet Card
  
4. Managing Side Effects
  - a. Symptoms to Report

5. Eating Well
  - a. Nutrition Department Letter
  - b. Eating Well during Your Cancer Treatment
  
6. Caregiving
  - a. Caregiver Resources
  - b. Caring Advice for Caregivers(Cancer Care)
  
7. Care at Home
  - a. Home Care Services
  - b. Preventing Falls at Home
  - c. Safety in the Home for Hazardous Drugs
  - d. Care at Home for the Immunocompromised Patient
  
8. Surviving Cancer
  - a. Surviving Cancer
  - b. Useful Websites for Cancer Information
  
9. Clinical Trials
  - a. Cancer Clinical Trials



**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.



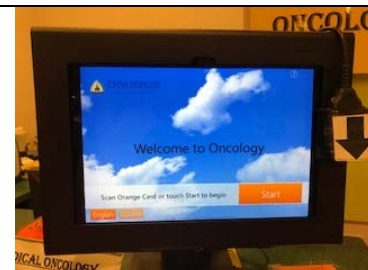
What do I do after I register?

1. If your printout says to go to the Lab in the 1<sup>st</sup> 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.





## The Johns Hopkins Hospital Patient Information

Original Date  
7/00  
Oncology  
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9/17

### 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

Original Date  
9/00  
Oncology  
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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 1<sup>st</sup> 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.

3/18



## 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/](http://www.hopkinsmedicine.org/physical_medicine_rehabilitation/)
  
- Use the American Physical Therapy Association Website
  - [www.apta.org](http://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

### **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 CLOSES 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  
SATURDAY: 8:00AM-12:00PM  
(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 AND HOLIDAYS: 7:00AM-7:00PM: STAT ORDERS ONLY)

## **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-5:00PM  
(NO WEEKENDS OR HOLIDAYS)

## **SIBLEY MEMORIAL HOSPITAL**

5255 LOUGHBORO ROAD NW  
WASHINGTON, DC 20016  
**PRE-SURGICAL TESTING CENTER (OUTPATIENT PHLEBOTOMY)**  
PHONE: 202-537-4437 PRESS 1 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  
1/19

## Understanding Your Bills

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





## The Johns Hopkins Hospital Patient Information

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



# My Personal Pages



# My Cancer History

Primary Care Physician \_\_\_\_\_

Allergies \_\_\_\_\_

Advance Directive or Living Will? yes no

MOLST (Medical Orders for Life-Sustaining Treatment)? yes no

Name of Cancer \_\_\_\_\_

Date of Diagnosis \_\_\_\_\_

Stage of Cancer \_\_\_\_\_

## Surgery

Date of Surgery \_\_\_\_\_

Type of Surgery \_\_\_\_\_

Surgeon's Name \_\_\_\_\_

Any Problems \_\_\_\_\_

## Chemotherapy/Biotherapy

Dates of Treatment \_\_\_\_\_

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: \_\_\_\_\_

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Answers I  
Received: \_\_\_\_\_

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(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  
Revised/ Reviewed  
2/18

### Symptoms to Report

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

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

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

Otherwise, please follow the guidelines below.

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

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

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

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



# 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

Original Date  
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Oncology  
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6/17

### 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 2<sup>nd</sup> floor, the 1<sup>st</sup> floor waiting area and at this website:

[http://www.hopkinsmedicine.org/kimmel\\_cancer\\_center/patient\\_information/resource\\_programs.html](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](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](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](mailto:husa@jhmi.edu). The website is [www.hopkinsmedicine.org/usa/](http://www.hopkinsmedicine.org/usa/). Our social workers can also make the referral for you.

#### Websites

[www.cancercare.org](http://www.cancercare.org)  
[www.caringbridge.org](http://www.caringbridge.org)

#### Resources

“Caring for Your Loved One with Cancer,”  
[http://www.cancercare.org/publications/1-caregiving\\_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](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.cancercare.org](http://www.cancercare.org) or call **800-813-HOPE (4673)**.

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

**Twitter:** @cancercare

*This fact sheet has been made possible by educational donations from: Genentech, a Member of the Roche Group; Lilly; and Amgen.*



**CANCERcare®**

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# Care at Home



The Johns Hopkins Hospital Patient  
Information

Original Date  
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## Home Care Services

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





## The Johns Hopkins Hospital Patient Information

Original Date:  
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### 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

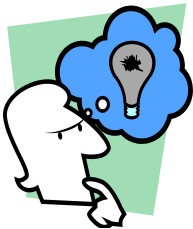
Original Date:  
7/20/06  
Revised date:  
9/10/15

### 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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## 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.



## The Johns Hopkins Hospital Patient Information

Original Date  
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7/17

### 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"> <li>• 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.</li> <li>• 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.</li> </ul>
<p>How can I prevent IV hazardous drug spills?</p>	<ul style="list-style-type: none"> <li>• Check all IV lines and tubing every day for cracks, tears or leaks. Call your home care nurse if you find any.</li> <li>• Keep sharp things away from supplies.</li> <li>• Prevent IV tubing from being pulled or tugged.</li> <li>• Make sure all connections are tight.</li> </ul>
<p>What do I do if there is an IV hazardous drug spill?</p>	<ul style="list-style-type: none"> <li>• Clean the spill right away using your spill kit and its directions.</li> <li>• Pregnant women and children should not clean a spill.</li> <li>• 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.</li> <li>• 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.</li> <li>• Remove your gloves. Wash hands very well with soap and water.</li> <li>• Call your home infusion company and ask them what to do with the materials. <b>Do not throw out with your trash!</b></li> <li>• A spill kit should be in the home at all times. If you require a replacement, please contact your home infusion company.</li> </ul>
<p>References</p>	<p>Chemotherapy and Biotherapy Guidelines and Recommendations for Practice, <sup>4th</sup> Ed. Oncology Nursing Society, 2014</p> <p>National Take-Back Initiative for safe disposal of prescription drugs: <a href="http://www.deadiversion.usdoj.gov/drug_disposal/takeback/index">www.deadiversion.usdoj.gov/drug_disposal/takeback/index</a></p>



The Johns Hopkins Hospital Patient  
Information

Original Date  
9/05  
Oncology  
Revised/ Reviewed  
3/18

## Care at Home for the Immunocompromised Patient

<p>What does immuno-compromised mean?</p>	<ul style="list-style-type: none"> <li>• Immunocompromised means your immune system is weaker than normal, probably from your disease or treatment. It is important to prevent infection during this time.</li> </ul>
<p>What can I do to prevent infection?</p>	<ul style="list-style-type: none"> <li>• Hand washing is the <b>best way</b> to prevent infection.</li> <li>• Carry hand sanitizer with you at all times.</li> <li>• Wash with soap and water or hand sanitizer             <ul style="list-style-type: none"> <li>-after you use the bathroom</li> <li>-before and after preparing or eating food</li> <li>-after touching pets or animals</li> <li>-after contact with someone who has an infection such as a cold or the flu</li> <li>-after touching surfaces in public areas (such as elevator buttons, handrails and gas pumps)</li> </ul> </li> <li>• Avoid crowds if possible. An area is crowded if you are within an arm's length of other people.</li> </ul> 
<p>When do I need to wear a mask?</p>	<ul style="list-style-type: none"> <li>• 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. Also, close all car windows and turn on the re-circulate button of your ventilation system.</li> </ul>
<p>Can I have visitors?</p>	<ul style="list-style-type: none"> <li>• Tell friends and family who are sick not to visit.</li> <li>• It may be a good idea to have visitors call you first.</li> </ul>
<p>Are there any precautions I should follow about my medicine?</p>	<ul style="list-style-type: none"> <li>• Do not take aspirin or aspirin-like products (such as Advil™, Motrin™ or Excedrin™) unless told by your doctor.</li> <li>• 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.</li> <li>• <b>Keep a current medication list with you at all times.</b></li> <li>• Do not take any herbal products.</li> <li>• Avoid grapefruit juice, which interacts with many medicines.</li> </ul>



The Johns Hopkins Hospital Patient  
Information

Original Date  
9/05  
Oncology  
Revised/ Reviewed  
3/18

**Care at Home for the  
Immunocompromised Patient**

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

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

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

- Check with your oncologist before having intercourse if your platelets or white blood cells are low.
- Clean your genital area very well.
- Urinate after intercourse to reduce bladder infections.
- Male patients and male partners of patients should use condoms to prevent infection and chemotherapy exposure.
- Female patients should use lubrication to minimize vaginal irritation.
- Avoid sexual practices in which oral exposure to feces may occur.

Can I still go swimming?

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

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

- Wash hands with warm soapy water before and after preparing food and before eating.
- Clean the areas where you prepare food. Use a separate cutting board for raw meat.
- Throw out all prepared foods after 72 hours in the refrigerator that have been opened, used or are left over.
- Refrigerate leftovers within 2 hours of cooking time in small shallow containers. Throw leftovers away that have been at room temperature more than 2 hours.





The Johns Hopkins Hospital Patient  
Information

Original Date  
9/05  
Oncology  
Revised/ Reviewed  
3/18

## Care at Home for the Immunocompromised Patient

- Meat, fish and shellfish should be cooked well done.
- Eggs and foods containing eggs must be fully cooked.
- Always check the “sell by” and “use by” dates. Do not buy or use products that are out of date.
- Avoid salad bars, delicatessens, and buffets.
- Please wash or peel raw fruits and vegetables.
- Use only **pasteurized** dairy, eggs, juice, honey and beer products.
- Never eat anything that has mold on it.
- Do not use herbal supplements.
- Patients with blood cancers should not use probiotics.
- Patients with other types of cancer should check with their doctor before using probiotics.
- Do not drink well water unless tested yearly and found to be safe.

Is it okay to  
garden?

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

Can I still take  
care of my  
pets?

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

Can I still  
smoke?

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

Can I travel?

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



# Surviving Cancer





The Johns Hopkins Hospital Patient  
Information

Original Date  
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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"> <li>• Get copies of your medical records</li> <li>• Continue to see your family doctor and oncologist</li> <li>• Get regular check ups and be alert to any signs of possible cancer return or treatment side effects</li> <li>• Ask your doctor about any concerns such as pain or fatigue</li> <li>• Adopt good health habits: eat right, do not smoke, get enough sleep and exercise to help you feel better</li> <li>• Do things you enjoy, even if you don't feel up to it.</li> </ul>
<p>What can I do about changes in my appearance or my ability to do things?</p>	<ul style="list-style-type: none"> <li>• Consider rehabilitation/home health services</li> <li>• Find out about cancer support organizations</li> <li>• The Image Recovery Centers, located on the first floors of the Weinberg (410-502-5623) and Viragh (410-502-7767) buildings offer free consultations.</li> </ul>
<p>How can I get help with my emotional health?</p>	<ul style="list-style-type: none"> <li>• Talk to a social worker, therapist or a clergyperson</li> <li>• Consider joining a cancer survivors' support group</li> <li>• Focus on the positive</li> <li>• Talk with friends and family</li> <li>• Talk about your feelings</li> </ul>



## The Johns Hopkins Hospital Patient Information

Original Date  
5/01  
Oncology  
Revised/ Reviewed  
4/18

### Surviving Cancer

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



## The Johns Hopkins Hospital Patient Information

### Useful Websites for Cancer Information

Original Date  
1/00  
Oncology  
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American Brain Tumor Association	<a href="http://www.abta.org">www.abta.org</a>	1-800-886-2282
American Cancer Society	<a href="http://www.cancer.org">www.cancer.org</a>	1-800-227-2345
American Lung Association	<a href="http://www.lungusa.org">www.lungusa.org</a>	1-800-548-8252
Aplastic Anemia and MDS International Foundation	<a href="http://www.aamds.org">www.aamds.org</a>	1-800-747-2820
Blood and Marrow Transplant Information Network	<a href="http://www.bmtinfonet.org">www.bmtinfonet.org</a>	1-888-597-7674
Cancer Care, Inc.	<a href="http://www.cancercare.org">www.cancercare.org</a>	1-800-813-4673
Cancer Support Community	<a href="http://www.cancersupportcommunity.org">www.cancersupportcommunity.org</a>	1-888-793-9355
American Childhood Cancer Organization	<a href="http://www.acco.org">www.acco.org</a>	1-855-858-2226
Colon Cancer Alliance	<a href="http://www.ccalliance.org">www.ccalliance.org</a>	1-877-422-2030
Corporate Angel Network	<a href="http://www.corpangelnetwork.org">www.corpangelnetwork.org</a>	1-914-328-1313
Fertile Hope	<a href="http://www.fertilehope.org">www.fertilehope.org</a>	1-855-220-7777
Healthfinder	<a href="http://healthfinder.gov">healthfinder.gov</a>	
International Myeloma Foundation	<a href="http://www.myeloma.org">www.myeloma.org</a>	1-800-452-2873
Johns Hopkins Breast Center	<a href="http://www.hopkinsbreastcenter.org">www.hopkinsbreastcenter.org</a>	1-443-287-2778
Johns Hopkins Hospital	<a href="http://www.hopkinsmedicine.org">www.hopkinsmedicine.org</a>	1-410-955-5000
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins	<a href="http://www.hopkinskimmeltcancercenter.org">www.hopkinskimmeltcancercenter.org</a>	1-410-955-5222
Kidney Cancer Association	<a href="http://www.nkca.org">www.nkca.org</a>	1-800-850-9132
Kids Konected	<a href="http://www.kidskonected.org">www.kidskonected.org</a>	1-800-899-2866
Susan G. Komen	<a href="http://ww5.komen.org">ww5.komen.org</a>	1-877-465-6636
Livestrong Foundation	<a href="http://www.livestrong.org">www.livestrong.org</a>	1-877-236-8820
Leukemia and Lymphoma Society	<a href="http://www.lls.org">www.lls.org</a>	1-800-955-4572
Lung Cancer Alliance	<a href="http://www.lungcanceralliance.org">www.lungcanceralliance.org</a>	1-800-298-2436
LUNGevity	<a href="http://www.lungevity.org">www.lungevity.org</a>	1-240-454-3100
Lymphoma Information Network	<a href="http://www.lymphomainfo.net">www.lymphomainfo.net</a>	1-310-689-7531
Lymphoma Research Foundation	<a href="http://www.lymphoma.org">www.lymphoma.org</a>	1-800-500-9976
Medicare	<a href="http://www.medicare.gov">www.medicare.gov</a>	1-800-633-4227
Medline Plus	<a href="http://medlineplus.gov">medlineplus.gov</a>	
Mothers Supporting Daughters with Breast Cancer	<a href="http://www.mothersdaughters.org">www.mothersdaughters.org</a>	1-410-778-1982
National Bone Marrow Transplant Link	<a href="http://www.nbmtlink.org">www.nbmtlink.org</a>	1-800-546-5268
National Brain Tumor Society	<a href="http://www.braintumor.org">www.braintumor.org</a>	1-617-924-9997
Coalition of Cancer Cooperative Groups	<a href="http://www.cancertrials-help.org">www.cancertrials-help.org</a>	1-215-789-3600
National Cancer Institute	<a href="http://www.cancer.gov">www.cancer.gov</a>	1-800-422-6237



The Johns Hopkins Hospital Patient Information

## Useful Websites for Cancer Information

Original Date  
1/00  
Oncology  
Revised/ Reviewed  
2/23/17

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



# Clinical Trials



## The Johns Hopkins Hospital Patient Information

Original Date  
7/04

Oncology  
Revised/ Reviewed  
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"> <li>• type of cancer you have</li> <li>• the stage of your cancer</li> <li>• your age</li> </ul>



## The Johns Hopkins Hospital Patient Information

Original Date  
7/04

Oncology  
Revised/ Reviewed  
3/16

### Cancer Clinical Trials

- 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?



The Johns Hopkins Hospital Patient Information

Original Date  
7/04

Oncology  
Revised/ Reviewed  
3/16

## Cancer Clinical Trials

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](mailto:SKCCCTrials@jhmi.edu)

Our website may be accessed at:

[www.hopkinskimmelcancercenter.org](http://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](http://www.cancer.gov/clinicaltrials) or **1-800-4-CANCER (1-800-422-6831)**

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

Coalition of National Cancer Cooperative Groups:  
[www.cancertrials-help.org](http://www.cancertrials-help.org) or **1-877-520-4457**

The Center for Information & Study on Clinical Research Participation:  
[www.ciscrp.org](http://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?

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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?

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

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**Please return this form to the Patient Education Room or mail to:**  
Patient Education Coordinator  
Room 4261, Weinberg Building  
401 N. Broadway  
Baltimore, MD 21231