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Communicating With Your Health Care Team

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Communicating With Your Health Care Team

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Your team of doctors, nurses and social workers is a valuable source of support as you cope with a cancer diagnosis.

When you first heard the word "cancer," you may have felt shocked, scared or numb. Reactions to a cancer diagnosis are unique; there is no right or wrong way to respond to such news. Many people who have been newly diagnosed with cancer face similar challenges. You may want to obtain more information about the diagnosis and your treatment options, ask questions to understand how the treatment plan will affect your life and find out what resources may help prepare you for what lies ahead.

The relationship you have with your health care team can make a big difference in how you cope with these challenges. Research shows that people who maintain and foster good communication with their health care team are more satisfied with their medical care than those who do not. They also tend to fare better emotionally and cope better with the symptoms of their cancer and the side effects of their treatment.

This booklet discusses ways to develop good communication with your health care team so you have access to the best possible care. It also explores ways you can take an active role in your care as a key member of that team. After all, you are the person who best knows how your treatment is affecting your quality of life and what issues are most important to you.

Meet the Members of Your Team

Today, cancer is treated through a "multidisciplinary" approach, with many different kinds of health care professionals coming together as a team to care for a patient. Some of the professionals who work with people coping with cancer are:

- Medical oncologists
- Surgical oncologists
- Radiation oncologists
- Oncology nurses
- Oncology social workers
- Registered dietitians
- Psychologists and psychiatrists
- Pain specialists (anesthesiologists, neurologists, orthopedic oncologists and others)
- Plastic surgeons (for reconstructive surgery)
- Rehabilitation specialists (physical therapists, occupational therapists and speech therapists)
- Community and hospital pharmacists
- Home health aides

One doctor, usually a medical oncologist, coordinates your care. Other important professionals include financial specialists, case managers and patient navigators to help guide newly diagnosed patients around any obstacles to receiving the best possible care. Keep in mind that you, too, are a key member of the team.

Making the Most of Your Medical Appointments

Your doctors' appointments provide the best opportunity to speak with members of your health care team.

It is normal to feel nervous when going in for an appointment; you might worry that you will forget to ask an important question or that your doctor will be too busy to listen to your concerns. Such fears are normal, and good preparation can improve how comfortable you are during your appointments. It also can make you more satisfied with your appointments overall. Here are some tips for communicating with your health care team during appointments:

Write down your questions or ask if you can record the discussion. Bring a written list of any questions you have.

Questions to Ask Your Doctor

Getting as much information as you can about the goals of your treatment and how it may affect your life will help you feel more satisfied with your care. Some questions you may want to ask your doctor include:

- What is the type and stage of my cancer?
- Where can I learn more about my diagnosis and treatment options?
- What is the recommended treatment?
- How often will I receive treatment?
- What are the possible benefits and risks of this treament?
- What are its possible side effects?
- How much will my treatment cost?
- If I have questions during my treatment and you are not available, who can I ask?
- Is another doctor, physician assistant, nurse practitioner, or other medical professional available if you're not?
- Is there any information I can read or watch about this treatment or procedure?
- Who should I call in case of an emergency?
- Is there anything else I should know?

Number your concerns in order of importance and ask the most important questions first. Let your doctor know you have a list so he or she can set aside some time during the appointment to go over it with you.

Take notes. Write down your doctors' answers to your questions. Take down any other important information you want to remember: for example, the names of the members of your health care team, places you were referred to, dates and times of future appointments and when and how to take any medicines you were prescribed.

Keep everything in one place. It may be helpful to have a file folder or binder where you can keep all the notes and papers you are receiving. This way, nothing gets lost, and you always know where to look for the information.

Bring someone with you. Let the person accompanying you know ahead of time how he or she can be most helpful to you during your appointment. In addition to giving you support, he or she can:

- Provide another set of ears to catch key points you may have missed.
- Take notes for you as you talk with your doctor.
- Remember important information about your cancer or other symptoms that you may have forgotten.
- Advocate on your behalf, especially if something is unclear to you.

Make sure you understand. If you don't understand what something means, ask. Make your questions specific and brief. Other tips include:

- Refer to yourself whenever possible; saying "I don't understand" is more effective than "You're being unclear."
- Try repeating the information back to your doctor: "So you mean I should...?"
- If you understand better with visual aids, ask to see the x-rays or MRIs or ask your doctor to draw a diagram.

Ask for a contact. Important questions may come up between appointments. Find out whether there is someone you can talk to if you have an important issue or emergency.

If your doctor is unavailable, is there someone else, such as another doctor, physician assistant, nurse practitioner or other medical professional you can call in an emergency? If you have a less-urgent issue, is a nurse or oncology social worker available that you can call?

Besides calling, is there another means of communication that you can use to contact your doctor? Some doctors provide their patients an e-mail address they may use to ask questions that arise between medical appointments.

Understanding Your Treatment Options

One of the best ways to begin making good health care decisions is to educate yourself. Your doctor and others on your health care team are very knowledgeable about the different aspects of cancer and will likely be your main source of information about your diagnosis and treatment. Here are some tips for communicating with your health care team about your treatment options:

Do your research. Once you know the type and stage of cancer you have, try to find out what the standard of care is for someone with your diagnosis. Ask your doctor or nurse to suggest reliable organizations, publications or websites that focus on the diagnosis or the recommended treatment. If you are unable to use the Internet yourself or feel overwhelmed with the amount of information you are finding, ask a family member, friend, patient navigator or local librarian to help you.

Use the Internet with caution; there is a lot of information online about various types of cancers and cancer treatments, and not all of it can be trusted. It is important to educate yourself with credible sources and information that is specific to your diagnosis. Is the source a major cancer center, cancer organization or hospital or an individual or company trying to promote a particular product or "cure"? If you're in doubt, print out the information and show it to your health care team on your next scheduled visit.

Work with a specialist. Doctors who specialize in treating cancer are called oncologists. For the best medical care, it's important to work with an oncologist who specializes in treating your type of cancer. This is especially important if you have been diagnosed with a rare cancer. To find a specialist, you can:

- Ask your primary care physician for a referral.
- Get recommendations from friends, family members or other people with the same diagnosis.
- Call your health insurance company's customer service line and ask a representative for a list of local specialists in your network.
- Search online—many professional and cancer organizations provide searchable listings of cancer specialists. For example, the American Society of Clinical Oncology maintains a database of oncologists on their website at www.cancer.net/find-cancer-doctor.

Another option is to choose a cancer center known for providing high-quality patient care and then select a specialist at that hospital. Many patients choose this option even if they need to travel long distances for appointments. For a list of cancer centers recommended by the National Cancer Institute, go to http://cancercenters.cancer.gov/ or call 800-4-CANCER.

It's important that you feel comfortable with and trust your doctor. If your oncologist does not specialize in treating your diagnosis, he or she can still consult with a specialist about your treatment options.

Agree on the treatment goals. When your doctor recommends a specific treatment or procedure, such as surgery, make sure you understand the reason or reasons why. Is the goal to cure the cancer, control it (by shrinking the tumor or stopping its growth) or relieve its symptoms, such as pain? Let your doctor know if you have certain wishes

Keeping a Side-Effect Journal

To help you get relief from side effects, your doctors and nurses need to know the details of any symptoms you experience during or after treatment.

By keeping a side-effect journal and bringing it with you to medical appointments, you can have this kind of information ready to share with them. Some of the things you may want to write down in your journal include:

- The date and time a side effect occurred;
- How long the side effect lasted;
- How strong the side effect was—for example, if you had pain, how strong it was on a scale from 0 to 10, where 0 equals no pain and 10 is the worst pain imaginable; and
- What impact the side effect had on your daily activities—for example, whether the pain kept you from sleeping, eating, walking, working or exercising.

You also may want to include any non-urgent questions or concerns that came up since your last medical appointment.

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or preferences with regard to treatment so that they can be taken into account. Your lifestyle and daily activities may also influence treatment recommendations.

Get a second opinion. Before you begin treatment, you may want to make an appointment with another oncologist to review your treatment options. No member of your health care team will mind if you seek a second opinion. In fact, many specialists encourage it and may even provide a referral.

If you are nervous about letting your doctor know that you want a second opinion, tell him or her that you are very satisfied with the care you are receiving but just want to make sure you are aware of all your options. It's important that you feel comfortable with any decisions made in regard to your treatment options, and getting a second opinion can help you make decisions about your medical care.

Find out how the treatment plan will affect your daily life. Cancer treatments are often given at a doctor's office or hospital. However, many of today's treatments, especially hormonal therapies and several targeted treatments, come in pill form and can be taken at home. Find out where you will be treated, how often you will receive treatment and for how long. Will you need someone to accompany you to appointments or to help care for you at home? Will you be able to continue your usual activities, such as working or going to school, while you're receiving treatment? Knowing such information ahead of time will allow you to prepare for changes in your routine.

Ask about possible side effects. Find out what potential side effects you can expect from your treatment and how your health care team plans to manage them if they occur. See if there is anything you or your health care team can do to prevent or reduce the chances that you will develop certain side effects. There are effective ways to prevent side effects such as nausea, vomiting, diarrhea, constipation and pain. It's important to advocate for yourself if side effects do arise during treatment. Don't be afraid to ask your doctor about the best ways to manage them.

Discuss the cost of your care. Research shows that many patients do not feel comfortable asking their doctors how much their treatment is going to cost, and many doctors do not normally bring it up during an office visit. If possible, it is important to find out the cost of your medications before starting treatment and whether your medical insurance will cover most or all of the cost. Your doctor may not know the answer, but he or she should be able to refer you to a social worker, pharmacist or financial health care specialist who can help. If you can't afford the treatment you need, financial assistance may be available to you. Some financial help resources are listed on page 21 of this booklet.

Get the facts about reconstructive and plastic surgery. Some surgeries, such as those for head and neck cancer, breast cancer or skin cancer, may affect your appearance. Reconstructive or plastic surgery often can be done at the same time as cancer surgery, so ask about this option as early as possible. A board-certified plastic surgeon can give you information about your options. The American Society of Plastic Surgeons maintains a list of such surgeons on their website at http://find.plasticsurgery.org.

Learn about fertility-preservation options. If you plan to have children in the future or are unsure, find out whether the treatment your doctor is recommending could affect your ability to conceive. It's important to speak with your doctor about fertility concerns before you begin treatment. He or she may be able to select a treatment or technique that preserves your fertility or may be able to refer you to a sperm or egg bank prior to treatment.

Doctors do not always discuss fertility preservation, especially if they want to begin treatment right away. If this is a priority for you, make sure to discuss your concerns with your medical team from the beginning. For further information, visit www.livestrong.org/we-can-help/fertility-services.

During Treatment and Beyond

The more you feel that you can openly discuss any matters of concern to you, the better you are likely to feel about your care over the long term. Don't be afraid or embarrassed to ask questions—always seek the care you need and deserve. Here are some additional topics to discuss with your health care team:

Side effects. Chemotherapy, surgery, radiation, targeted treatments, hormonal therapy and other cancer treatments may all result in different side effects. Most side effects can be prevented or managed with medications and other techniques. Some common and often manageable side effects include:

- Fatigue (feeling very tired)
- Nausea and vomiting
- Hair loss
- Diarrhea or constipation
- Mouth sores
- Pain
- Rash and other skin changes
- Neutropenia (a low white blood cell count that puts you at risk of infection)
- Lymphedema (swelling, usually of an arm or leg)
- Neuropathy (nerve damage often resulting in periodic numbness or tingling in the hands and feet)

Talk with your doctor about any side effects or symptoms that come up. Some patients worry that if they bring up a side effect, their doctor will be distracted from treating their cancer; that is not true. Side-effect management is an important part of comprehensive cancer care—managing symptoms will make it easier for you to stick with your treatment plan.

Your feelings and emotions. Often, people need help coping with challenging emotions raised by cancer, such as sadness, anger or fear. Although family members and friends are likely to be your main source of support, you may want to seek additional help. If so, your doctor or nurse can refer you to an oncology social worker, counselor or other professional who specializes in helping people cope with the emotional challenges of cancer.

Support groups connect you with others in a similar situation to share experiences and feelings and provide support. Ask your health care team if there are local support groups that would give you an opportunity to talk face-to-face with other cancer patients in a similar situation. Cancer*Care* offers free support services such as telephone and online support groups. You also may want to explore peer-to-peer networks, which match you individually with someone facing the same or a similar diagnosis.

Practical matters. Experts agree that the highest-quality care for people with cancer is care that addresses not just their medical needs but also their "psychosocial" needs. Psychosocial support refers to services that deal with emotional concerns, as described above, and with practical issues that can interfere with completing treatment. It also includes providing support to help patients cope with day-to-day concerns so that they can have the best possible quality of life during treatment.

Some of the many practical issues your health care team may be able to help you with include:

- Getting transportation to and from treatment;
- Talking to your children about your diagnosis;
- Deciding whether, when and how to talk with your employer about your diagnosis;
- Adjusting a treatment schedule to attend a special event;
- Finding financial help for medications or household bills; and
- Arranging for home care or other services.

The members of your health care team can assist you directly with many practical matters or refer you to other support services as necessary.

Resources for caregivers and family members. A cancer diagnosis often has a ripple effect, impacting loved ones and family members. To help ensure that the needs of your loved ones are met, ask your doctor about resources available to them. For example, Cancer*Care* provides specialized support services for children and teens to help them understand and cope with a parent's or sibling's cancer diagnosis. Teenagers, for example, who have a loved one with cancer can join an online support group led by an oncology social worker at Cancer*Care.* The organization also provides free services, including individual counseling and support groups specifically for caregivers.

Your survivorship care plan. As you get close to completing treatment, it's important that you and your medical team discuss what your follow-up care will be like. In the months and years ahead, your doctors will continue to monitor you for any long-term side effects of your treatment. They also will check for cancer symptoms and signs of recurrence (return) of your cancer, of your cancer spreading or of new cancers developing.

To manage your follow-up care, ask your doctor to put together a written survivorship care plan. This document should include a summary of your diagnosis and all the treatments you received, as well as a follow-up plan of the steps you need to take to achieve the best health and well-being possible.

Cancer*Care*® Can Help

Being diagnosed with cancer raises many concerns. As discussed in this booklet, strong communication with your health care team can improve your care and quality of life as you go through treatment.

Cancer*Care* is also here to help. We are a national nonprofit organization providing free, professional support services to anyone affected by cancer. Our professional oncology social workers specialize in helping people affected by cancer, whether they are patients, relatives, caregivers or people mourning the loss of a person to cancer. We provide support through individual counseling, support groups, Cancer*Care* Connect® Education Workshops, publications, financial assistance and referrals to resources. To learn more about how we help, call us at 800-813-HOPE (4673).

More About Doctor/Patient Communication

Frequently Asked Questions

Q. Where can I find a simple explanation of some of the complicated medical terms my doctor uses?

A. The first and best place to turn to is your health care team itself. Whenever your doctor uses a term that you don't understand, ask what the word means. It is okay to tell your doctor, "I don't know what that word means. Could you please explain it to me?" Asking questions will help you understand medical terms better and what they mean for your treatment.

Another valuable resource that provides simple explanations for complex medical terms and procedures is the National Cancer Institute's Dictionary of Cancer Terms, a resource with more than 7,900 terms related to cancer and medicine. This resource is especially helpful if you are doing research between doctors' appointments. You can search the dictionary at www.cancer.gov/publications/dictionaries/cancer-terms.

Q. I know my oncologist is focused on treating my cancer, but I wish he were more compassionate toward me. What can I do?

A. Some doctors and health care teams may not have as much time as they would like to sit down and talk with you about your needs and concerns. It's also possible that some medical professionals lack training in regard to effective ways to communicate and cope with emotions. Some health care professionals are trying to change that, and many medical schools now require coursework on doctor/patient communication. Many organizations, such as Cancer*Care,* also are raising awareness of how important it is to address the full range of patients' concerns.

This booklet discusses many steps you can take to improve communication with the members of your health care team. You also can speak with an oncology social worker at Cancer*Care,* 800-813-HOPE (4673), for additional tips.

Q. I have tried to improve my relationship with my oncologist, but it's just not working with her. I really want to try another physician, but I'm scared to switch doctors. Should I just stay with my current doctor?

A. A strong relationship with your oncologist can make a tremendous difference in how you cope with your cancer and treatment. However, she is only one member of your medical team. If you are not able to communicate well

with your oncologist, try talking to a nurse, nurse practitioner or social worker associated with his or her practice. Someone else may be able to meet your needs.

If you have tried many of the tips in this booklet and nothing works, or you really believe changing doctors would improve how you feel about the care you are receiving, trust your instincts. You have a right to feel comfortable with your health care team and satisfied that you are getting the best care possible. Before selecting another oncologist or health care team, do your research. Ask other patients for recommendations or contact diagnosis-specific cancer organizations for a list of recommended doctors or cancer centers. Many cancer centers and medical centers have physician referral services to help you.

Q. I'm a newly diagnosed patient. Are clinical trials an option for me?

A. Many people think that clinical trials are only for patients who have already tried many other treatments. This is not true. In most clinical trials, patients either receive the current standard of treatment for their type and stage of cancer or a treatment that shows promise of being just as good or better than the standard one.

In addition to being among the first to receive a new treatment, people who take part in clinical trials are closely monitored by their doctors and other researchers and help future patients by advancing the science of cancer. Your doctor can tell you whether there are any trials that might be right for you, or you can look up available clinical trials online (see the list of recommended websites on the following page).

Resources

MEDICAL INFORMATION

American Cancer Society
800-227-2345
www.cancer.org

Cancer.Net
888-651-3038
www.cancer.net

National Cancer Institute
800-422-6237
www.cancer.gov

National Comprehensive Cancer Network
215-690-0300
www.nccn.com

EMOTIONAL SUPPORT

Cancer*Care*®
800-813-HOPE (4673)
www.cancercare.org

Cancer Hope Network
800-467-3638
www.cancerhopenetwork.org

Imerman Angels
877-274-5529
www.imermanangels.org

CAREGIVING

Cancer*Care*
800-813-HOPE (4673)
www.cancercare.org

Caregiver Action Network
202-454-3970
www.caregiveraction.org

FINANCIAL HELP

Cancer*Care*
800-813-HOPE (4673)
www.cancercare.org

Cancer*Care* Co-Payment Assistance Foundation
866-55-COPAY (552-6729)
www.cancercarecopay.org

Cancer Financial Assistance Coalition
www.cancerfac.org

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org

Partnership for Prescription Assistance
888-477-2669
www.pparx.org

CLINICAL TRIALS

Coalition of Cancer Cooperative Groups
215-789-3600
www.cancertrialshelp.org

EmergingMed
877-601-8601
www.emergingmed.com

National Cancer Institute
800-422-6237
www.cancer.gov/clinicaltrials

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