

## Are you newly diagnosed with cancer? Here's what you need to know:

- 1. **Know your exact diagnosis and stage of disease –** gather the facts and write them down in a notebook. Ask questions like:
  - a. What is the exact name of my cancer?
  - b. What is the stage of my cancer?
  - c. Is there anything we know or can learn about my disease that will help guide my treatment decisions such a biomarker or genetic test?
- 2. Write down your questions and concerns in advance of your appointment and bring the questions to your appointment. Think about what it is you want the health care team to know about you personally and your goals as you explore treatment options together.
- 3. **Bring a family member or friend with you to medical appointments** to listen, take notes, ask questions and help you to talk through the information after the appointment.
- 4. Become informed about your treatment options and goals of care.
  - a. Are there treatments available, if so, what are the different treatment options?
  - b. What are the goals of treatment can my cancer be cured or are we treating it with other goals in mind?
- 5. Ask about the risks and benefits of any given treatment.
  - a. How well has the treatment been shown to work in my type of cancer?
  - b. What are the potential side effects of the treatment and how are they prevented or managed?
  - c. How will the treatment be given?
  - d. How often will my treatment be given?
  - e. How much will my insurance pay for the treatment and all of the surrounding care and how much will I have to pay myself?
- 6. Ask your doctor how much time you have to make a decision and begin treatment. In most cases, you have time to make decisions about your care and treatment. This will allow you time to do more research, get a second opinion and even consult with a decision counseling expert to discuss your options and personal goals and wishes.
- 7. **Get a second opinion.** Every patient has a right to a second or even third opinion, and your doctor should support your desire to do so. Oftentimes people seek a second opinion from a doctor in a different cancer center or academic medical center in order to explore all care options and to see if there is any new science they should know about.

- 8. **Ask if there might be a clinical trial that is right for you.** Many people don't realize that a clinical trial can be explored at the point of diagnosis and may be a possible treatment option early on. Here are three common myths about cancer clinical trials:
  - MYTH: *I will get a placebo or sugar pill in a cancer treatment trial.* FACT: You will get the standard of care OR the standard of care plus the new medicine being studied. Cancer clinical trials rarely use a placebo unless there is no existing standard of care.

MYTH: You should only consider a clinical trial as a "last ditch effort" when all other treatments have not worked.

FACT: Clinical trials are available for many different cancers at many different stages of disease. Ask about trials early on in your diagnosis. It may be that if you start a treatment and then discover a trial later on, you may not qualify for the trial since you have already started treatment.

- MYTH: I will not get good medical care in a clinical trial I will be a guinea pig.
  FACT: People in clinical trials report getting excellent care and medical attention. In addition, many people feel as if they are giving back by helping to advance the science.
- 9. Take time to get to know your insurance coverage. Most people say you don't really know how good your coverage is until you have to deal with a serious health issue. Ask if there is a financial counselor or social worker who can help you find out how much of your doctor and hospital bills, surgery, cancer treatment and other medications and supportive care will be covered under your plan. Ask about co-pays, deductibles and other costs you may have to pay. Make sure all of the health care professionals and the locations of care are considered in your network or that you understand what it means to be treated out of network.
- 10. Ask to be screened or talk to someone about emotional and social distress. Please know that a diagnosis of cancer can raise many personal issues including feeling depressed, anxious, and scared or confused. These feelings are normal and are experienced by many people diagnosed with cancer. A brief distress questionnaire and a discussion with a professional such as a social worker or navigator can help you with your concerns and connect you to helpful resources and support. Whether you are looking for information on how to talk to your kids, challenges at work, information about financial and insurance concerns, or are just looking for someone to talk to about the stress cancer has brought into your life, help is available.
- 11. **This is not your grandmother's cancer.** We are doing a better job than ever before of treating cancer in the United States. There are many new treatment options for different cancers and new treatments that do a better job of targeting the disease to create a personalized cancer care plan for you. Ask your doctor about targeted therapy, immunotherapy and other new treatments that may be right for you.

## For information, support and additional resources, contact the Cancer Support Community at 1-888-793-9355 or visit our website at <u>www.cancersupportcommunity.org</u>

So that no one faces cancer alone. ®