

Cancer is a complex group of diseases, and cancer treatment involves making many choices about your options, and your life. You can be an informed partner with your health care team in making these decisions to help ensure that your values and goals drive the decision-making process. Here are some tips to help you make informed choices to treat your cancer and address the key issues in your life.

## HOW TO BE A MORE EFFECTIVE ADVOCATE FOR YOURSELF



- **Communicate.** Make sure you have a doctor, or doctors, and a health care team with whom you can communicate openly and honestly. It's important that your health care providers know and trust you, and that you trust them.
- **Listen and make sure your voice is heard.** Your health care providers need to listen to you and your caregivers, and you need to listen to them.
- **Prepare for your appointments.** Make a list of your most important questions. Take notes during the appointment. Whenever possible, bring someone with you as another set of ears and eyes.
- **Know your diagnosis and the details of your cancer.** Cancer treatment is complex and depends on the exact type of cancer you have. Find out as much as you can about your precise diagnosis and stage, the cell type, genetic variations and other factors that influence treatment decisions.
- **Ask for explanations.** If you don't understand what your doctor is recommending, ask them to explain it, again, and until you do understand. You cannot make shared decisions if you don't understand the treatment and care recommendations.
- **Tell your health care team what matters to you.** Making informed choices often depends on communicating your personal and health care goals and priorities at every critical decision point in your journey. This includes telling your health care team if you are having problems with the cost of your care or paying for the essentials in your life.
- **Use your whole team.** Your doctors are key, but good cancer care is a team effort. Nurses, nurse practitioners, patient navigators, social workers, pharmacists and financial counselors are all important sources of information. These team members often have more time to spend with you and answer your questions.
- **Don't be afraid to get a second opinion.** Cancer is a serious diagnosis, and it is often a good idea to get a second opinion especially if you and your doctor are not communicating well, or if you want to learn about other treatment options.
- **Ask for information.** Your cancer center and health care team often have good information about your cancer and its treatment and know where to find additional resources.
- **Ask about options.** Today, there are often options for treatment. These can have different potential benefits and side effects. They may be more or less expensive. Some options may require more appointments or procedures. You can discuss what is best for you with your treatment team.

**Ask questions. Advocate for yourself and others. Talk to other patients. Ask for information that is specific to your cancer.**

- **Ask about the costs of your care.** If you are worried about your ability to pay for your care or the cost of your care on your life, tell your provider. This will not affect the quality of your care.
- **Patients and caregivers vary enormously in how much information they want to find from sources other than their health care teams.** Whatever your preference, use only reliable sources. These include information from the National Cancer Institute and other government agencies, comprehensive cancer centers and well-respected patient organizations and advocacy groups. If you're not sure, ask your doctor or nurse about the source.
- **Ask for a Care Plan.** This can be either a written document or entered into your electronic medical record. A Care Plan is an excellent way to help you understand your treatment and make shared decisions.
- **Use your electronic medical record or patient portal.** There's a lot of important information in this resource, including your test results and medications. It's also a useful way to communicate with your health care team.
- **You will learn as you go.** Almost no one knows much about cancer treatment on the day they are diagnosed. That can be overwhelming. But, as you go through treatment, you will learn more about your condition and its treatment and care. You will "speak the language," and ask more informed questions.
- **Know that things will change.** Today, people are living for long periods of time with their cancers. This means that you will have many decisions to make about your life, your treatment and your care.
- **Talk to and listen to other patients and caregivers.** You can learn from other people who share parts of your experience and help others as well. It's important to remember that your care and treatment are individual and that they will often be different from what other people experience.



This tip sheet was developed in collaboration with PAF and the VCU Massey Comprehensive Cancer Center, with support from the Danaher Foundation, to promote patient education and empowerment.

The VCU Massey Comprehensive Cancer Center's mission is to reduce the state cancer burden for all Virginians by addressing the confluence between biological, social, and policy drivers through high-impact, cutting-edge research; person-centered care across the continuum, from prevention through survivorship; community integration; and training the next generation of community-centric researchers and healthcare professionals.

**ADDITIONAL RESOURCES**



- Resources Addressing Financial Barriers
- Resources Related to Health Insurance Communications
- Resources Addressing Medical Costs
- Additional Self Advocacy Resources



Patient Advocate Foundation (PAF) is a national 501(c)(3) non-profit organization that assists patients with chronic or severe illnesses in accessing high-quality, affordable, equitable health care. PAF provides in-depth case management, financial and social needs navigation, patient education, and direct financial aid for eligible patients. PAF works to ensure a more equitable healthcare system and to bring patient voices to the center of treatment and care.