

Communicating With Your Doctor

Narrator

Good communication with doctors is important to get the most out of your visits. Your doctor is the expert on medicine and medical treatments for your condition. However, you are also an expert. You know your body, your past health history, and your life conditions that impact your health. It is important that you share this relevant information with your doctor so you can get the best care possible.

We will present five key skills to help you improve your communication with your doctor. You may not need every skill in every visit.

Use the word “PACES” to help you remember the five key skills.

Here’s what PACES stands for:

- P – Present information
- A – Ask questions
- C – Check understanding
- E – Express concerns
- S – State preferences

P – PRESENT INFORMATION

Before you go to the doctor, think about what you want to talk about. Tell your doctor what is important to you at the beginning of the visit so your time can be used most efficiently. When describing problems or concerns, be prepared to be specific and detailed.

Meet Michelle and her husband, Bob. Michelle already knows her diagnosis, and they have come today to talk about treatment options. Let’s watch how Michelle and Bob present information to the doctor.

Bob

Caregiver

Before we get started, doctor, I just want to talk about how Michelle has been feeling. She really has been really tired lately, so I want to make sure we get a chance to talk about that.

Ruben A. Mesa, MD, FACP

*Mays Cancer Center at UT Health San Antonio
MD Anderson Cancer Center*

Thank you for bringing that up. We’ll definitely have a chance to talk about that. I did want to check on a couple things...

...Now, Bob had mentioned earlier that you had been feeling very tired. Can you tell me more about that?

Michelle
Survivor

Yeah. I just feel exhausted. No matter how much sleep I get, I just never know. Some days are harder than others. I-- no matter how much I tried to rest, I just, I have no energy. I just want to lay around and it's so frustrating.

Ruben A. Mesa, MD, FACP

Well, from what you've described, it sounds to me like you're experiencing cancer-related fatigue...

Narrator

Did you notice how Bob told the doctor at the beginning what he wanted to talk about during their visit? Also, Michelle presented details about her symptoms.

You or your family member may not have similar symptoms to Michelle's, but you can still present detailed information to your doctor and present it clearly.

A – ASK QUESTIONS

Narrator

As a patient or caregiver it is your right to ask questions. It is a good idea to think through what you want to know and write down your questions before your visit. You may have other questions that arise during the visit. You should ask questions about anything you don't understand.

Ruben A. Mesa, MD, FACP

Okay. I've been talking a lot. What questions do you have?

Michelle

Since I have this cancer, what is the likelihood that my sons will get it?

Ruben A. Mesa, MD, FACP

Well, that's a good question and a frequent one for individuals that suffer from lymphoma like yourself...

...Now I see you wrote down some additional questions in your book before you came. Is there anything else on your list we haven't covered yet?

Bob

So I've heard that cancer, cancer treatments can cause nausea and Michelle really has a sensitive stomach, so are there treatments that can better work with her sensitive stomach over others?

Ruben A. Mesa, MD, FACP

Well, yes, some patients have to deal with nausea and stomach issues, however...

Narrator

Here we saw Michelle and her husband asking questions clearly and directly, some of which they had prepared before they came.

C – CHECK UNDERSTANDING

Narrator

Misunderstandings can result in poor health or quality of life. It is important that you check your understanding of what your doctor has said to you by asking the doctor to repeat or clarify information. You can summarize what you heard back to the doctor to ensure you understand.

Previously, Dr. Mesa explained to Michelle some of the possible ways she could manage her fatigue. Let's see how Michelle and Bob check their understanding of what the doctor said.

Ruben A. Mesa, MD, FACP

One way to combat fatigue is to make sure that you're doing some sort of structured exercise every day, at least 15 to 20 minutes sustained as a way to battle that fatigue.

Now your blood tests will also tell us if you're anemic. So, let's take a look...

Michelle

What do you mean by anemic?

Ruben A. Mesa, MD, FACP

Oh, I'm sorry, I should've explained that better. It means a decreased number of red blood cells...

Bob

So, doctor, I just want to make sure I understand what you're telling us. So, if I get her to maybe go for a walk three times a week around the block with regard to her fatigue, that's going to help her. At the same time, you're going to be monitoring her anemia, I think was the word you used, through blood work and things like that. Am I understanding that correctly?

Communicating With Your Doctor and Talking About Clinical Trials

Ruben A. Mesa, MD, FACP

Well that's right, although except if she's able, she should try to exercise at least 15 minutes every day, but not too late in the evening.

Bob

All right. Got it.

Michelle

Well Doctor Mesa, thank you so much. I appreciate all the information you've given us...

Narrator

Michelle and Bob did a few things to make sure they understood what Dr. Mesa was saying. Michelle asked Dr. Mesa to clarify when she didn't understand the term "anemia"; and at the end, Bob summarized what he understood should be done for his wife's fatigue. It was important that Bob summarized because he had remembered the recommendation for exercising differently than what the doctor said.

E – EXPRESS CONCERNS

Narrator

Michelle tried what Dr. Mesa recommended for her fatigue and nausea, but neither seemed to work well. She and her husband knew they needed to speak to the doctor about these concerns at their next visit.

Ruben A. Mesa, MD, FACP

Well, it's, it's good to see you again both. I see you've had your first treatment. How are you feeling?

Michelle

It's going okay.

Ruben A. Mesa, MD, FACP

Well, I'm looking at your numbers. They look pretty good. It seems like things are working well, so why don't you keep it up and we'll see you back in a month.

Michelle

Well, doctor, wait. I don't think I'm doing, okay. This nausea is, is too much for me. I don't think the medicine is working.

It's just I'm wiped out. It's making me sick.

Bob

Yeah. Not just that. She's really tired and, and we really have been trying to do what you told us to do.

Ruben A. Mesa, MD, FACP

Well, I'm glad you told me about this. So why don't we take one thing at a time? Why don't we start with the nausea...

Narrator

Michelle was hesitant bringing these problems up to her doctor, especially because it seemed like he was in a hurry. However, it was important that she did this so her doctor could help her solve the problems.

S – STATE PREFERENCES

Narrator

Tell your doctor your preferences for information and treatment so together you can make the best decisions about your care.

Ruben A. Mesa, MD, FACP

Well we have a new medication for, for nausea. We'll go ahead and give you a prescription and we'll also give you a referral to a nutritionist, to see if they might be of any further assistance.

Bob

And I'd really like to read more about cancer-related fatigue. So, are there any resources you recommend?

Ruben A. Mesa, MD, FACP

Fortunately, there are. The Leukemia & Lymphoma Society website...

Michelle

Okay. Well doctor, I know you said we needed to wait and see how it went with the fatigue, but I don't want to wait. I can't function like this.

Ruben A. Mesa, MD, FACP

Well let's talk more about what else we can do to try to help with some of the difficult fatigue that you're facing.

Narrator

Here we saw how Michelle and Bob stated their preferences, both for information and for her treatment.

Please remember P.A.C.E.S. for better communication.

- P – Present information
- A – Ask questions
- C – Check understanding
- E – Express concerns
- S – State preferences

For more information about communicating with your medical team, please visit [LLS.org/PACES](https://lls.org/PACES).

Understanding Clinical Trials

Ruben A. Mesa, MD, FACP

Clinical trials are careful studies conducted by doctors and researchers to either test new cancer treatments, or to test treatments we've had in the past but in a different way. The goals of cancer clinical trials are to help people live longer, help them live better through better quality of life, and ideally to cure the diseases that they have. Indeed, clinical trials are crucial, because that's really the only way that we know that a new treatment, or an old treatment used in a different way, really is more effective than the treatments that we're currently using, or the treatments of the past.

There are many patients today that are living longer, living better, or they've been cured of their disease because of clinical trials.

WHY SHOULD I PARTICIPATE IN A CLINICAL TRIAL? WHEN CAN I PARTICIPATE IN A CLINICAL TRIAL?

Narrator

Taking part in a clinical trial may be the best treatment choice for some blood cancer patients. Some patients may think they should wait after trying standard treatment before they consider a clinical trial. However, trials are not only for patients whose disease did not respond well to the past treatments.

There may be trials for patients at any point during the course of their disease. There are trials for newly diagnosed patients, patients whose disease has returned or not responded well to current treatment as well as trials that are studying therapies to prevent patients' cancers from returning.

HOW DO CLINICAL TRIALS WORK?

For a new drug or treatment approach to become a standard treatment, it must be tested in clinical trials. The clinical trials process for cancer drugs is divided into steps, called “phases.” Each phase is designed to answer certain questions about the new drug or treatment approach. In all phases, patient safety is the top priority, and researchers closely monitor patients for side effects.

Alissa Gentile, MSN, RN

Director, Clinical Trial Support Center
The Leukemia & Lymphoma Society

There are four phases of clinical trials. In a phase I clinical trial, researchers are trying to determine the maximum tolerated dose that has therapeutic benefits to the patient.

Narrator

Researchers want to learn how the treatment affects the cancer and what the side effects are. In a phase I study, the drug could be a treatment that is being studied in humans for the first time. Or the drug could be approved for another cancer and now it is being testing in other cancers.

In a phase II clinical trial researchers test the effectiveness and further study the side effects of the drug. Phase II clinical trials enroll more patients than a phase 1 clinical trial. There are times if the phase II clinical trial is effective in the treatment of cancer, the treatment could be submitted for U.S. Food and Drug Administration (FDA) approval.

In a phase III clinical trial researchers are looking at the effectiveness, the side effects and whether or not the drug is beneficial to the treatment of the patient’s cancer.

Phase III trials are open to many patients and are offered at more locations than a phase I or II clinical trial. A phase III clinical trial can be to determine whether the treatment being investigated is more effective than the current standard treatment, or has a similar effect on the disease, but with fewer side effects.

Some trials compare a patient’s quality of life on one treatment versus another; patients may be asked to fill out questionnaires in order to gather this information.

A phase IV clinical trial gathers long-term data on safety and effectiveness after FDA approval. There are several thousands of patients that are in a phase IV clinical trial.

Each clinical trial specifies the type of patient eligible to participate. The criteria may include:

- Disease type
- Age of the patient
- The stage of the patient’s disease
- Prior treatments the patients may have received
- The presence of any other illness or conditions

WHAT ARE THE RISKS AND BENEFITS OF CLINICAL TRIALS?

Alissa Gentile, MSN, RN

Patients need to weigh the risks and benefits of clinical trials.

Narrator

To help understand some of the risks and benefits, let's use the example of clinical trials for chimeric antigen receptor T-cell therapy, or CAR T-cell therapy for short. CAR T-cell therapy uses the patient's own T cells, a type of white blood cell, to recognize and attack cancer cells. In 2017 and 2018 the FDA approved two types of CAR T-cell immunotherapy, and today research continues to expand the use of these therapies.

Some benefits of clinical trials include:

- Close care and monitoring from the treatment team – Because clinical trials are closely regulated by the FDA, patients are closely followed by doctors who are experts in their disease.
- Access to promising treatments that may not be available yet outside of clinical trials.
- Additionally, some patients like knowing that their participation contributes to the body of knowledge that will help other cancer patients, now and in the future.

The CAR T-cell therapy clinical trials offered these benefits to many patients and led researchers to a greater understanding of the ways in which the body's own immune system defenses can be used to treat cancer.

Things that should be considered are:

- Financial costs – There are three types of costs typically associated with a clinical trial:
 - Research study costs – These are the costs related to the clinical trial such as the cost of the treatment being studied, extra doctor's visits, and laboratory and imaging tests done solely for research purposes. Often, the trial sponsor will cover such costs.
 - Routine medical care – These costs are related to the patient's cancer treatment, whether or not the patient is in a clinical trial. These costs may include, doctor's visits, hospital stays, laboratory and imaging tests, standard care cancer treatments, and treatments to manage cancer symptoms or the side effects of treatment. These costs are billed to the patient's health insurance.And
 - Out-of-pocket expenses – These are the additional patient costs; they include travel expenses, food, lodging, etc.

In the example of CAR T-cell therapy, CAR T-cell therapy is not available at all cancer treatment centers. If a patient does not live near a center that offers CAR T-cell therapy, the patient will need to consider the costs of travelling to the center for treatment. These costs are not covered by insurance. However, there are often organizations and companies that can help with these costs. It's important for patients to talk with the treatment team to discuss financial concerns.

- Unknown side effects – Researchers may not be aware of the side effects of some of the newer drugs that are being developed. It is important for patients to talk with their treatment team about these concerns, including the side effects of other treatment options that may be offered.

Ongoing clinical trials for CAR T-cell therapy are helping researchers further understand and reduce the side effects of the therapy and find ways to improve the management of side effects.

WHAT ARE SOME COMMON CONCERNS ASSOCIATED WITH CLINICAL TRIALS?

Alissa Gentile, MSN, RN

There are some common concerns associated with clinical trials. Some of these include:

Narrator

- Receiving a placebo – A placebo is a pill, liquid or powder that looks like the drug being used in the treatment regimen, but it does not have any effect on the disease. The placebo is inactive. Placebos are not used in cancer clinical trials involving patients who need treatment for their disease unless the placebo is given along with an active drug.

In some clinical trials, researchers want to learn if adding a new drug to the standard therapy makes the treatment more effective. In these studies, some patients get the standard treatment and the trial drug, while other patients get the standard treatment and a placebo. Placebos may also be used in clinical trials for patients under “watch and wait,” meaning the patient’s disease does not require treatment at the time, or in trials studying ways to prevent cancer from returning after treatment. It is unethical to give someone a placebo if there is a treatment available that could work. You will always be told if the study uses a placebo.

- Fear of being a guinea pig – The fear of having no control is a common concern among patients. The idea that a trial patient is being used as a guinea pig is very misleading. It implies that a patient is at the mercy of researchers and may be experimented on without his or her consent. This is not the case. Clinical trials are carefully designed studies that put the health and safety of patients first.
- Informed consent – Before you agree to participate in a clinical trial, you will be taken through the informed consent process. This process gives you the opportunity to obtain information about the study and ask questions. Only by signing the informed consent, do you decide that you want to join the study. Participation in a clinical trial is always voluntary and patients can leave the study at any time.
- Being randomized – If you’re in a randomized study, you will not be able to choose your treatment group. Randomization gives each patient an equal chance of being assigned to any of the groups.

Some patients find the idea of not being able to choose their treatment group distressing, especially if they want to be in the group receiving the study treatment. It is important to

remember that it is not known whether the study treatment is actually better than, the same as, or less effective than the standard treatment and every patient in a clinical trial can expect to receive medical care, regardless of whether he or she receives the new treatment or the standard treatment.

HOW DO I FIND A CLINICAL TRIAL?

Narrator

If patients are interested in learning more about clinical trials, or finding a clinical trial, they can call The Leukemia & Lymphoma Society at 1-800-955-4572. The Leukemia & Lymphoma Society has registered nurses who work with patients and their caregivers one-on-one to find, enroll, and overcome barriers to clinical trials.

LLS also has a clinical trial conversation guide for patients and caregivers to use to discuss clinical trials with their treatment team.

Talking to Your Doctor About Clinical Trials

Ruben A. Mesa, MD, FACP

Patients and doctors are partners who need to work together to make decisions that meet the needs of each patient. For doctors, that means providing information to patients about their diagnoses and possible treatments in a way that patients and family members can understand. For patients and family members, that means telling doctors what's important to them and what concerns them, and also asking questions to make sure they fully understand. When they work together, patients and doctors can get the most out of their visits and make the best possible plan.

Narrator

You can prepare for a visit with your doctor by thinking ahead about what you want to ask and tell your doctor. This will help you get the information you need to make the best decision for you.

Ruben A. Mesa, MD, FACP

Clinical trials should be considered as an option when discussing treatment choices. This includes your initial treatment or subsequent treatments throughout the disease journey. So, a conversation about clinical trials is appropriate to have at any time.

Narrator

When asking about clinical trials, a conversation guide may help you to consider what questions you have before your visit. You can look through the guide and mark the questions you want to ask. Remember that you are an essential part of your treatment team, and it is okay to initiate a conversation with any of your questions or concerns.

Communicating With Your Doctor and Talking About Clinical Trials

When talking with your doctor, five key skills may help you get the most out of your visit. Watch as this patient, Michelle, and her husband, Bob, use PACES to talk to her doctor about clinical trials as a treatment option.

Michelle

So, I wanted to talk about clinical trials. I have been hearing that people go on clinical trials, I've looked through the internet at some of the trials that other patients are going on and I don't know if they're trials that would be right for me. And quite honestly, I don't even know how I feel about trials. But I have a lot of questions and so I'm wondering is a trial right for me, a clinical trial?

Ruben A. Mesa, MD, FACP

Well, I'm glad that you brought this up and I like that you came in with questions. Yes, I think there might be some trials that...

Bob

Okay so we might be interested, but I have some questions. You used the word "randomized." I guess I don't know what that means. Does that mean she may not get the medicine?

Ruben A. Mesa, MD, FACP

So, you ask a good question. First, a randomized study means that...

Narrator

By asking these questions and checking understanding, Michelle and Bob are able to get the information they need about clinical trials.

It is important to have a discussion with your doctor to clear up any misconceptions you may have about clinical trials.

Michelle

So, I'd still be getting the treatment, though, for my cancer?

Ruben A. Mesa, MD, FACP

Correct. You would still be getting a treatment for your cancer, and again when you're randomized you will either receive...

Communicating With Your Doctor and Talking About Clinical Trials

Michelle

So, but what might be some of the side effects, because I'm still working, and I cannot afford to miss a lot of work, and quite honestly, I'm concerned about not having hair and what I might look like while I'm going through the treatment.

Bob

Truthfully, if this ends up taking us out of town, to another hospital, or something like that, I don't know that we can do that. So, I'm a little concerned for that.

Ruben A. Mesa, MD, FACP

Well, I'm glad you told me about these concerns about your work and travel. Let me go over some of the details about the side effects...

If you think of any more questions, please give me a call. We want you to be comfortable with this decision before proceeding. I'd be happy to set up a time for you to speak further with the study team. And then we can schedule a time to visit perhaps a week from now so that we can finish going over your questions and seeing whether you'd like to proceed with the study.

Michelle

All right. Thank you. I think we're going to discuss it and think about it, and, of course, I'd like to discuss it with my family, because I think they're going to have some questions as well.

Narrator

As you saw, Michelle and Bob used the PACES approach and the Clinical Trial Conversation Guide to discuss clinical trial options with her doctor. By using these tools, you can get the most out of your visit.

To receive a Clinical Trial Conversation Guide you can call a Leukemia & Lymphoma Society Information Specialist at 1-800-955-4572 or you may print the guide from www.LLS.org/ClinicalTrialCommunication. Check off questions that you want to ask your doctor, and talk with your caregivers to see what questions they have. Bring it with you to your doctor's visit to help you remember the questions you want to ask.

LLS is ready to assist you in finding a clinical trial that may be right for you. Our Information Specialists and Clinical Trial Nurse Navigators may be reached by calling 1-800-955-4572 or visiting www.LLS.org/ClinicalTrials.