PATIENT AND
CAREGIVER
RESOURCE GUIDE

Advanced Cancer Care Resources

A guide for people living with cancer and their caregivers

PARTNERPLUS MEDIA

American Cancer Society®

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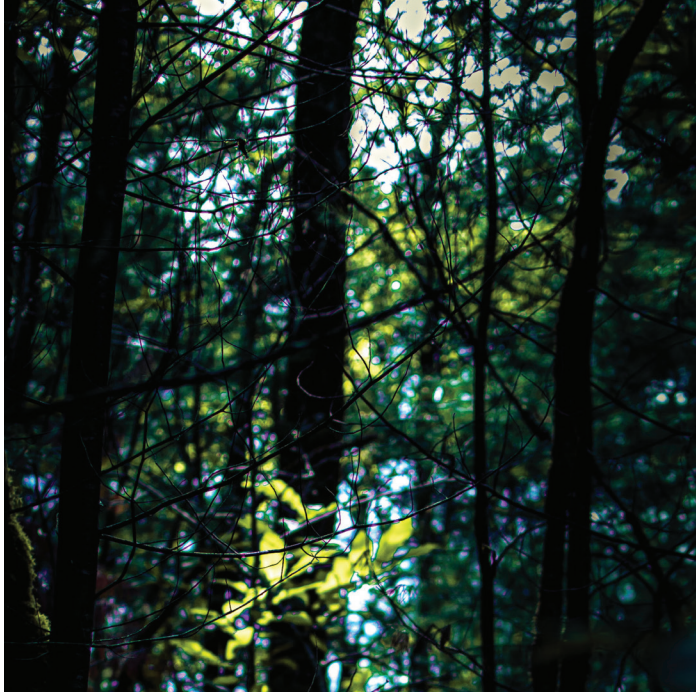

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Introduction

The goal of this guide is to help you, your loved ones, or whoever helps you, get the information about your care that you may need. This will help support you and allow you to stay safely at home.

People living with cancer often go to the doctor's office, emergency room, or hospital when their symptoms get bad, but with this type of program, your symptoms can be managed at home. You can get:

- A nurse to see you at home regularly. That nurse will get to know you and those caring for you. They will check your symptoms and help you manage them.
- A care team that has special training for those living with cancer. The team works with your cancer doctor and/or other doctor(s).
- Medicines ordered by your doctor to manage symptoms or for any other problems. Your care team will go over your medicines with you. They will help manage those medicines to help you feel your best.
- Additional visits by a social worker, a nursing assistant, a chaplain, a counselor, and/or another team member if you so choose.
- Help in an emergency. Please call your nursing team with any problems. They are here for you when you need them.

We appreciate you as part of this cancer care program. We look forward to working with you and those who care for you. Together, we can help you live as well as possible with your cancer.

American Cancer Society Statement:

At the American Cancer Society, we are dedicated to supporting those living with cancer and their caregivers. This collaboration reflects our unwavering commitment to providing essential information and resources, so that everyone can navigate the complexities of cancer care with confidence and support.

Living With Your Cancer

Cancer is different for everyone. Sometimes it can be stopped or cured while other times it can just be controlled. Although there are more and newer treatments available every day, at times treatment can stop working and the cancer can no longer be controlled. Ask your doctor/nurse any questions about your particular situation. It is important to work with them to decide what treatments are right for you. Below are links to some helpful resources.

What is Cancer?

When Someone You Know Has Cancer

Cancer Staging

Advanced Cancer

When Cancer Treatment Stops Working

NPHI Diversity in Cancer Care

We believe that everyone with cancer should get the best care, but sometimes there are barriers that prevent that from happening. To help with this, we believe it is important for doctors and nurses to learn how to understand and respect different cultures. This helps build trust between patients and their care teams.

Studies show that having members of the patient's own community and culture as part of the Cancer Care team can make a big difference. This is especially true for people of color, like those from Black, Indigenous, and other communities of color (BIPOC). Including these community members on the care team can help overcome language and cultural barriers that stop people from getting the care they need.

Managing Symptoms

The following suggestions are on how to help manage the most common cancer symptoms:

Symptom	Ways to Manage
Pain	• Take pain medicines as directed. Do not wait for pain to be bad before taking medicine. • Take extra medicine before doing an activity that you know will make the pain worse. • Talk to your doctor/nurse if taking the medicine as directed does not work. They may need to adjust the dose. • Try deep-breathing exercises to help you relax. Or guided imagery or meditation. • Distract yourself by watching TV or listening to music. • Applying heat or cold may reduce pain. Check with your doctor/nurse.
Fatigue	• Get help with meal preparation and other daily tasks. • Increase physical activity as best as possible. This can help manage fatigue. • Take breaks between activities.
Shortness of Breath	• Talk to your doctor/nurse about whether home oxygen or medicines can help. • Relax by encouraging slow and deep breathing. Meditation or guided imagery can help. • Save energy between activities, pace yourself. • Create a calm and cool environment. A fan blowing gently on your face can help.
Loss of Appetite and/or Weight Loss	• Eat when you feel hungry but do not force yourself. Loss of appetite is natural with advanced cancer. • Try eating several small protein-rich meals or snacks throughout the day. • Be more active, if possible, to help stimulate appetite. • Drink plenty of liquids. • Talk to your doctor/nurse about whether medicines could help. Sometimes they do.
Nausea and/or Vomiting	• Take any prescribed medicine for nausea an hour or so before eating. And continue taking it to keep the nausea away. • Eat small frequent meals instead of large ones. • Avoid strong smells and eliminate odors in the room. • Try foods that are gentle on the stomach (bananas, rice, applesauce, toast, saltine crackers, tea, ginger ale, peppermint candy). • Gently massaging the wrist may help. • Speak to your doctor/nurse if the nausea and/or vomiting cannot be managed with these tips.

Please see Appendix A for a full list of symptoms and ways to help manage them.

When to Call Your Doctor/Nurse

Green Zone means no new symptoms	
My symptom(s) are under control: • Able to do usual activities • Sleeping well at night • Appetite is good and has not changed suddenly	Keep doing: • Take your medicines as directed • If on oxygen use as directed • Continue usual activity and exercise • Continue recommended diet • Watch for changes in daily routine
Yellow Zone means a change in usual symptoms	
Symptom(s) are getting worse: • More tired and less energy for daily activities than usual • More nausea/vomiting • More pain • More shortness of breath • Poor sleep or new symptoms that cause awakening • Less appetite than usual • Medicines are helping less than usual • Increased or new swelling • More difficulty swallowing foods or medicines • New or worsening memory loss • Change in bowel habits, new constipation or diarrhea • Changes in skin like new bruising, discoloration	Actions to follow: • Take your extra "as needed" medicines as directed • Track use of "as needed" medicines to share with your doctor/nurse • Track your episodes of nausea/vomiting and/or bowel movements • Call your doctor/nurse if symptoms get worse • Your doctor/nurse may adjust your medicines Phone number: .....
Red Zone means symptoms need immediate attention by your doctor/nurse	
Symptom(s) are NOT under control: • Medicines are no longer helping your symptoms • Pain that cannot be controlled • Severe shortness of breath • Unable to eat/drink and/or take medications by mouth • Wound or skin red, swollen, and/or hot to the touch • Fever • Seizure(s) • Unable to sleep for more than 24 hours • Significant change in usual bathroom habits • Sudden drop in mental alertness • New facial swelling • Loss of ability to move or limb weakness	Actions to follow: Call your doctor/nurse right away, 24 hours a day, 7 days a week You may need to be checked to see if there are other ways to manage your symptoms Phone number: .....

Managing Medicines

You may be taking one or more medicines. These could be for your symptoms and/or side effects from your cancer or cancer treatment. Take all medicines as directed by your doctor/nurse. Speak to them before making any changes.

Pain Prescribed medicine name, if any:	You can take pain medicine when needed, or throughout the day and night. At first, some may make you sleepy, but this usually goes away. Opioids cause constipation, so always use a laxative along with them.
Fatigue Prescribed medicine name, if any:	Only a few medicines help with fatigue. Ask your doctor/nurse if nothing else has helped. Take any medicines as directed. They usually work in a few days. Stop taking them if they do not work.
Shortness of Breath Prescribed medicine name, if any:	There are different medicines for shortness of breath. You can take them when needed, or throughout the day and night. Some of these medicines can make you jittery and/or make you sleepy at first. Oxygen can also help with shortness of breath. If your doctor/nurse suggests oxygen, please see Appendix D for oxygen safety tips.
Loss of appetite/weight loss Prescribed medicine name, if any:	Unfortunately, losing your appetite and losing weight are normal with many cancers and there are not many good medicines to help with this. Ask your doctor/nurse if nothing else has helped. Take any medicines they suggest as directed.
Nausea/Vomiting Prescribed medicine name, if any:	These medicines work best when you take them an hour before eating or throughout the day as directed. A combination of medicines, diet, and size of meals may work best.

Your doctor/nurse will order the medicine that best fits your specific symptoms. They may change medicines over time.

Taking Care of Yourself

Eating Well

Eating Well Tips

A healthy diet is an important part of living with cancer. Eating well can help with:

- Feeling better
- Having more energy
- Preventing weight loss
- Keeping up strength
- Side effects of nausea, diarrhea, or taste changes
- Lack of appetite

Please see Appendix C for recommendations for handling cancer eating challenges.

Spiritual and Emotional Well-Being

Spiritual Life and Cancer

Your spiritual and/or religious beliefs may help you cope with your cancer diagnosis. They can help with:

- Feeling better
- Reducing depression, anxiety, and hopelessness
- Additional treatment options

Grieving your losses

Grief can happen with cancer. There can be many losses and it's normal to grieve the ways your life has changed. Ways to manage this are:

- Let yourself feel and process your feelings. Try to enjoy the time you have with those who matter. Writing in a journal may help.
- Recognize that it is common to have feelings of both letting go and holding on all at once. There is no right or wrong way to grieve.
- Talk with someone you trust about your grief. It could be a family member, friend, trusted coworker, or someone who has had a similar experience.
- Make sure to take care of yourself. Take breaks when you can. Ask for help if you need it and consider a support group.

Additional Treatment Options

Having cancer is stressful physically, emotionally, and spiritually. Cancer treatment can also be hard. It is also stressful for those close to you. Having extra resources can help. Here are some you should ask about:

Palliative/Supportive Care

In addition to your cancer treatment, you can also get palliative or supportive care. This kind of care helps people living with cancer stay at home instead of going to the ER/hospital. Palliative care can reduce physical discomfort, improve quality of life, and make living with cancer easier both for you and those who help care for you. The goal of palliative care is to improve your quality of life. It may also help you tolerate your cancer treatments better. That means you may get them for a longer period of time, and you may get better results, while still living your life and doing things that are important to you.

Palliative or supportive care involves a team. A nurse, doctor, aide, pharmacist, social worker, and chaplain are often on this team. They work together with your doctor(s) to provide an extra layer of support.

Hospice Care

Unfortunately, sometimes cancer treatment stops working, or treatment becomes too hard to take. Stopping treatment often means the cancer will get worse. This can cause physical discomfort, emotional distress, and more symptoms.

You and those who matter most to you will need even more help at this point. That is when people choose hospice. Hospice is a team that comes to your home or wherever you are to help you live as well as possible. They will be there when you need them. Their team will support you—whenever, wherever, however you need them.

Palliative Care (Center to Advance Palliative Care)

Palliative Care (ACS)

Hospice Care

End-of-Life Care

Questions About Hospice Care

Find a Hospice Provider Near You

Talking About Cancer

It can be hard to know what to say when talking to someone who has cancer. If you are the one living with cancer, it may also be hard to keep friends and other loved ones updated. Here are some suggestions:

- Ask Open-Ended Questions
  Ask questions that start with "what," "when," "where," and "how." This encourages people to think and reflect on what is happening. It lets someone tell you what is important to them. This may help you know where things stand and decide on any next steps.

- Use Simple, Easy-to-Understand Language
  Use plain language when possible to help reduce miscommunication. It gives people a better chance of understanding each other. Try to use familiar words and phrases.

- Actively Listen
  Talking about cancer can be hard. Make sure you keep the focus on the person talking and spend time listening to what they say. Be sure to make eye contact, repeat points back, and be supportive. This shows that you have been listening, which means a lot.

- Be aware of your boundaries
  Talking about cancer does not have to mean doing something uncomfortable. The important thing is to start the conversation. Remember to stay within your boundaries. And do not feel obliged to talk if you do not want to.

How to Talk About Cancer

Planning Ahead: Talking to Those Who Matter About What's Important to You

- You have a say in your care

  - Getting the health care you need often involves decisions. You can and should speak up about the kind of care you want. Tell your doctors what matters most to you. And tell those closest to you what you would want if you can no longer make decisions for yourself.

  - You do not need to cover everything at once. It is a process, and you can change your mind even after you have stated your thoughts. Once you start talking, it will get easier.

- Ways to start talking
  - Talk about a recent illness of someone you know, maybe someone else with cancer. What did you think about what happened? Is that the kind of care you would have wanted? Why or why not?
  - Use a doctor's appointment or change in your cancer symptoms to talk about what matters most to you.
- What to do
  - Pick someone who understands your choices and can speak for you, if you are no longer able, as your health care power of attorney/proxy.
  - Write your thoughts down in an Advance Directive document. Focus on your values and preferences. You may not be able to predict every choice you may have to make, but you can give those who matter the most the principles to make decisions for you.
  - Share your Advance Directive with those who matter to you and with your doctor.
- Common Concerns
  - There is no need to talk about this because "those important to me know what to do."

    You cannot assume that others know what your wishes are. They may need to make decisions for you whether you have told them what you want or not. It may put a burden on them to have to make decisions for you when they're not sure what you would want. Talk to them now to make sure they know.
  - I'm not sure talking about what I want will make a difference.

    You may worry about losing control when you're ill. But letting those who matter most to you and your doctor know what you want can make a difference. Otherwise, they will have to guess. Talking now lets you have some control over what happens to you in the future.
  - I'm feeling fine, so we don't need to talk about this now. Let's wait and handle things as they come up.

    We like to think we'll always be able to make decisions for ourselves. But things can change suddenly and quickly. Your cancer could get worse, and you might not be able to speak for yourself. Making your values, preferences, and choices known now will help everyone, including the doctors, be able to care for you the way you want.

Prepare for Your Care

Conversation Project

Five Wishes

Advance Care Planning

ACS Giving Docs

Appendix A: Managing Other Cancer Symptoms

Symptom	Action to take
Anxiety or Worry	• Take any medication for anxiety as directed. • Create a calm and quiet environment. Decrease over-stimulation. • Provide active listening, validation, and reassurance without judgement. • Distract by going for a walk or outside. Thinking about good things, watching a movie, walking outside, or listening to music can help. • Relax by taking slow and deep breaths. Meditation or guided imagery can also help. • Use essential oils like lavender, sandalwood, or lemon. Make sure there are no allergies or skin sensitivities. • Offer a caring touch, such as holding hands or a hand on the shoulder.
Urinary Problems	• Take any medication for this as directed. • Drink eight glasses (8 oz. each) of fluid daily if you can. This helps reduce bladder irritation. But stop at least 4 hours before bedtime to avoid getting up often at night. • Avoid caffeine (coffee, tea, or colas), alcoholic beverages, spicy foods, and tobacco products. • Get plenty of sleep. • Increase physical activity if you're able.
Confusion or Restlessness	• Take any medication for this as directed. • Create a calm and quiet environment. Decrease over-stimulation. • Redirect and reassure someone using a calm voice. • Explain what you're going to do before you do it. • Do not startle, rush, or argue. Ask or let them know before touching. • Stick to a routine. Keep a regular schedule for meals, activities, and sleeping. • Keep surroundings familiar. Keep familiar items close. • Speak to the doctor/nurse if agitation and restlessness cannot be managed with these tips.

Constipation	• Take whatever laxative may have worked for you in the past. Something that stimulates your GI system is better than a stool softener. • Move more if you can. Walk, stretch, get gentle exercise. • Drink more fluids. • Eat fiber such as bran, whole grains, popcorn, fresh fruits and vegetables if you can. • Talk to your doctor/nurse about other medicines for this.
Depression, Sadness	• Look to those who matter most to you for support. • Consider talking to a counselor or spiritual advisor. • Talk to your doctor/nurse about your feelings. • Be open to medicine for depression.
Diarrhea	• Take any medication for this as directed. • Try to drink a lot of fluids so you do not get dehydrated. • Avoid caffeine and alcohol. • Avoid extremely hot or cold fluids. • Avoid milk and milk products (except yogurt).
Dry Mouth and Lips	• Use alcohol-free mouthwash and/or saliva substitutes regularly. • Use mouth moisturizer sprays and/or ointments. • Try lip balm or petroleum jelly on your lips. • Try sugar free candy, or chewing gum if you can. • Try sucking on ice chips. • Sleep with a humidifier in the room.

Sleep Problems	• Take any medication for this as directed. • Try to go to bed and get up at the same time each day. • Reduce/avoid napping during the day. • Open blinds/curtains during the day to let in natural light. • Make sure the room is cool, dark, and quiet at night. • Reduce stimulation 30 minutes before bedtime. • Reduce/avoid liquids, heavy meals, and caffeine and alcohol before bedtime. • Relax by taking slow and deep breaths. Try meditation or guided imagery. • Try white noise such as rain or calming nature sounds. • Set a comfortable temperature in your bedroom. • Stop using your devices before sleeping. • Talk to the doctor/nurse before taking/giving any over-the-counter sleep medicines.
Mouth Sores	• Keeping your mouth and teeth clean can help. • Rinse mouth frequently with solution of 16 oz. warm water, 1 tsp. baking soda, and 1 tsp. salt if you can. • Avoid smoking/chewing tobacco. • Avoid acidic drinks like orange or tomato juice. • Avoid commercial mouthwashes. They often have alcohol that can sting. • Drink through a straw to keep fluids away from the sore spots.
Nerve Discomfort in Hands or Feet	• Take any medication for this as directed. • Reduce your risk of falling by making sure your home is safe. Clear pathways of rugs, furniture, etc. Use handrails on stairs and install handrails in the bathroom.
Sexual Dysfunction	• Speak to your doctor/nurse if your treatment causes any issues with sexual activity.

Appendix B: Additional Resources

American Cancer Society Side Effect Manager

American Cancer Society

Cancer Today Magazine

Lance Armstrong Foundation

MyLifeLine.org

National Cancer Institute

National Center for Complementary and Integrative Health

National Coalition for Cancer Survivorship

Appendix C: Managing Eating Challenges

Appetite Changes	If you do not feel hungry or feel full too quickly	• Eat 5-6 small meals throughout the day, instead of 3 big ones. • Eat with others or watch TV to take your mind off your appetite. • Have easy-to-eat, easy-to-prepare foods in the house. • Keep an eating and drinking schedule. Set an alarm to remind you to eat. • Keep snacks nearby.
Changes in Taste/ Smell	If everything tastes bland/has no taste	• Add stronger flavors onto foods. Try condiments, sauces, dressings, etc. • Add spices or seasonings. • Suck on sour candies before/after a meal. • Try different foods to find what's appealing.
	If everything tastes metallic/bitter	• Add sweeteners like honey or maple syrup to mask a bitter taste. • Eat fish or chicken if red meat tastes metallic. • Use plastic utensils instead of silverware. • Avoid cooking on iron skillets.
	If the smell of food makes you not want to eat	• Avoid being in the kitchen while food is made. • Eat cold/room-temperature foods instead of hot ones. • Light a scented candle. • Open a window or turn on a fan.
Problems Chewing or Swallowing	Eat foods that are easier to chew and swallow	• Eat soft foods like eggs, oatmeal, soft pasta, soups. • Try soft proteins like fish, ground meat, beans. • Try high calorie drinks like smoothies, milkshakes, or nutritional supplements.
	Stay away from hard foods that cause chewing or swallowing pain	• Avoid hard foods like crackers, crusty breads, raw vegetables, crunchy cereals. • Avoid tough meats like steak, pork chops, or chicken breast. • Avoid acidic foods like tomatoes or citrus.
	Make foods easier to chew and swallow	• Add dressings, sauces, or gravy. • Puree foods in the blender.

Constipation		• Try high-fiber foods like whole grains, fruits, vegetables, nuts, beans, if you can. • Try prunes and other dried fruits and juices. • Drink hot beverages like tea or decaf coffee.
Diarrhea		• Drink fluids with electrolytes like coconut water, broth, electrolyte drinks like Gatorade. • Eat probiotics like yogurt, kefir, or fermented foods.

Dry Mouth		• Avoid alcohol and limit caffeinated drinks.
		• Increase saliva.
		  • Suck on sugar free tart candies before eating.
		  • Chew on sugar free gum between meals.
		  • Add lemon/lime to water.
		  • Use citrus fruits in marinades/dressings.
		• Limit dry/hard-to-swallow foods (baked potatoes, peanut butter, tough meat, doughy bread).
		• Drink enough fluids to prevent dehydration.

Mouth Sores and Mouth Pain	Food tips for mouth sores and mouth pain	• Eat soothing foods.
		  • Cold foods (popsicles, ice cream).
		  • Soft, mild foods (cottage cheese, yogurt).
		  • Well-cooked, soft foods (potatoes, macaroni and cheese, casseroles).
		• Avoid irritating foods.
		  • Acidic/spicy foods (citrus, tomatoes, peppers, vinegar).
		  • Alcohol and carbonated drinks.
		  • Crunchy/hard foods (pretzels, chips).
		  • Hot foods (eat room temperature or cold).

	Non-food tips for mouth sores and pain	• Drink through a straw to avoid sore spots. • Suck on ice chips to help with mouth pain. • Use a baking soda rinse before and after meals.

Nausea and Vomiting	Food tips for nausea and/or vomiting	• Eat small amounts of food every 1 – 2 hours as an empty stomach can make nausea worse. • Eat bland foods (plain pasta, rice). • Eat room temperature or cold foods. • Drink ginger tea or chew ginger candies. • Drink hydrating fluids. • Limit fried, greasy, "heavy" foods.
Weight Loss		• Eat healthy high-calorie foods (avocado, olive oil, nuts, seeds, cheese, dried fruit, peanut butter). • Eat 5-6 small meals throughout the day instead of 3 big meals. • Include high-calorie smoothies/nutritional drinks. • Include high-protein foods (nuts, beans, meat, fish, poultry, eggs, dairy products).
Weight Gain	Eat healthier foods	• Avoid higher-calorie foods (rich sauces, cheese, oils, fried foods). • Eat more lower-calorie fruits, non-starchy vegetables, and high-fiber whole grains. • Eat baked/broiled fish and lean meats (skinless chicken, turkey breast). • Avoid empty calories.

Appendix D: Oxygen Safety

Oxygen can help those with cancer breathe better. Having oxygen in your home can be hazardous and requires special handling. It is very important to keep any type of fire or flame away from you and your oxygen supply.

Tips for Using Oxygen Safely

- Turn off oxygen when not using.
- NEVER smoke or allow anyone else to smoke in the room when oxygen is turned on.
- Put "no smoking" signs in your house, on the door.
- Avoid any open flame, including cigarettes, matches, pipes, lighters, candles, fireplaces, gas burners, and pilot lights.
- Keep all oxygen tanks 5-10 feet away from any heat source or anything that could create a spark. This includes space heaters, e-cigarettes, electric razors, hair dryers, electric blankets, and friction toys.
- Keep the door to the room open to circulate air.
- Do not spray aerosol cans when oxygen is turned on.
- Do not use petroleum-based lotions or creams like Vaseline.
- Store oxygen in a well-ventilated area away from direct sunlight.
- Do not change the rate of oxygen flow without talking to your doctor/nurse.

TURN OFF OXYGEN IMMEDIATELY IF IT STARTS MAKING A HISSING NOISE

Appendix E: Glossary

- Adjuvant Therapy: Additional treatment to the main treatment. This can be hormone therapy, chemo, radiation, or immunotherapy. These may be added after surgery to increase the chances of controlling the cancer.
- Advance Directive: A legal form that lets you have a say about how you want to be cared for if you cannot speak for yourself.
- Anemia: When your blood does not have enough red blood cells. This can make you feel short of breath, or you may tire easily.
- Chemotherapy (Chemo): A general term for drugs given to stop or slow cancer cells from growing.
- Chemo Brain: A change in mental "sharpness." You may have trouble remembering certain things, and/or finishing tasks. Your concentration may go down. This can happen at any time during the cancer, before or after treatment.
- Complete Blood Count (CBC): This test tells the number of red blood cells, white blood cells, and platelets in your blood.
- Hematologist: A doctor who treats blood disorders, including blood cancers.
- Hormonal Therapy: Drugs that slow or stop cancers using hormones.
- Immunosuppression: When your immune system is weak. This can happen with cancer or cancer treatments. It means you have a higher risk of getting an infection.
- Immunotherapy: Drugs that use the body's immune system to fight cancer.
- Living Will: A legal form that lets you have a say about how you want to be cared for if you cannot speak for yourself. This is also called an advance directive.
- Medical Decision Maker: A form where you say who should make medical decisions for you if you cannot.
- Metastasis: When the cancer has spread from the original site in the body to other parts of the body.
- Neutropenia: Having a lower number of white blood cells. White blood cells fight infections. A lower number means you have a higher risk of getting an infection and/or harder to get over one.
- Oncologist: A specialist doctor who treats cancer.
- Radiation/Radiotherapy: A treatment that uses x-rays to kill cancer cells.
- Radiation Oncologist: A specialist doctor who uses radiation to treat cancer.
- Side Effects: Effects of treatment such as hair loss, low blood counts, and being tired. Many side effects can be managed.
- Targeted Therapy: Cancer treatment that attacks proteins that help cancer cells grow, divide, and spread.

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