

HOW TO USE THIS GUIDE

Cancer care is complex. You will get a lot of information during your cancer journey. We created this guide as your central source of information.

We cover many topics, including cancer treatment, side-effects and suggestions for your care.

You will also find information on Avera Cancer Institute resources, including social workers, dietitians, chaplains, patient advocates and many others. You have access to these resources.

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IMPORTANT PHONE NUMBERS

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

AVERA CANCER INSTITUTE LOCATIONS

Aberdeen, S.D.

605-622-8700

Pierre, S.D.

605-224-3370

Marshall, Minn.

507-537-9000

Sioux Falls, S.D.

605-322-3000

Mitchell, S.D.

605-995-5756

Yankton, S.D.

605-668-8850



MY PROVIDER AND TREATMENT APPOINTMENTS

During your first visits, doctors will give you a lot of information about your diagnosis and treatment. You should think about what facts you need to make good choices about your care.

These ideas may help you remember more details of your visit.

- Bring a loved one or close friend to your visit. Ask them to take notes.
- Write down questions before your visit. This will help you remember them. Be sure to write down answers, too.
- If you have many loved ones who want to attend your appointment, call ahead to coordinate room arrangement with your nurse.
- Ask your doctor if you can use your phone to record parts of your visit.
 This will help you remember details about your diagnosis and treatment options. You later can listen to this recording.

MY OUFSTIONS

It's normal to have questions before and during treatment. We want to answer all your questions. And we want you to take part in your care. It helps to write down questions for your doctor or nurse before each visit. You can also keep a list of things that your health care team needs to know.

Listed below are good guestions to ask after your diagnosis. Please add your own questions to this list. What type of cancer do I have? _____ What's my cancer stage and size? Has it spread to other places in my body? _____ Will more tests be needed to confirm my diagnosis? ______ What treatments are there? How will treatments affect my quality of life? _____ How long will the treatments last? How often will I have treatments? _____ Where will I get my treatments? _____ What type of side effects might I have? What can I do to help avoid them? What complications might I have with the treatments? What are the risks and benefits of treatment? Is there anything I should not eat or drink? What type of follow-up care might I expect? Are there any lifestyle changes I should consider? What resources are available to help me better understand my cancer and treatments? Additional questions: _______

MY LAB RESULTS

Date	WBC	ANC	НСТ	HGB	PLT	

During your care, you may have blood work and various tests performed. You may use these pages to track the dates and results.

AveraChart is an easy and secure way to access your health care information.
AveraChart helps you be an active partner with your health care.

To register, or for more information on AveraChart and the Oncology Patient Portal, visit **AveraChart.org**

MY TEST RESULTS

Test Name	Date	Body Area	Facility	Notes



MY SAFETY

WE CARE ABOUT SAFETY

We are dedicated to giving you excellent health care. This includes the most advanced technology and the safest care. To do this, we need your help. You are the most important person on the health care team. We encourage you and your loved ones to become involved in safety by:

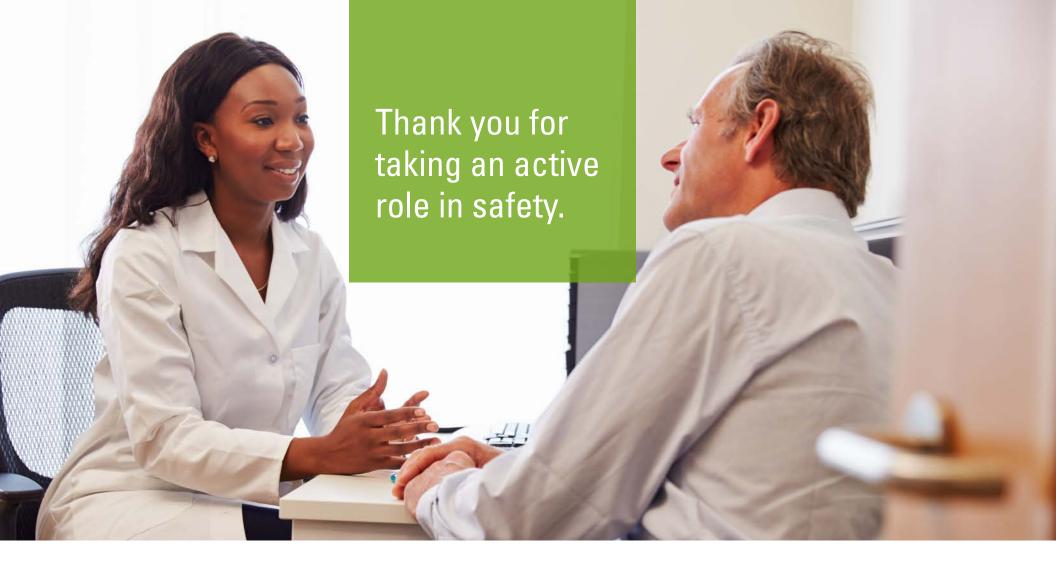
- Speaking up
- Asking questions
- Reporting concerns
- Asking for help

Speaking Up: If you have questions, concerns or if you don't understand what's happening, ask your care team. It's your body. You have the right to know what's happening.

- Don't be nervous to speak up if you don't understand.
- If you are having a procedure, ask questions to ensure that you understand what will be happening.
- If you feel you are not getting the right treatments or medicines, ask your doctor.
- Ask who is caring for you. The health care team should say who they are and wear ID badges. If they don't, just ask.
- Make sure you speak up if you are not asked for your name and date of birth before receiving medicine or having a treatment or procedure.
- Speak up right away and tell your health team if something seems unsafe or does not seem right.

Ask Questions: Clear communication helps you have a safer visit. By asking questions, you are taking an active role in your care.

- Ask questions about your diagnosis, treatment plan, medicines and procedures.
- Your loved ones can support you. They can ask questions and help you remember answers.
- Write down information a doctor tells you. Ask a member of your care team if they have education material for you to read.
- Know the names of your medicines. Medicines have 2 names: the brand name and the generic one. Ask questions if you don't understand.
- If you do not recognize a medicine, ask your nurse to explain the medicine before you take it.



- Ask providers and nurses about allergies and reactions to all medicines before
 they are prescribed. Ask about over-the-counter medicines or herbal supplements
 you take. Check if they might cause issues with your current medicine, treatments
 and procedures.
- Ask about the side effects of your medicine and how to manage them.

Reporting Concerns: You and your health care team work together to make sure you have a safe visit.

- Tell your health care team if you feel there is a safety risk. Examples include:
- If the floor looks shiny, ask if the floor is wet or slippery before walking on it.
- Tell someone about an uneven floor that might trip you.
- Share safety concerns outside the facility, such as icy sidewalks or parking lot issues.

Asking for Help: The health care team and volunteers are here to help you with your needs:

- Ask for valet help when parking your car.
- Ask a care team member or volunteer to help you to your appointment.
- Ask for support services and resources.
- Ask for help treating your pain.
- Ask for help with physical and emotional side effects of your treatment.

NAVIGATION SERVICES

AVERA CANCER INSTITUTE NAVIGATION CENTER

The Avera Cancer Institute Navigation Center is a free, 24-hour service for anyone impacted by cancer. We are an education and support hub made up of registered nurses and social workers who help patients and loved ones. We can support you with resources and education about symptom management, drug education and emotional support. The navigators work with you, your loved ones and all members of the care team. You can call anytime.

How the Navigation Center can help:

- 24/7 nursing access for urgent needs with symptoms, medicine or treatment questions.
- Social and emotional support to patients and their loved ones.
- Help with addressing barriers to care. This can include connecting you to lodging or travel resources.
- Education on cancer screenings and connection to screenings close to home.
- Post-treatment assessment calls. These calls provide peace of mind by addressing symptoms you may experience and answering your questions.
- Phone coverage outside of clinic hours for all Avera Cancer Institute locations.
- Education on cancer-related questions from community members, patients, caregivers or doctors.



Call 24/7

605-322-3211 or 888-422-1410



NUTRITION AND YOUR WELL-BEING

Nutrition is a key part of your cancer care. Regular, well-balanced meals or small, frequent snacks can help you feel stronger. A good diet can give you the energy you need. Drink up to 2 quarts of fluid each day which will help keep your body hydrated.

You can also talk to a dietitian about how to improve your nutrition and feel better. Dietitian and health coach resources are available.

NUTRITION TIPS

- Eat 6 to 8 small meals and snacks during the day. Choose foods that are easy to make and eat.
- If meats are hard to eat or you don't like how they taste, try chopped
 or ground meats mixed with a sauce or casserole. Other protein may
 be easier to eat. Try eggs, cottage cheese and peanut butter. A higher
 protein diet can help your recovery.
- Fruits and juices are easy to eat and drink. They may perk up your taste for other foods. Have them with your meals.
- Let friends and family make meals or shop for you. Accept their help. Tell them if there are foods that you can't eat or don't like.
- Try eating a big breakfast to keep your up energy during the day.

- Exercise can improve digestion and hunger. If you can, try to walk or exercise most days.
- Keep nutritional supplement drinks on hand for days you don't feel like eating.
- Constipation can cause a poor appetite. For relief, add 1 or 2 tablespoons of wheat bran to your food. You can also drink warm prune juice 3 or 4 times a day.

CONCERNS TO SHARE WITH YOUR DOCTOR

- Tell your doctor if you have gut pain, diarrhea, nausea or vomiting.
 Medicine may help you feel better.
- If you have constipation, ask your doctor if you should start a daily bowel care program. This may include stool softeners or laxatives.
- An appetite stimulant can be helpful. Talk to your doctor about how a stimulant could help.

HOLISTIC CARE

Holistic care involves treating the whole person: mind, body and spirit. This typically includes a combination of traditional medicine and complementary medicine. There are many complementary methods that have been shown to be safe and can help relieve symptoms or side effects. For instance, a holistic way to treat cancer could include chemotherapy along with aromatherapy and/or mindfulness.

'The body heals with play, the mind heals with laughter, and the spirit heals with joy'

PROVERB

SPIRITUAL HEALTH AND SUPPORT

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.

PHYSICAL ACTIVITY (NATIONAL CANCER INSTITUTE, AMERICAN CANCER SOCIETY AND CDC)

Physical activity is any movement that uses skeletal muscles and requires more energy than resting. It can include working, exercising, and household chores. Activity could also include walking, tennis, hiking, bicycling, swimming and more.

Physical activity is movement that helps balance the number of calories you eat and the number of calories you use. It can include:

- Work
- Exercise
- Walking
- Tennis
- Swimming
- Cycling

Using fewer calories than you eat leads to obesity. Obesity has been linked to greater risks of some different cancers. Long periods where you don't move, such as sitting watching TV or lying down puts you at risk for cancer, cardiovascular disease and type 2 diabetes.

Is physical activity beneficial for cancer survivors?

Research shows physical activity may help cancer survivors in many ways. Benefits may help with weight, quality of life and cancer return or growth. Physical activity may even improve your prognosis or the likely path of your diagnosis.

Some benefits cancer survivors may see from exercise are:

- Body image
- Self-esteem
- Emotional well-being
- Enhanced feelings of sexuality
- Sleep disturbance
- Social functioning
- Less anxiety
- Less fatigue
- Less pain

How much physical activity should you get?

Talk with your doctor about the types and amounts of activity that are right for you during your cancer treatment. Ask your doctor before starting a new or intense exercise.

In general, adults should get:

- At least 150 minutes of medium-challenge exercise per week;
- At least 75 minutes of hard activity each week; or,
- A combination of the 2.

This activity is best when spread throughout the week.

Consider 2 to 3 sessions per week of strength training. You could include 2 to 3 sets of 10 to 15 repetitions of each exercise. It helps to stretch at least 2 days a week.

If you haven't been active, you should start with moderate activities and slowly increase your effort. Most people start with 20 minutes of light to moderate activity 1 to 3 days per week. If you are already active but want to do more, raise the challenge of your current routine. If you are active and want to stay at your current fitness level, try adding new activities to use different muscles and keep your interest.

To increase activity, join a class or program. You can also get a trainer or set short and long-term goals. Avera has many resources, and you can ask your care team about ones closest to you. Wearing a pedometer or fitness tracker or using a tracking app is helpful. A good goal for many people is to reach 10,000 steps each day.

SAFE ACTIVITY

By following these tips, you can keep your physical activity fun and safe.

- Warm up and stretch to help avoid injuries.
- Be active with a partner.
- Drink plenty of water before, during and after exercise.
- Don't overdo it. There is no gain from pain.
- Always follow instructions and safety recommendations when using equipment.
- Wear comfy clothes and proper shoes.
- Use the stairs instead of the elevator.
- Take a short break at work to stretch or take a quick walk.
- Walk to visit coworkers instead of sending emails.

Whether you set aside time to exercise or do short bursts of activity throughout your day, the best thing you can do is get up and get moving.

EMOTIONAL WELLNESS

Cancer patients may have mental or emotional symptoms that may include:

- Anxiety
- Depression
- Emotional distress
- An ongoing fear of cancer coming back. This fear may be unique to cancer survivors.

Anxiety, depression and distress are common after treatment ends, and they can range from mild to severe. Fears such as physical symptoms, changes to body image, stress about money and social isolation can lead to these conditions and their symptoms can impact your quality of life.

Emotional wellness involves self-care, reducing stress and building strength. It is good to seek emotional wellness during cancer diagnosis, treatment and survivorship.

Your emotional wellness and mental health are just as important as your physical well-being. Avera offers a variety of services that will take care of your emotional wellness and needs.

- Social workers are experts certified to be an extra emotional support.
- You may visit with a mental health therapist specialized in treating individuals with cancer. This service is offered at all Avera Cancer Institute locations via telemedicine and onsite in Sioux Falls.
- You can take part in Avera integrative medicine activities, such as mindfulness, art and music therapy.

Ways to manage emotional health:

- Try for 150 minutes of medium-effort physical activity each week.
- Try mind-body classes, guided imagery, stretching, massage or aromatherapy services.
- Counseling can help with your feelings around your cancer journey.
- Your doctor may look to integrated medicines and clinical services, such as acupuncture or supplemental weight management consulting, to help treat some symptoms.



INTEGRATIVE AND COMPLEMENTARY SERVICES

Integrative and complementary services are available through the Avera Cancer Institute and Avera Medical Group Integrative Medicine Clinic. Integrative medicine practices enhance traditional medicine.

Some of the services offered include:

- Mind-body courses, such as stretching, singing bowls and mindfulness training
- Therapeutic massage
- Aromatherapy
- Art, music or guided imagery
- Acupuncture
- Medical weight loss
- Herb/supplement guidance or consultation

Integrative medicine professionals offer services by telemedicine at many locations.



What is mindfulness?

*Sources: mindful.org/what-is-mindfulness, merriam-webster.com/dictionary/mindfulness, helpguide.org/harvard/benefits-of-mindfulness.htm

Mindfulness is being aware of your thoughts, emotions or experiences on a moment-to-moment basis. It is the ability to be fully and calmly present in the moment. You are very aware of where you are and what you're doing.

How is mindfulness helpful?

Mindfulness improves well-being. Practicing mindfulness supports attitudes that contribute to a satisfied life.

It is easier to enjoy the pleasures in life as they occur when you are mindful. It helps you get into activities, and you can better deal with negative events.

By focusing on the here and now:

- You're less likely distracted by future worries or past regrets.
- You're less concerned about success.
- You're able to form better connections with others.

Mindfulness can also better your physical health as it:

- Relieves stress
- Lowers blood pressure
- Reduces chronic pain
- Improves sleep
- Improves mental health

Mindfulness Techniques

The goal of mindfulness is to be at a state of alert, focused calm. Concentrate on thoughts and sensations without judgment. It allows the mind to refocus on the present moment. All mindfulness techniques are a form of meditation.

Basic mindfulness meditation:

- Stillness: Sit quietly in a stable seat. Focus on your breathing or on a soothing "mantra" or phrase that you silently repeat. This mantra can be a single word. Allow thoughts to come and go without judgment. Return to your focus on breath or mantra.
- Body sensations: Notice subtle body sensations, such as an itch or tingling. Notice these without judgment and let them pass. Notice each part of your body from head to toe.
- Sensory: Notice sights, sounds, smells, tastes and feelings. Name them without judgment and let them go.
- Emotions: Allow emotions to come up without judgment. Practice a steady and relaxed naming of emotions: "joy," "anger," "frustration." Accept the presence of the emotions without judgment and let them go.
- Thoughts: You may find your mind wandering constantly. That's normal. Accept it, and observe your thoughts without needing to react.
- When ready, gently lift your gaze: Take a moment to notice any sounds in the environment. Notice how your body feels right now. Pause for a moment before continuing with your day.



SOCIAL WORK SUPPORT

A cancer diagnosis can bring with it many emotions and issues. It might help to talk to someone about your emotions. At Avera, patients can get individual professional counseling. Social workers are available to help you with various topics that may come up during your cancer journey.

These topics may include:

- Identifying barriers to care (lodging, travel and more)
- Help with care changes
- Counseling for anxiety and depression related to your cancer diagnosis
- Support maintaining or improving quality of life
- Advocating for you to make sure your voice is heard and your needs are met
- Connecting you to additional support and community resources
- Help with advance care planning, advance directives, family meetings and other decisions

Advance Care Planning includes conversations between a patient, their loved ones and health care providers. It can help patients get ready for current and future medical decisions based on a patient's personal goals, life values and preferences. These choices can be recorded in documents called advance directives.

Advance Directives are legal documents that direct your health care. These forms are often separate from a general will or power of attorney for financial purposes.

 Health Care Power of Attorney is a document that says who can make health care choices for you if you cannot speak for yourself. You can appoint a loved one or trusted person to take this role, and you and a notary or witness will sign the document.

- A Living Will is a document that says what type of end-of-life care you want. It can explain this to health care providers and loved ones. This document is used if you cannot speak for yourself. You and a notary or witness will sign the document.
- DNR (Do Not Resuscitate) is a request made by you that allows natural death to
 occur. It requires providers to stop (or not give) chest compressions, defibrillation,
 advanced airway procedures, assisted breathing or administration of resuscitation
 medicines. EMS typically find these on refrigerators. You and your provider sign
 this document.
- Comfort One is a South Dakota-based program for DNR. You must complete a form
 that will be signed by a health care provider. The program may include an identification
 bracelet which lets emergency medical service providers to recognize patients who
 prefer DNR status at all times.
- Physician Orders for Life Sustaining Treatment (POLST) are written, signed provider
 orders for persons with advanced, progressive illness. POLSTs ensure patients receive
 treatment consistent with their values, wishes and best interests. It functions as a
 transportable medial order that applies across facility, community and state lines.
 It serves to complement Advance Directives.
- Similar orders have distinct state names, including:
 - MOST (South Dakota)
 - POST (Minnesota)
 - IPOST (Iowa).

Where can I find these forms?

All health care facilities can give you the forms mentioned. There is no cost. You can discuss the legal forms for the state in which you live. A social worker can help you complete these forms.

References:

www.avera.org/patients-visitors/advance-directives-end-of-life-planning/ www.advancedcareplanningsd.com/ doh.sd.gov/providers/most/

www.uptodate.com/contents/advance-care-planning-and-advance-directives



It can be hard to talk about your cancer diagnosis, even with spouses or close family. It also can be hard for your loved ones to know what to say. They want to help you feel better.

- Tell family and friends only when you are ready.
- Set limits if you think you will feel overwhelmed.
- Tell your loved ones how you feel so they can truly be there for you.
- Let others help you and tell them what kind of help you really need.

Your social worker, doctor or counselor may have tips. Support groups can be helpful.

If there are young children in your family, you may worry about how to tell them. You also may worry about how they respond. Talk with your loved ones about how to talk to them. Tell them things in a way they can understand. Give them time to ask questions. Your social worker can give you tips. You may want to talk to their school counselor for extra support as well.

PALLIATIVE CARE

Palliative care helps with pain, symptoms and stress that serious or life-limiting illnesses cause. It can be delivered at any age and any stage of illness. This care is also offered to patients' loved ones.

Palliative care can be delivered alongside curative or disease-directed treatments. It complements care provided by other medical teams. Palliative care specialists are experts in pain and symptom management. Because they work as a team, they are good at helping with emotional, spiritual and psychosocial distress.

Avera's mission of caring for the mind, body and spirit connects with palliative care. This care helps to reduce suffering and improves your quality of life. It can enable patients to live as well as possible, and it often improves your ability to succeed during medical treatments. It also helps you better understand your condition and choices for medical care.

Your palliative care team can include:

- Physicians
- Advance practice providers
- Registered nurses
- Social workers
- Chaplains

FINANCIAL CONCERNS

Many patients have financial concerns when faced with a cancer diagnosis. Patient Advocates are available to answer your questions and connect you with financial resources.

Here are some questions to think about when you start cancer treatment:

- 1) What will the treatment cost?
- 2) Will my insurance cover treatment? If so, how much will I still owe?
- 3) Is there any financial help for what I owe?
- 4) Can I make payments?
- 5) Is there help for travel costs or lodging?



Advocates can help you with insurance, benefit gaps, billing issues and options.

Patient financial aid programs exist, but each case is different. Your care costs will vary, and may depend on things such as:

- Self-pay versus insurance
- Local patient versus those who have to travel for care

Talk with your patient advocate at your care facility. They can answer all of your financial questions.

TYPES OF TREATMENT

There are several types of treatment that your doctors will consider depending on your diagnosis. The main types of treatment include:

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

The type of treatment will depend on your diagnosis. Treatment will also depend on the cancer stage, your age, current health status and other needs you may have.

You are the most important part of your health care team. We encourage you to talk with your physician about your treatment options and take part in the planning.

SURGERY

Surgery is often the first treatment choice for many cancers. If the cancer is localized to one area, 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.

There are 4 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.
- Therapeutic or palliative Treatment that is intended to relieve symptoms, but not cure disease.

Treatment schedules vary depending on the type of cancer. Treatment 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 contains organs such as intestines, stomach and liver.
- Intravenous Given directly into a vein.
- Orally Given as a tablet or liquid that is swallowed.
- Power port/port-a-cath Given as medication injected through a special implanted catheter device which allows easy internal access.

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 or 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.

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. It also works 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 treatments 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.





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 you have:

- Painful sores in the mouth that do not allow you to eat or drink
- 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
- Change in breathing
- New skin rashes and/or itching

Note: If you experience decreased kidney function (less frequent urination), increase fluids to 3 to 4 quarts per day. Report decreased urination to your health care provider.

Call your doctor immediately if you have any of the following symptoms:

- Vomiting that does not get better (always report vomiting of blood immediately)
- Oral temperature of 100.4 degrees 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
- Pain, swelling or new redness anywhere
- Pounding feeling in the chest or extra beats, pain or heart symptoms

Go to the ER right away if you have:

- 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 medicines or other interventions such as Tylenol® (if appropriate), ice, heat, massage, lidocaine patch or others
- 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 that could show a 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 or other sudden pain
- 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
- Sudden loss of vision or speech or function of an extremity

CALL THE AVERA CANCER INSTITUTE NAVIGATION CENTER 24/7 AT

605-322-3211 or 888-422-1410



Your doctor and care team will talk to you about side effects.
Side effects depend on your type of cancer and your treatment.

ANEMIA

Anemia is having a low number of red blood cells. It's also called low hemoglobin. Chemotherapy and bleeding can cause anemia.

What are symptoms of anemia?

- Fatigue
- Weakness
- Having to stop and rest more than usual
- Short of breath
- Feeling lightheaded
- Chest pain or skipped heart beat

Can I prevent anemia?

Talk with your doctor about digestive issues or if you are on a special diet. Vegans and vegetarians can struggle with anemia. People who had gastric bypass surgery also can develop anemia. There may not be much that you can do to prevent it.

What should I do if I think I have anemia symptoms?

Let your care team know about nose bleeds, bloody or black and tarry stools, blood in your pee or any other bleeding. A blood test may be needed. At times, you may need a blood transfusion.

CONSTIPATION

Constipation means that you often have hard stools. It may be hard to poop or you may strain when you do. You may also poop less than 3 times per week. Ideally, you would have a soft bowel movement each day.

Constipation may be caused by:

- Diets low in fiber or green leafy vegetables
- Chemotherapy
- Certain medicines, such as anti-nausea medicines Zofran[®] (ondansetron) or Imodium[®] (loperamide)
- Blockages in the digestive system

What can I do if I have constipation?

- Eat foods that are high in fiber
- Try fruits, such as apples (with skin), oranges and prunes
- Eat veggies like green beans, beans, celery, carrots, peas and potatoes (with skin)
- Drink more fluids. Try to drink 8 to 10 cups of water or 2 to 3 water bottles per day. Prune juice can also be helpful
- Walk or do more physical activity

What are safe over-the-counter medicines to treat constipation? If you have not had a bowel movement in 2 days, you can try Milk of Magnesia (magnesium hydroxide). Take 60 milliliters once at bedtime, then repeat daily or twice a day as needed.

If you often struggle with constipation, you should use a stool softener such as MiraLAX® (polyethylene glycol), Dulcolax® (docusate sodium), docusate sodium or sennosides such as Senokot-S® and Senna-S.

If those options do not work, you can ask your doctor about other options, including magnesium citrate such as Citroma®, a stool softener suppository or an enema.

When should I call my doctor?

- If you are vomiting AND you are constipated. This could be a sign of a blockage
- If you have major stomach pain
- If the above ideas have not worked

DECREASED APPETITE

There are several reasons why you might be less hungry than normal. Causes could include:

- Some chemotherapies
- Certain cancers or diseases
- Pain
- Nausea, constipation or difficulty swallowing
- Changes with taste

What do I do if chemotherapy changed the way my food tastes?

- If your food tastes like metal, do not use metal spoons, forks or knives. Use a plastic utensils.
- Add more spices or find foods that taste flavorful and tart.
- Try foods that stimulate your taste buds. You can try lemon drops or fresh ginger.
- Marinate meats in sweet juices that include honey, sugar or herbs/ sweeteners.

What if I can't eat as much as I used to?

You should not lose weight during chemotherapy. Drink 1 to 3 protein supplements a day, such as Boost® or Ensure®. These are not meant to replace your food intake. You should eat regular meals when possible. Ask someone to cook for you; try to eat those meals, even if you're not hungry.

DEHYDRATION

Dehydration is when your body does not have enough water. It can happen when people do not eat or drink as much as they should. Chemotherapy can increase dehydration. Certain medicines can cause dehydration as well. Vomiting and diarrhea can also lead to dehydration.

What can I do to prevent dehydration?

- Drink plenty of fluids: 8 to 10 cups OR 2 to 3 water bottles per day.
 - Remember coffee or high-caffeine drinks do not hydrate you.
- Eat food. There is water content in your food.
 - You may be dehydrated if you're not eating as much as you should.

Can dehydration be treated?

If you are dehydrated, you may need help at your nearest clinic or infusion center.

When should I call my doctor?

- If you think that you are dehydrated
- If you feel weak or dizzy when you stand
- If you have not been eating or drinking for 2 days
- If you are not peeing
- If you have had a lot of diarrhea or vomiting

DIARRHEA

Diarrhea is loose or watery poop. It can be caused by chemotherapy or a bowel/colon infection. It is often caused by something you ate.

If you have diarrhea, eat bland foods such as:

- Crackers
- Rice
- Toast
- Broths
- Clear soda
- Bananas
- Oatmeal

If you have diarrhea, you should avoid:

- Dairy
- Spicy, greasy or heavy foods
- Stool softeners or laxatives

What are safe over-the-counter medicines to treat diarrhea?

- If you have diarrhea because of chemotherapy, it is safe to try an anti-diarrhea medicine such as Imodium® (loperamide).
 - Take 2 tabs after first loose stool, then 1 tab after each loose stool. You may take up to 8 daily.
- Sometimes it is best to allow for loose stools to pass on their own. Allow for a couple of loose stools after chemotherapy before taking anti-diarrhea medicine.

When should I call my doctor?

- If you have taken antibiotics in the last 2 days or were just in the hospital
- If you have 4 or more loose stools for more than 1 day
- If you tried anti-diarrhea medicine but you still have diarrhea
- If you have significant cramping and belly pain or bloody stools

How can my doctor help?

Your primary care or oncology doctor may order tests to check your electrolytes and kidney function. They may order fluids if you are dehydrated. Your doctor may also give you other medicines to help with diarrhea.

FATIGUE

Fatigue means not having a lot of energy or having less energy than normal. It can mean you are tired from illnesses or events. It could also mean you feel weaker. Fatigue is a common side effect.

Reasons you might feel fatigue:

- You have no breaks in between activities
- You are not sleeping enough or your normal sleep routine is interrupted
- Low levels of hemoglobin, which means it is hard to carry oxygen to vital organs
- Dehydration due to not drinking enough. Your body may not absorb fluids well, and it can lead to weakness or dizziness.

What are symptoms of fatigue?

- You are more weak or dizzy
- You aren't getting enough restful sleep at night
- You cannot focus
- You are short of breath with little to no activity
- You have less energy for activities
- You need to rest a lot between activities that are normal for you
- You are still tired after a good night's rest

What can I do to prevent fatigue?

- Take breaks, rest in between activities or take short naps (30 minutes)
- Do stretches, get a massage or take a warm bath
- Drink plenty of water
- Do activities most important to you when you have the most energy
- Ask your family to help with chores
- Have a sleep schedule and go to bed the same time each night
- Eat foods high in calories, high in protein and rich in iron
- Do not have caffeine or drink a lot of fluids before bed
- Listen to your body, know your limits and don't work too hard

When should I call my care team about fatigue?

If your loved one finds you sluggish or out of it, call 911. You should call your care team if you are:

- Short of breath with activity or rest
- You can't stop feeling dizzy or weak
- Your fatigue is getting worse each day, so keep a daily journal of your energy levels
- You need more help, such as a better cane or walker

FEVER

Take your temperature if you feel warm, have chills or if you feel ill. If you do not have a thermometer, affordable digital ones (for your mouth) are easy to find and buy.

Your temp should be around 98 degrees F. A fever is a temp of 100.4 degrees F or higher. If your temp is between 99 to 100.4, check it again in an hour. If you don't feel well, call our 24/7 Navigation Center at 605-322-3211 or 888-422-1410.

What should I do if I have a fever?

- Watch your fever. You might need to see your doctor to check if you have a major infection
- Call your care team, as your doctor may ask you to medicine like Tylenol[®] or Advil[®] to bring it down
- If after clinic hours, call the 24/7 on-call Navigation Center at 605-322-3211 or 888-422-1410
- You may be seen at your local Urgent Care clinic or Emergency Department

What will the clinic do for my fever?

The clinic will test your blood, pee and take a chest X-ray. If your blood counts are very low, or if the clinic suspects you have a major infection, you may be hospitalized. You will be given medicine to help you over a couple nights at the hospital.

If your blood counts are OK, you feel well enough and your care team thinks it's safe, you will be sent home.

HAIR

During treatment, you may lose some or all of the hair on your head. You may also lose hair on other parts of your body. This should be temporary; your hair will grow back. When your hair grows back, it may look and feel different.

What can you do?

- Plan for this side effect by getting a wig or hair piece before treatment
- Cover your head with a scarf or hat
- You should avoid:
- Using too much shampoo
- Hair dryers
- Hairspray
- Rollers
- Getting too much sun on your head
- Letting your head be too cold
- Too much brushing or combing
- Use a wide-toothed comb

Ask your care team about other options to help stop hair loss. Avera offers wig and other services in many communities.

INFECTION

The biggest thing you can do to stop infections is simple: wash your hands. Use warm soapy water. Scrub your hands before you eat or take medicine. Wash your hands after you use the bathroom. Wash your hands after you meet someone who might be sick.

You should have a thermometer at home. Take your temp if you feel ill. Call your doctor if you have an oral temp of 100.4 degrees F or greater.

Tips to stop infection

- Stay away from people who are sick
- Take care when you make your food by washing vegetables and fruits and making sure meat is thoroughly cooked
- Stay away from soil, lawn waste or compost
- Stay away from litter in cat boxes or bird cages

MOUTH SORES

Mouth sores are spots that hurt on the tongue or cheek. The lining of your mouth may become red and sore. Small white blisters may appear 1 to 2 weeks after treatments start. They can look like canker sores.

Some chemotherapies or radiation to the head or neck may cause sensitive taste buds and/or mouth sores. This side effect is common and it often heals on its own. It is not common for you to have 5 or more mouth sores. It is not common to have mouth pain that you cannot bear.

What can I do?

- Do not eat spicy, salty foods. Flavor your foods with sugar, basil, lemon juice or mint
- Do not eat zesty, chewy foods. You should eat soft, bland food
- Use a soft toothbrush or foam swab to massage mouth
- Avoid alcohol, caffeine and cigarettes
- Keep your lips moist with a lip balm
- Drink liquids through a straw for easy swallowing
- Practice good mouth care:
 - If you have dentures, clean them often. You may leave them out unless eating
 - Use oral rinses to prevent infection. Do not use alcohol-based mouth rinses
 - Rinse your mouth with a mix of water, salt and baking soda every 4 hours. Mix a half-teaspoon of salt, a teaspoon of baking soda with a guart of water.

What can I use for pain?

- Over-the-counter: You should use together antihistamines like Benadryl® and antacids like Maalox®.
- Call for a prescription: Magic Mouthwash

What else could I do for mouth sores?

• Mix 1 to 2 drops of lavender in 1 teaspoon honey. Put this on the mouth sore. Call your doctor if you see white patches or if you start bleeding.

NAUSEA

Nausea is when you have an upset stomach or you feel like you need to throw up. Chemotherapy, heartburn, constipation, diarrhea or some medicines can cause it.

What are ways to stop nausea?

- Do not eat large meals. Eat 5 to 6 small meals.
- Avoid an empty stomach. Try snacking on saltine crackers.
- Do not eat spicy or greasy foods. Stay away from heavy foods.
- Do not eat or drink dairy.
- Eat bland foods such as:
 - Crackers
 - Rice
 - Toast
 - Broths
 - Clear soda
 - Bananas
 - Oatmeal

What medicines can help with nausea?

- Over-the-counter medicines such as Mylanta® (as instructed) or Tums® (as instructed on bottle) are OK.
- Ask your doctor about other medicines.

What are other ways of treating mild nausea?

- Ginger (in food)
- Lavender or lemon to smell
- Rub your pressure points
- Relax and focus on your breathing

When should I call the clinic?

Call the clinic if you still feel nauseous and you can't keep food or water in your stomach. Call the clinic if you are vomiting after taking prescribed medicines for your nausea.

What can your clinic do to help?

Your clinic may get you a different nausea medicine. They may also order IV fluids or IV nausea medicine at a clinic or infusion center near you.

PAIN

Pain can be caused by many things. It is important to find the cause to help stop future pain. Cancer, certain diseases, constipation and even depression can cause pain.

Chemotherapy can cause some people to have "flu-like" aches and pains. However, it should not cause any distinct pain.

What can I do if I have aches from chemotherapy?

- Use pain relievers with acetaminophen like Tylenol®.
- Try not to use ibuprofen or naproxen unless your doctor gives it to you. These medicines can hurt the kidneys, stomach and heart if used for a long time.

What if I need stronger pain medicine?

Talk with your doctor. Different medicines or narcotics have side effects. Some side effects are sleepiness, constipation and slowed breathing. If you take too much, you could become confused.

Are there other recommendations for pain?

- Massage and light stretching
- Ice, heat or a warm bath
- Nerve blocks

When do I go to the emergency room for pain?

- I have new chest pain
- My medicines do not help with current pain
- I feel numb or a tingle down my legs
- I can't control when I pee or poop
- I have shortness of breath, left-sided weakness or jaw pain

Call the 24/7 on-call provider if you're considering going to the ER.

SKIN IRRITATION / SUN EXPOSURE

Your skin may become more sensitive to the sun with cancer treatment. Protect your skin with a sunscreen with a sun protection factor (SPF) of 30 or higher when outdoors.

Wear sunscreen even on cloudy days. Wear hats, sunglasses, pants and long-sleeved shirts to cover your skin.

SWELLING / EDEMA

Swelling/edema means you retain fluid in your hands, legs or feet. Certain drugs can cause it, but an infection, lack of activity or heart/kidney problems also can lead to edema.

What are symptoms of swelling/edema?

- Fluid buildup in the hands or feet
- Socks or shoes are too tight
- Shortness of breath
- Fever
- The skin on your hand or foot takes a little longer to bounce back when pressed
- Your hand, leg or foot has grown in size

What can I do to help with swelling or edema?

- Watch for signs of infection
- Be active but don't push yourself
- Raise or prop up your feet with pillows
- Wear TED hose or compression socks
- Do not wear tight socks
- Ice area of swelling
- Take prescribed medicines from your doctor
- Watch for signs of pain or swelling on either side of your body

When should I call my care team about swelling?

- Your swelling does not go away even if you tried things to help it
- Swelling is getting worse over a short amount of time
- You feel more pain
- You see a new change in your hands, feet or legs that's larger than the other
- You are short of breath
- You have signs of infection
- You are weaker, feel numb or cannot feel things that you touch

GENETIC COUNSELING AND CANCER

WHAT IS A GENETIC COUNSELOR AND WHAT DO THEY DO?

Genetic counselors are members of your health care team who have specialized training in genetics. They can help you and your family understand and manage the risk of hereditary conditions.

What is cancer genetic counseling?

Most adult cancers are random. They're unrelated to your genes. A small number of people have an inherited risk in one or more of their genes. This risk makes it more likely for them to develop certain cancers.

Genetic counselors can help you with medical and genetic information. They can help you understand your risk for cancer and the chance there is an inherited risk in your family. Genetic counselors can help you understand:

- What options you have for testing.
- How these tests could impact your care.
- How the test results could impact your family.

FOR YOUR INFORMATION

- Increased screening may help detect cancer at an early stage when it is easier to treat.
- Risk reduction strategies may prevent cancer.
- For some people with cancer, genetic testing and counseling can help determine medical treatments.

Your genetic counselor will:

- Ask about your family and health history.
- Talk about the chance there is an inherited risk in your family.
- Discuss the benefits, risks and limitations of genetic tests.
- Help you make informed choices.
- Tell you what test results mean.
- Get you in touch with medical experts, researchers, social services and support groups.

Who does counseling help?

Genetic counseling can help anyone with questions about genetics. Genetic counselors can help with questions about your risk or your child's risk of getting cancer. There are signs in a family history that make an inherited risk more likely. Some families have only one sign while others may have many signs.

These signs could include:

- More than 1 family member with the same type of cancer
- A cancer that happens at age 50 or younger
- Rare cancers like male breast cancer, ovarian cancer or medullary thyroid cancer
- More than 1 cancer in the same person
- Family history of a known genetic risk
- Multiple colon polyps
- Jewish ancestry and a family history of breast, ovarian or pancreatic cancer

What are the benefits of learning more about genetic risk?

Genetic counseling and testing can help you know more about the risk for cancer for you and your family members. It may help guide screening and health care decisions. The results of your tests can sometimes be used to help treat cancer.

There are options for management, screening and prevention for many types of cancer. Some of these are only offered to people known to be at a higher risk.

How are genetic tests done?

Most tests use DNA taken from a sample of blood or tissue. Blood is the most common source. It is easy to get, and labs only need a small amount.

After the lab gets the DNA, they look for changes in the genes that may cause a risk. The size of the gene and the type of test affect the wait time. It may take 2 to 6 weeks to get results.

Will my insurance cover the cost of the test?

An office visit with a genetic counselor is free. If you decide to have genetic testing, those tests will be billed through your health insurance.

The genetic counselor will discuss your insurance options with you and help you know what your insurance company covers. If your insurance does not cover the cost of genetic testing, the genetic counselor will talk about out-of-pocket costs and financial assistance options.

Can the test results hurt me?

A federal law protects people from discrimination based on their genetic makeup. The Genetic Information Nondiscrimination Act, the law's formal name, prevents discrimination by employers and health insurance companies.

Learn more about this law and others in your state online at Genome.gov/10002077.

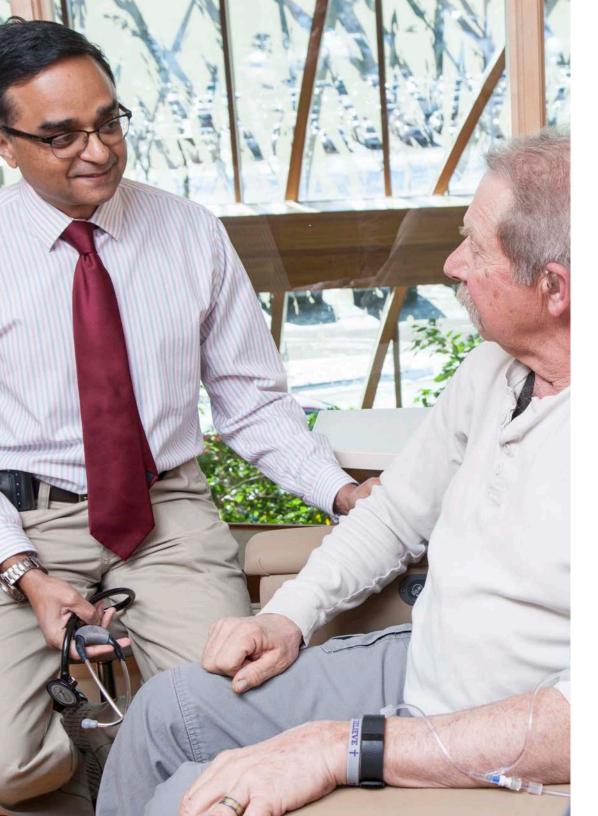
Can I talk to a genetic counselor if I don't know whether I want genetic testing?

Yes. People who do not have genetic testing can still learn about cancer risks and prevention during a visit. The choice to be tested can be hard. The concerns and feelings you have are unique and valid. A counselor can help you decide if testing is right for you.



If you have questions about genetic counseling or are interested in making an appointment, talk to your physician about a referral or call **605-504-4363**.

Telemedicine visits are available.



CANCER RESEARCH AND CLINICAL TRIALS

Clinical trials are research studies that involve patients who can help doctors learn more about new treatments in a safe manner. Through clinical trials, doctors find new ways to improve treatments and the quality of life for people with disease. Some studies also look at the emotional impact of cancer and symptom control.

Your doctor will talk with you if a clinical trial would be a good treatment option for your type of cancer. If you are a candidate for a clinical trial, ask about the side effects, risks and expected benefits.

- Your doctor can help answer any questions you have about the clinical trial before you agree to participate.
- You must sign an informed consent document to participate in a clinical trial.
- You can choose to stop participating at any time.
- Side effects of a clinical trial may be similar to those you
 might experience with standard treatment. However,
 because clinical trials are researching new areas of treatment,
 some side effects may be unknown.

Clinical trials proceed through 4 phases of testing:

- Phase 1 Trials: Researchers test a new drug or treatment in a small group of people to determine a safe dosage and to identify side effects.
- Phase 2 Trials: The treatment is given to a larger group of people to see if it's effective and to further evaluate its safety.
- Phase 3 Trials: The treatment is given to an even larger group of people. Researchers see if the new treatment works better than current treatments.
- Phase 4 Trials: Research is continued to determine its effectiveness and safety with long-term use. These studies also test new dosages.
 Phase 4 trials may also test new uses for a drug that is already safe for other uses.

Why should I take part in a clinical trial?

People volunteer for clinical trials for many reasons. Participation is the only way new medicines and therapies can become available for everyone. When you take part in a clinical trial, you add to our knowledge about cancer and help improve cancer care for future patients. Clinical trials are the key to making progress against cancer.

Only you can agree to take part in a clinical trial. You should discuss it with those close to you as well as with your doctors.

What should I think about before joining a clinical trial?

If you are in a clinical trial, you will have a team of experts taking care of you and closely watching your progress. You may have more doctor visits and lab tests than you would with standard treatment.

Yet there are risks. No one knows whether the treatment will work or what side effects you might have. That's what the study is trying to find. While most side effects go away in time, some may last longer. Others may even be life threatening. Keep in mind that side effects from standard treatments also vary.

In a clinical trial, you also may be part of a control group. This group receives the standard care instead of the study treatment. You need to be comfortable with these facts before you join a clinical trial.

No trial will keep you from getting treatment for your cancer. In most cases, the study compares a standard treatment for your type of cancer to a trial approach to the same cancer.

What is informed consent?

Informed consent is a process where you're presented complete information about a study to help you decide whether or not to take part. The informed consent document (ICD) explains:

- The purpose of the study.
- The study length.
- What procedures will take place.
- If there are other therapies available.
- Risks and benefits of the treatment.
- The confidentiality of your research record.

Importantly, an ICD lets you talk to an expert member of the research team about any questions or concerns you have.

What is the screening process?

Research staff will have you take part in the screening process if you meet the study's requirements. Each clinical trial has guidelines that tell the staff how the study must be done.

You must meet certain criteria to be included in a study. They may include:

- Age
- Gender
- Health history
- Particular medicine use requirements

Sometimes questionnaires, examinations, lab testing or other tools are used to screen volunteers.

For Avera clinical trial information, call 888-422-1410 or visit
Avera.org/innovation-research/
research/cancer-clinical-trials

For general clinical trial information, visit clinicaltrials.gov

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: Conversations between a patient, their family and health care providers that help patients prepare for current and future medical decisions 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 TRAIL: 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, spiritual healing, stretching, Tai Chi, 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 and 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 cause by an accumulation of lymphatic fluid. Lymph nodes in the body help to clean lymph fluid. When lymph nodes are absent or damaged, fluid builds up under the skin causing the arm or leg to swell.

 $\begin{tabular}{ll} \textbf{METASTASES:} Cancer that has spread from one part of the body to another. \\ \end{tabular}$

NAVIGATOR: A medical professional who helps patients navigate through their health care team. Navigators can offer supportive resources and education throughout the course of a patient's treatment. The navigator acts as a liaison 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 a patient's mental, physical and emotional health. It covers not only the physical health of the patient, but also the patient's perception of self and his or her ability to function in the community. It consists of a clinical interview with a self-report questionnaire.

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.

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. But 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.

EMOTIONAL DISTRESS: A condition which occurs when a person is under stress affecting their emotions. (Examples include: eating or sleeping too much or too little, pulling away from people, loss of interest, having low or no energy, having unexplained aches and pains, or feeling helpless or hopeless.)

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. Types of WBCs are granulocytes (neutrophils, eosinophils, basophils), monocytes, and lymphocytes (T cells, B cells). 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).

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.

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.



CANCER POLICY TRACKING

Policy Company	
Policy Number	
Policy Phone Number	
Provider Name	

STEP 1

Check if your policy requires an **initial claim form**. If this is needed, please provide the form to your patient advocate. Ensure your name and policy number is listed on it. The advocate will complete the form and fax it to the policy.

STEP 2

Keep track of dates of service that you had visits related to your cancer or critical illness.

- Use the worksheet on the reverse side to organize this information.

STEP 3

Call Avera Business Office at **888-370-6525**, *option 1* and request they send your **UB-04 statements** for all service dates.

- We recommend waiting to call the business office until 2-4 weeks after you have completed your treatment to allow your bills to finalize.

STEP 4

If your policy reimburses for oral chemotherapy, get a receipt from the pharmacy filling your prescription. The pharmacy phone number should be listed on your prescription bottle.

STEP 5

If your policy reimburses for mileage, submit proof of each visit.

- You can either use your bills for this or a copy of your appointment schedule which can be provided by the clinic front desk
- Some companies will request a print off showing distance from your home to the clinic.

STEP 6

Submit your cancer claim. Many companies have online portals or an option to upload via the internet. You may also fax or mail in your claim. Make sure you include your policy number with your claim submission.

We are here to help. If you have any questions on starting your claim, please contact your patient advocate.

If you have questions on your itemized statements, please contact the Avera Business Office at 888-370-6525 option 1

Date of Service	Clinic Office Visit	Treatment	Scan (CT, MRI, PET)	Radiation Therapy

RESOURCES

Listed below are websites and resources that may be helpful. Keep in mind these sites may change. We encourage you to visit with your social worker, advocate, navigator or nurse if you have questions.

EDUCATION

Avera Cancer Institute

Avera.org/cancer 888-422-1410

American Cancer Society

cancer.org

American Society of Clinical Oncology (ASCO)

cancer.net

Be The Match

bethematch.org

Breast Cancer

breast360.org

Colorectal Cancer Alliance

ccalliance.org

Clinical Trial Search for Patients

cancer.gov/clinicaltrials

Go2Foundation for Lung Cancer

go2foundation.org

Foundation for Women's Cancer

foundationforwomenscancer.org

International Myeloma Foundation

myeloma.org

Leukemia and Lymphoma Society

lls.org

LiveStrong Foundation

livestrona.ora

Lymphoma Research Foundation

lymphoma.org

National Brain Tumor Society

braintumor.org

National Coalition for Cancer

Survivorship

canceradvocacy.org

National Ovarian Cancer Coalition

ovarian.org

National Cancer Institute (NCI) – NIH

cancer.gov

National Comprehensive

Cancer Network

nccn.org

National Library of Medicine

nlm.nih.gov

Oncolink

oncolink.org

Pancreatic Action Network

pancan.org

Prostate Cancer

ustoo.org

CAREGIVER SUPPORT TEAM – SET UP

Lots a Helping Hands

lotsahelpinghands.com

Patient Partner Project

thepateintpartnerproject.org

Caring Bridge

caringbridge.org

Share the Care

sharethecare.org

TELEPHONE SUPPORT

4th Angel Program

4thangel.org

Cancer Survivors Network

(American Cancer Society)

cancer.org

1-800-227-2345

Cancer Hope Network

cancerhopenetwork.org

1-877-467-3638

Connections National Brain Tumor Foundation

braintumor.org 1-800-934-CURE

First Connection (peer-to-peer)

Program: Leukemia and Lymphoma Society

1-800-955-4572

Support for People with Oral and Neck Cancer

spohnc.org

1-888-220-4440, #110

Imerman Angels

imermanangels.org

1-877-274-5529

After Breast Cancer Diagnosis

Support Line

1-800-221-2141

ONLINE SUPPORT GROUPS FOR SURVIVORS AND CAREGIVERS

Cancer Support Community

cancersupportcommunity.org

Meta Cancer: Metastatic Cancer Survivors and Caregivers

metacancer.org

Cancer Care Support Groups

cancercare.org / support groups

Hope Has Arrived

hopehasarrived.com

FINANCIAL RESOURCES

Social Security
Administration

ssd.gov

Bone Marrow & Cancer Foundation

bonemarrow.org

CancerCare

cancercare.org

LLS Co-Pay

lls.org

Healthwell Foundation

healthwellfoundation.org

Patient Advocate Foundation

patientaccessnetwork.org

Patient Services, Inc.

patientservicesinc.org

Chronic Disease Foundation

cdfund.org

National Organization for

Rare Disorders (NORD)

rarediseases.org

Fertile Hope

fertilehope.org

Needy Meds

needvmeds.com

COMPLEMENTARY THERAPIES AND INTEGRATED MEDICINE

National Center for

Complementary and Integrative

Health (part of NIH)

nccih.nih.gov

Memorial Sloan-Kettering Cancer Center (MSKCC): About Herbs,

mskcc.org/cancer-care/

integrative-medicine/about-herbsbotanicals-other-products

Office of Dietary Supplements (part of NIH)

Botanicals & Other Products

ods.od.nih.gov

MY JOURNAL/NOTES





Learn more about cancer care at Avera Cancer Institute. **Avera.org/cancer**

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