

Cancer Handbook: *My Personal Journey*

Cancer Handbook:

My Personal Journey



Penn Medicine



Virtua
Health

C A N C E R P R O G R A M

About the Virtua Health Cancer Care Program

You want the best possible care

A diagnosis of cancer can be a frightening experience for any individual and their loved ones. You face many decisions during this challenging time. You have unanswered questions and concerns and want the best possible care. We understand your needs and are here to help you.

This book has been designed to inform you and help you keep all of your cancer care information organized. Each person's journey is a very personal experience, and we believe that the information provided in this guide will help you with the questions and decisions in the days ahead.

This book has been developed to help educate you, decrease your anxiety and assist you as you deal with the physical and emotional aspects of cancer.

The goal of this manual is to provide general information about what to expect and how to care for yourself. Your healthcare providers will be sharing many things with you and may have specific instructions regarding your care.

The pages of this book are designed to supplement that information and provide information and answers about most of what you will encounter through this journey.

There is a great deal of information contained in this book, and we don't recommend reading it all at once. The table of contents will help you find and choose the information you need.

We sincerely hope that *The Cancer Handbook* will be a valuable tool for you as you make your *Personal Journey*. We welcome any thoughts you would like to share with us about this manual.

This guide cannot answer every question or prepare you for every situation.

Please feel free to call your team – your doctors, nurse navigator, social worker and other team members if you have any questions.

About the Penn Medicine Virtua Health Cancer Program

www.virtua.org/services/cancer-treatment

The Penn Medicine Virtua Health Cancer Program combines sophisticated technology and broad-based expertise with personalized care as well as access to the latest cancer treatments, clinical trials, support services and education programs. Closely integrated teams of medical, surgical, radiation, pathology, pharmaceutical, nursing and related cancer specialists combine their expertise to offer patients a care plan that reflects the most current approaches to treatment. Dietitians, social workers, physical, occupational and speech therapists, and home-care professionals support the treatment team. The team's active involvement in clinical research, pursuit of continuing education and direct patient care keeps Virtua at the forefront of cancer treatment.

- A closely integrated team of oncology professionals offers each patient an individual, state-of-the art treatment plan.
- Comprehensive oncology services are available to treat breast, prostate, lung, colon, rectal, liver, stomach, bone and other types of cancer.
- Radiation oncology delivers advanced treatments in a comfortable setting.
- State-of-the-art chemotherapy medications and techniques are available including innovative methods such as chemoembolization.

- The Cancer Care Oncology Nurse Navigator Program matches a patient to a nurse navigator who ensures that patients obtain all necessary appointments in an expedited manner. The navigator also helps guide the patients to support services and other available resources through the Penn Medicine Virtua Health Cancer Program.

www.virtua.org/services/cancer-treatment/oncology-nurse-navigation

- An Oncology Licensed Clinical Social Worker provides comprehensive counseling services to patients and their family members. Individual, family, and group counseling services are available.
- Surgeons, medical oncologists, radiation oncologists, radiologists, pathologists, oncology nurses and social workers specializing in cancer care attend cancer conferences. These interdisciplinary meetings are forums to discuss treatment options and planning for newly diagnosed patients.

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- The Cancer Genetics Program at Virtua Health helps patients with a personal and/or family history of cancer learn more about risk factors associated with hereditary cancer. Patients learn up-to-date information about their risk factors as well as screening and prevention options to reduce their risk. Genetic testing is offered for eligible patients. The staff includes licensed and board-certified genetic counselors, medical oncologists, and social workers trained in cancer prevention.
- Renowned physicians provide pathology services and sophisticated techniques for tissue and cell examination.
- Radiology services provide diagnostic examinations and therapeutic procedures using magnetic resonance imaging (MRI), interventional and nuclear radiology, ultrasonography, computed tomography (CT), positron emission tomography (PET) and mammography.
- Clinical trials sponsored by the National Cancer Institute (NCI) and pharmaceutical companies are available.
- Cancer conferences consisting of distinct multidisciplinary groups of clinicians, discuss new or unusual cases.
- Inpatient oncology care is provided by a team of oncology professionals who provide high-quality care in a comfortable setting.
- Physical and occupational therapies are used to manage some of the side effects of cancer.
- Nutritional counseling provides customized support, meal recommendations and information about food and drug interactions.
- Community outreach and home-based programs such as home health care are provided.
- Pastoral care, by clergy of various faiths, is available upon request for spiritual counseling, guidance and prayer.
- Patient education provides special programs and materials to enlighten and to reinforce patient/clinician discussions.
- Exercise programs are in place to help improve both emotional and physical health. Several exercise program options are available to fit individual preferences.

Is the Penn Medicine Virtua Health Cancer Program accredited?

Yes, the Penn Medicine Virtua Health Cancer Program meets state and national accreditation standards that are designed to ensure high-quality care for oncology patients. The Penn Medicine Virtua Health Cancer Program is accredited by the Commission on Cancer of the American College of Surgeons, and has been recognized with their Outstanding Achievement Award for providing comprehensive care in a community setting. The Penn Medicine Virtua Health Cancer Program is a member of the Association of Community Cancer Centers. Our Radiology and Radiation Oncology Departments are fully accredited by the American College of Radiology and the Food and Drug Administration. Virtua Health is also accredited by the Joint Commission on the Accreditation for Healthcare Organizations (JCAHO), and has been recognized with the New Jersey Governor's Award for Quality.

All of our Penn Medicine Virtua Health Cancer Program physicians are board certified in their specialties, and many of them have completed specialty fellowship training in surgical, medical and radiation oncology. They have been selected by Virtua Health for their clinical expertise in cancer diagnosis, treatment, and clinical research. Many of our inpatient and ambulatory registered nurses are oncology certified. A mark of advanced training in the specialty of cancer care.

We support many national cancer advocacy organizations and their local affiliates. A number of our physicians, nurses and staff have been recognized for their outstanding contributions to cancer care in our community.

Where a patient chooses to go for treatment can impact the care they receive and ultimately the results they achieve. Our physicians, nurses, navigators, counselors and social workers from across the disciplines meet regularly to develop and review a plan of care for our patients. The Penn Medicine Virtua Health Cancer Program provides patients every significant advantage in their battle against cancer:

- Board-certified physicians
- Treatment by multidisciplinary team of experts
- Continued support during and after treatment
- Information about ongoing clinical trials and new treatments
- Nurse navigators to guide them through treatment and follow-up care

Cancer Genetics Program at Virtua Health

www.virtua.org/services/cancer-treatment/genetic-counseling-and-testing-cancer

The Virtua Health Cancer Genetics Program is a unique and comprehensive program designed to assist in determining the risk for developing cancer. Licensed and board-certified genetic counselors provide risk counseling designed to meet the unique needs of every patient.

During your Assessment

Risk factors for breast, colon, and other associated cancers as well as the benefits and limitations of available screening methods will be reviewed. Participants will learn the cancer patterns within their own family as well as ways to reduce risk. Information for high-risk individuals and genetic testing options for cancer related genes will be provided.

- Colon, rectal or uterine cancer diagnosed under age 50
- A personal or family history of both colon and uterine cancer
- Two or more colon or rectal cancers
- 10 or more colon polyps
- Ovarian cancer at any age
- Personal history of prostate cancer under age 55, metastatic prostate cancer, or prostate cancer with a Gleason score greater than or equal to 7
- A personal or family history of one of more breast, ovarian, pancreatic or prostate cancers
- Ashkenazi Jewish ancestry and a personal or family history of breast, ovarian or pancreatic cancer

Cancer genetic evaluation through the Virtua Health Cancer Genetics Program is usually a two-step process. The first visit consists of a family history and medical history evaluation and possibly a blood test. The second visit includes a discussion of your test results and their meaning for you and your family with a genetic counselor, and possibly a physician. Personalized recommendations of cancer screenings, surgical options and available research for the patient and their family members are also made at this time.

Test Results and Reports

Understanding Your Cancer

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Treating Cancer

Preparing for surgery

All of the information you have received from your doctors, healthcare professionals, family and friends can be confusing and overwhelming at times. It is important that you understand and are well informed about your surgery, recovery time and treatment plan. Having all of your questions addressed and knowing what to expect can decrease some of your anxiety and concerns.

Sometimes it can be intimidating talking to doctors. You may feel like you are “bothering” them that they are “too busy” or even that your questions are silly. We want to reassure you that none of that is true. We are here to support you through this challenging time. Always feel free to call your doctor or nurse to ask any questions you have about the surgery, recovery time or care. Write down questions and call the office. This book should serve as a supplement to the conversations that you have with your healthcare team.

How is my surgery scheduled?

The staff in your surgeon’s office will make the arrangements for your upcoming operation. They will discuss with you all of the details of the surgery including date, time, location, type of procedure, insurance information and pre-certification, and any tests that need to be done before surgery.

What type of tests do I need before surgery?

Prior to surgery, your doctor will order tests called Pre-Admission Testing (PATs). These tests are used to evaluate your current health, to “clear” you for surgery and to see if the cancer has spread beyond the primary site. Blood tests, EKG and chest x-rays are common tests for all surgical patients.

What is a consent form?

Before surgery, you will be asked to read and sign a consent form. Signing the form means that you understand everything about the procedure, the risks, the benefits and all of your options. It is important that you read this form carefully and ask questions.

One technique that can help you understand your treatment plan is to say to your doctor: “I have heard all the information you told me about the surgery. Now, I’m going to repeat the information back to you.” This will allow your surgeon to correct any misunderstandings or to clarify points that are confusing. Writing information down, reading education pamphlets or having a loved one with you to be an “extra set of listening ears” can also help you understand your treatment plan.

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What happens the night before surgery?

The night before surgery, one of the hospital staff members will call you at home and tell you what time to arrive at the hospital. This time will be earlier than the actual start time of your surgery. This allows time for you and the staff to prepare for surgery.

Do I have to fast (not eat or drink) the night before?

Follow hospital instructions

Do I take my usual medications the day of surgery?

You need to discuss medications with your doctor. You will be given specific instructions. It is important to tell your doctor about each medication you take, even over-the-counter pills such as aspirin, pain relievers and herbal medicines. Some medications affect blood clotting or cause bleeding. These are usually stopped several days before surgery. If you are told to take any pills the morning of surgery, you may take a few sips of water to help swallow your pills.

Medication instructions:

The hospital can provide you with toothpaste, a toothbrush, soap, a comb and slippers should you need them. If you prefer, bring your own favorite products (lotions, make-up). It is a good idea to leave your jewelry in the safety of your home. All jewelry is removed before your surgery.

Other items to bring to the hospital:

A loved one to support you	A calling card or cell phone for long distance calls
Insurance card, referrals and paperwork	Pen, note paper, magazines
Any written instructions from your doctor or the hospital	Any comfort items such as a photo, stuffed animal, book or religious item
This book	A few dollars for newspaper, candy or other items

The day of surgery

You should report to:

(Hospital department)

on (date) _____

at (time) _____

What can I expect to happen before my operation?

It is normal to be anxious and nervous before any procedure. Knowing what to anticipate the day of surgery will help decrease some of your concerns. Generally, you can expect the following to occur regardless of the type of surgery you will have or where it will take place (the hospital or the outpatient surgery center). Your nurse will review the specific plan with you the day of surgery.

When it is time for your surgery, you will completely undress and put on a hospital gown. You will need to remove your jewelry, watch, personal items, eyeglasses, contacts, hearing aids and dentures. You can give them to a family member, or your nurse will safely secure these items for you.

You may go to the operating room by stretcher, by wheelchair or by walking with your nurse. Your nurse will check your vital signs (temperature, pulse, respiration and blood pressure), check all of your surgery paperwork, review the surgical plan and answer any questions. You will meet with the anesthesiologist to discuss the medication that will be used during your operation. An intravenous (IV) line will be

started in your hand or arm to provide fluids and medications throughout the surgery.

Your surgeon will talk with your loved ones in the surgical waiting room while you are in the recovery room.

What can I expect to happen after my operation?

When you wake up from surgery, you will be in the recovery room. You will be drowsy and will probably feel cold. You will be covered with warm blankets. Your nurse will monitor you closely, checking your bandage and IV. You will feel the blood pressure cuff inflating several times. Your nurse will also keep you comfortable and give you medication for pain or nausea if needed. You will slowly wake up, but will probably be drowsy for the first few hours.

You will stay in recovery for one to two hours before you are brought to your hospital room. If you are not being admitted and are going home the same day, you will stay in this area until you are fully awake and you are discharged from the surgery center or hospital.

Caring For Yourself after Surgery

Your surgeon will come see you before you are released from the hospital or outpatient surgery center. The type of surgery you have and the way you feel will impact when you go home. You may be discharged on the same day as your operation or within the following day or two.

Before you leave the hospital or surgery center, your nurse will explain to you and your family all of your care instructions. Your nurse will review with you how to care for yourself at home, when to call your physician and any follow-up instructions and prescriptions. Use this book to write down any information.

Call your surgeon

• • •

If you have any of the following:

- Fever of 100.5°F or higher or shaking chills
- Increased pain, warmth, swelling, pus or redness at the incision site
- A discharge at the incision site that is thick, a yellowish/green color and/or has a foul odor

What is radiation therapy?

During radiation therapy, high-energy x-rays are used to destroy cancer cells. Radiation therapy is sometimes used to shrink tumors before surgery as well. A machine called a linear accelerator delivers the treatment to the affected area and in some cases the lymph nodes. Extensive treatment planning goes into the delivery of precise radiation. This limits the amount of normal tissue that will be affected by the therapy.

Physicians who treat cancer using radiation therapy are called radiation oncologists. Radiation therapy is usually given in an outpatient center. At the Penn Medicine Virtua Health Cancer Program, patients undergoing radiation therapy treatment have access to many services, support programs and a team of oncology specialists to help anticipate their needs.

How long does it take to get radiation treatments?

The usual radiation therapy schedule is five days a week (Monday through Friday) for five to seven weeks depending on the type of surgery you had as well as other factors. You may be asking why you have to go five days a week. Simply put, the total radiation dose is divided so you can safely receive small doses daily. By using small amounts, less damage is caused to your normal cells allowing them to recover more quickly. To get the full benefit of radiation, you need to complete all of the scheduled treatments.

You will meet with your doctor to discuss your treatment in detail. After your initial consultation with the doctor to learn about your treatment options and radiation therapy, you will return to the center for a simulation appointment. It will take about

two hours to set up your treatment plan, target and mark the area to be radiated and set up the equipment.

A therapist will use permanent ink to place permanent medical markings on your skin (dots) that pinpoint the exact area where you will receive the treatment. These marks guide the therapist to aim the radiation at the same area for every treatment appointment.

Do not remove or wash any of the ink markings that the technician placed on your skin unless specifically instructed that you can. Do not use lotion, soap, perfume, powder or deodorant directly on the skin of the treatment area. These can irritate your skin and/or interfere with treatment.

After your simulation appointment, your subsequent treatment visits are about fifteen minutes each day. You will be in the department about 30 minutes each day. The treatments are painless during delivery. They do not make you radioactive or a danger to your family.

Just like any medical treatment or procedure, before you begin radiation therapy you will learn about the treatment plan, side effects and when and how the therapy will be given each day. Your team of doctors, nurses and technicians will monitor you closely during treatment. If you have any questions or concerns, always contact the radiation facility and someone will be able to assist you.

Chemotherapy

Chemotherapy is the use of medications to destroy growing cells, a hallmark of cancer. The drugs are usually given intravenously (IV). Often a combination of chemotherapy drugs will be administered as clinical trials have demonstrated that combination chemotherapy is more effective than the administration of a single chemotherapy medication. Almost always, chemotherapy is administered in the outpatient setting, usually in a medical oncologist's office. Chemotherapy is administered intravenously by an oncology nurse (specialty trained cancer nurse) certified in the administration of such medications. Different chemotherapy drugs have different potential side effects. When a medical oncologist consults with their patients, the reason for the use of chemotherapy is discussed, as well as the potential side effects. Over the past 30 years improved chemotherapy has become available and side effects are less likely to occur.

What financial resources are available for patients who do not have a prescription plan?

Some pharmaceutical companies have special programs for financial assistance. Your doctor, nurse or social worker can assist you with accessing these resources. Major pharmaceutical companies have a hotline to provide information and financial help to patients that cannot afford medications. Assistance is limited and patients need to qualify for this program. For more information, call the Pharmaceutical Manufacturers Patient Assistance Program (800) 762-4636.

Clinical trials

www.virtua.org/services/clinical-trials

Your doctor may offer you the opportunity to take part in a cancer treatment clinical trial as part of your overall treatment plan. Clinical trials are another treatment option available to patients.

What is a clinical trial?

Clinical trials are carefully controlled research studies that test new treatments in patients. These studies test the safety and potential benefits of new medications, new approaches to surgery or radiation therapy or new combinations of treatments. The goal of this research is to find better ways to treat cancer and help cancer patients. Federal rules ensure that clinical trials are safe and ethical.

To ensure patient safety and the quality of the research study, clinical trials must follow a strict plan called a protocol. The protocol explains what is being studied, the treatment plan and the reason for the study.

Before enrolling in any clinical trial, all patients must read and sign an informed consent form. This form describes in detail what is involved in participating in a clinical trial. The consent form contains information about the medication treatment plan and possible side effects along with the risks and benefits of the study. You are encouraged to read this form carefully and go over it with your doctor. If there are parts you do not understand, ask your doctor to clarify the information.

Remember that participation in a clinical trial is voluntary. You do not have to enter the study and you can leave the study at any time if you feel it is no longer in your best interest to participate.

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Does the Penn Medicine Virtua Health Cancer Program offer clinical trials?

Yes, our program participates in many national cancer institute sponsored treatment and cancer prevention studies. Clinical trials take place at cancer centers, hospitals and doctor's offices all over the country. Your physician will determine if a study is available for you and discuss that treatment plan with you and your family. A clinical research coordinator is always available to explain the clinical trial and works with your doctor following you closely throughout the course of your treatment and beyond to ensure the integrity of protocol.

If I am offered a clinical trial as part of my treatment plan, do I have to go on the study?

No, participation in a clinical trial is voluntary. If you decline to participate, you will receive the standard care for cancer. Standard care is treatment that has gone through years of clinical trial study. Some patients worry that their doctor or healthcare team will treat them differently or are upset with them because they said "no" to taking part in a clinical trial, but this is not true. Whether you have standard treatment or go through a clinical trial, you will receive the best possible care

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This chart can be used to keep track of your weight as well as any symptoms you experience. Enter the date in the first box and your weight in the second box, and place a mark (x) in the box that corresponds to any symptoms you are having that day. Be sure and record your temperature if the doctor has you taking that daily.

My Symptom Record

Date											
Weight											
Temperature											
Shaking/Chills											
Mouth Sores											
Rash											
Diarrhea											
Constipation											
Nausea											
Vomiting											
Loss of Appetite											
Numbness in Hands/Fingers											
Numbness in Feet/Toes											

Notes for my health care provider:

Care and Treatment

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My Care Team

Specialty	Name	Contact Information
Surgeon		
Multi-site Clinical Nurse Navigator		
Medical Oncologist		
Radiation Oncologist		
Plastic Surgeon		
Primary Care Doctor/ Nurse Practitioner		
Oncology Clinical Social Worker		
Genetics Counselor		
Clinical Trial Nurse Coordinator		
Home Care Agency		
Other		

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My Treatment Plan

My type of cancer: _____ Stage of my cancer: _____

Diagnostic tests I am going to need:

- 1. _____
- 2. _____
- 3. _____
- 4. _____

Clinical Trial Information (if I am participating):

My Surgery Plan

My Surgeon: _____

Name of my surgery: _____

Date of next visit with surgeon: _____

Date of my surgery: _____

Other doctors (if any) to see before my surgery: _____

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Question to assist you when you are talking to your surgeon:

Diagnosis

- What are my biopsy results?
- What kind of cancer do I have?
- What is the stage of my cancer and how does it affect my treatment options and prognosis?
- Is it invasive has it spread to my lymph nodes or internal organs? What tests will you do to see if it has spread?
- Will you recommend a cancer specialist for a second opinion?
- Could my cancer be hereditary? Are my family members at risk?

Treatment

- What are my treatment choices and what is best for me? What do you recommend for me and why?
- Are there any clinical trials available to me?
- What are the expected benefits and risks of each kind of treatment?
- What are the chances my cancer will come back with each of the treatment programs?
- Is there anything I should do to get ready for treatment?
- Do I need to follow a special diet?
- Will I be able to have children after my treatment?

- Are there new treatments being studied and would they be appropriate for me?

Surgery

- Are there different kinds of surgery that I can consider?
- Which operation do you recommend for me?
- How long will the surgery take?
- Where will the scars be? What will they look like?
- How will I feel after the operation?
- How long will I be in the hospital?

Recovery

- How is my pain going to be managed?
- Will special care be required for my incision?
- Are there any activities I won't be able to do while I am healing?
- Do I have to any special exercises?
- When will I be able to get back to my normal activities?

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My Radiation Therapy Plan

My radiation oncologist:

Date of my next visit:

Date of my simulation:

Date I will start radiation therapy:

Number of treatments I will need:

Expected date of my last treatment:

Questions to assist you when you are talking to your radiation oncologist

Radiation

- Why do I need this treatment?
- What are the risks and side effects?
- What happens during the treatment and how long does it last?
- When will the treatments begin and end? How many times will I have to have radiation therapy?
- Are there any clinical trials available to me?

- Is there anything special I have to do to take care of myself during therapy?
- Can I continue my normal activities?

NOTES:

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My Chemotherapy Plan

My Medical Oncologist:

Name(s) of my chemotherapy drug(s):

Date of my chemotherapy education:

Date of Port-A-Cath placement, if needed:

Date I will start chemotherapy:

Number of treatments I am expected

to have: _____

How often my treatments will occur:

Expected date of my last treatment:

Questions to assist you when you are talking to your medical oncologist

Chemotherapy

- Why do I need this treatment?
- How soon after surgery will I start chemotherapy?
- What drugs will I be taking? How are they given?
- Are there any clinical trials available to me?
- How often will I require treatment?
- What are the risks and side effects?
- How do I manage the side effects?
- Will I be able to work and do normal activities during the treatments?
- Will I be able to drive myself to and from treatments?

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My Medication Record

It is very important to have an up-to-date list of all the medication you are taking during your treatment. The following chart will help you keep track of all your medications and will be at your fingertips when a health care provider asks what medications you are on. Whenever you start taking a new medication or stop taking a medicine, make note of it on this chart.

Medication	Dose/How Much	How Often	Prescribed by	Started on	Stopped on
Reason for taking this medicine:					
Pharmacy name & phone that I used to fill this prescription:					

Medication	Dose/How Much	How Often	Prescribed by	Started on	Stopped on
Reason for taking this medicine:					
Pharmacy name & phone that I used to fill this prescription:					

Medication	Dose/How Much	How Often	Prescribed by	Started on	Stopped on
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Pharmacy name & phone that I used to fill this prescription:					

Medication	Dose/How Much	How Often	Prescribed by	Started on	Stopped on
Reason for taking this medicine:					
Pharmacy name & phone that I used to fill this prescription:					

Medication	Dose/How Much	How Often	Prescribed by	Started on	Stopped on
Reason for taking this medicine:					
Pharmacy name & phone that I used to fill this prescription:					

Medication	Dose/How Much	How Often	Prescribed by	Started on	Stopped on
Reason for taking this medicine:					
Pharmacy name & phone that I used to fill this prescription:					

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My Appointment Record

This section will help you keep track of your appointments by providing a place to record appointment details and any notes you need to make when talking with your healthcare providers at those appointments.

Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				

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My Appointment Record

Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
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Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				
Day	Date	Time	Phone Number	Place
M Tu W Th F Sa Su				
<i>Notes:</i>				

Symptom Management after Recovery from Cancer Treatment

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Muscle Aches and Neuropathy

Experiencing muscle aches and nerve pain at various times during or after your surgery/treatment is expected. There are several factors that can influence these symptoms:

- Post-surgical healing
- Pain related to chemotherapy
- Pain related to radiation

Following surgery you may experience stiffness and general aches related directly to your body's automatic response to guard and protect your surgical incisions. Over time this posturing as well as self-limitations in movement can cause pain and soreness.

Pain and other symptoms related to chemotherapy and radiation are dependent upon type, dose, duration, and the schedule of your treatment. These may include:

- Joint aches
- Muscle spasms
- Tingling
- Numbness
- Sensation as if you are wearing gloves or socks
- Skin damage

Lymphedema Therapy

Virtua Health provides Lymphedema Therapists for post-operative patients who may have lymphedema related to lymph node removal. Your healthcare provider can refer you for a consultation.

Pelvic Floor Therapy

Many patients experience side effects from surgery and cancer treatment. Virtua Health provides Physical Therapy for Pelvic Floor Rehabilitation. Your healthcare provider can refer you for a consultation.

Bone Health

Certain types of chemotherapy may cause deficiencies in bone health

These types of therapies combined with other risk factors including inactivity, use of corticosteroids and inadequate intake of calcium and vitamin D can contribute to decreased bone density.

Heart Effects

Personal behavioral risks as well as exposure to some forms of chemotherapy/radiation may increase risk of developing heart disease. Risk factors include: age, body mass index, diet, physical activity levels, smoking, and elevated cholesterol and blood lipids.

Weight Gain

It is common to experience weight gain during your cancer treatment. The extent of change in body weight is influenced by: treatment type, activity level and nutrition. Exercise and proper nutrition are an important part of your overall health and journey towards healing.

Fatigue

During treatment for cancer, the level and duration of fatigue can vary. Studies show that exercise programs specifically aerobic exercise, is the number one recommended non-pharmacologic treatment for cancer related fatigue.

Emotional Recovery

The Emotional Side of Cancer

A diagnosis of cancer typically brings with it an array of emotions that can include fear, anger, sadness, depression, anxiety and others. You may ask yourself, “Why is this happening to me?” or “Can this really be true?”

At the same time, family and friends are experiencing many of the same kinds of feelings and wondering how they can help. You may all find it difficult to know how to talk with one another about the diagnosis. This is not unusual. The following are some tips to help you and your family deal with the emotions you are experiencing.

Tips to Help you Cope with Your Diagnosis

- Keep yourself informed. Fear of the unknown can cause you needless worry and anxiety.
 - Write down your questions and concerns and share them with your care team.
 - Learn about your disease and treatment options
 - Seek out reliable sources of information (not everything on the Internet is accurate) Ask your care team for help finding trustworthy resources.
- Spend time with family and friends, and allow them to help you.
- Get the support you need:
 - Talk with trusted family members and/or friends
 - Participate in a support group
 - Seek out a professional counselor if you feel that would be helpful
- Try to maintain balance in your life. As much as possible, stick to doing the things you typically do every day, this

may help to relieve some of the negative feelings that come with a cancer diagnosis.

- When you are feeling up to it, try and do some physical exercise. This may help relieve some of your symptoms. It is believed that with exercise, the body releases chemicals that affect mood, pain, perception and feelings of fatigue.
- Engage in activities that will help lift your spirits such as light, funny books and movies.

Tips to Help Children Cope with Your Diagnosis

- Engage in an age appropriate discussion with your child regarding your diagnosis and treatment.
- Assure your child that it is okay for them to be sad or upset or angry, and help them to discuss their feelings.
- If your child is worried about sharing their thoughts with you because of your cancer, help them find another trusted adult who is available to talk with them when they need someone. Some possibilities are: grandparents, aunts/uncles, minister/rabbi, teacher/counselor, neighbor, psychologist or social worker.
- Keep your child’s school informed of any changes in your household that may affect behavior. The school is often the first to observe changes in the child’s demeanor and behavior.
- Emphasize and maintain routine for your child as much as possible.
- Camp Oasis – a day of fun, support, and education for children and teens with loved ones who have cancer.
<https://foundation.vitua.org/camp-oasis>

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Tips to Help Family and Friends Help You

- Let them know that it is okay to visit and that you welcome their company. Be sure and tell them when it is okay to visit and when it is not, prepare them that you may tire easily and have to cut their visit short.
 - Ask them to listen when you need to talk about your illness.
 - Ask them to talk about things other than your illness.
 - Tell them that it's okay to laugh and to cry with you.
 - Allow them to pray for you and share their faith if you are comfortable with that.
- When someone offers help – say YES! Tell them what you need and how they can help:
 - Bring you a meal (in disposable containers - no clean-up or dishes to return)
 - Watch your children so you can go to medical appointments, rest, spend time alone or with other loved ones, or just to give the kids a break from you.
 - Invite your family to do things.
 - Come stay with you so your family can feel comfortable going out.
 - Drive you to your medical appointments.
 - Do some of your household chores or run an errand for you.
 - Bring over books, movies, music and a positive attitude that will lift your spirits.

The emotions associated with cancer include anger, loss of control, fear of recurrence, and issues of self-image, intimacy and sexuality. Expressing these emotions to your loved ones, friends, spiritual leaders and healthcare team can help with emotional recovery. Individual counseling and/or support groups for cancer survivors can also help. Virtua Health offers an array of programs to help you and your family cope and heal, including various Support Groups and Spiritual Support Counseling. We also can refer you to other support programs in the community.

The time from initial diagnosis to the start of treatment can be difficult for you. You want to start fighting the disease, but you have to wait. You and your spouse (or significant other) are trying to navigate through all of the appointments, decisions and information. Loved ones and friends are calling daily for an update on your health, asking how you are doing and how they can help. You wonder: Should I tell my children? Should I call the school and tell my child's teacher? What about work? Should I call my boss and share this information with co-workers? These are common reactions and concerns. Being honest and truthful is the best answer.

“Either you run the day...
or the day runs you”
Jim Rohn

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Why would I need to see a social worker?

A clinical social worker can help you identify and address your concerns and provide a safe place for you to talk freely about how your cancer diagnosis and treatment have impacted your life and the lives of your loved ones. Our licensed clinical social workers can help you identify and utilize your own support network, which can be family, friends, religious leaders, co-workers or members of your healthcare team and even help you “find the words” to tell your children, loved ones and friends.

Social workers can help you access a number of resources for emotional support including booklets and pamphlets that address coping topics as well as materials for children, teenagers, and loved ones. Social workers can also help you address practical concerns by providing referrals to community and national cancer resources, insurance information resources, and resources for wigs and prostheses.

Are support groups helpful?

Support groups are not meetings where you cry, tell your cancer story and go home. A support group offers an opportunity to meet with other people who are dealing with the same issues as you. You learn that you are not alone and that many things that you are feeling are normal. Some patients who were initially reluctant to attend a support group often discover it was helpful to meet other people in a similar situation. Still other patients never attend a support group. It is a personal choice and only you know what will be most helpful for you and your situation.

Do you offer support groups or classes?

The Penn Medicine Virtua Health Cancer Program sponsors and hosts several support groups and classes to meet the emotional and educational needs of patients. Many of our doctors, nurses, chaplains and social workers facilitate or participate as speakers for these groups.

Some support groups have speakers discuss a specific topic relevant to cancer patients such as managing side effects and talking to children about cancer.

Free professionally facilitated support groups are available for those living with cancer. The groups offer an opportunity to learn from survivors and health professionals and to share concerns and triumphs.

The time, location and date of each group can change throughout the year due to holidays or weather. Always call 1-888-Virtua-3 to get a current list of dates, locations, topics and times.

A list of support programs in our community can be found on the next page.

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Support groups

www.virtua.org/ClassesEvents

The Penn Medicine Virtua Health Cancer Program is committed to helping patients and their families manage the lifestyle issues that accompany a life with cancer. Services range from nutritional counseling and fatigue management to special support groups. Programs are led by trained professionals and offer an opportunity to learn ways of coping with uncertainty and change as well as approaches to care. They also provide a chance to meet others who face similar issues.

For more information about the programs listed including dates, times and locations, call 1-888-Virtua-3 (1-888-847-8823).

Cancer Survivors Support Group

This support group focuses on cancer patients who have completed active treatment and are learning to live life as cancer survivors. This group offers an opportunity to discover how your life has changed after cancer and embrace your “new normal.” The group is professionally facilitated by an Oncology Chaplain and meets the 4th Tuesday of every month from 6:00-7:00 pm at the Virtua Samson Cancer Center – Moorestown (no group in December).

Gynecologic Cancer Support Group

This women’s only support group focuses on women with ovarian, cervical, uterine, endometrial and other gynecologic cancers. Come share your feelings and concerns with other women who have had similar experiences. The group is professionally facilitated by an oncology social worker. This group meets the 4th Wednesday of every month from 6:30 -7:30 pm at the William G. Rohrer Center for Health and Fitness – Voorhees (no group in December).

Lung Cancer Screening

Current and former smokers reduce by 20 percent their chances of dying from lung cancer when they are screened for tumors. X-ray images from a low-dose CT scan can detect tumors early, improving the effectiveness of treatment. Please call (856) 247-7393 to discuss eligibility and appointments.

Cancer Fitness

www.virtuafitness.org

Whether you are undergoing cancer treatment or have completed it, exercise plays an important role in improving both emotional and physical health. It helps you become stronger, less tired and enjoy a better quality of life.

For more information and to make an appointment, call the location of your choice: Moorestown Center for Health and Fitness (856) 291-8800 or William G. Rohrer Center for Health and Fitness (856) 325-5328. There is a fee for this program.

Lung Wellness Programs

www.virtua.org/services/lung-wellness-program

Smoking Cessation Education

Smokers trying to kick the habit learn how to better manage stress, develop new routines, and change behaviors during this free three-session support group overseen by a trained tobacco treatment specialist. Call 1-888-VIRTUA-3 for class dates, times and location.

LifeCare/Survivorship Program

www.virtua.org/services/palliative-medicine

Cancer can limit your quality of life. **LifeCare** can restore it. **LifeCare** concentrates on relieving your symptoms. These services compliment, rather than replace, your medical treatment plan. Virtua Health and Samaritan Healthcare have partnered to provide this unique service. **LifeCare** physicians and staff provide the following services:

- Pain management
- Relief from symptoms such as depression, anxiety, stress, fatigue, shortness of breath, loss of appetite, mobility, and balance
- Counseling support including social work and pastoral care
- Guidance with complex treatment choices
- Shaping personal goals of care
- Facilitation of advance care planning
- Medical decision support

Frequently Asked Questions

What is Palliative Care?

Palliative care is different from hospice. Palliative care can be provided along with your active cancer treatment and can be provided at any stage of your illness. Hospice care is provided when you are no longer are receiving active treatment for your cancer.

Will my insurance cover palliative care?

Most insurance plans cover all or part of palliative care, just as with other hospital and medical services. This is also true of Medicare and Medicaid.

Can I have curative treatment together with palliative care, such as chemotherapy and radiation?

Yes, absolutely. Your treatment choices are up to you. You can have palliative care at the same time as treatment meant to cure you.

Who else, besides the patient, can benefit?

Patients as well as family caregivers are the special focus of palliative care. Your doctors and nurses benefit too, because they know they are meeting your needs by providing care and treatment that reduces your suffering and improves your quality of life.

How can I schedule an appointment?

To schedule an appointment in Moorestown or in Voorhees call: (856) 264-9953.

Nutrition

www.virtua.org/services/medical-nutrition-therapy

It is very important that you eat well as you go through your cancer treatments. Both the illness and the treatment will probably affect your appetite, but eating well will help you to obtain the nutrients your body needs to deal with the treatments, fight infection and get you on the road to recovery.

Everyone responds differently to cancer and cancer treatments. You may need extra calories and protein as you go through treatment in order to maintain your weight and fight the disease. Plan on keeping some nutritious high-protein snacks around that are easy to prepare and will help you get the extra calories you need. You might also try eating small, frequent meals instead of the usual 3 big meals a day. Eat your big meals when you feel hungry, don't wait for dinner if that's not the time you feel hungry. Stock-up on foods you like and can tolerate so you will have things on hand when you feel like eating. Drink most of your fluids between and not at meals so you won't feel full to eat.

Be sure and talk with someone on your healthcare team before using herbal products or supplements. Some of these products are not safe and may even interfere with your treatments. That includes vitamins and minerals which can be harmful or may reduce the effectiveness of your treatments.

Treatments and Nutrition

Chemotherapy Side Effects

- Food may taste funny
- Feeling full even if you haven't eaten
- Feeling sick after treatment
- Diarrhea
- Constipation
- Mouth sores
- Feeling tired

Radiation Therapy Side Effects

- Feeling full even if you haven't eaten
- Weight loss from not eating enough
- Diarrhea
- Mouth sores
- Feeling overly tired

Individualized counseling is available with a registered dietitian (RD) specially trained in developing meal plans for cancer patients. They will provide patients with meal plans that incorporate food preferences, help counteract physical reactions to treatments and develop strategies to achieve nutrition goals. Nutrition services are provided at no cost to patients in our Radiation Oncology locations. For others requesting nutritional services please contact your provider to see if services are covered. A fee-for-service discount may apply if you do not have insurance coverage. Call 1-888-Virtua-3 for additional information.

Spiritual Care

Spiritual help can be a source of strength for many people, particularly those facing challenges. Many patients acknowledge that a diagnosis of cancer can create a spiritual crisis for them. Some patients find themselves questioning God or another Higher Being to explain why they were diagnosed with cancer. Others may turn away from their faith because they feel it has deserted them. And yet, some patients find that their faith and beliefs are a great comfort and source of inspiration during this time. Some return to previous habits of prayer or meditation, or attend religious services. Some even turn to these practices for the first time.

To help each patient and family interested in finding spiritual and emotional strength during a time of crisis, the Penn Medicine Virtua Health Cancer Program provides a resource for spiritual power through its pastoral care department.

The pastoral care department offers the following services to patients, their families and visitors of all faiths:

- Visitation (spiritual support and, if desired, prayer) from chaplains and trained volunteers (chaplain aides, Eucharistic ministers, clergy and volunteers) upon request
- Referrals to congregation, spiritual leaders or other support services
- Devotional resources such as Bibles and prayer books

- Non-denominational chapels for patients, family members and visitors (chapels are open 24 hours a day)
- Various non-denominational prayer services throughout the year
- Memorial services and bereavement support for patients and their families
- Communion for Roman Catholic patients daily upon request (The pastoral care department can assist in arranging the Sacraments of Reconciliation, Anointing of the Sick or Communion of the Dying)
- Visits from a Rabbi upon request

The experience of cancer is different for each patient. There is no right or wrong feeling, thought or action when it comes to spiritual care.

Can I access these services even if I'm not religious?

Yes. Spirituality and religion are two very different concepts and terms. Religion typically refers to an organized belief system whereas spirituality is your experience or your connection to your beliefs. If you have a spiritual or religious network in place, we hope that you turn to this resource for support. We will gladly assist you in any way possible. For those patients who may not have such a resource, we encourage you to access our pastoral care department. Please remember that we offer interventions that are for individuals of all backgrounds, faiths and beliefs.

Due to patient confidentiality, you will not automatically receive visits from pastoral care volunteers, faith leaders or clergy. Please ask your nurse to make arrangements for a visit if you are interested. If you have a spiritual or religious network in place, you

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are welcome to call them and make them aware of your admission (hospital, room number, phone number and anticipated length of stay).

How do I access pastoral care at each Virtua Health facility?

The easiest way to access this resource is to simply call the director of the program at each facility. The numbers are listed below:

Virtua Health Memorial Mt. Holly
(609) 914-6365

Virtua Health Berlin
(856) 322-3100

Virtua Health Marlton
(856) 355-6662

Virtua Health Voorhees
(856) 247-2729

Marian Mitchell, BSW, M. Div., Ed. S
Outpatient Spiritual Support Counselor
Oncology Services
(609) 321-0234

For more information about spiritual care, call the Cancer Information Service at 1-800-4-CANCER and request the following publication:

Taking Time: Support for People with Cancer and the People Who Care About Them.

“Faith is being sure of what we hope for and certain of what we cannot see”

Coping with the physical changes

A diagnosis of cancer changes many things in your life including your body image, self-esteem, sexuality and intimacy. It is important to recognize these issues, to learn techniques to help you cope, and to maintain open communication with your partner throughout your experience. We also encourage you to share your feelings with your healthcare provider. They can offer you resources (counseling, education programs, support groups and booklets) to help you cope with these changes. Some patients find it helpful to talk to a cancer survivor. Your team can help arrange this for you.

How do I cope with the changes to my body?

Cancer treatment can result in many physical changes: loss of hair, scars on the body, weight changes and skin changes. All of these can affect how you view yourself and your self-esteem. There is no easy answer to help you accept all of the changes that are happening to you. However, learning about each one and ways to cope can help. Not every suggestion will work for every person. In time, you will find ways that work for you. There are no right or wrong answers. Remember that there is more to you than the outward appearance that you show to the world. Learning to accept the new you is an important step in recovery.

General guidelines to help you cope with body image changes

- Go easy on yourself. It takes time to adjust to your new body.
- Look at yourself and the changes that have happened to your body. Viewing and touching your body and sharing your feelings can help you feel more comfortable in time. Learn to view them as necessary marks toward healing, recovery and a new life.
- You can explore options for wearing a wig, turban, scarf or head wear to help hide your hair loss.
- Talk about your concerns and feelings with your partner, your healthcare team or even a cancer survivor.

Wig information

Many chemotherapy drugs used to treat cancer can cause hair loss, also called alopecia. As discussed earlier, chemotherapy not only attacks cancer cells, it also attacks some healthy cells. This can result in hair thinning, complete scalp hair loss and/or loss of body hair (facial, arm, pubic and leg). It is normal to be upset about losing your hair. This does not make you a vain person. Hair loss not only changes your appearance and body image; it is an outward reminder that you are receiving treatment.

The extent of hair loss varies with each patient and depends on the type of chemotherapy. Generally, hair loss can begin about seven to 10 days after your first treatment. You will notice an increase in hair loss (greater than you normally see) in your hairbrush, shower drain and even bed linens. Some patients' state that they have had scalp sensations (pulling, tingling or tenderness) just before their hair began to fall out. Again, it is normal to be upset, depressed or even angry about hair loss.

It is important to remember that although hair loss is upsetting, this is a temporary side effect to treatment. Once you have completed chemotherapy treatments, your hair will grow back. Hair grows back about an eighth to a half of an inch each month. Many times your hair will grow back a different texture, very fine and often curly. Not every patient chooses to wear a wig or turban. It is a personal decision. However, scalp care is important regardless of your choice. You lose a large amount of body heat from your head, so you need to protect it. In cold weather, wear a hat, scarf, turban or wig. In warm or sunny weather, keep your head covered and wear sunscreen (at least SPF 15) to prevent skin damage.

General guidelines to help you adjust to and conceal hair loss

- Cut your hair shorter before beginning treatment.
- Go shopping for a wig prior to losing your hair. This will help the stylist match your natural color and style. It can also be comforting to some women to have their wig when hair loss occurs.
- Wear hats, scarves and other head coverings. Experiment with different looks and accessories.
- It can be uncomfortable talking about hair loss and upsetting to go shopping for a wig. Bring a loved one or friend. It helps to go to a stylist or shop that has the sensitivity and experience of working with patients receiving chemotherapy. A list of such salons and stylists can be found on the next page.

Does my insurance pay for a wig?

Wigs vary greatly in price. Human hair wigs can be very expensive. Synthetic wigs are usually less expensive. Your health insurance company may pay for a wig due to hair loss from treatment. Call the member services department of your company (the phone number should be on the back of your card or in your insurance handbook) to find out the specific coverage and reimbursement.

To be covered by insurance, you will need a prescription from your doctor. Depending on your particular coverage, you may need to pay for the wig and submit the receipts and prescription to your insurance company for reimbursement. A representative from your insurance company will review the specific coverage and how you will be

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reimbursed. Another reimbursement option is to contact the Internal Revenue Service (IRS) to find out if your wig/hairpiece is a tax-deductible medical expense.

How can I get a wig if I don't have insurance or can't afford one?

Manufacturers and cancer survivors often donate new or “gently used” wigs that are clean and in mint condition. Selection can be limited by availability. The following organizations offer free wigs, turbans and fittings for patients in need.

RCCA Hair Boutique (services by Rizzieri)
(856) 372-2222

American Cancer Society (“tlc” catalog)
(800) 850-9445

This list of vendors is not inclusive and is not an endorsement by Virtua.

Sexuality and intimacy

Adjusting to a diagnosis of cancer takes time. It not only affects you physically, emotionally and spiritually, but can also affect you sexually. Side effects from medications, physical changes from surgery or treatment and your emotions can all impact your sense of self, your relationships, your desires and level of intimacy.

Of all treatments for cancer, chemotherapy can have the most effect on sexuality. Fatigue, nausea and hair loss can impact your desire or interest in intimacy.

Sexuality and intimacy can often be a difficult or embarrassing topic to discuss with your partner or healthcare providers. However, many of the issues can be treated. Your healthcare provider can refer you to Virtua Health's Sexual Wellness and Pelvic Health Program. You can learn methods to cope with each concern. We encourage you to discuss these issues with your healthcare team and your partner.

Talking to other cancer survivors or attending support groups can help as well. If you are in need of additional resources or support please contact your Oncology Social Worker or Nurse Navigator.

Some ideas for dealing with sexuality issues that may occur during your cancer treatment:

- Plan for your intimate moments if possible by:
 - Taking something for pain one-half to one hour prior to any sexual activity
 - 'Schedule' intimacy at times when you are well-rested
- Look for new ways to enjoy intimacy with your partner such as:
 - Light touch or massage

- Focus on the parts of your body that do feel pleasure (neck, ears)
- Try different positions
- Spend more time becoming aroused
- Be patient and communicate well with one another about your needs, desires and feelings

Follow-up Care

Once you have completed your treatment, your doctors will continue a follow-up care program. The purpose is to monitor your healing and emotional recovery and watch for health changes. Once you have had cancer, you are at a more increased risk of developing cancer than someone who has never had cancer. You will have doctor appointments, periodic blood work and x-rays, and other screening tools. Your doctor will discuss the specifics of your follow-up plan (frequency of appointments, tests).

You should continue to see your family physician or internist for general care and for health, other than cancer treatment-related problems. Females should also continue to see your gynecologist on an annual basis.

Coping between office visits

For many patients, the time in-between and after treatment can be anxiety provoking and somewhat scary. Completion of treatment marks a new beginning in your life. It can also feel like the end of the constant support and care you received from your healthcare providers. You were watched so closely during treatment and now it will be three months until your next appointment. It seems like such a long time.

With everything that you have been through – surgery and treatment – this is a normal concern and fear. You may find yourself questioning each headache or bruise, thinking something is wrong. Over time, the concerns will decrease. It may help to talk to other cancer survivors and learn how they coped with “living between visits.” The best way to reassure yourself and to have some peace of mind is to call your doctor and discuss your concerns. Don’t wait for your next scheduled visit.

Questions

Questions and concerns will often come to mind in between doctor's visits with members of your healthcare team, and it may be difficult to remember them when you are at your appointments. It is important that you get your questions answered and this section provides a place for you to jot things down as they come to mind. Use this section to record any questions you have for your care providers so that you will remember to ask when you speak to your doctor, nurse or other members of your healthcare team.

Employment Concerns

Your diagnosis may necessitate your making some changes in your work schedule or taking some time off from work. The Family Medical Leave Act was passed to protect your rights in the work place. This Act requires employers to allow “eligible” employees to take up to 12 weeks of unpaid job-protected leave from their jobs for certain family and medical reasons.

- Who is an “eligible” employee?
 - Someone who has worked for their employer for at least one year
 - Has worked 1,250 hours during the past year for that employer
 - The employer has at least 50 employees within 75 miles
- Reasons for taking leave:
 - To care for your spouse, son, daughter or parent who has a serious health condition
 - For a serious health condition that makes the employee unable to perform his/her job
- Conditions of the leave
 - The employer may require advance notice if the leave is foreseeable
 - The employer may require medical certification

This information was obtained from the United States Department of Labor and is included here to give basic information about the Family and Medical Leave Act, and is not a source of legal advice or guidance. To obtain more information via the Internet go to:

www.dol.gov/whd/fmla.

You may also contact the United States Department of Labor by phone at 1-866-4-USA-DOL. If you want information regarding how the FMLA might apply in your situation, we suggest you contact your employer’s Human Resource Department.

The Equal Employment Opportunities commission can also provide you information on your rights in the workplace and other federal laws that protect you on the job. They can be contacted at 1-800-669-EEOC or on the web at www.eeoc.gov.

You may also want to ask your employer about temporary and/or long-term disability options and if there is an Employee Assistance Program (EAP) at your workplace.

Insurance and Tax Tips

- Review your insurance policy and coverage; contact the customer service representatives with any questions about your coverage:
 - Are pre-certifications or referrals needed for any of my care?
 - How do I submit claims?
 - Are second opinions covered?
 - Is reconstruction covered?
- Have your insurance carrier give you a list of healthcare providers for radiation therapy and medical oncology should those services be necessary.
- Keep all bills, checks and records of these purchases and anything related to your medical care for tax purposes.
- If you are Medicare or Medicaid eligible they may pay for some of your medical expenses.
- If you are uninsured, call the American Cancer Society at 1-800-ACS-2345 for a list of insurance companies that may provide coverage and organizations that may have assistance plans.

Glossary of Terms

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Adenocarcinoma - Cancer that begins in cells that line the inside of organs. These organs make substances like hormones or milk. Most breast cancers are of this type. They begin in cells that make milk or in the cells that drain the breast milk.

Adenopathy - Large or swollen lymph nodes.

Adjuvant therapy - More treatment given to lower the chance of a cancer coming back. It comes after the main treatment plan. It may include chemotherapy, radiation therapy, hormone therapy, immune treatment, newer forms of treatment.

Advanced cancer – A general term describing stages of cancer in which the disease has spread from the primary site to other parts of the body.

Alopecia – Hair loss, which often occurs as a result of chemotherapy or from radiation therapy to the head. In most cases, the hair grows back after treatment ends.

Alternative medicine - Alternative medicine includes the use of dietary supplements, special teas, vitamins herbal preparations, and practices such as massage therapy, acupuncture, spiritual healing, and meditation. Alternative medicine includes treatment that may not be fully accepted by the main established medical community.

Antiemetics - Drugs that stop or reduce nausea and vomiting.

Benign - Has no signs of cancer. The growth of the cells in the tumor, cyst, lump, tissue, or cells is under control. There is no spread to nearby tissue or to other parts of the body.

Biological response modifier therapy (BRM therapy, immunotherapy, or biological therapy) - Treatment to help the

body's defense system (or immune system) fight infection and disease. It is also used to help the immune system heal from the side effects of cancer treatment.

Biomarkers - These substances are normally present in small amounts in the blood or other tissues. Cancer cells can sometimes make these substances. When the amount of these substances rises above normal, cancer might be present in the body. Examples of biomarkers include CA 125 (ovarian cancer), CA 15-3 and 27-29 (breast cancer), CEA (ovarian, lung, breast, pancreas, and gastrointestinal tract cancers), and PSA (prostate cancer).

Biopsy - Removing cells or tissues to look at under a microscope. There are several types of biopsies, depending on how the sample is acquired. Cells are analyzed with a fine needle aspiration whereas pieces of tissue are evaluated with a core needle biopsy. A needle biopsy samples the area to make a diagnosis while an excisional or surgical biopsy removes the area for biopsy.

Bone marrow - The soft, sponge-like tissue in the center of bones that makes white blood cells, red blood cells, and platelets.

Bone marrow biopsy (bone marrow aspiration) - Removing a small sample of bone marrow to examine under a microscope. This is done with a hollow needle, usually from the hip.

Bone metastases - Cancer that has spread from the place where it started to the bone.

Bone scan – An imaging method that gives important information about the bones, including the location of cancer that may have spread to the bones.

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Bone survey (skeletal survey) – An x-ray of all the bones of the body; often done when looking for metastasis to the bones.

Brain scan – An imaging method used to find anything not normal in the brain, including brain cancer and cancer that has spread to the brain from other places in the body. A low-dose radioactive substance is injected into a vein and images are taken to see where the radioactivity accumulates, pointing to an abnormality.

CAM (complementary and alternative medicine) - Forms of treatment that are used in addition to, or instead of, standard treatments. Their purpose is to strengthen your whole mind and body to maximize your health, energy, and well-being. These practices are not considered "standard" medical approaches. They include dietary supplements, vitamins, herbal preparations, special teas, massage therapy, acupuncture, spiritual healing, visualization and meditation.

Cancer – Cancer is not just one disease but rather a group of diseases. All forms of cancer cause cells in the body to change and grow out of control. Most types of cancer cells form a lump or mass called a tumor (not all tumors are cancer). A cancerous tumor can invade and destroy healthy tissue. Cells from the tumor can break away and travel to other parts of the body. There they can continue to grow. This spreading process is called metastasis. When cancer spreads, it is still named after the part of the body where it started (breast cancer that spreads to the lungs is still breast cancer, not lung cancer).

Carcinoma - Cancer that begins in skin or tissues that line the inside or cover the outside of internal organs.

CAT scan (computerized axial tomography scan/computed tomography/CT scan/ computerized tomography) - A series of detailed pictures of areas inside the body, taken from different angles, created by an x-ray machine linked to a computer.

Chemotherapy - Treatment with drugs that kill cancer cells or makes them less active.

Clinical trial (clinical study) - Research that tests how well new medical treatments or other medical practices work in people. Each study is carefully designed to test new methods of screening, prevention, diagnosis, or treatment of a disease.

Combination chemotherapy - Treatment using more than one anticancer drug.

Combined modality therapy – Two or more types of treatment used alternately or together to get the best results such as surgery followed by chemotherapy.

Complete remission (complete response) - When all signs of cancer disappear in response to treatment. This is based on your symptoms, physical exam, and radiology and lab tests. This does not always mean the cancer has been cured.

Diagnostic procedure - A method used to see if a disease is present or not. It is also used to figure out what kind of disease is present.

Dysplasia - Cells that do not look normal under a microscope but are not cancer.

Edema – A build-up of fluid in the tissues causing swelling.

Gene - The basic unit of a cell that passes on the traits of parents to their children through the egg and sperm. Genes are pieces of DNA. They have information for making

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specific proteins that control specific traits or activities. Examples of traits controlled by genes are eye color, foot size, and height. Examples of activity include the growth and repair of cells.

Gene therapy - Treatment that tries to fix a gene that's causing a cancer or making the cancer grow. It may also help the body's ability to fight the cancer. It may help make cancer cells easier to attack with new treatments.

Genetic counselor – A specially trained health professional who helps people as they consider genetic testing, as they adjust to the test results, and as they consider whatever screening and preventive measure are best for them.

Genetic testing – Tests done to see if a person has certain gene changes known to increase cancer risk. This testing is not recommended for everyone, but rather for those with specific types of family history.

Grade – The grade of a cancer reflects how abnormal it looks under the microscope. There are several grading systems for breast cancer, but all divide cancer into those with the greatest abnormality (*Grade 3* or poorly differentiated), the least abnormality (*Grade 1* or well differentiated) and those with intermediate features (*Grade 2* or moderately differentiated). Grading is done by the pathologist who examines the biopsy specimen. Grading is important because higher grade cancers tend to grow and spread more quickly and have a worse prognosis.

Hyperplasia - Cells in an organ or tissue that is growing too fast.

Immune system – The complex system by which the body resists infection.

Immunocompromised - Having an immune system that is weak because of treatment or disease.

Immunodeficiency - The ability of the body to fight infection and disease is low.

Immunotherapy (biological therapy, biological response modifier therapy, or BRM therapy) - Treatment to help the body's defense system (or immune system) fight infection and disease. It is also used to help the immune system heal from the side effects of cancer treatment.

Irreversible toxicity - Side effects that do not go away.

Lesion - An area of abnormal tissue change. For example, a lump, wound, or area of injury.

Leucopenia - A condition in which the number of white blood cells in the blood goes down.

Linear accelerator - A machine used in radiation therapy to treat cancer. It gives off gamma rays and electron beams.

Local cancer - An invasive malignant cancer confined entirely to the organ where the cancer began.

Local therapy - Treatment that affects cells in the cancer and the area close to it.

Lymph (lymphatic fluid) - The special fluid that travels through the lymphatic channels or vessels. It carries cells that help fight infection and disease.

Lymph node - A rounded mass of lymphatic tissue that is surrounded by a covering of connective tissue. Also known as a lymph gland. Lymph nodes are spread out along lymphatic vessels and contain many lymphocytes, and act as a filter system for the lymphatic fluid (lymph).

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Lymphadenopathy - Disease or swelling of the lymph nodes.

Lymphangiogram - X-rays of the lymphatic system. A dye is injected into a **Lymphatic system** - The tissues and organs that produce, store, and carry white blood cells that fight infection and disease. This system includes the bone marrow, spleen, thymus, and lymph nodes. It also includes the network of thin tubes that carry lymph and white blood cells. These tubes branch, like blood vessels, and pass through all tissues of the body.

MRI (magnetic resonance imaging) - This is a test that looks at areas inside your body. Detailed pictures are made by a magnet linked to a computer. These are read by a radiologist.

Maintenance therapy - Treatment that is given to help a primary (original) treatment keep working. Maintenance therapy is often given to help keep cancer in remission.

Malignant - Cancerous; a growth that tends to spread into nearby normal tissue and travel to other parts of the body.

Medical oncologist - This is one kind of cancer doctor. This type of doctor gives treatment to the whole system, like chemotherapy, hormone therapy, and immune therapy. After these treatments are over, this doctor follows you over time to make sure you are well.

Metastasis - The spread of cancer from one part of the body to another.

Micrometastases - The spread of cancer cells in groups so small that they can only be seen under a microscope.

Multidrug resistance - This is when cancer cells are able to survive despite the effects of

anticancer drugs. This means the drugs become less effective. For example, sometimes cancer cells figure out how to change so they can go on living despite chemotherapy drugs.

Multidrug resistance inhibition - Treatment used to make cancer cells more vulnerable to the effects of anticancer drugs.

Multimodality treatment - Therapy that combines more than one method of treatment.

Natural killer cells (large granular lymphocytes) - A type of white blood cell that contains granules with enzymes that can kill cancer cells or microbial cells.

Necrosis - Dead cells.

Neoadjuvant therapy - Treatment that's given first to help make the next treatment step go more smoothly. For example, chemotherapy, radiation or hormones may be given before surgery. In breast cancer, this therapy is mainly used to shrink a large tumor so that it's easier to take out.

Neoplasm - A collection of cells that are growing in an uncontrolled way. It can be benign or cancerous.

Nuclear medicine scan - A method for localizing diseases of internal organs such as the brain liver or bone. Small amounts of a radioactive substance (isotope) are injected into the bloodstream. The isotope collects in certain organs and a special camera is used to produce an image of the organ and detect areas of disease.

Oncologist - A doctor who specializes in taking care of people with cancer. Some specialize in one type of cancer treatment. For example, a radiation oncologist treats cancer with radiation, and a medical oncologist treats cancer with medications.

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Some oncologists also specialize in one kind of cancer. For example, a breast cancer oncologist diagnoses and treats breast cancer.

Oncology nurse - A nurse who specializes in treating and caring for people who have cancer.

Palliative therapy - Treatment to relieve symptoms caused by advanced cancer. Its purpose is to improve the quality of life.

Partial remission (partial response) - This is when a cancer shrinks, but does not completely go away, in response to therapy.

Pathologist - A doctor who checks tissue or fluid taken from the body using a microscope to see if it is normal or abnormal.

Pathology report - A report that describes what was found in tissue removed from the body. The cancer and surrounding normal tissue are checked with a microscope and other special tests. The report tells you many things about the extent and nature of the disease.

PET scan (positron emission tomography scan) - A computerized image of the energy-producing activity of the body tissues, used to determine the presence of disease.

Plasma cells - A type of white blood cell that makes antibodies. (These are special proteins that protect you against infection.)

Platelets (thrombocytes) - Blood cells that help stop bleeding. They do this by forming blood clots.

Port-a-cath (port) - A small device placed under the skin. It empties into a blood vessel and makes it easier to give chemotherapy and to take blood for tests.

Precancerous (pre-malignant) - A term used to describe a condition that may, or is likely to become, cancer.

Primary tumor - The main original cancer.

Prognosis - How you are expected to do after a disease is diagnosed. It is based on many things, including stage of disease, kind of disease, response to treatment, and your general state of health. It may be presented as a kind of forecast by your healthcare provider.

Prophylaxis - An attempt to prevent disease.

Radiation oncologist - A doctor who specializes in using radiation to treat cancer.

Radiation surgery (radiosurgery/stereotactic external beam irradiation) - A radiation therapy technique that delivers radiation directly to the cancer while sparing healthy tissue.

Radiation therapy (radiotherapy) - The use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body in the area near cancer cells (internal radiation therapy, implant radiation, or brachytherapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body.

Radioimmunotherapy - Treatment with a radioactive substance linked to an antibody that attaches to the cancer cells when injected into the patient.

Radioisotopes - Unstable chemicals that give off radiation as they break down. They

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can be used in imaging tests or as a treatment for cancer.

Radiologist - A doctor who specializes in taking pictures of areas inside the body and figuring out what they show. The pictures are made with x-rays, sound waves, or other types of energy.

Radiosensitization - Using a drug to make cancer cells more sensitive to radiation therapy.

Randomized clinical trial - A study in which the participants are assigned by chance to separate groups that compare different treatments. Neither the researchers nor the participants can choose which group they may join. Using chance to assign people to groups means that the groups can be compared objectively. At the start of the trial, it is not known which treatment is best. The patient can choose to be part of a randomized trial—or not.

Recurrence - This is when a cancer comes back after treatment. It can come back in the same place as the original one or in a different part of the body.

Refractory cancer - Cancer that has not responded to treatment.

Regional cancer - Cancer that has grown beyond the original (primary) cancer to nearby lymph nodes or organs and tissues.

Regional lymph node - A lymph node that drains lymph fluid from the area around a cancer.

Relapse - The return of signs and symptoms of cancer after a period of improvement.

Remission - A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In

complete remission, all signs and symptoms of cancer have disappeared, although there still may be cancer cells present in the body.

Residual disease - Cancer cells that are left over after surgery.

Resistance - When a cancer does not respond to treatment.

Response rate - The percentage of patients whose cancer shrink or disappear because of treatment.

Screening - Checking for disease when there are no symptoms.

Sequential treatment - One treatment after the other.

Side effects - This is when treatment for a disease causes problems for healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

Sonogram - (ultrasonogram/ultrasound) - A test that uses sound waves to create images of structures within the body. The pictures appear on a computer screen. They can also be put on film.

Stable disease - Cancer that is neither decreasing nor increasing in its range or severity.

Stage - The range of a cancer, especially whether the disease has spread from the original site to other parts of the body. It is important to know the stage of a disease in order to plan the best treatment.

Systemic disease - Disease that affects the whole body.

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Thrombocytopenia - This is when the number of platelets in the blood is too low. Platelets are blood cells that help stop bleeding. This condition may result in easy bruising and excessive bleeding from wounds. It may also cause bleeding in the inside lining of your mouth and intestinal tract as well as in other tissues.

Thrush - An overgrowth of yeast in the mouth. Usually white spots appear in the mouth and throat. It is a relatively common side effect of chemotherapy or long-term steroid use.

Toxic - Poisonous or harmful to the body. Drugs used to kill cancer cells can also have toxic effects on normal tissue.

Tumor - An abnormal mass of tissue resulting from an overgrowth of cells. It may be benign (not cancerous) or malignant (cancerous).

Tumor markers (biomarkers) - These substances are normally present in small amounts in the blood or other tissues. Cancer cells can sometimes make these substances. When the amount of these substances rises above normal, cancer might be present in the body. Examples of biomarkers include CA 125 (ovarian cancer), CA 15-3 and 27-29 (breast cancer), CEA (ovarian, lung, breast, pancreas, and gastrointestinal tract cancers), and PSA (prostate cancer).

Ultrasound - A test that uses sound waves to create images of structures within the body. The pictures appear on a computer screen. They can also be put on film.

Unresectable - Tissue that cannot be removed with surgery.

White blood cells (leukocytes) - Cells that help the body fight infection and disease.

Cancer Resources

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Several national organizations were formed to help patients and their families cope with a diagnosis of cancer. These resources can help answer questions, give you additional information to assist in your decision-making, help you cope emotionally and guide you through this journey. You can contact these groups and access a variety of resources: free education materials on cancer related topics, on-line support groups, and information on local resources and support group meetings in your community.

Penn Medicine Virtua Health Cancer Program
1-888-Virtua-3 (1-888-847-8823)
www.virtua.org

National Cancer Institute
Cancer Information Service
1-800-4-CANCER (1-800-422-6237)
www.cancer.gov

The American Cancer Society
1-800-ACS-2345 (1-800-227-2345)
www.cancer.org

Cancer Care, Inc
1-800-813-4673
www.cancercare.org

The Cancer Support Community
1-888-793-9355
www.cancersupportcommunity.org

The Advocacy Connector
<http://www.advocacyconnector.com>

Cancer and Careers
<http://www.cancerandcareers.org/en>
Cancer and Careers empowers and educates people with cancer to thrive in their workplace by providing expert advice interactive tools and educational events.

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How can I help?

There is life after cancer. Although it takes time before some patients can call themselves a “cancer survivor” by definition, anyone living today with a cancer diagnosis is a survivor. Some patients want to forget and put the experience behind them. Others want to use what they have learned and give back to the community by helping other women. Helping others can sometimes give a sense of meaning to patients who wonder why they were diagnosed with cancer. Reaching out to other survivors can be a source of emotional healing. But it is a different experience for each patient and there is no right answer.

This may not be the right time for you to help others. Give yourself some space and time to reflect and accept all that you have experienced throughout this journey. You cannot help others until you have healed yourself.

Be an advocate

www.virtua.org/services/cancer-treatment/njceed-at-virtua

If you know someone that cannot afford cancer screening tell them about the New Jersey Cancer Education and Early Detection Program (NJ CEED).

The NJ CEED program provides education and cancer-screening services to residents of Burlington and Camden counties. The CEED program and the Penn Medicine Virtua Health Cancer Program provide services free-of-charge to eligible individuals who are uninsured or lack adequate health insurance. For patients, this includes breast, cervical, colorectal and prostate cancer screenings. To learn more about the program call, (856) 247-7388.

“Be kind for everyone is fighting a hard battle”

Plato

Additional ways that you can help

- Share your story with loved ones, co-workers and neighbors
- Share your story with a bigger audience. You do not have to be a professional speaker to talk about your experience from the heart. We are always looking for survivors to join doctors, nurses and educators when speaking at community events. The hospital staff will educate others about cancer – you can talk about living with cancer. Sharing your story can make a difference and may inspire patients to go for their screening scans or to see their doctor.
- Volunteer at the center or hospital where you received treatment. If you would like to volunteer at the Penn Medicine Virtua Health Cancer Program, please call 1-888-Virtua-3 (1-888-847-8823).
- Participate as a walker, volunteer or donor to support the local cancer fundraisers.
- Give to a national non-profit organization that provides programs and services for cancer patients or funds cancer research.
- You can also make a financial donation to Virtua Foundation in support of the Penn Medicine Virtua Health Cancer Program where you received treatment. Gifts designated to oncology can benefit patients in many ways. They often help pay for genetic counseling, provide wigs, scarves and hats during chemotherapy, or offset prescription and transportation costs to patients who cannot otherwise afford it. For information on how you can help, please call (856) 355-0830 or online at www.foundation.virtua.org