

HOW DO I TALK TO MY
Parent's Doctor?

A Caregiver's Guide

A photograph of a doctor in a white lab coat with a stethoscope around her neck, seen from the side, talking to an elderly woman. The woman is wearing a blue and white striped sweater and is looking at the doctor with a slight smile. The background is a bright, slightly blurred clinical setting.

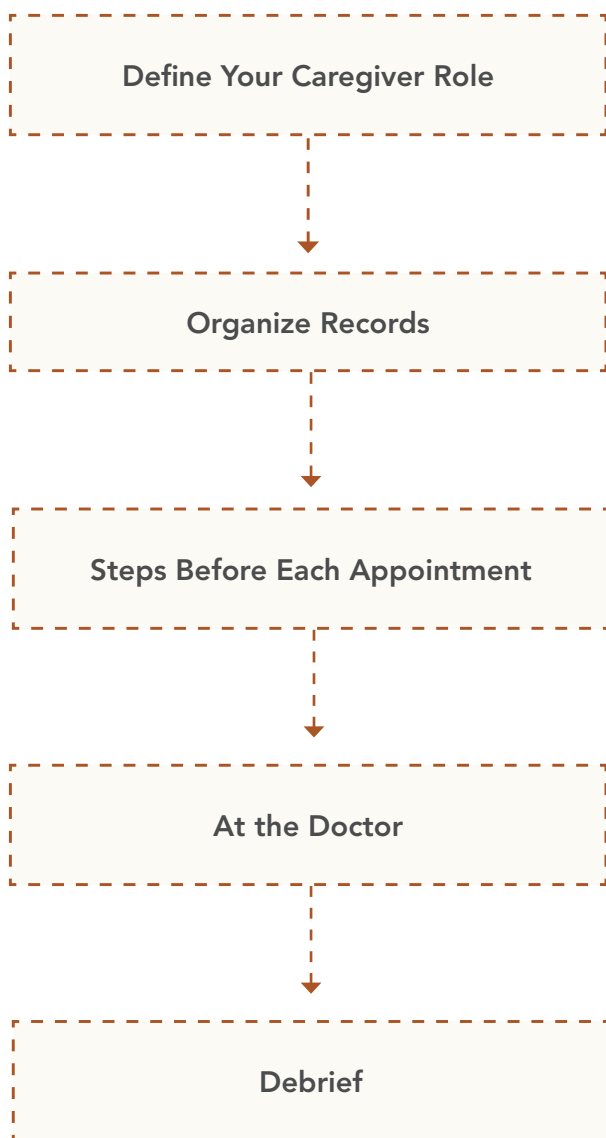
Capital Caring

PALLIATIVE CARE | COUNSELING | HOSPICE

How Do I Talk To My Parent's Doctor?

Talking to doctors can be hard enough when you're discussing your own health care. So it's understandable if you're unsure about how to best advocate for your loved one during their medical appointments.

As is usually the case when doing anything new or challenging, you'll have more success if you first have a plan.



DEFINE YOUR CAREGIVER ROLE

As a caregiver, it's your job to have your loved one's wishes and best interests at heart, and work with them to see that those wishes and interests are satisfied. The best place to start, then, is to find out what your loved one wants. Here are some key things to consider:

- How much does your loved one want you involved? You may want to help, but you may not be your loved one's first choice as caregiver. The best you may be able to do is try to make sure that your loved one and their preferred advocate begin the conversation about their caregiving relationship, and then continue to assist them however they may want you to.
- How much should you participate in appointments and communicating with doctors? Would your loved one like you to be at every appointment or just initial appointments? At any appointment, should you be in the room the entire time, or just part of it? During appointments, should one of you take the lead in asking questions, or split it equally? Are there some questions or issues your loved one would prefer to bring up himself?
- What kind of life does your loved one consider worth living? Some patients are not willing to accept treatments that may prevent them from doing many things they have always enjoyed, or that give their life meaning and define who they are. Others want doctors to do everything possible to keep them alive. Knowing where your loved one falls on this scale will help the doctor provide care tailored to him or her, and not the average patient who has the same medical condition.

This discussion can be a good time to talk about the legal documents you should have to make sure that your loved one's wishes are followed. A **healthcare proxy** or **durable power of attorney** gives you the legal authority to make medical decisions with your loved one, or on their behalf. An **Advanced Directive** states which medical procedures your loved one will and won't allow in order to save or maintain their life.



Finally, the federal Health Insurance Portability and Accountability Act (HIPAA) requires that patients give permission to anyone who wants access to their medical records, history or care. Make sure that your loved one is willing to give their consent, either verbally to doctors or on written forms.

ORGANIZE RECORDS

It's easier and more productive to communicate with your loved one's doctor if you have all pertinent information easily at hand. It's especially important to have this data available, updated where necessary, if and when your loved one starts to see additional doctors and specialists.



In addition to the documents mentioned above, it's advisable to maintain:

- **A health status diary.** You can write down anything that you think might be helpful for the doctor to know at the next appointment. This could include your loved one's blood pressure, blood sugar and weight (if you record those statistics on a regular basis) or any symptoms or issues you've noticed about your loved one's health that may be of concern to you.
- **A personal health history.** Before any appointment with a new doctor, this will provide a good general picture of your loved one's health. We've provided a form that you can download and use to compile this health history.
- **A record of all diagnoses, treatments and lab tests.** You can use this to track your loved one's care, and coordinate information among various doctors that he or she might see. We've provided a spreadsheet that you can download and duplicate to use for each of your loved one's medical providers.

Bring all of these records to every appointment. You can also email or upload them if the doctor's office uses a dedicated website or portal.



BEFORE EACH APPOINTMENT

Every doctor appointment is valuable. Each appointment determines the approach to maximizing your loved one's health, until the next appointment. So it's important to make sure you accomplish all your goals, each time you see each doctor.

Before every appointment, take time to sit down with your loved one and come up with an agenda. It doesn't have to be complicated: just the main issue or issues you want to cover with the doctor, with perhaps one or two specific points to discuss under each issue. For example, maybe you want to talk about a new therapy you've read about and whether it might be helpful in your loved one's case. Or perhaps you've noticed an improvement in your loved one's health that might enable him to lower the dosage on a medication.

Decide together what this topic or topics will be, write it down and bring it to the appointment. It's the best way to avoid getting home from the doctor and realizing you forgot to mention something important.



AT THE DOCTOR

A productive, successful doctor appointment should be a collaboration. Neither the doctor nor the patient should dominate the discussion. It should be a give and take in which both parties are open and flexible, and spend at least as much time listening as they do talking.

Older people, like your loved one, grew up at a time when doctors were rarely questioned. And some doctors did, and still do, think of themselves that way. But for the most part, those days are over. Medical schools have increasingly emphasized training in interpersonal communication, what many patients call “bedside manner.” During your appointment, you should note whether the doctor does the following:

- Avoids “commanding” or “scolding” language: “I want you to do X” or “Why did you do X?!” His or her comments should never make your loved one feel inferior, ashamed or guilty.
- Takes a genuine interest in your loved one by asking how they’ve been since the last appointment, or how their condition is affecting specific aspects of their work or personal life.
- Seems relaxed and willing to devote time to you, even though the actual appointment time is limited.
- Expresses appropriate empathy and concern with statements like “I’m sorry you’re feeling that way” or “Thanks for telling me about that. That must be difficult for you.”
- Invites your participation and collaboration by asking “What concerns or questions do you have?” or “What do you think about what I’ve told you?”

In return, a patient should be prepared, in the ways we’ve discussed, to take advantage of the doctor’s request for input and feedback. An important component of this is honesty. Doctors develop the ability to suspect when the patient might be holding back information, or not being entirely truthful. But this skill only goes so far, and the whole truth can only come from the patient him or herself.

Many patients are hesitant to be completely honest because it could lead to additional unpleasant tests, or a diagnosis that they fear. For this reason, your loved one may be hesitant to open up to the doctor about certain things they’ve been experiencing. Or they may exhibit worrisome symptoms or behavior at home, but manage to suppress them or seem much better when they are at the doctor.

If this is the case, try to talk to your loved one before the appointment about how doctors appreciate openness from patients. You might suggest simply showing the doctor the diary you've been keeping if your loved one is uncomfortable with bringing up his concerns in conversation. If those approaches don't work, you can try to alert the doctor to these issues ahead of the appointment through an email, letter or an in-person appointment between the two of you. Before doing, this, however, do your best to give your loved one every opportunity to open up to the doctor himself, as being seen as going behind his back could damage your relationship.

10 (OR SO) QUESTIONS YOU SHOULD ALWAYS ASK THE DOCTOR

Here are basic, key questions that should be answered — whether the doctor volunteers the information or you ask — about a diagnosis, test, treatment or medication.

- How sure are you about this?
- How will this affect daily life or routine?
- Why do you recommend this?
- What are the benefits?
- What are the side effects or drawbacks?
- How likely is it that this will help me, and how will I know if it's working?
- What are the alternatives?
- Can we wait to do it and, if so, how long?
- What if we don't do it?
- When should I return for a follow up appointment?
- If the condition worsens, when should we call you and when should we go to the ER or call 911?

Bonus question: “I've heard/read about this test/treatment/medication. What do you think?” Don't be shy about asking this. At worst, the doctor will tell you that it hasn't been supported by clinical evidence and she can't vouch for it. But it may be something with which she is unfamiliar that she may embrace after further inquiry. Or it may remind her or get her thinking about additional approaches that didn't immediately spring to mind, and which could be of benefit.

DEBRIEF On the ride home, or when you get home, spend a few minutes reviewing the doctor appointment with your loved one. Were you able to cover the agenda you set before the appointment? How did the two of you work together? Was one of you overbearing? Was one too quiet? If the appointment was with a new doctor, you can compare impressions of her performance and how you interacted.

A quick debrief will go a long way toward making subsequent appointments more effective, and nurture your caregiver relationship.

**Need more help?
Call 1-800-869-2136 to speak with someone
24 hours a day, 7 days a week.**

DOCTOR APPOINTMENT CHECKLIST

You can use this quick checklist to evaluate a current or new doctor, or to make sure your basic questions are answered. It shouldn't replace the list of questions you compile yourself, but any box left unchecked should prompt you to bring up that issue with the doctor.

The doctor should explain everything using plain, everyday language. If/when he or she uses a medical term that you don't understand, ask the doctor to stop and explain it. Write the term and its explanation down in the spaces below

During the appointment, the doctor:

- Asked if I had any questions at least once during the appointment.
- Asked if I had any concerns at least once during the appointment.
- Expressed appropriate empathy (“I understand you’re concerned about this,” “I’m sorry you’re going through this,” “I know this must be difficult”) at least once during the appointment, either as a general statement, or in response to your question or body language).
- Provided a primary diagnosis (the most likely reason you are not feeling well).
- Explained essential details of this diagnosis (What causes the condition, how common it is, and whether it is curable, manageable, or difficult to treat.).
- Provided one or more secondary diagnosis/es (either other possible but less likely causes of why you are not feeling well, or other things that are probably contributing to how you feel but are not the main cause).
- Explained essential details of this diagnosis or diagnoses (What causes the condition, how common it is, and, whether it is curable, manageable, or difficult to treat).
- Recommended a course of treatment or treatments (lab tests, imaging, medication, surgery, referral to a specialist, etc).
- Explained the benefits of the recommended treatment or treatments.

- _____ Explained the risks and or side effects of the recommended treatment or treatments.
- _____ Made it clear whenever general or local anesthesia will be required for any test or treatment, and how much discomfort I am likely to experience.
- _____ Asked my opinion of his or her recommended treatments (“What do you think of what I’ve told you?” “Does what I’ve said sound reasonable?” “What questions or concerns do you have?”).
- _____ Asked me to repeat back what he or she has recommended to me and/or provided written or video instructions/explanations for the recommendations.
- _____ Discussed or explained what will happen next (“Please pick up the medicine I prescribed and start taking it in the morning,” “I’d like to see you again in two weeks,” “Please make an appointment with Dr. Smith as soon as possible,” “Go directly to the emergency department and sign in at registration”).
- _____ Explained situations that could occur in which I should call his office immediately.
- _____ Explained situations that could occur in which I should call 911.

EZ PATIENT HISTORY

Name: _____

Male/Female: _____ DOB: _____ / _____ / _____

Address: _____

Phone Number Home: _____

Work: _____

Cell: _____

Email: _____

Primary Insurance: _____

Secondary Insurance: _____

Other Insurance: _____

Pharmacy Information Name: _____

Address: _____

Contact: _____

IN THE LAST MONTH, I've noticed the following personal health issues that concern me:

I receive **TREATMENT** for the following medical conditions:

I take these **PRESCRIPTION MEDICATIONS:**

| <i>Name</i> | <i>Dose</i> | <i>Times Per Day</i> | <i>Taking Since (Year)</i> |
|-------------|-------------|----------------------|----------------------------|
| • | | | |
| • | | | |
| • | | | |
| • | | | |
| • | | | |

I also take these **OVER THE COUNTER VITAMINS/SUPPLEMENTS/HERBALS:**

| <i>Name</i> | <i>Dose</i> | <i>Times Per Day</i> | <i>Taking Since (Year)</i> |
|-------------|-------------|----------------------|----------------------------|
| • | | | |
| • | | | |
| • | | | |

I am **ALLERGIC** to these medications:

I am also **ALLERGIC** to:

I've had these **SURGERIES:**

Outpatient

Year

-
-
-
-

Inpatient

Year

-
-
-
-

Other than surgery, I've been hospitalized for:

Year

-
-
-

MY FAMILY HAS THESE MEDICAL CONDITIONS:

Maternal Grandfather

Maternal Grandmother

Paternal Grandfather

Paternal Grandmother

Father

Mother

Brothers/Sisters

Sons/Daughters

I Work As: _____

(Circle applicable responses)

I Live: In a house / condo / apartment

With stairs / without stairs

With my wife or husband

With relatives/roommates

By myself

TOBACCO

of packs? / # of years?

I don't smoke and never smoked

I don't smoke but used to smoke _____

I smoke _____

ALCOHOL

How many drinks per week?

I don't drink

I drink

DIET

For breakfast I usually have: _____

For lunch I usually have: _____

For dinner I usually have: _____

I like to snack on: _____

I exercise _____ times per week

I like to: _____

Things that I think are important to know about me:

CAREGIVER EMERGENCY CONTACT

Name: _____

Relationship to Patient: _____

Address: _____

Phone Number Home: _____

Work: _____

Cell: _____

Email: _____

DOCTOR APPOINTMENT SPREADSHEET

Physician Name: _____

Specialty: _____ Phone #: _____

Address _____

Email: _____

Website: _____

User/Password: _____

Appointment date: #1 _____ #2 _____ #3 _____

PRIMARY DIAGNOSIS

Notes:

**ALTERNATE.
DIAGNOSIS/ES**

Notes:

**RECOMMENDED
TREATMENT PLAN**

Benefits:

Drawbacks

**ALTERNATE
TREATMENT PLAN**

Benefits:

Drawbacks

**PHYSICAL EXAM
RESULTS**

**POST APPOINTMENT
NOTES**

LABS

*Test name/Numerical value/
High, Low, Normal?*

*Test name/Numerical value/
High, Low, Normal?*



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