

Conversations with Your Physician: Being Heard, Getting Answers

If you are dealing with serious illness, open and honest communication with your physician is vital to your well being, regardless of the stage of this illness. But sometimes discussions may be less than satisfying or productive, and you may feel like it's the healthcare provider who drives these talks rather than *you* – the one who needs answers. Your appointments occur within the constraints of the doctor's available time, and yet the days of your life may be limited. It may feel like you're on an uneven playing field. Of course, it is the physician who has the knowledge and skill, but *you* are the one who is sick.

The fact that you are ill is out of your control, but you can regain some control by being clear about what you need from the healthcare provider. Both of you can commit to thoughtful listening and speaking. You can be on equal ground, and you can work effectively together when the truth is spoken and heard.

There is no set script for dealing with illness or confronting difficult choices about care. Your life is unique. Being sick is the latest chapter in a life story that is all your own, and navigating the illness journey will look a lot like the way you have handled other transitions. The issues raised and questions suggested in this article are comprehensive, but all of them may not be for you. Choose what works best. Some people need detail and seek vast amounts of information about their disease, treatments and outcomes. For them, the unknown is scarier than the most worrisome facts. Others may decide they can function best without knowing what seems frightening.

Frank discussions with those closest to you can help you sort out what feels right. But bear in mind that healthcare decisions are best made with good information, so shutting out the unpleasant can make life more difficult for you and family members in the long run.

Thinking Ahead About Your Values

Preparing for meaningful talks with your doctor begins early in a critical illness and starts at home. It's time for a conversation with yourself about the road ahead. You may have some ideas about what you need from your doctor... for how much you want to know.

To guide your introspection and family discussions, here are some questions for you to evaluate on your own so you can share them with your doctor later:

- What do I most value in my life?
- What makes a good day for me, a meaningful day?
- What is an acceptable treatment outcome, and what am I willing to endure to achieve it?

These are all things that your physician will need to understand. Your faith and spiritual values may impact your answers, and you may want to talk with your spiritual advisor about this.

Keeping the Devil Out of the Details

When you make your appointment, tell the receptionist you need extra time for discussion, and do so every time you need an in-depth talk. Take a trusted person with you to take notes during this and other appointments. It will help you listen more attentively.

Before this first expanded meeting, you will want to confirm your confidence that this is the right doctor for you. Review the logistics with the office manager, or the practice's website may give you guidance.

- What hospital do you use? Do you use a hospitalist (a physician who is contracted to manage your care if you are hospitalized)?
- Are you comfortable with second opinions?
- When I call with a question, who will return my call, and how soon? Is there a best time to call?
- How do you handle insurance? Will you bill the insurer or me?
- I am giving you permission to speak openly to _____ about my case. (You may need to put this permission in writing.)
- I would like to keep copies of my operative notes, pathology reports, and tests so if I'm ever in a situation requiring emergency help, I can provide the needed information. Can I get these from your office?
- I have an advance directive for my healthcare decisions, and it also identifies my proxies. Please keep a copy, I will want to review it later.

For this first visit and others, be sure to write down your questions, or the things you want your doctor to know, before the appointment. It's a good idea to share that list with the person accompanying you so nothing will fall through the cracks.

Talking About Your Diagnosis

- (If you have a cancer:) What type of cancer do I have, and what is the current stage and grade? What do these terms mean?
- What is the expected course of my disease?
- Is it reversible?
- If not, can my life be extended? By what means, and how successful is that for people in my condition?
- How long can I expect that extension to continue?
- What lifestyle changes should I consider?
- Can you recommend some other reliable resources (written, on-line) for learning more about my diagnosis?

Tell your doctor if you are anxious or depressed. You may have an initial depressive reaction to your diagnosis, and as you receive treatment, medications or the disease process may also cause depression. It can be treated, so speak up.

When Treatments or Tests Are Discussed

- What, specifically, does this treatment do?
- Does this treatment cure me, change the course of the disease, or slow it down?
- What would success look like?
- Will this treatment help me be more active in the future?
- Will it make me more comfortable in the future?
- When can I expect to feel some results?
- What should I expect during this treatment – physically, mentally, emotionally?
- Tell me what symptoms you want me to promptly report to you.
- Would a palliative care consultation, to work with you on managing my symptoms, be helpful? Is there a palliative care physician you've worked with?
- I want you to tell me if you would choose this treatment for yourself or a loved one.
- What would happen if I didn't have to this treatment?
- Do I need this test? Will it tell us something we don't already know?
- Will the results of this test change my treatment? What if I don't have this test?
- When will I have results, and will you call me?
- Are there any clinical trials for my condition? If so, do you have access to these trials?

If you are interested in participating in any relevant investigational treatments or clinical trials, let the doctor know.

If/When Treatments No Longer Have the Desired Effect

Re-visit a discussion of “extraordinary measures.” You may have thought about what they mean to you, be they tube feedings, ventilators or CPR. What about IV fluids or antibiotic medications? Be sure that you and your doctor have the same understanding.

A number of states now endorse POLST – **Physician Orders for Life-Sustaining Treatment**. POLST documents your wishes as a standard medical order; it can travel with you if you change care settings. Whether you have an advance directive or not, POLST is a new and valuable way to transform your wishes into a tool, signed by your doctor, that can be acted upon. Ask your healthcare provider about POLST.

If palliative care was not considered earlier and your symptoms have become more troubling, ask about it again. If you have not already talked about the following, this is the time for further discussion:

- Will you tell me when hospice is the best option for me? I want the benefits of hospice comfort care and support for my family.
- I want to discuss my feelings about alertness vs. sleepiness when we treat my pain.
- I'd like to talk again about what is most important to me so we can be sure you understand what I want.

This surely seems like an overwhelming list of things to think about. You don't have to consider or discuss them all at once. And again, you need to do what is consistent with the way you live your life. The value of information, however, and the value of mutual understanding between you and your physician offer the greatest assurance that you will live your best life every possible moment.