perspectives »»

MY CANCER GUIDEBOOK AND JOURNAL

GET CONNECTED WITH OHIOHEALTH'S CANCER RESOURCES:

Learn about cancer and treatment options
Keep records of your cancer experience
Find recommendations for local resources and support services
Learn what questions to ask
Make health and life planning decisions
WWW. OHIOHEALTHCANCERCARE.COM

OhioHealth

perspectives »»

MY CANCER GUIDEBOOK AND JOURNAL

NAME ______________________________

ADDRESS ______________________________

PHONE ______________________________

EMAIL ______________________________

IN CASE OF EMERGENCY CONTACT ______________________________

INTRODUCTION

"Perspectives: A Cancer Guidebook and Journal" was developed by OhioHealth with input from our patients and their family members who wanted to be more involved in their cancer treatment. Because cancer is unique, this comprehensive guidebook was designed to help you better understand this disease and the ways we treat it, give you access to information and resources available to help you along the way and reassure you that on your journey, you are never alone.

No matter which OhioHealth care site you choose for treatment, a team of healthcare professionals is dedicated to providing care and offering you support – from physicians, nurses, therapists, dietitians and pharmacists to counselors, social workers, chaplains and volunteers. Beyond treating your cancer, this team is here to guide you, educate you and connect you to countless other resources available to you – most of which you'll find in the pages to follow.

You'll also see that throughout this guidebook, members of our healthcare team, our patients and their family members have taken a moment to share their perspective on the cancer experience – thoughts and stories that may give you a fresh perspective on your own cancer diagnosis and treatment. We encourage you to share your thoughts and insights in the journal pages we've provided.

Every case of cancer is as different as every individual diagnosed, which is why we believe a positive mindset – ours, yours and your family's – is essential to the healing process. While ensuring the highest level of expertise and the most advanced treatments and technologies are available to you, we also insist on a philosophy of care that is collaborative, patient-centric and compassionate. This guidebook and journal was designed to help.

We are, after all, not just treating cancer. We are treating people *with cancer.*
We are treating your cancer.

To get connected with an OhioHealth cancer expert to talk about your cancer diagnosis, treatment or survivorship, please call CancerCall at (614) 566-4321 or toll-free at 1-800-752-9119. We are available Monday through Friday, 8 a.m. to 5 p.m. You, your friends or family members can also visit us online at OhioHealthCancerCare.com.

‹‹‹‹manifesto

“It’s cancer.”

At OhioHealth, we realize that nothing can prepare you or your loved ones to hear those words from a physician.

In seconds, your life has changed.

Those words are more than a diagnosis. To us, they are a call to arms. And with those two words, your OhioHealth cancer care begins in earnest.

Our team of world-class oncology experts collaborate to create a care plan that is as unique as you are to best treat your cancer.

With proven treatment methods and leading-edge breakthroughs, we walk alongside you, step by deliberate step, on your path throughout your care.

Personal. Powerful. Precise.
These are the words that will define your treatment.

Sound Treatment. Deep Expertise. Compassionate Care.
This is how we fight cancer at OhioHealth.

OhioHealth

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OHIOHEALTH PATIENT BILL OF RIGHTS

MY CARE TEAM

THIS SECTION INCLUDES:

Team Directory

Telephone Directory

From my perspective | Laura, Patient

"I feel as though I am receiving the best treatment in the country. Everyone is very professional. My family and friends are going through this with me and they also are proud of how well my whole treatment team is taking care of me! I am grateful."

My Team Directory

NAME/PHONE	ADDRESS
Primary Care Doctor Name: ______________________ Phone: ______________________	
Medical Oncologist Name: ______________________ Phone: ______________________	
Radiation Oncologist Name: ______________________ Phone: ______________________	
Surgeon Name: ______________________ Phone: ______________________	
Patient Navigator Name: ______________________ Phone: ______________________	
Doctor Name: ______________________ Phone: ______________________	
Doctor Name: ______________________ Phone: ______________________	

NAME/PHONE	ADDRESS
Dentist Name: ______________________ Phone: ______________________	
Pharmacy Name: ______________________ Phone: ______________________	
Nurse Name: ______________________	
Nurse Name: ______________________	
Counselor Name: ______________________	
Dietitian Name: ______________________	
Social Worker Name: ______________________	
Physical Therapist Name: ______________________	
Occupational Therapist Name: ______________________	
Ambulance Name: ______________________	
Medical Supply Source Name: ______________________	

My Telephone Directory

NAME/PHONE	ADDRESS

NAME/PHONE	ADDRESS

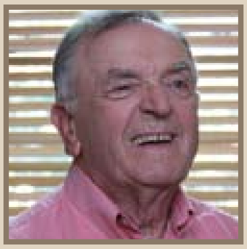
NAME/PHONE	ADDRESS

MY CALENDAR

THIS SECTION INCLUDES:

Month-at-a-Glance

From my perspective | John, Patient
Patient Family Advisory Council Member



"What we're doing (at OhioHealth) is to put this program together so that all people – caregivers, patients and even, I believe, doctors – learn more about what goes on with someone in recovery from cancer."

Month-at-a-Glance

MONTH ____________________ YEAR ____________

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Month-at-a-Glance

MONTH ____________________ YEAR ____________________

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Reprints are available at OhioHealthCancerCare.com

Month-at-a-Glance

MONTH ______________________ YEAR ____________

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Month-at-a-Glance

MONTH ______________________ YEAR ______________

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Month-at-a-Glance

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Month-at-a-Glance

MONTH ____________________ YEAR ____________

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Month-at-a-Glance

MONTH YEAR

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Month-at-a-Glance

MONTH ______________________ YEAR ______________

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

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Month-at-a-Glance

MONTH YEAR

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Month-at-a-Glance

MONTH ____________________ YEAR ____________________

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

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Month-at-a-Glance

MONTH YEAR

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Month-at-a-Glance

MONTH ____________ YEAR ____________

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

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MY MEDICINE

THIS SECTION INCLUDES:

Medicine Record

Medicine Log

From my perspective | Thomas Sweeney, MD, Medical Oncologist

"Once the initial shock is over from the diagnosis, people start to regroup and make plans. And once they have a plan on how they are going to take care of the cancer and what their expectations are in terms of survival, that allows them to get down to the business of taking care of themselves and their cancer."

My Medicine

MEDICINE RECORD

Please record all medications including those prescribed by your doctor and those purchased over the counter. Place an "X" through the medicine when it is stopped.

NAME	DOSE	HOW OFTEN	WHY	PRESCRIBED BY DR.	START DATE	STOP DATE	COMMENTS/WHY STOPPED

Reprints are available at OhioHealthCancerCare.com

My Medicine

MEDICINE RECORD

Please record all medications including those prescribed by your doctor and those purchased over the counter. Place an "X" through the medicine when it is stopped.

NAME	DOSE	HOW OFTEN	WHY	PRESCRIBED BY DR.	START DATE	STOP DATE	COMMENTS/WHY STOPPED

Reprints are available at OhioHealthCancerCare.com

My Medicine

MEDICINE LOG

Use these weekly logs to keep track of when and how often you take your medicine.

DRUG	DOSE	HOW OFTEN	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
DATE									

Reprints are available at OhioHealthCancerCare.com

My Medicine

MEDICINE LOG

Use these weekly logs to keep track of when and how often you take your medicine.

DRUG	DOSE	HOW OFTEN	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
DATE									

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MY NOTES

THIS SECTION INCLUDES:

Appointment Notes

From my perspective | Donna, Patient
Patient Family Advisory Council Chair

"To me, it's not a battle, it's a journey. A battle sounds like something you can win and go on, but a journey is just what is the next phase."

MY NOTES

Appointment Notes

Use these pages to prepare for appointments. You can also record information and updates provided by your doctor and other members of your healthcare team.

DATE	**DOCTOR**

- Questions for the doctor:

1. ______________________________

Answer: ______________________________

2. ______________________________

Answer: ______________________________

3. ______________________________

Answer: ______________________________

4. ______________________________

Answer: ______________________________

- Things I want to tell the doctor:

1. ______________________________

Response: ______________________________

2. ______________________________

Response: ______________________________

3. ______________________________

Response: ______________________________

4. ______________________________

Response: ______________________________

- Our plan:

____

DATE	DOCTOR

- Questions for the doctor:

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Answer: ______________________________

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3. ______________________________

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4. ______________________________

Response: ______________________________

- Our plan:

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- Questions for the doctor:

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Answer: ______

2. ______

Answer: ______

3. ______

Answer: ______

4. ______

Answer: ______

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1. ______

Response: ______

2. ______

Response: ______

3. ______

Response: ______

4. ______

Response: ______

- Our plan:

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2. ______________________________

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3. ______________________________

Response: ______________________________

4. ______________________________

Response: ______________________________

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2. ______________________________

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3. ______________________________

Answer: ______________________________

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Response: ____________________

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4. ______________________________

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Answer:

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Answer:

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Answer:

4.

Answer:

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Response:

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Response:

3.

Response:

4.

Response:

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Response: __________

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Response: __________

4. __________

Response: __________

- Our plan:

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Reprints are available at OhioHealthCancerCare.com

MY RECORDS

THIS SECTION INCLUDES:

Diagnostic Test Record
Treatment Record
Body Weight Record
Lab Test Results Record

From my perspective | Anne, Patient

"To me, being thoroughly informed means five or ten years from now, I'll have no regrets. As a patient, you have the responsibility to become educated in order to pursue the course of treatment that's right for you."

Diagnostic Test Record

Use this record to track diagnostic tests. You may find it helpful to file a copy of the report with this record.

TEST	DATE	TEST LOCATION	RESULTS

Diagnostic Test Record

Use this record to track diagnostic tests. You may find it helpful to file a copy of the report with this record.

TEST	DATE	TEST LOCATION	RESULTS

Treatment Record

Please record all your treatments, dates and side effects.

Treatment:
Date:
Side effects:

Treatment:
Date:
Side effects:

Treatment:
Date:
Side effects:

Treatment:

Date:

Side effects:

Treatment:

Date:

Side effects:

Treatment:

Date:

Side effects:

Body Weight Record

Use this record to keep track of your weekly weight.

DATE	WEIGHT (LBS/KG)	WHAT I ATE TODAY

Body Weight Record

Use this record to keep track of your weekly weight.

DATE	WEIGHT (LBS/KG)	WHAT I ATE TODAY

Lab Test Results Record

Your physician will keep records of your laboratory values, but some people like to keep their own records.

TEST	FUNCTION	NORMAL LEVELS	LOW LEVELS	WHAT YOU CAN DO
White Blood Cells	Fight Infection	4,000-10,000 (4-10)	Leukopenia	See Symptoms Management: Low Blood Counts P. 87
Red Blood Cells	Carries Oxygen	4.7-6.1	Anemia	
Hemoglobin	Part of Red Blood Cell that Carries Oxygen	12.0-18.0	Anemia	
Platelets	Helps Clot the Blood	150,000-400,000	Thrombocytopenia	
Absolute Neutrophil Count (ANC)	Type of White Blood Cell	1,500 or Greater	Neutropenia	

	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE
TEST														
White Blood Cells														
Red Blood Cells														
Hemoglobin														
Platelets														
ANC														

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	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE
TEST														
White Blood Cells														
Red Blood Cells														
Hemoglobin														
Platelets														
ANC														

Reprints are available at OhioHealthCancerCare.com

MY DIAGNOSIS

THIS SECTION INCLUDES:

Types of Cancer

Diagnosing and Staging of Cancer

From my perspective | ***Mark Cripe, DO, Surgeon***

"Many people, although it sounds odd initially, will go through their cancer diagnosis, cancer treatment, and one year – maybe five years – down the line, will say, 'You know, because I have had cancer, I am a better person. I look at life differently. I am able to find out and differentiate what's important.' A lot of people eventually – not initially – come to the place where cancer has made them a better person."

MY DIAGNOSIS

Cancer is a group of more than 100 diseases that have the following in common:

- Cancer cells grow, divide and replace themselves in an unorganized way. If the cells continue to grow and divide when they are not needed, a tumor can form. A tumor is an abnormal mass of tissue.
- Cancer cells can invade and destroy normal tissue.
- Cancer cells sometimes break away, travel through the body and start new tumors (metastasize).

The term *malignant* tumor refers to a tumor that is cancer. A benign tumor is not cancer.

Types of Cancer

Cancer is described according to where it started (for instance, lung or breast), the type of cancer cells involved (for instance, carcinoma) and if and where the cancer has spread (cancer stage).

Carcinomas are cancers of certain skin cells (squamous cell carcinoma) and gland cells (adenocarcinoma). These cells are in the skin and also line body organs, such as the mouth, throat, stomach, intestines, rectum, lungs, bladder, ovaries, cervix and uterus.

Sarcomas come from cells such as muscles or other connective tissue like bone or cartilage. Examples include osteosarcomas (bone), liposarcomas (fat), leiomyosarcomas (smooth muscle), rhabdosarcomas (skeletal muscle) and chondrosarcomas (cartilage).

Lymphomas come from cells in the lymph tissue. Lymph tissue is found in many different places in the body. Lymphomas are divided into two groups: Hodgkin’s Lymphoma and Non-Hodgkin’s Lymphoma. Lymphomas can further be divided into B-Cell Lymphomas (coming from B lymphocyte cells) and T-Cell Lymphomas (coming from T lymphocyte cells).

Leukemias are cancers of the blood. They can involve white blood cells (that fight infection), red blood cells (that carry oxygen) and/or platelets (that clot the blood).

For more information about your specific type of cancer, feel free to ask your healthcare professional. You can also find additional information online at www.cancer.gov.

Diagnosis and Staging of Cancer

When cancer is suspected, the doctor will talk with you about your health history and perform a physical exam. A biopsy, blood tests, scans and other tests may be ordered to determine the type of cancer, whether it has spread and, if so, to where. With this information, your doctor can plan the treatment that is best for you.

TUMOR SPECIMENS AND BIOPSY

The most accurate way to diagnose cancer is to examine and test the suspicious cells. To get these cells, the doctor will have to do a biopsy, test body fluid where the abnormal cells may be or get a scraping of the cells (for instance, a pap smear). Cells are then placed on slides, stained with dye and examined under a microscope.

BLOOD TESTS

Your physician will order blood tests, including blood counts and tests for liver or kidney function. Some types of cancer make proteins called *tumor markers*. A high level of a tumor marker may mean that a certain type of cancer is in the body. Examples of tumor markers include CA 125 (in ovarian cancer), CA 15-3 (in breast cancer), CEA (in ovarian, lung, breast, pancreas and gastrointestinal tract cancers) and PSA (in prostate cancer).

IMAGING STUDIES

Imaging studies are done to locate the tumor and determine its size:

X-rays focus on a specific body part and project its image onto film. Because soft tissues (for instance, the colon) cannot be seen very well on X-rays, contrast agents such as barium may be used. A fluoroscope is used to view a continuous, moving image.

CT Scan looks at a selected cross section of the body.

MRI provides cross-sectional images similar to CT scans but in multiple directions. No X-ray is used. A powerful magnet makes certain parts of the body vibrate, resulting in a computer-generated image.

PET Scan A procedure during which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body.

Endoscopy Using a flexible "scope," the doctor is able to see inside body cavities, take pictures or take a biopsy. Examples of endoscopy include colonoscopy and sigmoidoscopy.

Nuclear Medicine studies can find abnormalities in many different organs in the body, using a very small amount of radioactive substance.

Ultrasound is a test that uses sound waves instead of X-rays to find tumors.

STAGING

Staging is the process of finding out whether the cancer has spread and if so, where it has spread. Staging is done at the time of diagnosis and is used to select the best treatment.

There are several types of staging systems. In one system, a "Stage I" means the cancer is only in one place; a "Stage 4" means the cancer has metastasized (spread) to a distant place. Another staging system used is called the TNM system. "T" stands for tumor size, "N" stands for the number of lymph nodes that have cancer and "M" stands for the number of metastases.

GRADING

Cancer cells are also graded. The grade measures how abnormal the cancer cell looks compared to a normal cell. A Grade I looks very similar to a normal cell; a Grade 4 looks very abnormal.

QUESTIONS FOR MY DOCTOR

1. What type of cancer do I have? ______

2. What is the stage of my cancer? What does that mean? ______

MY TREATMENT

THIS SECTION INCLUDES:

From my perspective* | *Dr. Shakir Sarwar, Medical Oncologist

"We try to get them (patients) treated in a way that doesn't affect their routine activities. Most of the treatments are now done as outpatient, so the patients come into the office maybe once a week, maybe once every three weeks, to get their treatments. We have had patients who get their chemotherapies, they are done at noon, and back to their job in an hour."

MY TREATMENT

Major cancer treatments include surgery, radiation therapy, chemotherapy, hormone therapy and biologics. You may receive one treatment or a combination of treatments. Your treatment plan and goals for treatment depend on the type and stage of cancer, other medical problems you may have, your age and personal decisions.

Goals for cancer treatment can include cure (getting rid of the cancer), control (controlling the spread of cancer), or palliation (helping to relieve the symptoms from cancer but not stopping the cancer). Good communication is important to assure that you and your doctor agree on the goals for your treatment.

Treatments can be considered *local* or *systemic*. Local treatments only destroy cancer cells in one area. They do not travel through the body to kill cancer cells at distant sites. Surgery and most types of radiation therapy are considered local treatments. Systemic treatments travel throughout the body to kill cancer cells. Most chemotherapy and biologic agents are considered systemic treatments.

Standard treatments, also called Conventional or Western Medicine, are based on rigorous testing and research. Examples include surgery, radiation, chemotherapy and biologics.

Surgery

Surgery is recommended for some, but not all, types of cancer. Depending on the type and extent of cancer, surgery is a local treatment that removes some or all of the tumor. Nearby normal tissue and lymph nodes may also be removed to determine if the cancer has spread.

Radiation Therapy

Radiation therapy is the use of high-energy waves or streams of particles to damage cancer cells. This treatment prevents the cancer cells from growing and multiplying. Radiation may be used alone, before surgery to shrink a tumor, during or after surgery. It is sometimes used in combination with chemotherapy.

Radiation can be given by a machine outside of the body *(external beam radiation therapy)*. External beam radiation therapy is usually given five days a week for at least several weeks. Many people receive external beam radiation therapy as an outpatient. Radiation can also be delivered by *brachytherapy* – placing radioactive materials, sometimes called "seeds," in the body near the cancer cells. And finally, radiation can be given as pills, a liquid or by IV. This type of radiation travels throughout the body and is considered systemic treatment.

Chemotherapy

Chemotherapy is the use of medication to stop cancer cells from growing and multiplying. It can be used alone or in combination with surgery, radiation therapy and biological therapy. Chemotherapy can be given many different ways, most commonly by pill or by IV. There are many different chemotherapy medications, different combinations of medications and different schedules. Chemotherapy can be given in the oncologist's office, an outpatient chemotherapy area or in the hospital. It can sometimes even be given at home.

The side effects of chemotherapy depend upon the medications used. Common side effects can include hair loss, nausea and vomiting, and low blood counts. Most side effects from chemotherapy are temporary and predictable.

Hormone Therapy

Some cancers grow when certain hormones are present in the body. Examples of hormone sensitive cancers are types of breast cancer, prostate cancer and testicular cancer. Hormone therapy stops the production or use of these hormones and prevents cancer growth. Hormone therapy can include the use of hormone or hormone-blocking medications or surgery involving the removal of the organ that produces the hormone needed for cancer growth.

Biological Therapy

Biological therapy is also known as immunotherapy or biologics. Biological therapy uses the body's immune system to fight cancer cells. One of the major jobs of the immune system is to defend the body against foreign invaders (bacteria, viruses) and diseases. It does this by recognizing normal cells from foreign or abnormal cells. The immune system can recognize cancer cells as abnormal and can attack to destroy them. Biological therapy helps stimulate or boost the immune system to help fight cancer cells. Examples of biological therapy include monoclonal antibodies, interleukins and interferons.

Clinical Research Trials

Clinical trials are research studies that help doctors find better ways to treat cancer and the problems it can cause. Before a drug or other treatment can be used to treat patients, it is carefully tested – first in the laboratory and then in animals. After these studies are completed and the therapy is found safe and promising, it is tested to see if it helps patients. After careful testing with patients shows that the drug or other treatment is safe and effective, the Food and Drug Administration may approve it for regular use.

OhioHealth conducts more than 100 nationally sponsored clinical trials that evaluate new and possibly better treatments, which may lead to future cures for cancers. As members of the Columbus Community Clinical Oncology Program (CCOP), the largest community hospital research consortium in Ohio, we are able to offer National Cancer Institute-sponsored trials, as well as institutional-based clinical trials. In addition to treatment trials, we offer many cancer-control clinical trials. These trials look at symptom and side-effect management.

For additional information on clinical trials, please visit www.cancer.gov/clinicaltrials.

Alternative Therapy

Alternative therapy refers to treatments that are unproven by research and are used in place of standard cancer treatments. People outside of the medical field often promote these treatments. Because these have not been rigorously tested using scientific methods, the safey of these treatments and how well they work are not known.

Complementary Therapy

Complementary therapies are used *along with* standard cancer treatment. Many of these therapies focus on symptom prevention and management.

- **Acupuncture and Acupressure:** the application of pressure to specific pressure points in the body to block pain impulses.
- **Aroma Therapy:** the use of fragrant substances, called essential oils, distilled from plants to alter mood or improve symptoms, such as stress or nausea.
- **Art Therapy:** the use of creative activities to help people with physical and emotional problems express their emotions. This is done by mainstream therapists with specialized training.
- **Biofeedback:** the use of monitoring devices to help people consciously control physical processes, such as heart rate, blood pressure, temperature, sweating and muscle tension that are usually controlled automatically.
- **Exercise:** an exercise plan helps to restore flexibility, strength and function.
- **Massage Therapy:** manipulating, rubbing and kneading the body's muscle and soft tissue. Some studies suggest massage can decrease stress, anxiety, depression and pain and increase alertness.
- **Meditation:** a mind-body process in which a person uses concentration or reflection to relax the body and calm the mind.
- **Music Therapy:** offered by a group of established healthcare professionals, music is used to promote healing and enhance quality of life.
- **Nutrition:** the use of botanicals, animal-derived extracts, vitamins, minerals, fatty acids, amino acids, proteins, probiotics, whole diets and functional foods to improve well being.
- **Prayer and Spirituality:** usually described as an awareness of something greater than the individual self, spirituality is often expressed through religion and/or prayer, although there are many other paths of spiritual pursuit and expression.

- **Qigong:** a component of traditional Chinese medicine that combines movement, meditation and controlled breathing.
- **Tai Chi:** an ancient Chinese martial art, Tai Chi is a mind-body system that uses movement, meditation and breathing to improve health and well-being. It can improve strength and balance in some people.
- **Yoga:** a form of non-aerobic exercise that involves a program of precise posture and breathing activities. In ancient Sanskrit, the word yoga means "union."

Integrative Medicine

Integrative Medicine is the use of standard treatments (conventional therapy) along with complementary therapies. It connects the most successful medical practices with a deep understanding of illness, health, and well-being.

OhioHealth offers Integrative Medicine services tailored to the needs of cancer patients. To learn more, call CancerCall at (614) 566-4321 or toll-free at 1-800-752-9119. We are available Monday through Friday, 8 a.m. to 5 p.m.

Questions About My Treatment Plan

What is the goal of my treatment? ______________________________

____

____

____

What is the best way to treat the disease? ______________________________

____

____

____

How successful can we expect this treatment to be? ______________________________

____

____

____

Are there other treatments for this condition?

If I choose not to have the treatment, what will happen?

How will I feel during treatment?

How long will the treatments last?

What kinds of changes in my daily life will I have to make while I am going through these treatments?

Will I be able to continue to work?

How will we know the treatment is working?

What side effects should I look for? What side effects should I report to you right away? Will I have all of the possible side effects?

Are there any changes I will have to make in my diet? Can I drink alcohol?

Is there a chance that, once cured, the cancer will come back? How will I know if it does?

How often and how long will I have to come for follow-up visits?

What will treatment cost? If I have trouble getting reimbursement, can you help me?

Should I get a second opinion? If so, can you recommend someone?

MY DAILY LIFE

THIS SECTION INCLUDES:

From my perspective | Gayle Jenkins, Radiation Oncology Clinical Receptionist

"The number one thing that patients have said, 'Surround yourself with positive, fun, good people. The word 'cancer' is not a real positive word, and there are so many 'bad' meanings behind it. But get on the positive side before you even start anything is what our encouragement to you, as a cancer patient, is."

Talking to My Healthcare Team

Your healthcare team is here to provide the best cancer care possible. Still, patients involved in their own care have better results. It is your right as a partner in your own care to expect complete information and respect. By talking openly with your doctors, nurses, social workers and others about your questions, concerns and fears, you become an active partner in your treatment. To help you become an active partner in your healthcare, the following are some suggestions:

- Read about your cancer and its treatment. Learn about side effects and how to prevent and manage them.
- Ask your healthcare professionals for literature and to recommend reliable sources of information. Two very helpful websites for cancer information are OhioHealthCancerCare.com and the National Cancer Institute's website, www.cancer.gov.
- Prepare to talk with your doctor by writing down your questions.
- Write down any problems or symptoms you may be having. Bring these to your doctor's appointment. Examples of problems you should share with your doctor include pain, change in appetite, weight loss or gain, difficulty sleeping or any other concern you may have.
- Listen carefully. Ask your healthcare professional to repeat or re-explain any information you don't understand. Review all instructions at the end of your discussion or appointment.
- And, finally, talk openly with your doctor. Request emotional support. If you are lonely or upset, let someone know. The doctors, nurses, dietitians, pharmacists, social workers, counselor and chaplains on your team can help.

BE SAFE BY SPEAKING UP

Your safety is very important to us. We strive to do everything we can do to provide safe, quality care, but we want you to partner with us as well. To help us provide the safest care, it is important that you speak up:

- Always tell your doctor about your health conditions, allergies and medications (prescription and over-the-counter), vitamins and herbs. Many cancer treatments can interact with medications, vitamins and herbs.
- Expect staff to introduce themselves and explain their role. If you are in a treatment area, the staff should always ask you your name and birth date before giving medication and providing care. They should always wash their hands before and after providing care.
- If you are in the hospital or a treatment area, always ask the name and dose of the medication before taking it.

Talking to Children

Adults are often concerned about what to tell children. Generally, children adjust best when they are given clear, honest information about your illness. Speak at a level they can understand. Children need to know that they can ask questions and get honest answers.

To speak with an expert in talking with children about cancer, please call CancerCall at (614) 566-4321 or toll-free at 1-800-752-9119. We are available from 8 a.m. to 5 p.m. Monday through Friday.

WHAT ARE ADVANCE DIRECTIVES?

"Advance directive" is a general term that refers to a person's verbal and written instructions about future medical care, should that person become unable to speak for himself or herself.

WHY DO I NEED AN ADVANCE DIRECTIVE?

Advance directives give you a voice in decisions about your medical care when you are unconscious or too ill to communicate. As long as you are able to express your own decisions, your advance directives will not be used and you can accept or refuse any medical treatment.

WHAT LAWS GOVERN THE USE OF ADVANCE DIRECTIVES?

Both federal and state laws govern the use of advance directives. The Patient Self-Determination Act, a federal law, requires healthcare facilities that receive Medicaid and Medicare funds to inform patients of their rights to execute advance directives. Laws vary from state to state. While a witness signature is required for all advance directives, you do not need to hire an attorney to create these documents.

WHAT TYPES OF ADVANCE DIRECTIVES ARE AVAILABLE IN OHIO?

- **Ohio's Living Will** is a type of advance directive in which a person puts in writing his or her wishes about life-sustaining treatments if he or she were to become permanently unconscious or terminally ill and, thus, unable to communicate. The person must be declared permanently unconscious or terminally ill and unable to communicate by two physicians before the Living Will is utilized.

- **Durable Power of Attorney for Healthcare (DPOA-HC)** is a type of advance directive that allows a person to appoint someone (an attorney-in-fact) to make medical decisions for the person in the event he or she is unable to do so. The DPOA-HC differs from the Living Will because the attorney-in-fact appointed through a DPOA-HC is authorized to make medical decisions in any situation where you are unable to communicate. It is not limited to the event of becoming permanently unconscious or terminally ill and unable to communicate as defined by law. If you have assigned someone as DPOA-HC, please be sure this person knows and keep him or her up to date with your wishes.
- **Ohio's Do-Not-Resuscitate Law** is an advance directive allowing a person the option of not being resuscitated in the event of a cardiac or respiratory arrest. By enrolling in this program, a person has a choice to die without heroic measures, and healthcare providers are provided with legal means to respect those wishes. It is necessary to be enrolled in this program by a medical practitioner and have acceptable forms of DNR identification.

For more information on advance directives, please visit www.osma.org and go to "Patient Resources."

Always provide your doctor with a copy of your advance directives and bring these with you any time you come to the hospital. We can provide additional information about advance directives and assist you in completing the paperwork to ensure your wishes are known.

Eating Healthy

Preparing and eating a healthy diet is often hard for people with cancer. Cancer itself can affect your appetite. Common cancer treatments, although they are effective in treating cancer, may have side effects that change the way you eat. And yet, eating a well balanced diet helps to provide the nutrients you need to maintain healthy, normal cells. Talk to a dietitian about what is the best type of diet for you.

Your nutritional goals:

- Maintain good nutrition.
- Maintain strength.
- Reduce treatment side effects.

Meeting your nutritional goals:

If you are having problems eating...

- Eat small, frequent meals and snacks.
- Take advantage of the "up" times to eat favorite foods.
- Discuss eating problems with your doctor.
- Make use of time savers, such as food that is already prepared.
- Create a pleasant atmosphere.
- Avoid foods that don't interest you.
- Stay away from raw eggs and raw meat.
- Avoid fatty or greasy foods.

Coping With Daily Life

Each person has different feelings and responds differently to the stress of cancer treatment. You may see changes in your lifestyle, income, relationships, energy level and your ability to manage and cope with normal activities. Everyday stresses may seem worse. New ones may appear. You may feel angry, uncertain or scared. These feelings are to be expected.

How do you cope? Talking about your thoughts and feelings with someone you trust is a good first step. Choose someone who will listen and offer suggestions for change or help. Education, support and counseling are available. Talk to your doctor, nurse, social worker or other member of your healthcare team for a recommendation.

Managing Stress

The first step in coping with stress is to know what's causing it. Examples of stressors include missing work, the cost of medical care, constantly feeling fatigued or nauseated and so on. After you've identified your stressors, you can start to develop a plan to learn to cope effectively. Ask your healthcare professional about available counseling services. Other services are also available to help manage stress, such as art therapy, pet therapy, exercise groups and support groups.

To find out more about these services, please call CancerCall at 614-566-4321 or toll-free at 1-800-752-9119. We are available Monday through Friday, 8 a.m. to 5 p.m.

Ways to manage stress:

1. **Choose how to spend your time and energy** by setting priorities and taking time out when needed. Learn to pace yourself and stop before you get tired.
2. **Build your strength and endurance** through exercise, physical activity and good nutrition.
3. **Create a supportive environment** by getting rid of clutter and surrounding yourself with what you like – art, music, furnishings, etc.
4. **Learn to relax** through relaxation exercise, warm baths, massage, yoga, visualization or meditation.
5. **Manage your "self-talk"** by choosing to think positively, translating worry into action and learning to turn off your inner critic.
6. **Learn to laugh** by looking for the humorous side of situations and seeking out sources of humor.
7. **Practice saying "no."** Save your strength for the really important things and let someone else do the rest.
8. **Ask for help.** You don't have to do it all yourself. It's okay to give away some problems and tasks. Let people know in advance that you will need support during treatment.
9. **Pay attention** to the small, daily pleasures of life, to the present, fleeting moments.
10. **Use other techniques** to reduce stress, such as relaxation exercises, autogenic training, support groups and prayer.

RELAXATION EXERCISES

Imagery

To achieve relaxation, a quiet environment, proper positioning, a mental exercise and a relaxation attitude are necessary. Turn off the TV or radio, close your door and ask others to remain quiet. Uncross your arms and legs, support your head and spine, and place your hands at your side or on your abdomen. A mental exercise quiets mental chatter and allows for inner peace. Your device for this exercise is imagery. Maintain a "let-it-be" attitude. Allow distractions of body, emotions or thoughts to come into the mind and then flow out.

Imagery uses your imagination to create the relaxation response. Read the following scene descriptions slowly into a tape recorder so you will have a guide each time you use imagery:

Beach Scene

You are walking along the beach. It is mid-July. It is very, very warm. It is 5 o'clock in the afternoon. The sun has not yet begun to set, but it is getting low on the horizon. The sun is a golden, blazing yellow, the sky a brilliant blue, the sand a dazzling, glistening white in the sunlight. Feel the cold, wet, firm, sand beneath your feet. Taste and smell the salt in the air. There is a residue of salt deposited on your lips from the ocean spray. You can taste it if you lick your lips. Hear the beating of the waves, the rhythmic lap to and from, back and forth, of the water against the shore. Hear the far-off cry of a distant gull as you continue to walk.

Suddenly you come to a sand dune, a mound of pure white sand. Covering the mound are bright yellow buttercups and deep pink moss roses. You sit down on its crest and look out to sea. The sea is like a mirror of silver reflecting the sun's rays, a mass of pure white light, and you are gazing intently into this light. As you continue to stare into the sun's reflection off the water, you begin to see flecks of violet, darting spots of purple intermingled with the silver. Everywhere the sand is silver and violet. There is a violet line across the horizon – a violet halo around the flowers.

Now the sun is beginning to set. With each movement, with each motion of the sun into the sea, you become more and more relaxed. The sky is turning crimson, scarlet, pink, amber, gold, orange as the sun sets. You are engulfed in a deep purple twilight, a velvety blue haze. You look up to the night sky. It is a brilliant starry night. The beating of the waves, the smell and taste of the salt, the sea, the sky, and you feel yourself carried upward and outward into space, one with the universe.

On the count of 3, you will open your eyes, you will feel completely refreshed, totally relaxed, 1...2...3.

Progressive Relaxation

To achieve relaxation, a quiet environment, proper positioning, a mental exercise and a relaxation attitude are required. Turn off the TV or radio, close your door and ask others to remain quiet. Uncross your arms and legs, support your head and spine, and place your hands at your sides or on your abdomen. A mental exercise quiets mental chatter and allows for inner peace. Your device for this exercise is progressive relaxation. Maintain a "let-it-be" attitude. Allow distractions of the body, emotions or thought to come into the mind and then flow out.

Progressive relaxation is a tensing and releasing of various muscle groups throughout the body. Read these instructions into a tape recorder or have someone read this to you. As you become more familiar with the process, you may not need the guide of the recorded voice.

- Close your eyes, take a deep breath. Slowly in, slowly out and relax.
- Now tighten your facial muscles (scrunch up your face). Hold the tightness, feel it. Now relax your facial muscles and feel the difference.
- Lift your shoulders up to the ceiling, tighten the shoulder muscles, feel that tenseness in your neck and shoulders. Relax those muscles and feel the difference. Good.
- Continue as stated above in this order: arms, chest, back, abdomen, pelvic area, thighs, calves, feet.
- Mentally scan your body once again from the top of your head to the tip of your toes. If any tension remains, gently let go. Good.
- Now sit or lie gently for awhile and experience this relaxed, comfortable body. Wait one minute.

- Now take another deep breath, relax, open your eyes, stretch comfortably and feel yourself filled with healthy energy.

Slowed Breathing

To achieve relaxation, a quiet environment, proper positioning, a mental exercise and relaxed attitude are required. Turn off the TV or radio, close your door and ask others to remain quiet. Uncross your arms and legs, support your head and spine, and place your hands at your side or on your abdomen. A mental exercise quiets mental chatter and allows for inner peace. Your device for this exercise is slowed breathing. Maintain a "let-it-be" attitude. Allow distractions of the body, emotions or thoughts to come into the mind and then flow out.

Slowed breathing is deliberately slowing your breathing rate from the normal of 18 times per minute to about six times per minute. This will automatically slow your pulse rate and decrease muscle tension.

Follow these instructions:

- Close your eyes, take a deep breath. Slowly in, slowly out and relax.
- Now breathe in slowly for two counts, hold for two counts, and then out slowly for two counts. Repeat once.
- Now breathe in slowly for three counts, hold for three counts, and then out slowly for three counts. Repeat once.
- Now breathe in slowly for four counts, hold for four counts, and then out slowly for four counts. Repeat once.
- Now resume relaxed breathing, open your eyes, stretch comfortably and feel the difference.

Autogenic Training

To achieve relaxation, a quiet environment, proper positioning, a mental exercise and a relaxation attitude are required. Turn off the TV or radio, close your door and ask others to remain quiet. Uncross your arms and legs, support your head and spine, and place your hands at your sides or on your abdomen. A mental exercise quiets mental chatter and allows for inner peace. Your device for this exercise is autogenic training. Maintain a "let-it-be" attitude. Allow distractions of the body, emotions or thoughts to come into the mind and then flow out.

These are self-generated statements designed to create health and relaxation. They are written in the first person, present tense and create what is desired rather than what is causing harm. Warmth, coolness, heavy or floating sensations are signs of profound relaxation.

Read the following into a tape recorder so that you can have the experience of autogenic training as often as desired:

Relax. Close your eyes. Take a deep breath, slowly in, slowly out and relax. Now, repeat after me, (not out loud, but inside your own head), each of these phrases. Pause when directed:

- My arms and legs are heavy and warm. *15 second pause*. My arms and legs are heavy and warm. *15 second pause*. My arms and legs are heavy and warm. *15 second pause*.
- Pause and repeat three times for each phrase below:
  - My heartbeat is calm and regular.
  - My body breathes freely and easily.
  - My abdomen is warm.
  - My forehead is cool.
  - My mind is quiet and still.
  - I am at peace (pause one time only).

Now, as you prepare to return to your normal level of consciousness, see yourself bringing with you the warmth, comfort and love that you see and feel. Take a deep breath, open your eyes, stretch comfortably and see yourself filled with healthy energy.

Ask about massage therapy to help you relax.

Support Groups

Support groups have long been a method used to help patients and family members cope with cancer. Support groups can satisfy a longing to be connected. Extended families aren't what they used to be. A family today often consists of one parent. Many live in social isolation. Cancer isolates people even more. Knowing that others have been down the same road helps you cope.

Being in a supportive, understanding environment can stimulate the release of pent-up emotion. Often, people don't realize how much they've been holding in. For some, it may be the first time they openly cry.

We know that support groups aren't for everyone. Some individuals are very private and find that family and friends are able to provide the necessary emotional support.

Prayer and Spirituality

When confronted with the diagnosis of cancer, a person may begin to question his or her long-held spiritual beliefs. Exploring, defining and coming to terms with your inner spiritual resources can help you, your family and friends to live with cancer.

Belief in God or a Supreme Being is a way to explain and accept the unknown. While concepts may vary by culture and religion, most center on an all-powerful Supreme Being who created and rules the universe. In every religion, people communicate with God or another Supreme Being through some form of prayer, either alone or in a group.

Because God is believed to be the Supreme Being able to create life and restore health, prayers often ask God for help, understanding, wisdom or strength in dealing with life's most difficult problems. Prayer may be in words or thoughts. Spirituality includes using prayer as the main source of communication with God.

There are different kinds of prayers. In prayers of supplication, people pray for themselves. Praying for others is called intercessory prayer. Some religions set aside certain times of the day and special days of the week for praying. Standard prayers written by religious leaders are often memorized by the faithful and repeated during prayer sessions privately and in groups.

Even if prayer will not cure a person's disease, it can have a helpful effect by reducing stress, promoting a positive outlook and strengthening the patient's will to live well and possibly overcome illness. Prayer and spirituality can provide an active means of coping with the stress of illness. Many believe that the spiritual dimension in healing is essential. Patients and families usually find great comfort in solitary and community acts of prayer.

If desired, we can help you arrange a visit with a hospital chaplain.

FOR MY CAREGIVER

THIS SECTION INCLUDES:

From my perspective | Suzette, Family Member of Patient

"Being a caregiver is extremely draining. So you're there to support this person each and every step of the way. And sometimes you need somebody to help take care of you."

CAREGIVING

A diagnosis of cancer affects the person with cancer, and it also affects the caregiver. A cancer caregiver is an individual who has a personal connection and commitment to someone with cancer. The extent of the role may vary. If the person with cancer can function on his or her own during treatment, caregivers may only be called upon for emotional support. If, on the other hand, he or she needs help with daily activities, caregivers may assume a much greater role. In such cases, one primary caregiver often takes the lead in organizing care routines and talking with doctors and other healthcare professionals.

When I am the Caregiver

Giving care to a person with cancer can require patience, flexibility, courage and a sense of humor. Try to understand the experience of cancer from the point of view of the person with cancer. Ask questions and listen closely to the responses. Looking beyond the physical aspects of care, try to promote a sense of independence and a positive outlook. Encourage the person with cancer to do what he or she can for himself or herself and include him or her in daily activities as fully as possible. Remember that because of treatment-related fatigue or appetite changes, there may be days when he or she doesn't feel up to doing or eating much. That's okay, too. An ongoing dialogue between both of you will help define your role and everyone's expectations.

Communicating with Doctors and Other Healthcare Professionals

Your best source of information is the physician. If possible, attend doctor's visits with the patient so that you won't miss important information, test results or other updates. Ask questions about your loved one's specific needs and how to recognize and manage symptoms. Use this guidebook to record instructions, appointments, tests and questions you may have for future appointments. Refer to other sections of this book for guidelines about doctor's appointments, diagnostic and symptom management concerns. **Remember: to receive medical updates after the appointment, you will need the patient's written permission.**

Should The Patient Get a Second Opinion?

A second opinion may be essential to the understanding of a cancer diagnosis. It may not be a different opinion, but it is a different conversation. A second opinion allows you to hear an additional explanation when you are more focused, helping provide the clarity needed before choosing a treatment option. You may want to discuss this option with the patient. If the patient chooses to get a second opinion, you can help by:

1. Obtaining copies of all medical records, including diagnostic test results.
2. Calling and making the appointment with the second opinion doctor's office.
3. Filling out provided paperwork before the appointment.
4. Making a list of questions to ask the doctor.
5. Going to the appointment.
6. Helping the patient process any new information after the appointment.

Visiting the Doctor

A physician will want to know the patient's chief complaint/symptom:

- When it began
- What makes it worse/better
- How often and when it occurs

Before the visit:

- Make a list of questions.
  - What are the side effects of the treatment?
  - After treatment, what do we need to watch for?
  - Are there any medicine interactions we need to discuss? (See "Medicines.")
  - Who can help us if we have questions or problems between doctor's visits?
  - When should we call the doctor?
- Be ready to describe current symptoms.

During the visit:

- Help the patient report his or her concerns.
- Describe symptoms in detail.
- Ask questions.
- Write down doctor's instructions.
- Repeat instructions back to the doctor to double-check understanding. ("Can you draw a picture of that?" "Will you write that down for me?")
- Check patient's prescriptions.
- Verify follow-up.
- Find out when you can expect to hear back about results of testing.
- Find out whether the patient has any limitations. ("Can the patient still walk his or her usual two miles a day?")

After the visit:

- Review your notes with the patient.
- Discuss the visit.
- Update your calendar.
- Call for test results.

Handling Emergencies

WHEN TO CALL THE DOCTOR:

This may vary, depending on the type of cancer and type of treatment. Refer to specific teaching sheets for detailed instructions. In general, call the doctor if the patient has:

- Fever of 100.5 F or higher (by mouth)
- Chills
- Cough
- Shortness of breath
- Diarrhea
- Burning when urinating
- Redness, swelling, pus
- Mouth sores, white patches
- Severe or frequent dizziness
- Uncontrolled pain or nausea

Doctor's phone number ____________________

IF YOU TAKE THE PATIENT TO THE EMERGENCY DEPARTMENT:

As soon as you arrive, be prepared to tell the Emergency Department nurse and doctor...

- Oncologist's Name ____________________
  and phone number ____________________
- Type of cancer ____________________
- Date of last chemotherapy ____________________
- Highest temperature and the time it occurred ____________________
- Symptoms (cough, sore throat, chills) ____________________
- Whether the patient has a catheter or port ____________________
- Medications the patient is taking:
  - Drug ____________________
    ____________ Dose ____________ Schedule
  - Drug ____________________
    ____________ Dose ____________ Schedule
  - Drug ____________________
    ____________ Dose ____________ Schedule

Taking Care of Myself

Caregivers can become physically exhausted and emotionally drained. Taking care of yourself is one of your main responsibilities.

Recognize the signs of burnout:

- Irritability
- Difficulty making simple decisions
- Withdrawal
- Fatigue
- Apathy
- Appetite changes
- Increased use of alcohol, drugs, tobacco
- Feelings of guilt (You think you are not doing enough, or you feel resentment for the amount of work you are doing.)
- Anger (over things you've lost – vacation, hobbies, free time)

What to do:

- Ask for help (household chores, cooking, yard work, childcare, transportation, looking up information).
- Designate a contact person to serve as "communicator" or to organize everyone who wants to help.
- Make time for yourself (exercise, read, get a massage, pursue hobbies, nap, garden, shop).
- Arrange for respite care (this can be a home-health aide or even a visit from friends or family that will allow you a break).
- Choose good listeners (tap into your own support network).
- Use your answering machine to take calls "after hours."
- Rely on expert help (home-health services, counselors, legal, financial and insurance specialists).
- Blow off steam – go to the movies, go out to dinner, have fun, play games, enjoy life.
- Relax – listen to music or relaxation tapes, yoga, take a warm bath, meditate or pray, practice deep breathing.
- Join a caregivers support group.

When I am feeling overwhelmed:

- Try not to make important decisions when you are tired, overwhelmed or upset. Don't hesitate to ask the doctor, nurse or social worker how long before a particular decision has to be made.
- Take time to sort things out. Give yourself enough time to become emotionally stable so that you can make plans and decisions with a clear mind and a peaceful spirit.
- Talk over important problems with others who have been levelheaded and helpful in the past.

Caregiver's Bill of Rights

I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.

I have the right to **seek help from others** even though my loved one may object. I know the limits of my own endurance and strength.

I have the right to **maintain parts of my own life** that do not include the person I care for just as if he or she were healthy. I know that I do everything that I reasonably can do for this person. I have the right to do some things just for myself.

I have the right to get angry, be depressed and **express difficult feelings** once in a while.

I have the right to **reject any attempt** by my loved one to make me do things out of guilt or anger. It doesn't matter if he or she is aware of doing this or not.

I have the right to **considerations, affection, forgiveness and acceptance** for what I do for my loved one, as I offer these in return.

I have the right to **take pride in what I'm doing.** And I have the right to applaud the courage it has taken to meet the needs of my loved one.

I have the right to **protect my individuality.** I also have the right to a life that will sustain me when my loved one no longer needs my full-time help.

(From "When Someone You Love is Being Treated for Cancer," National Cancer Institute, NIH Publication No. 05-5726, September 2005; author unknown.)

Respite Care

Respite care can give you some much needed time away from the intensity and responsibility of caregiving. Respite care comes in many forms:

- A healthcare worker who comes into the home for an extended period of time so that you can have a vacation, attend a special event or just get some much needed rest
- A planned visit from a friend or family member so that you can run some errands or attend to your own family's needs

Resources for Respite Care

- OhioHealth CancerCall: (614) 566-4321
  Caregiver support group information

- OhioHealth HomeReach: (614) 566-0888
  Home Health Aides, Skilled Nursing, Home Medical Equipment and Supplies

- OhioHealth Gerlach Center: (614) 566-5858
  One-on-one consultations to help caregiver

MANAGING SYMPTOMS

THIS SECTION INCLUDES:

Hair Loss (alopecia)
Constipation
Diarrhea
Fatigue
Low Blood Counts
Mouth Sores
Nausea and Vomiting
Pain
Peripheral Neuropathy
Sexuality and Reproductive Changes

From my perspective* | *Melanie Boren, RN, Lung Cancer Patient Navigator

"It's always great to see the patients who go through treatment and who are considered survivors and to know that they were able to conquer something that at the beginning, they didn't think was possible."

MANAGING SYMPTOMS

Cancer and its treatment can cause physical challenges. The type of symptoms you may experience depend on many different factors, including:

- The type of cancer
- The type of treatment
- Your age
- Any other health problems you may have

Here are some things to keep in mind about side effects from chemotherapy and radiation:

- Many side effects are temporary and go away after the treatment is stopped.
- The onset of side effects and how long they last can usually be predicted.
- Side effects are usually more severe if you are receiving more than one chemotherapy drug or chemotherapy and radiation at the same time.
- There is the possibility that you may have some rare side effects that may not be listed on educational materials.

There are many things that you can do to prevent or manage these physical challenges. The following information covers some common symptoms. Ask your doctor or nurse for information about other symptoms you may have.

Hair Loss *(alopecia)*

Some cancer treatments cause hair loss. The hair can thin or fall out completely. Most people lose only the hair on their head, but body hair, pubic hair, eyelashes and eyebrows can also be lost. Hair loss is usually temporary. Sometimes, the hair grows back a slightly different color or texture.

Causes of hair loss:

- Some chemotherapy medications
- Radiation to the scalp area
- Certain medications
- Stress

Steps to slow and manage hair loss:

- Avoid blow dryers, hot curlers and curling irons.
- Avoid permanents.
- Avoid hair products with hydrogen peroxide.
- Use wide-toothed combs and soft-bristled brushes.

Managing hair loss:

- If you lose your hair, protect your scalp from the sun.
- Cover your head in the winter to prevent heat loss.
- If your scalp itches, use any lotion without alcohol to keep it moist.
- If you lose your eyelashes, protect your eyes with sunglasses or a wide-brimmed hat.
- Some people like to wear wigs. Some insurance companies pay for wigs. You may need a prescription from your doctor. If you decide to wear a wig or toupee, you may want to buy it before you lose all your hair so you can match the wig to your own hair color. Most wigs need to be trimmed. Many hair stylists will trim and style your wig.
- Other people choose to wear hats, scarves or turbans. Many wig stores sell bangs that attach to the inside of turbans.
- The American Cancer Society, The National Cosmetology Association and the Cosmetic Toiletry and Fragrance Foundation offer a free program for women called, “Look Good – Feel Better.” This program teaches you how to wear makeup, wigs and scarves. *To find out more about this class, please call the American Cancer Society at 1-800-227-2345.*

Constipation

Constipation is infrequent, hard, dry stools. It can be uncomfortable and annoying. Fortunately, constipation can often be prevented and/or managed.

Causes of constipation:

- Not eating enough fiber
- Not drinking enough fluids
- Ignoring the urge to pass stool
- Using too many laxatives or enemas
- Decreased exercise
- Medical conditions, such as problems with the nervous system
- Bowel disorders (such as tumors)
- High blood-calcium levels
- Medications
  - Pain medications
  - Medications for anxiety and depression
  - Chemotherapy
  - Stomach antacids
  - Vitamin supplements with iron or calcium
  - Sleep medications

Steps to help prevent and manage constipation:

- Drink at least eight to 10 (8-oz.) glasses of fluid a day, unless your doctor has told you to limit fluids.
- Drink a warm or hot drink about one half hour before your usual time for a bowel movement.
- Eat foods high in fiber, such as bran, whole grain breads, cereals, fresh fruits and vegetables.
- Drink more fluid if you increase dietary fiber. Fiber alone may increase constipation. People who have a bowel obstruction or who have undergone bowel surgery (for instance, a colostomy) should not increase dietary fiber. Talk with a dietitian about what to eat to prevent constipation.
- Exercise, such as walking, every day. Talk to your physician or physical therapist about the type and amount of exercise that is right for you.

- If necessary, ask for help to use the toilet or commode rather than a bedpan.
- If these suggestions don't work, ask your physician about medication to help relieve constipation. Most people who take pain medications on a regular basis need to take stool softeners or laxatives.

Check with your doctor first,* before *taking any remedies such as enemas, stool softeners or laxatives. If you are taking pain medications, do not take bulk forming laxatives, such as Metamucil®, or serious problems can result.

Call your doctor or nurse if you have:

- Severe abdominal pain
- Vomiting
- Inability to pass gas
- No bowel movement in three days

Diarrhea

Causes of diarrhea include:

- Cancer
- Antibiotics
- Radiation to the abdominal area
- Certain medication
- Certain chemotherapy drugs
- Emotions
- Sensitivity to certain foods

Steps to help prevent and manage diarrhea:

- Eat small, frequent meals.
- Drink plenty of fluids to help prevent dehydration.
- Eat foods high in potassium, such as potatoes, bananas and oranges (unless your doctor has told you to avoid these foods).
- Cleanse the skin around the rectal opening with soap and water after each loose stool to decrease skin breakdown and infection.
- Warm sitz baths may also cleanse and comfort.

Avoid the following:

- Coffee, tea, alcohol
- Fried, greasy or spicy foods
- Foods high in fiber and residue: whole grain breads and cereals, fresh fruits and vegetables, gas-forming vegetables (broccoli, cabbage) and foods with seeds, hulls or nuts

When the diarrhea starts to improve, try eating small amounts of low-fiber foods such as rice, bananas, applesauce, yogurt, mashed potatoes, low-fat cottage cheese and dry toast.

If diarrhea continues, ask your doctor about medications to help control diarrhea. Check with your doctor* before *taking any over-the-counter medicines.

Call your doctor or nurse if you have:

- Diarrhea lasting longer than 24 hours
- Pain and cramping with the diarrhea
- Fever
- Blood in the stool
- Nausea and vomiting

Fatigue

Cancer and its treatment can be very tiring. Fatigue is the most common symptom reported by people with cancer. Cancer-related fatigue is not related to physical exercise, nor can it be relieved with a good night's sleep.

Causes of fatigue include:

- Cancer
- Chemotherapy
- Radiation therapy
- Surgery
- Anemia
- Fever
- Pain medications
- Depression

Symptoms of fatigue can include:

- Feeling tired
- Difficulty climbing stairs or walking short distances
- Difficulty paying attention and concentrating
- Shortness of breath after light activity
- Difficulty cooking, cleaning or taking a shower
- A desire to sleep more
- Slower speech
- Feeling like crying or feeling depressed
- Paleness or shakiness

Steps to help prevent and manage fatigue:

- Pace yourself and reduce your workload. This allows you to save energy for activities that you enjoy as well as those you must do.
- Get enough rest.
  - It is important to start or follow a normal and regular sleeping routine.
  - Go to bed at the same time each night.
  - Don't fight fatigue. Rest when you need it.
  - Avoid caffeine or alcohol in the evening.

- Conserve energy.
  - Try to keep a regular daily routine that is reasonable, but don’t feel like you have to keep up with your normal activities.
  - Place and store objects nearby. Have equipment and supplies for each activity in one work area. Set up your work area like an assembly line.
  - Sit down when doing household and personal activities.
  - Alternate heavy tasks with lighter, easier tasks.
  - Use both hands as much as possible, using slow, rhythmic movements.
  - Do the most important things when your energy level is high.
  - Accept offers from friends and family to help.

MANAGE YOUR STRESS

Take time to put stresses in perspective and work to eliminate unhealthy or unnecessary stress in your life. Refer to the chapter, “Your Daily Life” for more information and for relaxation techniques.

STAY ACTIVE

Exercise increases appetite, promotes a feeling of self-worth, increases or maintains muscle strength, promotes relaxation and sleep, and improves heart and lung stamina. Regular light exercise such as walking can help relieve fatigue. Plan to get some form of exercise every day. Pace yourself, and choose something you like to do, whether it is walking, bicycling or swimming. Talk to your doctor about the type and amount of exercise you should do. Gentle exercise and relaxation classes are available.

Call your doctor or nurse if you:

- Have been too tired to get out of bed for the past 24 hours
- Feel confused or cannot think clearly
- Feel a loss of balance when walking, getting out of bed or out of a chair
- Notice the fatigue is getting worse

Low Blood Counts

Cancer and its treatment can sometimes affect the blood, causing low blood counts. Three important parts of the blood are red blood cells (RBCs), white blood cells (WBCs) and platelets. Red blood cells carry oxygen. White blood cells fight infection. Platelets clot the blood to prevent bleeding.

Your doctor will order a test called a Complete Blood Cell Count (CBC) to determine the levels of red blood cells, white blood cells and platelets in your blood. The CBC also measures the hemoglobin (HgB), the ability of your red blood cells to carry oxygen.

Normal values for a CBC:

WBC	4,500 to 11,000 (4.5-11)
RBC	4 to 5.2 M/UL
HgB	12 to 16 Gm/DL
Platelets	150,000 to 400,000 K/UL

ANEMIA

Anemia is a low red blood cell count, low level of hemoglobin and/or low level of iron. Hemoglobin is a protein in red blood cells that carries iron. When a person has anemia, blood cannot carry enough oxygen to meet the body's needs.

Causes of anemia:

- The cancer itself (such as, leukemia)
- Blood loss
- Chemotherapy or radiation therapy
- Kidney problems
- Nutritional problems

Common symptoms of anemia:

- Extreme weakness and tiredness
- Pale skin, pale lips
- Rapid heartbeat
- Pounding heartbeat

- Shortness of breath
- Dizziness or fainting
- Loss in concentration

Steps to manage anemia

Treatment for anemia depends upon the cause and can include medications and blood transfusions. The following are things you can do to help manage the symptoms of anemia:

- Get plenty of sleep.
- Exercise for a few short periods rather than one long period.
- Conserve energy. Rest before planned activities.
- Drink plenty of fluids.
- Eat foods high in iron, such as green leafy vegetables, red meats, nuts and beans, unless contraindicated.
- Stand up slowly to prevent dizziness.
- Ask family and friends for help with big tasks, such as grocery shopping and house cleaning.

Call your doctor or nurse if you have:

- Shortness of breath
- Dizziness or fainting
- Rapid or irregular heartbeat

NEUTROPENIA

Neutrophils are a type of white blood cell that play an important role in fighting infection. *Neutropenia* is when the neutrophil blood level is less than 1,000. People with neutropenia have a high risk of getting an infection, so it is very important to protect yourself against infection. If you believe you might be getting an infection, you need to call your doctor.

Causes of neutropenia:

- The cancer itself (such as, leukemia)
- Chemotherapy
- Radiation therapy
- Certain medications
- Immune system problems

Common symptoms of infection:

- Temperature of 100.5 F (by mouth) or higher
- Chills, sweating, muscle aches, extreme fatigue
- Redness, swelling, pus, tenderness or drainage anywhere
- Cough, runny nose, yellow or green phlegm, shortness of breath
- Mouth sores, white patches in your mouth or throat
- Pain at the site of your IV catheter or tunneled catheter (such as, Groshong catheter)
- Diarrhea, abdominal pain
- Burning when you urinate, feeling the need to urinate often, change in color or smell of urine

Steps to help prevent infection:

Hand washing is the most important way to stop the spread of infection. Keep antibacterial wipes in your car, purse or pocket when you do not have soap or water. Encourage your friends and family to wash their hands often.

- **Wash your hands:**
  - Before eating, drinking and taking medicine
  - After using the bathroom
  - Before touching food
  - After shaking hands
  - After contact with pets

  To wash your hands correctly:
  - Wet your hands under a stream of water.
  - Use liquid antibacterial soap and scrub for at least 15-30 seconds.
  - Scrub under your nails at least daily.
  - Rinse well under a stream of warm water.
  - Use a paper towel to turn off the faucet.
  - Dry your hands thoroughly.

- **Visitors and crowds:**
  - You can have visitors, but stay away from people who are coughing, sneezing, sniffling and those who have a cold, flu or other contagious diseases.
  - Avoid contact with people who have recently had live vaccines, such as the intranasal flu vaccine and the chicken pox vaccine. Contact your oncologist for questions about the length of time to avoid exposure and any other questions you may have.
  - Avoid crowds. If you have to be in a crowd, you should wear a mask because you do not know who may have an infection. You don't need to wear a mask if you go outdoors, as long as there is not a crowd.

- **Pets:**
  - Pets can be an important part of your life, so contact with your pet is encouraged. However, to help prevent infection:
    - Do not clean cat litter boxes, bird cages, aquariums, and reptile and amphibian cages.
    - Wash your hands after contact with your pet.

- **Hygiene:**
  - Take a shower or bath every day. Use a mild, nondrying soap. Use lotion. Avoid products that contain alcohol or perfume.
  - Use a soft-bristled toothbrush and brush after meals and at bedtime.
  - Always wipe front to back when going to the bathroom.
  - Avoid nail salons, and do not use artificial nails.
  - If you have a catheter, such as a PICC line or Groshong catheter, strictly follow the instructions for care to help prevent an infection.

- **Food and food preparation**
  - Do not eat raw meat, poultry, seafood or raw eggs.
  - Avoid foods or dietary supplements that contain probiotics – these are live bacteria.
  - Drink eight to 10 glasses of water a day, unless you are told otherwise.
  - Wash hands and counters before preparing food.
  - Do not eat from other people's plates or drink from their glasses.

- Encourage your family and friends to get flu shots, however, avoid contact with people who have recently had the intranasal flu vaccine, because it is a live virus. **Contact your oncologist for questions about the length of time to avoid exposure and any other questions you may have.**
- **Talk with your oncologist before having the flu shot or any other immunization.**
- **Check with your doctor before having any dental work done, including cleanings.**

If you are in the hospital and are neutropenic:

- You will be in a private room. The door must be kept shut.
- If you leave the room, you must wear a mask.
- Staff and visitors do not need to wear a mask.
- You may have visitors. However, they should not visit if they have a fever, cough, runny nose, sore throat, any other infection or recent exposure to someone with a contagious illness.
- Tell friends and family not to send fresh flowers, dried flowers or plants.

Call your doctor or nurse at once if you have:

- A fever of 100.5 F (by mouth) or any other symptom of infection.
- A fever in someone with neutropenia can be serious. Notify your doctor immediately.

If your doctor tells you to go to the Emergency Department:

As soon as you arrive, tell the Emergency Room nurse and doctor...

- That you have neutropenia and a fever
- The highest temperature you have had and the time it happened
- Any symptoms you have (cough, sore throat, chills)
- Your oncologist's name and phone number
- Type of cancer or blood problem you have
- Date of last chemotherapy
- Medications you are taking (name, dose, schedule)
- If you have a catheter or port

You can expect that the Emergency Room staff may...

- Take your temperature, blood pressure, pulse and breathing rate
- Check you for signs and symptoms of infection
- Draw blood
- Take a urine specimen
- Order a chest X-ray
- Start antibiotics if they suspect that you have an infection

THROMBOCYTOPENIA

Thrombocytopenia means a low platelet count, which can cause an increased risk for bleeding. A normal platelet count is 150,000 to 400,000. If your platelets are less than 100,000, you are at a higher risk for bleeding. If your platelets are less than 50,000, you should follow the instructions below to help prevent bleeding. For very low platelet counts or if bleeding occurs, a platelet transfusion may be ordered by your oncologist.

Causes of thrombocytopenia:

- The cancer itself (such as, leukemia)
- Chemotherapy
- Radiation therapy
- Certain medications
- Immune system problems (such as, Immune Thrombocytopenia Purpura)

Symptoms of bleeding:

- Blurred vision, headaches, confusion
- Uncontrolled nosebleed
- Easy bruising or tiny red spots on the skin
- Blood in your urine
- Belly pain or blood in the stool – blood can make the stool look red or black
- Coughing up blood
- Menstrual period longer than eight days or heavy bleeding during your period

Steps to prevent bleeding:

- Ask your doctor before taking any medicine, herbs or dietary supplements. Some medicines, like aspirin, can make you bleed more easily.
- Hygiene:
  - Use lotion to prevent dry skin and cracking.
  - Use a water-based lip moisturizing lip balm on your lips to prevent cracking.
  - Use an electric razor.
  - File your nails, don't cut or bite them. Do not cut cuticles.
  - Use a soft-bristled toothbrush.
  - Use sanitary napkins – no tampons or douches.
  - Use water-soluble lubricant during intercourse to reduce friction.
- Talk to your oncologist before having any dental work, even cleaning.
- Prevent falls or bumps to the head:
  - Avoid contact sports
  - If you feel lightheaded or have been lying down for a long time, sit at the side of the bed first before slowly getting up.
  - Remove throw rugs, keep sidewalks and driveways free from ice and snow.
- Apply pressure to cuts for at least five minutes.
- Drink eight to 10 glasses of water each day. This helps to prevent constipation and straining.
- Avoid enemas, suppositories and rectal thermometers.
- If you are nauseated, take your anti-nausea medicine as prescribed. This will prevent "dry heaves," which can cause bleeding.

Call your doctor or nurse if you have:

- Blurred vision, headaches, confusion
- Uncontrolled nosebleed
- Easy bruising or tiny red spots on the skin
- Blood in your urine
- Belly pain or blood in the stool – blood can make the stool look red or black
- Coughing up blood
- Menstrual period longer than eight days or heavy bleeding during your period

Mouth Sores

Medications, some cancer treatments and infections can all cause a sore mouth and sore throat. Cancer and its treatment can sometimes cause mouth sores. Good mouth care can help prevent problems and can reduce the severity of the mouth sores.

Causes of mouth sores:

- Certain chemotherapy medications
- Radiation therapy to the mouth and neck
- Certain medications
- Infections
- Mouth and throat cancer

Steps for good mouth care:

- Rinse your mouth with salt water after meals and at bedtime. If you are in the hospital, the nurses will give you salt water. To make the salt water at home, mix one teaspoon of salt with one quart of water.
- Use a soft-bristled toothbrush. Brush all tooth surfaces two times a day for at least 90 seconds.
- Store your toothbrush upright. Do not place it in a sealed container. Rinse after each use. Buy a new toothbrush every two to three months.
- Do not use commercial mouthwash that contains alcohol – this can sting and dry out your mouth.
- If you wear dentures, remove them at night. Clean them thoroughly. If you develop mouth sores, leave your dentures out as much as possible.
- Use a water-based lip moisturizing lip balm to moisten your lips.
- Do not smoke or drink alcohol. Both may irritate the mouth.
- If you are on chemotherapy, tell your dentist.
- Drink plenty of water and other fluids.

Steps to care for mouth sores or a sore throat:

- If your mouth is sore, rinse your mouth every two hours while awake with salt water.
- If your mouth is too sore to use a toothbrush, use a sponge swab (toothette) that is made for this purpose. The swabs are available in the hospital, or if you are at home, from a pharmacy. Dip the sponge swab in the salt water and brush the surfaces of your teeth, tongue and cheeks. Use a new swab each time you dip into the salt water.
- Notify your doctor if you have pain or discomfort. He/she may prescribe a medication to manage the pain while your mouth heals. Take this medication before meals to help you eat better. Your doctor may also check your mouth for infection and order medication to fight the infection, if needed.
- Avoid salty and spicy foods. Avoid high acid foods (such as oranges, grapefruit, tomato juice).
- Soft, bland foods may be easier to eat.
- Chilled or room-temperature foods are sometimes easier to eat.
- Moisten foods by dunking them in milk or broth. Use gravy.
- Avoid hard, harsh foods like pretzels and potato chips.
- If you have a dry mouth, you may want to use a product like Biotene®, which helps decrease the dryness. After using Biotene®, wait at least 30 minutes before using any other mouth-care products or eating or drinking.
- Drink plenty of fluids, at least eight 8-ounce glasses a day. Using a straw can make swallowing easier.

Call your doctor or nurse if:

- Your mouth does not heal.
- You have a temperature of 100.5 F (by mouth) or more.
- You have white patches in your mouth.
- You have difficulty eating or drinking.
- Any other questions or concerns you may have.

Nausea and Vomiting

Nausea and vomiting can be a very uncomfortable and distressing side effect of cancer and its treatment. However, there are many things you can do to prevent and control nausea and vomiting.

Causes of nausea and vomiting:

- The cancer itself
- Chemotherapy
- Radiation therapy
- Surgery
- Pain
- Pain medications
- Constipation
- High blood calcium levels

Steps to help prevent and control nausea and vomiting:

Antiemetics are medicines used to prevent and control nausea and vomiting. Most work best when used at the first sign of an upset or queasy stomach. *Aprepitant* only works to prevent nausea and vomiting and is not effective if you already have nausea.

Anti-nausea medication	**Common side effects**
Aprepitant (Emend®)	Drowsiness, hiccups, constipation, diarrhea
Dexamethasone (Decadron®)	Increase in blood sugar while taking this medication, restlessness
Lorazepam (Ativan®)	Drowsiness
Metoclopramide (Reglan®)	Drowsiness, diarrhea
Ondansetron (Zofran®)	Headache, constipation
Prochlorperazine (Compazine®)	Drowsiness

Eating hints:

- Drink clear, cool liquids, such as ginger ale, weak iced tea, colas and apple juice.
- Dry food, such as toast and crackers, can help ease an upset stomach. If you have nausea in the morning, eat crackers before you get up.
- Cool foods or foods served at room temperature are sometimes helpful. These include sandwiches, popsicles and Jell-O.
- Sour foods, such as lemon drops or sour candy, can help disguise any bad tastes in your mouth.
- Drink liquids one hour before or one hour after meals. If you are not able to eat solid foods, drink plenty of liquids.
- Eat lightly on the day of your chemotherapy.
- Try different eating patterns. Eat smaller, more frequent meals. Try six meals a day instead of three big meals.
- Eat whatever tastes good to you.
- Relax before meals. Play soft music. Dim the lights.
- Try to stay out of the kitchen while food is cooking; aromas from foods can cause nausea.
- Take a walk outside; open a window for fresh air.
- On a day when you are feeling well, cook several small meals that can be frozen.

Call your doctor or nurse if:

- Nausea/vomiting lasts longer than 12 hours.
- You have belly pain and cramping or blood in the vomited material.
- You cannot take your medicines.
- Nausea medications are not working.

Pain

Cancer and its treatment can sometimes cause pain, which is an uncomfortable feeling that tells your body that something is wrong. In most cases, the pain goes away when the injury is gone. This type of pain is called **acute pain**. Sometimes pain signals in the nervous system keep firing for weeks, months and even years. This type of pain is called **chronic pain**.

Causes of pain:

- The cancer itself
- Side effects of chemotherapy
- Side effects of radiation
- Surgery
- Procedures

HOW PAIN CAN AFFECT YOUR LIFE

Pain can affect you in many ways. Sometimes, it can prevent sleep, limit your normal daily activities and cause you to lose your appetite. These changes can affect your emotions and your social relationships. Some people feel stressed, depressed and isolated. It can affect your ability to work and to care for yourself and your family.

YOUR RIGHTS AND RESPONSIBILITIES

You have the right to treatment of pain during all aspects of your care. Pain should be managed to a level that is acceptable to you. The hospital is committed to working with you and your family to manage your pain.

Patient Rights

As a patient in this hospital, you can expect...

- information about pain and pain relief measures,
- concerned staff committed to pain prevention and management,
- healthcare professionals who respond quickly to your reports of pain, and
- your reports of pain will be believed.

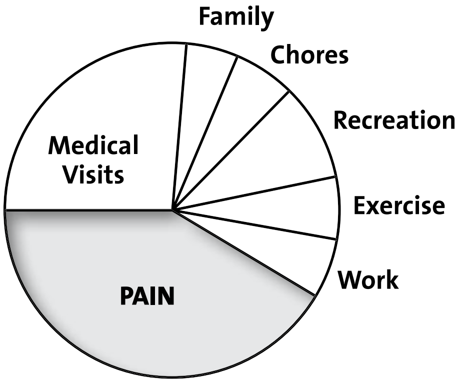
Patient Responsibilities

As a patient in this hospital, we expect that you will...

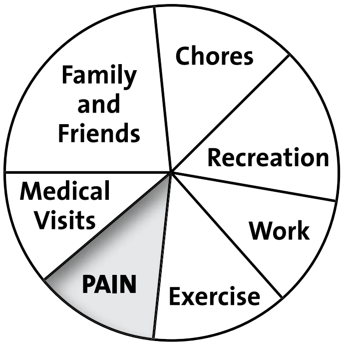
- ask your doctor or nurse about what to expect regarding pain and pain management,
- discuss pain relief options with your doctor or nurse,
- work with your doctor or nurse to develop a pain management plan,
- ask for pain relief when pain first begins,
- help your doctor or nurse assess your pain,
- tell your doctor or nurse if your pain is not relieved, and
- tell your doctor or nurse about any worries that you may have about taking pain medication.

MANAGING PAIN

Controlling your pain is often hard, but it is important to live your life to the fullest. The goal is for you to control the pain, not for the pain to control you.



Pain in Control of You



You in Control of Pain

WAYS TO CONTROL PAIN

There are different ways to control pain, including the psychological and physical aspects of pain. Examples of ways to help control your pain are listed on the following pages. Because this information is general, you may want to refer to resources specific to your type of pain (that is, headache, arthritis, cancer pain). Your healthcare team will work with you to help develop an individualized plan.

Pain medications

Pain medications work differently for different people and for different types of pain. Sometimes pain medications are given on a routine schedule, or they are given only when needed. If pain medication is the best treatment for you, your healthcare team will work with you to help you get the best pain relief. You can help by telling them about:

- Pain medications you have used in the past and if they worked
- Allergies, including allergies to medications
- Medications and other treatments you are taking, including health foods, herbs and vitamins
- Your fears and concerns about pain medications or other treatments for pain

Types of medications:

- **Non-narcotics:** acetaminophen (Tylenol®), aspirin and non-steroidal anti-inflammatory drugs (for instance, Motrin®, Advil®) are useful for many types of pain. Many can be purchased without a prescription. Although they may not require a prescription, it is still important to follow the recommended dose and schedule for the drug in order to control your pain and to avoid side effects.
- **Opioids (sometimes called narcotics):** morphine, hydromorphone (Dilaudid®), methadone and oxycodone are useful for moderate to severe pain. A prescription is needed for opioids. Side effects from opioids can include constipation, nausea, sleepiness and closed breathing. If opioids are appropriate for you, the healthcare team will work with you to help prevent or manage these side effects.
- **Antidepressants** are sometimes helpful for burning and tingling pain. A prescription is needed.
- **Muscle relaxants** (for instance, Valium®) are helpful for muscle pain and also help decrease anxiety.

Non-drug treatments:

- **Acupuncture and acupressure:** These therapies involve the application of pressure to specific pressure points in your body, blocking pain impulses.
- **Biofeedback:** Some people can learn to control blood pressure, pulse and muscle tension through biofeedback exercises.
- **Relaxation and meditation:** These therapies can help relax tense muscles, decrease anxiety and distract thoughts from pain. Tension, anxiety and fear can contribute to pain, therefore, decreasing these can help decrease pain.
- **Counseling:** Some patients may benefit from individual or group counseling. With counseling, the healthcare professional teaches coping skills and provides support for the person with chronic pain.

Controlling your life and your pain:

- **Take an active role in your pain control.** Get involved. Talk to your healthcare team. Talk to others with chronic pain. Read about chronic pain management.
- **Maintain relationships, social contacts and open communication.** Friends and family are vital in combating stress and depression. The person with pain may feel like a burden and avoid friends and family.
- **Be aware of your emotions.** Depression is common. These feelings are normal and can make pain seem even worse. Dealing with depression is important to decreasing your physical pain and improving your quality of life.
- **You are not alone.** Millions of people experience pain. By talking with others, you can learn new ways to help yourself and can also help others.

Peripheral Neuropathy

Peripheral neuropathy is nerve changes that can cause numbness, tingling and other sensations. Peripheral nerves are those located outside the brain and spinal cord. Peripheral neuropathy most often affects the fingers, hands, arms, toes, feet and legs.

Causes of peripheral neuropathy:

- Certain chemotherapy medications, such as Paclitaxel and Vincristine
- Diabetes
- Tumor pushing on a nerve

Symptoms of peripheral neuropathy can include:

- Numbness and/or tingling in your hands and feet
- Not being able to move your fingers easily, for example, to button shirts or tie shoes
- Changes in your ability to walk. You may have trouble picking up your feet.
- Loss of balance, muscle strength and coordination
- Muscle cramps, heaviness or weakness in arms, legs or both

Steps to manage peripheral neuropathy:

- Ask your doctor if any of your medications cause peripheral neuropathy.
- Ask your doctor if it is safe to drive based on your specific symptoms.
- Avoid exposing fingers and toes to very hot or very cold temperatures.
- Take lukewarm baths.
- Do not use heating pads.
- Wear sturdy shoes or slippers with rubber soles that fit well.
- Avoid shoes that are floppy and loose or too tight. Do not go barefoot.
- Wear gloves when doing work with your hands, such as washing dishes or gardening.
- Wear warm boots and gloves in cold weather.
- Use potholders in the kitchen.
- Remove throw rugs or other objects in your home that might cause you to trip.
- Use handrails when going up or down stairs.
- Use bath mats in the tub or shower.
- Use a walker or cane if you are unsteady on your feet.
- Purchase special equipment to help you dress.
- Wear clothes with zippers or pull-ons rather than buttons.

Sexuality and Reproductive Changes

The diagnosis of cancer and its treatment can cause sexual and reproductive changes. Sexuality is a very important part of everyday life for most people. It has a profound effect on how you feel about yourself, as well as your enthusiasm for life. Warm, loving sexual relationships are always encouraged.

Causes of changes in sexuality and reproductive issues:

- Changes in body image and self-esteem from the disease and treatment can affect how people feel about their sexuality. Hair loss, surgery and weight loss are all things that can affect how a person feels about themselves.
- Fatigue
- Anxiety
- Depression
- Pain
- Direct effect of the treatment and/or cancer on hormone levels
- Direct effect of the treatment and/or cancer on fertility

Common problems (depending on your disease and treatment):

- Decreased desire for sexual relations
- Decreased ability for sexual relations
- Uncomfortable or painful sexual relations
- Temporary or permanent infertility from certain types of chemotherapy and radiation therapy

Steps to manage changes in sexuality and reproduction:

- Talk to your healthcare professional about possible changes that may occur from the cancer or its treatment.
- Explain any problems you may be having and ask for suggestions for help.
- Ask for a recommendation for a counselor, if necessary.
- If appropriate for your age and situation, discuss with your physician the possible impact of cancer and its treatment on fertility. Ask for possible options for fertility, such as sperm banking.
- Always notify your physician if you think you may be pregnant. Many cancer treatments are harmful for the fetus and could cause miscarriage or birth defects.

- If appropriate for your situation, discuss appropriate birth-control options with your doctor. Birth control is recommended while receiving many cancer treatments and for at least two years after treatment is completed.

SURVIVORSHIP »»

THIS SECTION INCLUDES:

Cancer Survivorship

Survivorship Resources

From my perspective | Kelly, Patient

"Something that is really important to me, is I continue to reach out and to help other people who are diagnosed with cancer.... when you've made it out on the other side, that you give back. You pay it forward."

MY SURVIVORSHIP

Cancer Survivorship

Cancer survivorship covers the physical, psychological and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get healthcare and follow-up treatment, late effects of treatment, second cancers and quality of life. Family members, friends and caregivers are also part of the survivorship experience.

Survivorship Resources

CONNECT IN PERSON

To get connected with an OhioHealth cancer expert to talk about your cancer diagnosis, treatment or survivorship, please call OhioHealth's CancerCall at 614-566-4321 or toll-free at 1-800-752-9119. We are available Monday through Friday, 8 a.m. to 5 p.m.

CONNECT ONLINE

To learn more about OhioHealth's capabilities and approach to fighting cancer, you, your friends or family members can visit us online at OhioHealthCancerCare.com.

OHIOHEALTH PATIENT BILL OF RIGHTS

THIS SECTION INCLUDES:

Statement of Patient Rights and Responsibilities

Rights of Patients

Responsibilities of Patients

From my perspective | Eileen Troutman, RN

"I am a Cancer Connections Nurse and I provide, with part of a team of people, what cancer patients need as they go through that cancer experience. Whether that's financial assistance, whether that's social work assistance, whether that's 'I don't know who else to call, I am calling you' assistance."

OHIOHEALTH PATIENT BILL OF RIGHTS

Statement of Patient Rights and Responsibilities

"We honor the dignity and worth of each individual."

To support this value and our commitment to our patients, their families and the community, we have a Statement of Patient Rights and Responsibilities. This statement is designed to inform you about what you can expect and ask for as a patient at any of the OhioHealth family of hospitals.

Rights of Patients

Patients have the right to competent, respectful and hospitable care, and for physicians and staff to strive to make their hospitalization as comfortable as possible.

Patients have the right to receive complete information from their physician regarding their diagnosis, treatment and prognosis. This includes the right to informed consent when surgical or other significantly invasive procedures are involved.

Patients have the right to expect medical records of their care to be treated confidentially as outlined in the hospital's confidentiality policies. Also, patients have the right to expect their right to visual, auditory and personal privacy and to keep information pertaining to their care confidential.

Patients have the right to actively participate in decision-making regarding their care through direct discussion with their physicians and nursing and other staff, and to review their medical records except when restricted by law.

Patients have the right to examine a copy of and request assistance in understanding their hospital bill and to know that charges will reflect only the care received by the patient.

Patients have the right to know by name and position the person caring for them, and to ask if the hospital or caregivers have relationships with outside parties that may influence their care.

Patients have the right to be informed about any experimental, research or educational activities that are involved in their treatment and the right to refuse to participate in any such activity.

Patients have the right to know that a policy and procedure exists in addressing the procurement and donation of organs to local agencies.

Patients or their surrogates have the right to request limitation or withdrawal of life-sustaining treatment in accordance with legal, clinical and ethical guidelines.

Patients have the right to know that the hospital has a policy in place to control any potential conflicts of interest and to establish guidelines for ethical behavior.

Patients have the right to execute Advance Directives (Living Wills, Healthcare Power of Attorney documents) in compliance with the Ohio law and to designate a surrogate decision-maker to act on their behalf.

Patients have the right to have their individual social, psychosocial, cultural and emotional needs respected and preserved while undergoing treatment. This hospital further recognizes the importance of these issues in the care of dying patients and their significant others.

Non English-speaking, blind and deaf patients have the right to request interpretation. The hospital will make every reasonable effort to provide this assistance.

Patients, families and visitors have the right to file a formal grievance through the Patient Relations Department regarding aspects of their care, and to expect a response from the hospital. If conflicts arise regarding the course of treatment, the patient has the right to contract the Bio-Ethics Committee for assistance.

Patients have the right to expect their standard of care to be consistent and their access to care to be unaffected by their ability to pay. This includes the right to an appropriate contiuum of care within an integrated system of different settings, services and care levels.

Patients have the right to request a copy of the Patients' Rights and Responsibilities Policy by contacting the Patient Relations Department, and to request a Patient Relations coordinator's assistance if they feel these rights are not being maintained.

Responsibilities of Patients

Patients have the responsibility to fully answer questions from physicians and staff regarding past illnesses, hospitalizations, medications and other matters pertaining to their health.

Patients have the responsibility to collaborate with physicians and staff in their diagnosis and treatment.

Patients have the responsibility to be considerate of other patients by following the hospital's policies regarding smoking, visiting and telephones and other policies addressed in the Patient Guide.

Patients have the responsibility to provide all needed information for insurance processing and for assuring that the financial obligations of their healthcare are fulfilled.

These responsibilities apply to family members, significant others, and/or surrogate decision-makers when they are acting on behalf of the patient.

MY PERSPECTIVE

THIS SECTION INCLUDES:

My Perspective Notes Pages

From my perspective* | *Mark, Patient

"The exposure this has given me to other cancer survivors has helped enormously. Part of the healing process is sharing what you've gone through and hearing the same from others."

MY PERSPECTIVE

MY JOURNAL NOTES PAGES