



**Avera**   
Cancer Institute

**A GUIDE FOR CAREGIVERS**

# WELCOME TO THE TEAM



As the loved one of a patient at the Avera Cancer Institute, we are glad you're here. Our team of physicians, health care providers and staff consider you an important part of the care team. We want to ensure you and your loved one feel heard and all of your questions are answered. As a caregiver, you will wear many hats at different times over the course of care. It is important you have tools for success.

Cancer care is complex. You and your loved one will receive a lot of information throughout this journey. We created this guide for you as a central source of information. We cover a variety of topics including care team roles, when to call the clinic, and caring for yourself. There are also useful worksheets at the end to help keep you organized. We are here to make sure you have the support you need.

You are a key partner in caring for your loved one.  
Thank you for taking on this role.

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# IMPORTANT PHONE NUMBERS

Care Team	Name	Phone Numbers	Additional Notes
Avera Cancer Institute Navigation Center		888-422-1410 or 605-322-3211	available 24/7
Surgeon			
Medical Oncologist/ Hematologist			
Radiation Oncologist			
Social Worker			
Navigator			
Patient Advocate			
Dietitian			
Chaplain			
Transplant Coordinator			
Research Coordinator			
Emergency		911	

# CARE TEAM MEMBERS AND RELATED SERVICES



## **SOCIAL WORKER**

A cancer diagnosis can bring up emotions and issues for patients and their loved ones. Social workers can assist you with a wide range of needs that may arise.

These may include:

- Helping you find a place to stay or a way to get to appointments
- Counseling for you related to your loved one's cancer diagnosis
- Connecting you to additional support and community resources
- Assisting with advance care planning, including filling out a living will and/or durable power of attorney for health care
- Facilitating family meetings and other difficult conversations

## **PATIENT ADVOCATE**

Patient advocates can help you explore your financial options. The cost of cancer care can be a top worry for patients and their loved ones. Patient advocates will answer your questions and provide guidance on:

- Insurance coverage and benefits
- Billing issues
- Work-related needs such as Family and Medical Leave (FMLA) paperwork
- Financial assistance

## **DIETITIAN**

Nutrition is an important part of cancer care. Side effects from treatment can often make it hard to eat. A dietitian is available to answer your questions about how to:

- Make food choices to better manage how you feel
- Help the body's ability to withstand side effects
- Improve health during and after treatment
- Speed up recovery through nutrition

## **CHAPLAIN**

Your spiritual health is important to us. It is also a vital role in your well-being. We have chaplains who can offer you spiritual and emotional support. Our chaplains will always respect your individual beliefs, traditions and culture. Chaplains can help with feelings of fear, anger and doubts about God and faith.

## OUTPATIENT THERAPIST

You or your loved one may face emotional distress after getting a cancer diagnosis. This can affect your ability to do daily activities, make decisions and keep up relationships. Our outpatient therapists can help teach you ways to manage:

- Anxiety
- Grief
- Relationship issues
- Other common concerns

You can schedule a visit by calling 605-322-3241.

## INTEGRATIVE MEDICINE TEAM

Wellness and self-care are important pieces of your health. Free services for caregivers include:

- Mind-body classes
- Aromatherapy
- Arts in Healing

Integrative services for a fee are also available and include:

- Mental health counseling
- Acupuncture
- Therapeutic massage

Ask the care team if these or other similar services are available in your area.

## PALLIATIVE MEDICINE CARE TEAM

Palliative medicine team members help manage pain and symptoms.

The palliative care team will help patients and their loved ones at any stage of illness along with the cancer care team. They provide relief from physical, emotional and spiritual distress. Ask the care team if this service is available in your location.

## GENETIC COUNSELORS

Genetic counselors are trained in medical genetics and counseling. They help patients understand and manage inherited health risks. Most adult cancers happen at random and are not related to a patient's family health history. A small number of families have an inherited risk that makes them more likely to develop certain cancers. Genetic counselors can help families know their family history and support feelings about inherited cancer risk.

## RESEARCH TEAM

A clinical trial is a controlled study to answer a scientific question.

Cancer clinical trials are done to test new treatments, which can involve:

- Chemotherapy
- Cellular therapy
- Radiation therapy
- Surgery
- A combination of treatments

Clinical trials help doctors learn if new treatments are safe and effective. Some studies look at the emotional impact of cancer, symptom control and ways to improve the quality of life in people with cancer. Your loved one's care team will discuss whether a clinical trial would be a good option for their type of cancer.

## TRANSPLANT AND CELLULAR THERAPY TEAM

Transplant and cellular therapies can be used with other treatment plans. These therapies can give certain cancers and blood disorders a longer remission length or a potential cure.

- A transplant uses stem cells found in the bone marrow. The stem cells will reboot or replace the bone marrow function after strong chemotherapy.
- Cellular therapy reworks part of the immune system to recognize and attack cancer cells.

Your loved one's provider will guide you through the different stages of transplant or cellular therapy if it is the best option for treatment.

## NAVIGATION TEAM

Avera Cancer Institute Navigation Center is a free 24-hour service for anyone impacted by cancer. It is an education and support hub with registered nurses and social workers who assist patients and loved ones. They can support you by providing resources and education. The navigators work with your cancer care team and you can call them anytime. This is a new journey for you — they are here to help you navigate it.

You can speak with a navigator by calling 888-422-1410.

# TYPES OF CAREGIVING

*Excerpts provided by American Society of Clinical Oncology*



Helping your loved one keep a sense of independence is important while realizing that their needs may change over time. Try to be flexible with them. Let them communicate to you what they need. It's common that individuals with cancer feel a loss of control. Allowing your loved one to lead the way on what help they need gives them a sense of control. It is important for the person with cancer to feel like an active member of their own care team. As a general rule, there are two types of caregivers.

## **CLOSE-PROXIMITY CAREGIVERS**

This is someone that lives with or near the individual with cancer. Usually, this is a spouse or significant other, but it may be a nearby friend or neighbor. Each person of the caregiving team has different skills and these strengths combine to provide effective care.

### **Tasks may include:**

- Going to appointments;
- Keeping notes about symptoms and side effects to report back to the health care team; and
- Helping keep track of medications and when to give them.

## **6 HELPFUL TIPS**

1. Keep a journal of symptoms and side effects to report at the next appointment. (See page 22.)
2. Make a list of questions before an appointment by sitting down with your loved one. These questions should reflect the doubts, concerns and issues of all family members. At the beginning of the appointment, make sure to tell the doctor that you would like to have time to ask questions.
3. Keep a notepad handy to jot down questions as they come up.
4. Identify a system that works for you and your loved one to ensure medication is taken on time.
5. Find emotional support. Many caregivers may feel overwhelmed by the challenges of coordinating care for a loved one. Seek out support for yourself from family, friends or a counselor to help deal with stress and emotional struggles. The Avera Cancer Institute has a counselor available to you. For more information, call the Navigation Center at 605-322-3211.

## LONG-DISTANCE CAREGIVER

Sometimes a family member or friend who does not live near the person with cancer becomes the primary caregiver. A long-distance caregiver often does many of the same tasks as a caregiver who lives nearby, but coordinates tasks and services by phone, text or email.

### Tasks may include:

- Identifying needs and creating a caregiving team;
- Providing support to your loved one; and
- Updating important individuals in your loved one's life.

## 6 HELPFUL TIPS

1. Be a part of the health care team. Because you will not be able to go to every appointment or treatment session, make a point to introduce yourself to the health care team. Ask if you can join appointments via phone. Give them your phone number(s) and other contact information in case they need to reach you. Ensure your loved one gives permission to discuss their medical condition and treatments.
2. Recruit and organize local volunteers. Family, neighbors, friends and members of religious, civic and social organizations who live nearby may want to help with caregiving tasks.
3. Explore professional services. Contact the health care team, social worker, or state or local health department for referrals for reliable home care services.
4. Put an emergency plan in place. Make sure your loved one's phone has important numbers on speed dial, including 911; yourself; other family, friends and support people; health care providers; and neighbors.
5. Prepare for unplanned travel. Be prepared to travel if the person with cancer needs your help. Try setting aside vacation or sick days from work and study the travel options that will work for you on short notice.
6. Find emotional support. Many long-distance caregivers feel guilty about living far away from the person with cancer. Or, they may feel overwhelmed by the challenges of coordinating care from afar. Seek out support for yourself from family, friends or a counselor to help cope with stress and emotional struggles.

# Tips for Caregiving

1. Take care of yourself.
2. Remember that caregiving is a team effort involving a group of people.
3. Be proactive, organized and plan as much as possible.
4. Be a problem solver — identify problems, find out what is needed, and follow through.
5. Recognize your personal strengths and weaknesses.
6. Ask for help when you need it.
7. Communicate openly and honestly.
8. Talk about your concerns.
9. Seek out information and guidance.
10. Realize that you aren't expected to do it all yourself.

# TYPES OF TREATMENT

There are several types of treatment that your loved one's physician will consider. Their options depend on the diagnosis, cancer stage, their age, current health status and other needs. The main types of treatment include:

- Chemotherapy
- Surgery
- Radiation therapy
- Cellular therapy
- Hormone therapy

We encourage you to talk with the health care team about options.

## SURGERY

Surgery is often the first treatment choice for many cancers. If the cancer is contained to one area (localized), surgery may be used to remove it. Surrounding tissue and/or lymph nodes that might contain cancer cells may also be removed. Surgery has a better chance of success if the cancer has not spread to other areas of the body. Other treatments such as radiation and chemotherapy may be used before or after surgery.

## CHEMOTHERAPY

Chemotherapy uses drugs to destroy cancer cells. It works by stopping or slowing the cancer cell growth. Chemotherapy can also damage healthy cells, such as cells found in the mouth, stomach and intestines, while trying to stop the growth of cancer cells. Treatment schedules vary depending on the type of cancer. It is given at regular intervals, such as weekly or twice per month over several months.

Chemotherapy can be given in many ways:

- **Injection** – given as a shot in a muscle or directly under the skin
- **Intra-arterial** – given directly into the artery that is feeding the cancer
- **Intraperitoneal** – given directly into the peritoneal cavity, which is the area that contains organs such as intestines, stomach and liver
- **Intravenous** – given directly into a vein
- **Orally** – given as a tablet or liquid that is swallowed

## RADIATION THERAPY

Radiation therapy is a common treatment for cancer. It uses high-energy radiation to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body. It may also come from radioactive material, or seeds, placed in the body near cancer cells.

Radiation therapy may be used with the goal of curing your cancer or helping you feel better. It is common to combine radiation therapy with other treatments. The precise treatment will depend on the tumor type, location and stage, as well as the general health of the patient. There are four treatment types:

- **Curative** – A treatment used to make other treatments more effective;
- **Adjuvant** – A treatment used in addition to the main (primary) therapy;
- **Neoadjuvant** – A treatment used before the main (primary) therapy to make a tumor smaller; and
- **Therapeutic or palliative** – Treatment that is intended to relieve symptoms, but not cure disease.





### **HORMONE / ENDOCRINE THERAPY**

Hormone therapy may be used for certain types of cancer. The goal of this therapy is to slow or stop the growth of hormone-sensitive tumors by blocking the ability for the body to produce hormones or by interfering with effects of hormones on the breast cancer cells. Hormone therapy can be used in addition to other types of treatment.

### **IMMUNOTHERAPY / CELLULAR THERAPY / TRANSPLANT**

Various treatment types help the immune system fight cancer. These can use immune cells made within your body, or in a laboratory, and can be given as a shot or intravenous infusion. These types of treatment can either suppress or stimulate the immune response to help boost or change how the immune system works so it can find and attack the cancer cells.

# MEDICAL ATTENTION GUIDELINES

When you're not sure if you should call — please call us! The Navigation Center is available 24/7 to answer your questions. We don't expect you to know what is "normal." Here are some general guidelines to follow.



**Call within 24 hours** if your loved one is experiencing:

- Painful sores in the mouth that do not allow eating and drinking;
- Diarrhea or loose, watery stool (3 or 4 times above normal number) lasting 2 days or more;
- New onset of constipation that does not improve with usual laxative within 2 days;
- Redness or swelling at an IV site;
- Change in color of urine;
- A change in breathing;
- New skin rashes and/or itching; or
- If your loved one experiences decreased kidney function (less frequent urination), increase fluids to 3 to 4 quarts per day and report decreased urination to your health care provider.

**Call immediately** if your loved one is experiencing:

- Oral temperature of 100.4°F or shaking chills;
- New onset of burning, pain or blood when passing urine;
- Nose bleeds, bleeding gums, bloody or black stools, or new bruising;
- New or increased red spots on extremities or torso;
- New shortness of breath or pain with breathing;
- Persistent coughing or a cough that produces mucus;
- Vomiting that does not get better (always report vomiting of blood immediately);
- Pain, swelling or new redness anywhere; or
- Pounding feeling in the chest or extra beats, pain or heart symptoms.

**Go to the ER immediately** if your loved one is experiencing:

- Dizziness that does not go away;
- Loss of consciousness or seizure;
- Shortness of breath or difficulty breathing that does not go away, regardless of activity level;
- Severe pain, despite using prescribed pain medications or other interventions such as: Tylenol® (if appropriate), ice, heat, massage, lidocaine patch, etc.;
- Suicidal thoughts;
- Back pain with numbness or tingling down the legs or new inability to control bowel or bladder function;
- Severe nausea/vomiting in the last 24 hours despite using anti-nausea medicine;
- Nausea/vomiting associated with severe abdominal pain (concern for blockage);
- Sudden drooping on one side of the face, or one side of the body;
- Headaches with vision changes, or severe headache;
- Sudden confusion;
- Chest pain with shortness of breath;
- Sudden chest pain with jaw pain, left-sided weakness, etc.;
- Worsening swelling on one side of the body with pain or can't put pressure on extremity;
- New onset of coughing up blood;
- Poisoning or overdose of drugs or alcohol;
- Not able to get out of bed or chair due to extreme weakness;
- Severe allergic reaction with hives and shortness of breath; or
- Sudden loss of vision or speech or function of an extremity.

**24/7 AVERA CANCER INSTITUTE NAVIGATION CENTER 605-322-3211 or 888-422-1410**

# TAKING CARE OF YOURSELF

One of the most important — but often neglected — tasks for caregivers is caring for themselves. Many caregivers believe their personal needs aren't important right now and their time and energy is better spent helping their loved one. However, your physical, emotional and mental health is vital to the well-being of the person with cancer. To be a good caregiver, you need to take care of yourself so that you have the energy to care for your loved one.

## COPING WITH STRESS

*Excerpts provided by  
American Society of Clinical Oncology*

Caregiving is a stressful experience. At times, you may feel like everything is on your shoulders or that no matter what you do, it's not enough.

This may lead to:

- Feeling exhausted all of the time;
- Getting sick more often than usual;
- Not sleeping enough;
- Feeling impatient, irritated or forgetful;
- Not enjoying things you used to like; or
- Withdrawing from people.



Recognizing signs of overload is important. There are many things you can do to make the situation better. The My Stress Management Plan worksheet at the end of this guide can help you identify sources of stress and find ways to manage it. Here are some ideas to get you started.

**Set boundaries.** Setting limits helps you and the person for whom you care. It's important to save your energy for the things that are most important right now. It is also important to say "no" when someone asks you to do something you don't want to do or for which you don't have the energy — this includes saying no to the person with cancer when your energy bank is spent.

**Ask for help.** Make a list of people who the person with cancer trusts and can help with specific caregiving tasks. Family, friends, members of religious groups, and people in community groups often want to help but aren't sure how. Consider using one of the websites listed in the "Resource" section of this booklet to set up a caregiving group.

**Find support.** Feeling angry, guilty, alone, afraid and/or sad is common for caregivers. Talking with other people who are caring for a family member or friend with cancer can help you cope. Ask the social worker to connect you with local resources.

**Make time for yourself and other relationships.** Doing something you enjoy gives you a much-needed break. Spend time with other people who are important to you, even if in shorter periods than usual. Maintaining supportive relationships is important for your continued health and well-being.

**Keep yourself healthy.** Taking care of your body is important to make sure you are able to provide the best possible care. This means making time to exercise, eat healthy foods and stay hydrated. It also means keeping up-to-date on your health care appointments and routine screenings.

**Get enough sleep.** Caregivers often have trouble sleeping. You may be getting up during the night to help your loved one. You may be staying up late to get things done. Your thoughts and emotions may keep you awake. Feeling rested will help you stay at your best, so try to go to bed and get up at the same time every day. If you're struggling to fall or stay asleep, reach out to the social worker for ideas that may help.

**Be mindful of alcohol and other substances.** Some caregivers turn to alcohol and other substances to help deal with the stress, anxiety, fatigue, sleep problems and fear they are experiencing. The line between use and abuse is not always clear. In general, limit the number of alcoholic beverages you drink to one drink a day for women and two drinks a day for men.

Sources: American Society of Clinical Oncology. Caring for a Loved One With Cancer.  
[https://www.cancer.net/sites/cancer.net/files/asco\\_answers\\_guide\\_caregiving.pdf](https://www.cancer.net/sites/cancer.net/files/asco_answers_guide_caregiving.pdf).

## Additional Ideas to Help You Cope

- Making a list of priorities for each day that sets out realistic goals
- Listening to soothing or uplifting music
- Practicing relaxation techniques, such as meditation or prayer
  - Reach out to the social worker if you aren't sure where to start
- Going outside regularly for fresh air and sunlight
- Keeping a journal to write down your personal thoughts and experiences

# RESOURCES

## GENERAL CANCER RESOURCES

### **Avera Cancer Institute Navigation Center**

Avera.org/navigationcenter  
605-322-3211  
Navigation@avera.org

### **American Cancer Society**

cancer.org  
800-227-2345

### **American Society of Clinical Oncology (ASCO)**

cancer.net

### **National Cancer Institute (NCI)**

cancer.gov

### **Oncolink**

oncolink.org

## ORGANIZING A SUPPORT SYSTEM

### **Lots a Helping Hands**

lotsahelpinghands.com

### **Patient Partner Project**

thepatientpartnerproject.org

### **Caring Bridge**

caringbridge.org

### **Share the Care**

sharethecare.org

## TELEPHONE AND ONLINE SUPPORT

### **4th Angel Program**

4thangel.org

### **Cancer Hope Network**

cancerhopenetwork.org  
877-467-3638

### **Imerman Angels**

imermanangels.org  
877-274-5529

### **Cancer Support Community**

cancersupportcommunity.org

### **CancerCare Support Groups**

cancercaresupportgroups.org

### **Hope Has Arrived**

hopehasarrived.com

## FINANCIAL RESOURCES

### **Social Security Administration**

ssa.gov

### **CancerCare**

cancercaresupportgroups.org

### **PAN Foundation**

patientaccessnetwork.org

### **Patient Services, Inc.**

patientservicesinc.org

### **Needy Meds**

needymeds.com



# GLOSSARY

## GENERAL ONCOLOGY

**ADJUVANT THERAPY:** A treatment used in addition to the main (primary) therapy. An adjuvant agent can modify the effect of another therapy agent combining different forms of treatment to fight cancer. Radiation therapy often is used as an adjuvant to surgery.

**ADVANCE CARE PLANNING:** Talks between a patient, their family and care team to help prepare for current and future medical decisions. The decisions are based on a patient's personal goals, life values and preferences. These decisions can be recorded in advance directives.

**ADVANCE DIRECTIVES:** Legal documents that tell physicians and family what a person desires for future medical care if that person becomes unable to make decisions for themselves. These may include whether to start or stop life-sustaining treatments. Another type of advance directive lets you choose a person to make decisions for you if you are unable to do so for yourself. Examples include: durable power of attorney for health care (DPOA), medical orders for scope of treatment (MOST) or living will.

**ALOPECIA:** The loss of hair from the body and/or scalp.

**ANEMIA:** Low red blood cell count; symptoms include shortness of breath, lack of energy and fatigue.

**AROMATHERAPY:** A holistic treatment that uses natural plant extracts to promote health and well-being. Also called essential oil therapy. It is thought to work by stimulating smell receptors in the nose, which then send messages through the nervous system to the part of the brain that controls emotions.

**BENIGN:** This describes a tumor that is not cancer.

**BIOPSY:** The removal of a small piece of tissue for microscopic examination to determine if cancer cells are present.

**CANCER:** A general term for more than 100 diseases that have uncontrolled, abnormal growth of cells that can invade and destroy healthy tissues.

**CANCER SURVIVOR:** Anyone living with a history of cancer including newly diagnosed survivors as well as long-term survivors.

**CLINICAL TRIAL:** A planned cancer study to investigate the effects of a specific type or combination of treatments in a human population.

**COMPLEMENTARY THERAPY:** Also known as holistic or integrative medicine. Used to enhance or complement standard medical therapies. These can include dietary supplements, aromatherapy, massage or movement therapy, mindfulness and/or music, art, visual therapies or more.

**CYTOLOGY:** The study of cells under a microscope.

**GENES:** Contain information that is inherited from parent to child and from cell to cell.

**GRADE FOR CANCER:** The grade of a cancer is determined by what the cells look like under a microscope. A lower grade indicates a slower-growing cancer. A higher grade indicates a faster-growing one. The grading system that is usually used is Grade I, II and III.

- Grade I – Cancer cells most resemble normal cells and are not growing rapidly
- Grade II – Cancer cells which do not look like normal cells and grow faster than normal cells
- Grade III – Cancer cells which look abnormal and may grow or spread more aggressively

**HOSPICE:** A special type of care for patients who are in the final phase of illness and who are no longer receiving active treatment. This care may take place in a patient's home or a homelike facility.

**LYMPHEDEMA:** The swelling of a body part caused by a buildup of lymphatic fluid. Lymph nodes in the body help to clean lymphatic fluid. When lymph nodes are absent or damaged, fluid builds up under the skin causing the arm or leg to swell.

**METASTASES:** Cancer that has spread from one part of the body to another.

**NAVIGATOR:** A medical professional who helps patients navigate through their health care team. Navigators can offer resources and education throughout the course of a patient’s treatment. The navigator acts as a contact between the patient, family and all members of the care team, and assists with symptom management and drug education.

**PALLIATIVE TREATMENT:** Treatment that is intended to relieve symptoms, but not cure disease.

**PROSTHESIS:** An artificial replacement for a missing part of the body, such as a breast or limb.

**PSYCHOSOCIAL ASSESSMENT:** An evaluation of an individual’s mental health and social well-being.

**STAGE FOR CANCER:** Various types of staging systems are used to describe different types of cancer. Stage 0 to IV is a common method of staging:

- Stage 0 – Indicates the cancer is where it started (in situ) and has not spread
- Stage I – The cancer is small and has not spread anywhere else
- Stage II – The cancer has grown, but has not spread
- Stage III – The cancer is larger and may have spread to surrounding tissues and/or lymph nodes
- Stage IV – The cancer has spread from where it started to at least one other organ; also known as “secondary” or “metastatic” cancer

**STOMATITIS:** A sore on the inside of the gastrointestinal tract (e.g., the mouth, stomach and/or intestines).

**TNM STAGING SYSTEM:** In the TNM system, each cancer is assigned a letter or number to describe the tumor, node and metastases.

- T stands for the primary tumor.
- N stands for nodes. It tells whether the cancer has spread to the nearby lymph nodes.
- M stands for metastasis. It tells whether the cancer has spread to other distant parts of the body.

**TRANSPLANT:** A type of treatment that can be used for blood cancers like leukemia, lymphoma and other diseases. A bone marrow or stem cell transplant is a procedure that infuses healthy blood-forming stem cells to replace damaged or diseased bone marrow.

**TUMOR:** An abnormal growth of cells or tissues; tumors may be benign (non-cancerous) or malignant (cancerous).

## MEDICAL ONCOLOGY

**ABSOLUTE NEUTROPHIL COUNT (ANC):** A measure of the number of neutrophils in the blood. Neutrophils are a type of white blood cell that helps fight infections. The blood count may be used to check for infection, inflammation, leukemia and other conditions. The lower the ANC, the higher the risk is of getting an infection. Cancer treatment, such as chemotherapy, may reduce the ANC.

**ANTIEMETIC:** A medicine that prevents or controls nausea and vomiting.

**CELLULAR THERAPY:** Involves the transplantation of human cells to repair or replace weakened or damaged cells. Designed to improve the immune system and fight cancer.

**CHEMOTHERAPY:** Chemotherapy is the use of any drug to treat a disease. To most people, the word chemotherapy or chemo refers to drugs used for cancer treatment. Chemotherapy can be used to help cure or control the cancer or as palliation to ease symptoms caused by cancer.

**HEMATOCRIT (HCT):** The amount of whole blood that is made up of red blood cells. It depends on the number and size of red blood cells. This blood test is usually part of a complete blood count (CBC). It may be used to check for anemia, dehydration, malnutrition and leukemia.

**HEMOGLOBIN (HGB):** A protein inside red blood cells that carry oxygen from the lungs to organs and tissues and carries carbon dioxide back to the lungs. Checking the amount of hemoglobin in the blood is usually part of a complete blood cell (CBC) test.

**HORMONE/ENDOCRINE THERAPY:** The goal of this therapy is to slow or stop the growth of hormone-sensitive tumors by blocking the ability for the body to produce hormones or by interfering with effects of hormones on the breast cancer cells.

**IMMUNOTHERAPY:** Treatment that uses certain parts of the body’s immune system to help treat cancer. The idea is to boost the immune system to attack cancer cells.



**INFUSION:** The process of dripping fluids or medicines into the vein through an intravenous/plastic tube.

**NEOADJUVANT THERAPY:** The administration of therapeutic agents before the main treatment plan. The goal of the neoadjuvant treatment typically aims to reduce the size or extent of the cancer prior to surgery.

**PLATELET (PLT):** A blood test showing the platelet count in blood. Platelets are necessary for clotting. Platelet transfusions may be given to prevent or control bleeding.

**PORT-A-CATH OR POWER PORT:** An implantable device designed to permit repeated access to veins to deliver medications with easy access. Ports are surgically inserted beneath the skin and can be removed when no longer needed.

**WHITE BLOOD CELLS (WBC):** The blood cell that is made in the bone marrow and found in blood and lymph tissue. WBCs are part of the body's immune system that helps fight infection and other diseases. Checking the number of WBCs in the blood is part of a complete blood cell (CBC) test. It may be checked to look for infection, inflammation, allergies and leukemia.

## RADIATION ONCOLOGY

**BEAM OR PORT IMAGES:** Images of the position of the radiation beams used to treat cancer. They are used to verify the position of the beams and confirm that treatment is delivered to the right place.

**BOOST OR CONE DOWN:** An additional dose of radiation that is given after an initial course of radiation to enhance tumor control. A boost may be given to the tumor and areas to which the tumor may have spread.

**BRACHYTHERAPY:** A procedure that involves placing radioactive material inside the body or on the skin surface to treat cancer. Brachytherapy is sometimes called internal radiation or surface brachytherapy.

**CENTIGRAY (CGY):** The preferred measurement of the amount of radiation dose absorbed by the body.

**ELECTRON BEAM:** A stream of high-energy particles called electrons used to treat cancer.

**EXTERNAL RADIATION:** Radiation therapy that uses a machine located outside of the body to aim high-energy rays at cancer cells. Some diseases can be treated with external radiation that are not cancer.

**FRACTIONATION:** Dividing the total dose of radiation into smaller doses in order to reduce damage to healthy tissues. The dose given at each treatment is referred to as a fraction.

**GAMMA KNIFE OR STEREOTACTIC RADIOSURGERY:** A form of radiation used to treat brain disorders. The "blades" of the gamma "knife" are actually beams of highly focused gamma ray radiation.

**HIGH-DOSE RATE BRACHYTHERAPY (HDR):** A higher activity radioactive source that is used to directly treat in or near the tumor for added precision.

**IMAGE-GUIDED RADIATION THERAPY (IGRT):** A radiation treatment guided by imaging equipment, such as CT scan, ultrasound or X-rays, taken in the treatment room just before radiation is given.

**IMMOBILIZATION DEVICE:** Device used to help a patient remain in the same position during every treatment.

**INTENSITY-MODULATED RADIATION THERAPY (IMRT):** IMRT is a specialized form of external beam therapy that can help improve how the radiation is shaped to fit your tumor.

**INTRAOPERATIVE RADIATION THERAPY (IORT):** Radiation treatment that's administered during surgery and allows direct radiation to the tumor bed target area while sparing normal surrounding tissue.

**LINEAR ACCELERATOR OR LINAC:** The most common type of machine used to deliver external radiation therapy.

**PHOTON BEAM THERAPY:** A type of radiation therapy that uses X-rays that come from a special machine called a linear accelerator (linac). The radiation dose is delivered at the surface of the body and goes into the tumor and through the body. Photon beam radiation therapy is different from proton beam therapy.

**RADIATION THERAPY OR RADIOTHERAPY:**

Energy carried by waves or a stream of particles. Types of radiation used to treat cancer include X-ray, electron beam, proton, alpha and beta particle, and gamma ray. Radioactive substances include forms of cobalt, radium, iridium, cesium, iodine, strontium, samarium, phosphorus and palladium.

**SIMULATION (SIM):** Process of planning radiation therapy to allow radiation to be delivered to the intended location.

**STEREOTACTIC RADIOTHERAPY:** One or multiple treatments delivering a precisely focused high-dose X-ray beam of radiation to destroy certain types of tumors. It is also called stereotactic radiosurgery (SRS).

**TOTAL BODY IRRADIATION (TBI):** Radiation of the entire body that is used to kill cancer and bone marrow cells. TBI prepares the body for bone marrow transplant (BMT).

**TREATMENT PLAN:** A radiation oncologist's prescription describing how a patient should be treated with radiation therapy. The radiation oncology team uses special software to administer the intended amount of radiation dose to the tumor, while sparing healthy tissue from receiving unnecessary radiation dose.

**VOLUMETRIC MODULATED ARC THERAPY (VMAT):** A specialized form of external beam therapy that can help improve how the radiation is shaped to fit your tumor.



# WORKSHEETS

These are tools you can use both for yourself and for your loved one throughout this journey. If you find these useful and need more copies, please contact the Navigation Center for additional copies by calling **605-322-3211** or emailing **[navigation@avera.org](mailto:navigation@avera.org)**.

## MY STRESS MANAGEMENT PLAN

*Excerpts provided by American Society of Clinical Oncology*

**Use this page to identify the best ways for you to manage caregiving stress.**

I know I am feeling stressed because \_\_\_\_\_  
\_\_\_\_\_

This stress is being caused by \_\_\_\_\_  
\_\_\_\_\_

My ideas on how to deal with this stress are \_\_\_\_\_  
\_\_\_\_\_

What I need from my family right now is \_\_\_\_\_  
\_\_\_\_\_

What I need from my friends right now is \_\_\_\_\_  
\_\_\_\_\_

# SELF-CARE CHECKLIST

It's important that you make sure to take care of yourself during this journey. Use this chart to ensure you're meeting your basic needs every day.

<b>My Needs</b>	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
<b>Stayed Hydrated</b>							
<b>Ate Healthy Meals</b>							
<b>Took Medicine</b>							
<b>Exercised for 15 Minutes</b>							
<b>Practiced Mindfulness for 5 Minutes</b> (prayed, breathed deeply, focused on surroundings)							
<b>Slept Restfully</b>							
<b>Connected with Support</b>							

# CAREGIVING ACTION PLAN

*Excerpts provided by American Society of Clinical Oncology*

Use this guide to help you coordinate tasks and keep track of which roles people are filling for your loved one.

Activity	Able to do alone	Needs help	Who can help
Bathing			
Dressing			
Grooming			
Using the Bathroom			
Getting Out of Bed			
Taking Medication			
Shopping for Food and Other Items			
Doing Housework			
Doing Laundry			
Cooking Meals			
Driving To and From Appointments			
Doing Yardwork			
Paying Bills			
Child Care and/or Pet Care			

Other support that has been asked for: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# TRACKING SYMPTOMS

Excerpts provided by American Society of Clinical Oncology

Check the box next to any symptom that your loved one experiences. **Next to each checked symptom, write a number from 1 to 10, indicating how severe it was. 1 = mild; 5 = moderate; and 10 = severe.** You may want to make copies of this page to use throughout this person's care.

Week of: \_\_\_\_\_ Treatment(s) received: \_\_\_\_\_

Symptom	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Appetite Loss							
Difficulty Concentrating							
Fatigue							
Fever							
Nausea and Vomiting							
Pain Location: Description:							
Sleep Problems							
Headache							
Loss of Balance							
Other							
Other							

Questions or concerns to talk about with the health care team: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

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Other							

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\_\_\_\_\_

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Nausea and Vomiting							
Pain Location: Description:							
Sleep Problems							
Headache							
Loss of Balance							
Other							
Other							

Questions or concerns to talk about with the health care team: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



# MEDICATION MANAGEMENT

This worksheet will help you and your loved one keep track of medications. If you have questions regarding the medications prescribed, please contact your health care provider.

Medication	Dose	Why You Take It	When to Take It									
			30 Min Before	Breakfast	One Hour After	30 Min Before	Lunch	One Hour After Lunch	30 Min Before	Dinner	One Hour After Dinner	Bedtime

# BILL WORKSHEET

This will help you to keep track of the bills that are due every month. Your loved one should consider completing a Financial Durable Power of Attorney or adding names to accounts for family to help manage bills.

Type of Bill/ Company	Date of the Month Due	Monthly Amount		Account Access	
Home Mortgage/Rent:				Login: Password:	Phone Number:
Car:				Login: Password:	Phone Number:
Phone, Internet, Cable:				Login: Password:	Phone Number:
Electric:				Login: Password:	Phone Number:
Water:				Login: Password:	Phone Number:
Trash:				Login: Password:	Phone Number:
Natural Gas:				Login: Password:	Phone Number:
Medical Bills:				Login: Password:	Phone Number:
Credit Card Payment:				Login: Password:	Phone Number:
Car Insurance:				Login: Password:	Phone Number:
Gas for the Car:					
Groceries:					
Medications:					
		<b>Total Bills:</b>		Bank Name-Checking Account: _____ Bank Name-Savings Account: _____	
		<b>Total Income:</b>			
		<b>Amount Leftover:</b>			

# SUPPLEMENTAL POLICIES

If your loved one is employed, it's a good idea to check with the employer's Human Resource Department to determine what policies your loved one has and what they cover. List benefits here so you or your family members can assist with claims.

Type of Policy	Company	Details	Amount	Policy Number
<b>EXAMPLE:</b> Short-Term Disability	Mutual of Omaha Phone: 888-888-8888	60% of Salary	\$800/month	55-555-5555
Short-Term Disability				
Long-Term Disability				
Cancer/Critical Illness				
Accident Insurance				
Basic Life Insurance				
Supplemental Insurance				
Health Insurance			<b>Deductible:</b>	
FMLA		No payment – keeps you employed with benefits (insurance)		

## NOTES

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Learn more about cancer care at Avera Cancer Institute.  
[Avera.org/cancer](https://www.avera.org/cancer)

Avera's mission is to make a positive impact in the lives and health of persons and communities by providing quality services guided by Christian values. If you think you may have problems paying part of your bill, contact your local business office or billing staff. We can discuss payment options that may be available to you.

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