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Communicating With Your Health Care Team

Presented by

Helen H. Miller, LCSW, ACSW
CancerCare

Learn about:

- Preparing for visits to your doctor
- Tips for improving communication
- Questions to ask
- Sources of support



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Help and Hope



CANCERcare®

CancerCare is a national nonprofit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling and support groups, education, financial assistance, and practical help—are provided by professional oncology social workers and are *completely free of charge*. Founded in 1944, CancerCare provided individual help to more than 100,000 people last year, in addition to serving more than 1 million unique visitors to our websites. For more information, call 1-800-813-HOPE (4673) or visit www.cancercares.org.

Contacting CancerCare

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1-800-813-HOPE (4673)
www.cancercares.org

If you are a health care professional interested in ordering free copies of this booklet for your patients, please use the online order form on our website, www.cancercares.org.

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

When you first heard you had cancer, you may have been shocked, scared, or numb. Everyone reacts to the news in his or her own way. However, most newly diagnosed people face similar challenges: they need to learn about their diagnosis and treatment options, understand how the treatment plan will affect their lives, and find out what resources are available to them.

The relationship you have with your health care team can make a big difference in how well you cope with these challenges. Research shows that patients who have good communication with their health care team are more satisfied with their medical care than patients who do not. They also tend to fare better emotionally and even have better management of symptoms such as treatment side effects and pain.

This booklet discusses ways to develop good communication with your health care team so you can get the best care possible. 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—that is, many different kinds of health care providers come together as a team to care for a patient. Some of the professionals who work with people with cancer are:

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



One doctor, usually your medical oncologist, coordinates your care. Other important professionals include financial specialists, case managers, and patient navigators. You, too, are a key member of your team.

Making the Most of Your Medical Appointments

Doctors' appointments are the main time you'll get to speak with the members of your health care team directly. It's common to be nervous when going in for an appointment. You may worry that you'll forget to ask an important question or that your doctor will be too busy to listen to your concerns. Such fears are normal, but good preparation can improve how comfortable you are during your appointments. It can also make you more satisfied with your doctor visits overall. Here are some tips for communicating with your health care team during appointments:

Write down your questions. Bring a written list of the questions you have. 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—the names of the health care professionals you met with, places you were referred to,



the 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 binder where you can keep all the notes and papers you are getting. This way, nothing gets lost, and you always know where to look for the information.

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

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

- Use "I" statements 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 slides, 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 a nurse or social worker, you can call?

Understanding Your Treatment Options

One of the best ways to begin making decisions about your health is to educate yourself. The various members of 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 your type and stage of cancer, try to find out what the standard of care is for someone with your diagnosis. You want to be sure that you are getting the best care that today's medicine has to offer. Ask

your doctor or nurse to suggest trustworthy organizations, publications, or websites that focus on your 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, or your local librarian to help you.

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 patients.
- 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 has a database of oncologists. Go to www.cancer.net and type “oncologist” in the search box.

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 opt to go this route even if they need to travel long distances for appointments. For a list of some recommended centers, see the National Cancer Institute's list at <http://cancercenters.cancer.gov/> or call 1-800-4-CANCER.

It's important that you feel comfortable with and trust your doctor. If your preferred 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 treatment or procedure, make sure you understand why. For example, if you are getting chemotherapy or another cancer drug, is the goal to cure the cancer, control the cancer (shrink the tumor or keep

it from growing), or relieve symptoms caused by the cancer? Let your doctor know if you have certain wishes or preferences with regard to treatment so these preferences can be taken into account. Your lifestyle and daily activities may also influence treatment recommendations.

Get a second opinion. Before you begin treatment, make an appointment with another oncologist to review treatment recommendations. No member of your health care team should mind that you seek a second opinion. In fact, many specialists encourage it and may even be able to provide a referral. Often, second opinions offer more insight into the recommendations of your doctor.



If you are nervous about letting your doctor know you want a second opinion, try this approach: emphasize that you are very satisfied with the care he or she is providing but just want to make sure you are aware of all your options.

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 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? Knowing such information ahead of time will allow you to prepare.

Ask about possible side effects. Find out what side effects you can expect from your treatment and how your health care team plans to manage them if they do 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 nausea, vomiting, diarrhea, constipation, and pain, for example.

Discuss the cost of your care. Research shows that many patients don't realize that they can ask their doctors how much treatment is going to cost. And most doctors don't normally bring it up either. But you should find out the cost of your medications before starting treatment. Your doctor may not know the answer, but he or she should be able to refer you to a social worker or hospital financial specialist who can help. And if you can't afford the treatment you need, financial assistance may be available to you. Some financial help resources are listed on page 20.

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. Most patients feel better about themselves and their appearance after reconstructive/plastic surgery. Reconstructive/plastic surgery can often be done at the same time as your oncology surgery, so ask about this option as early as possible. A Board-certified plastic surgeon can give you information about your options. To find a certified plastic surgeon, visit the website of the American Society of Plastic Surgeons at www.plasticsurgery.org and click on "Find an ASPS member surgeon."

Learn about fertility-preservation options. If you plan to have children in the future, find out whether the treatment your doctor is recommending could affect your ability to

conceive. It is 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 spares your fertility or refer you for sperm/egg banking prior to treatment.

Questions to Ask Your Doctor

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

- What is my type and stage of 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 side effects?
- What are the possible benefits and risks of this treatment?
- How much will my treatment cost?
- If I have questions during my treatment and my doctor is not available, who can I ask? For example, is a nurse, social worker, or other specialist available?
- Is there any information I can read about this treatment or procedure?
- Is there anything else I should know?
- Who should I call in case of an emergency?

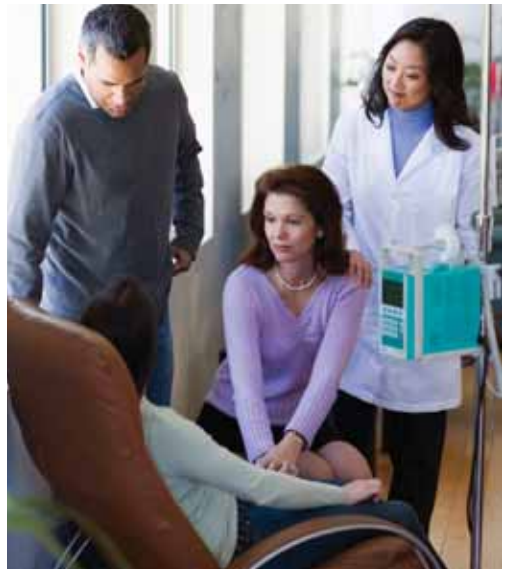


During Treatment and Beyond

Once you begin treatment, the need for good communication with the various members of your health care team continues. The more you feel 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 you can and should discuss with your health care team:

Side effects Chemotherapy, surgery, radiation, targeted treatments, hormonal therapy, and other cancer treatments can all lead to different side effects. The good news is that today, most side effects can be prevented or managed with medications and other techniques. Some common, 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 (low white blood cell count that puts you at risk of infection)
- Lymphedema (swelling, of an arm or leg, for example)
- Neuropathy (nerve damage)



Talk with your doctor about any side effects or symptoms that come up. Some patients worry that if they bring up a side effect, such as pain, their doctor might be distracted from treating the cancer. That is not true. Side effect management is an important part of your cancer care—it may even make it easier for you to stick with your treatment plan.

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

Ask your health care team if there are local support groups, which would give you a chance to talk face to face with other patients. Other resources include free telephone and online support groups, such as those offered by *CancerCare*, and peer-to-peer networks, which match you one on one to another person facing the same diagnosis.

Practical matters Experts agree that the highest-quality care for people with cancer is care that addresses not just their medical needs, but their “psychosocial” needs as well. Psychosocial support refers to helping patients with emotional concerns, as described above, and with practical issues that can interfere with completing treatment. It also includes providing support to patients with day-to-day concerns so they can have the best quality of life possible during treatment. Some of the many practical issues your health care team can help you with are:

- Getting transportation to and from treatment
- Talking to your children about your diagnosis

Keeping a Side Effect Journal

To help you get relief, your doctors and nurses need to know specific details about your symptoms. 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 occurs
- How long a side effect lasts
- How strong the side effect is—For example, if you experience pain how strong is it on a scale from 0 to 10, where 0 equals no pain and 10 is the worst pain possible?
- What impact the side effect has on your daily activities—Does the pain keep you from sleeping, eating, walking, working, or exercising?
- Any non-urgent questions or concerns that come up between appointments



- 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
- Locating home care or other services

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

Resources for caregivers and family members The effects of cancer are not limited to the person who is

diagnosed. Cancer can be difficult on your loved ones as well. To help ensure that the needs of your loved ones are met, ask your doctor about resources available to them. For example, CancerCare has a program—CancerCare for Kids®—that provides practical support, education, and advice to parents,



as well as counseling for children and teens to help them understand cancer. CancerCare also has a program that provides individual counseling and support groups just 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 lingering or long-term side effects of your treatment. They will also check for symptoms of recurrence (a 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. For details about specific items to include in your plan, see CancerCare's booklet *After Treatment Ends: Tools for the Adult Cancer Survivor*, which can be ordered online at www.cancercare.org or by calling 1-800-813-HOPE (4673).

CancerCare® Can Help

Being diagnosed with cancer raises many concerns. As discussed in this booklet, good communication with your health care team can improve your care and the quality of your life as you go through treatment. CancerCare is also here to help. We are a national nonprofit organization that provides free, professional support to anyone affected by cancer. Our oncology social workers specialize in helping people with cancer, caregivers, and loved ones face the challenges of living with cancer. We provide support through individual counseling, support groups, Connect® Education Workshops, publications, financial assistance, and referrals. To learn more about how we help, call us at **1-800-813-HOPE (4673)** or visit **www.cancercare.org**.

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 better understand medical terms 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 6,000 terms related to cancer and medicine. This resource is especially helpful if you are doing research in between doctors' appointments. You can view the glossary at www.cancer.gov/dictionary.

Q I know my oncologist is focused on treating my cancer, but I wish she was 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. Another issue is that medical schools don't always give doctors enough training in how to communicate well with patients. Some health

care professionals are trying to change that, and many medical schools now require coursework on doctor-patient communication. Many organizations, such as CancerCare, are also 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 can also speak with a social worker at CancerCare for additional tips.

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

A A good relationship with your oncologist can make a tremendous difference in how you cope with your cancer and treatment. However, he or she is only one member of your medical team. If you are not able to communicate directly with this person, try talking to a nurse, nurse practitioner, or social worker associated with your oncologist's 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 some 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. That is not true. This is because in most trials, patients either receive the best, 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. 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. So clinical trials are definitely an option worth considering. Your doctor can tell you whether there are any trials that may be right for you. You can also do some research online. For more information, see the medical information resources on page 19.

Resources

The following are just some of the many reliable resources for medical, emotional, financial, and practical support. For referrals to additional resources, contact CancerCare at 1-800-813-HOPE (4673).

MEDICAL INFORMATION

- **American Cancer Society**

1-800-227-2345
www.cancer.org

- **Cancer.Net**

Patient information from the American Society of Clinical Oncology (ASCO)
www.cancer.net

- **National Cancer Institute (NCI)**

1-800-4-CANCER
www.cancer.gov

To view ASCO’s oncologist database, go to www.cancer.net and type “oncologist” in the search box.

To find an NCI-designated comprehensive cancer center, visit <http://cancercenters.cancer.gov/>.

To find a certified plastic surgeon, visit the website of the American Society of Plastic Surgeons at www.plasticsurgery.org and click on “Find an ASPS member surgeon.”

For information about clinical trials, visit www.clinicaltrials.gov.

For information on fertility and cancer, visit www.fertilehope.org.

EMOTIONAL SUPPORT

- **CancerCare**
1-800-813-HOPE (4673)
www.cancercares.org
- **Cancer Hope Network**
1-877-467-3638
www.cancerhopenetwork.org

RESOURCES FOR CAREGIVERS AND LOVED ONES

- **CancerCare**
1-800-813-HOPE (4673)
www.cancercares.org
- **CancerCare for Kids**
1-800-813-HOPE (4673)
www.cancercaresforkids.org
- **Family Caregiver Alliance**
1-800-445-8106
www.caregiver.org

FINANCIAL HELP

- **CancerCare Co-Payment Assistance Foundation**
www.cancercarescopay.org
1-866-55-COPAY
- **Cancer Financial Assistance Coalition**
www.cancerfac.org
- **Partnership for Prescription Assistance**
1-888-4-PPA-NOW
www.pparx.org



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The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

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When one word changes your world,

CANCER*care*®

makes all the difference



With CancerCare,
the difference comes from:

- Professional oncology social workers
- Free counseling for you and your loved ones
- Education and practical help
- Up-to-date information

Our trusted team of professionally trained oncology social workers provides free counseling, education and practical help for you and your loved ones.



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Help and Hope

1-800-813-HOPE (4673)

www.cancer.org