

# Oncologist-approved cancer information from the American Society of Clinical Oncology

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## **Taking Charge of Your Care**



Listen to the Cancer. Net Podcast: Cancer Self-Advocacy [1], adapted from this content.

Being a self-advocate involves taking an active role in your cancer care. It can be a positive experience, often giving people a sense of control in a time of uncertainty. Self-advocacy doesn't have to be time-consuming or difficult; it can be as simple as asking more questions at a doctor's appointment. Furthermore, being a self-advocate doesn't mean that you alone are responsible for your cancer care. In fact, it commonly involves seeking additional support from others, including friends, family members, and health care professionals.

#### Being a self-advocate

Self-advocacy is an ongoing process that begins at diagnosis and continues through follow-up care after treatment. To get started as a self-advocate, you may want to:

- Ask questions of your doctor and other <u>members of your health care team</u> [2].
- Learn more about your <u>type of cancer</u> [3] from reliable websites, such as Cancer.Net and the <u>National Cancer Institute</u> [4], or from your doctor. Cancer.Net also lists <u>patient information resources</u> [5], which includes organizations that provide educational material, programs, services, and support for people with cancer and their families. Discuss this information with your doctor or nurse.
- Ask about and take advantage of other services offered at your doctor's office, hospital, or clinic, such as <u>counseling</u> [6], patient navigation services, <u>support groups</u> [7], nutritional counseling, and fitness or movement classes. Before you begin an exercise program, consult your doctor.
- Make connections with other people living with cancer, and learn from those who have had similar experiences. Some patient organizations have programs that pair survivors with people who have been recently diagnosed with cancer. Some examples include the American Cancer Society?s Reach to Recovery program [8], the Pancreatic Cancer Action Network's PALS (Patient and Liaison Services) Survivor and Caregiver Network [9], and Imerman Angels? [10] matching program. Learn more about finding a support buddy [11].
- Consider seeking a second opinion [12] about your diagnosis or treatment plan, which may help you feel more confident about your choices.
- Don't be afraid to ask for help managing nonmedical issues, such as the cost of cancer care [13], health insurance [14], transportation, and childcare. Learn more about how to address psychosocial issues [15] (emotional or social effects of cancer).

## Tips on talking with the doctor

Talking with your doctor about cancer may seem challenging. Some people experience "information overload" in these conversations and are unable to comprehend everything they hear, while others feel that asking too many questions may seem disrespectful. However, it is important to find ways to effectively communicate your needs, ask questions to understand your options and learn the doctor?s opinion, and express your preferences. Some effective strategies include:

- Keeping a record of your symptoms to help you remember the details you want to discuss with your doctor during your appointment.
- Preparing a list of questions for your doctor before your next appointment. For some ideas, read about types of questions [16] you may want to ask your doctor.
- During your appointment, take notes, record important conversations, or bring a friend or family member to keep track of the details. All of
  these methods allow you to more accurately review the information after the appointment.
- Tell your doctor up front how much information you want. For example, some patients like to know everything about their disease, including statistics and chances for recovery, while others prefer to hear the least amount of information necessary to make good decisions about their treatment plan.
- Don't be afraid to speak up if the information you receive doesn?t make sense. Doctors want to ensure you fully understand the information they provide to you.
- Make sure you know the next step of your care before leaving the doctor's office.
- Ask if there is any written information you can take home to help you remember what you discussed in your appointment or to share with friends and family.

#### Finding additional help

Sometimes, even after taking these steps, you may still have concerns. In such cases:

- Talk with a third party, such as the head nurse or your family doctor. They may be willing to discuss the matter with the doctor or offer helpful
- If you are having a problem with a doctor or another member of your health care team while in the hospital, speak with a social worker [17] or a hospital patient service representative.
- If your doctor's communication style does not match yours or you want a different approach for your care, consider finding a new doctor or health care team. Ask for references from friends, family members, and other people with the same type of cancer. In addition, call your insurance company to find out whether the new doctor is part of your plan?s network and how much extra it would cost to see the doctor if he or she is not in-network. Learn more about choosing a doctor [18] and finding a treatment facility [19].

#### **More Information**

Managing Your Care [20]

### **Additional Resources**

Cancer Patient Navigation [21]

National Coalition for Cancer Survivorship: The Cancer Survival Toolbox [22]

The Patient Advocate Foundation [23]

#### Links:

- [1] http://www.cancer.net/sites/cancer.net/files/Cancer\_Self-Advocacy.mp3
- [2] http://www.cancer.net/node/24957
- [3] http://www.cancer.net/cancer-types [4] http://www.cancer.gov/
- [5] http://www.cancer.net/node/25325
- [6] http://www.cancer.net/node/24699 [7] http://www.cancer.net/node/25383
- [8] http://www.cancer.org/treatment/supportprogramsservices/reach-to-recovery
- [9] http://www.pancan.org/section\_facing\_pancreatic\_cancer/find\_support\_resources/connect\_with\_survivors\_caregivers.php [10] http://www.imermanangels.org/
- [11] http://www.cancer.net/node/24526
- [12] http://www.cancer.net/node/25355
- [14] http://www.cancer.net/node/24918
- [15] http://www.cancer.net/node/25010
  [16] http://www.cancer.net/all-about-cancer/newly-diagnosed/questions-ask-doctor?cpsextcurrchannel=1
- [17] http://www.cancer.net/node/24556
- [18] http://www.cancer.net/node/24949 [19] http://www.cancer.net/node/24527
- [20] http://www.cancer.net/node/25015
- [21] http://www.cancerpatientnavigation.org [22] http://www.canceradvocacy.org/toolbox/
- [23] http://www.patientadvocate.org/