

Doctor Visits

Caregiving involves not only major crises, but also routine experiences like going to the doctor.

You as a family caregiver make a difference. Just by being present, you can affect what is being said, to whom, and how well this information is understood. You can also listen, ask questions, and be a support when your family member feels anxious or confused. This guide is about ways to help when your family member visits the doctor.



HIPAA is a federal law that protects patient privacy, while allowing for communication with family members and others involved in the patient's care. Unless your family member objects, you have the right to be present during your family member's doctor visits and to be informed about his or her diagnosis, treatment, and follow-up care. For details, see the Next Step in Care guide to HIPAA for family caregivers: www.nextstepincare.org/Caregiver_Home/HIPAA.

How Much to Participate

How active or quiet should you be during your family member's doctor visits? Here are stories about two family caregivers:

Michael goes with his mother, Verna, to the doctor each month. These visits are to check how well she is doing with her diabetes and high blood pressure. Michael is not usually shy. But during these doctor visits, he tends to be very quiet, looks down a lot, and does not seem to listen. As a result, he sometimes misses important information about her medicine and does not make appointments for all the tests she needs. Michael wants to talk with the doctor about Verna's memory problems but is reluctant to do so in front of his mother.

Kate goes to all of her husband Dave's doctor visits. She brings printouts from the Internet along with a long list of questions. Kate takes charge of the conversation, talking to the doctor about Dave's Parkinson's disease, his symptoms, and response to his new medicines. Dave has trouble with his speech and is self-conscious about tremors. Even though he would like to participate, he does not make much of an effort to speak up when he and Kate are with the doctor.

Think about your own recent experiences during doctor visits. By staying in the background, are you missing opportunities to contribute, like Michael? Or, by taking the lead, are you limiting your family member's participation, like Kate?

Before the Doctor's Visit

Try to schedule doctor visits for times when you and your family member have the most energy and are not distracted.

Doctor visits are stressful enough without your being worried about picking up a child from daycare or finishing a project at work. The time of day may be important; your family member may be better able to participate in the doctor visit in the morning before the activities of the day, or in the afternoon because of sleeping late.

Gather information from visits with other doctors. Bring this information along with a list of questions and topics you want to discuss with the doctor.

Know the medicines your family member takes. This includes all prescriptions as well as herbal remedies, creams, supplements, and other over-the-counter medicines. You can make a list of these medicines or put them in a bag to take with you. Here is a form you can use to help manage medications:

http://nextstepincare.org/Caregiver_Home/Medication_Management_Form.

Talk with your family member about what you want to accomplish during this doctor's visit. For instance:

- ▶ What are your family member's main concerns? Is it about physical symptoms, like pain or shortness of breath? Or feelings, such as being sad and worried?
- ▶ What are your main concerns? Are they the same as your family member's? If you and your family member share the same concerns, then you know what to focus on during the visit. But if you and your family member have very different concerns, try to agree on one or two that each of you will discuss with the doctor.
- ▶ Figure out how to talk with the doctor about sensitive issues. These might include a symptom that feels embarrassing (like incontinence) or worrisome (like memory loss or concerns

about driving). Each of you may need time to talk alone with the doctor.

Talk about ways you can help during doctor visits. Here are some options:

- ▶ Your family member may want you to stay in the waiting room while he or she is being examined by the doctor.
- ▶ Your family member might want you to come into the doctor's exam room.
- ▶ When it's time to talk, your family member might prefer that you remain quiet. This way, you help just by taking notes or making sure you have correct information, such as about a new medicine.
- ▶ You might have the list of concerns and be the person to make sure those are discussed. This may be by prompting your family member.
- ▶ You might take the lead in asking questions and giving information. For some family members, this is a relief and does not feel like you are taking over.
- ▶ If your family member has advanced dementia or is otherwise unable to communicate, then you will need to take a more active role.



You may want to speak with the doctor alone, either before or after the visit. Many doctors will be available for scheduled telephone calls. To make this call most effective, have your list of concerns ready. Where possible, limit the list to the items that you do not wish to discuss in front of your family member.

During the Doctor Visit

Tell the doctor at the beginning of the visit that you and your family member both have concerns and questions. Decide in advance which of you will say this to the doctor.

Notice your family member's verbal and nonverbal cues. For instance, your family member may give wrong or untrue answers. This might be because she cannot remember certain facts or does not want to upset the doctor. Your family member may also frown, look away, or give other nonverbal cues expressing anger and frustration.

Speak up when you feel you need to. Maybe it seems like the doctor is urging your family member to make a treatment choice before you have enough information. Or maybe the doctor is

not giving complete enough answers to your family member's questions. Perhaps your family member is getting conflicting advice from other doctors. In serious situations like these, your role may shift from giving quiet support to being a more active advocate.

The doctor may be used to you either speaking for your family member or not talking much at all. But **your family member's situation may mean that you need to guide the doctor into a new way of communicating**, which can be with words or actions. For instance, if you have always been quiet during visits but your family member is having difficulties communicating, you may need to start asking more questions to make sure you understand the doctor's instructions and explanations. Or if your family member wants to speak when the doctor asks you a question, turn towards your family member and suggest that she or he answer.

Advocate for yourself, too. You have an important role in caregiving. Make sure that you understand how to do new tasks, such as caring for a wound or helping your family member use a new walker or cane. Beyond hearing what to do, you might want to watch someone else do this procedure and then try it yourself. As needed, you might want to make an appointment for more training.

After the Doctor Visit

Following each visit with the doctor, it may be helpful to review with your family member how the visit went. Here are some questions you might want to discuss:

- ▶ Was the visit a good experience? What could I have done to make it better? Do you think you should have done anything differently?
- ▶ Did you feel that you had enough time to ask the doctor all your questions?
- ▶ Did you think that I asked too many questions? Did that make you think that I didn't trust the doctor? Or that I didn't let you speak up for yourself?

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- ▶ Would you like to have some time alone with the doctor? For the next visit, I can call ahead and ask to make sure that happens. I won't be upset.
- ▶ Would it be okay if I ask to see the doctor alone? I don't want to keep anything from you, but sometimes there are things that worry me, and I would like to discuss these with the doctor.

When You and Your Family Member Do Not Agree

There may be times when you and your family member disagree. This may be about the doctor's visit itself or other tensions that show up at times of stress. Think about alternatives when you and your family member disagree:

- ▶ **Is there another family member or friend who can go with your family member to the doctor and then reliably report the results to you?**
- ▶ **Would a scheduled call with the doctor or nurse get you the needed information?** This might allow you to stay focused on the purpose of the visit, rather than your disagreement.
- ▶ **Ask the doctor for help if you and your family member disagree about medical care.** Maybe there is someone on the doctor's staff who can help you and your family member come to an agreement. The doctor may be able to refer you to a counselor or community agency to help with long-term problems in your relationship.

Conclusion

Remember the stories about Michael and Kate? They were able to adjust how they communicate during doctor visits.

Michael talked with a social worker about Verna's memory problems. The social worker encouraged Michael to discuss this directly with his mother and ask permission to talk about it

at the next doctor's visit. The social worker also helped Michael figure out that one reason he was so shy was because he felt embarrassed about being in the room when the doctor examined his mother. From then on, Michael stayed in the waiting room during the exam. When the exam was over, he then met with his mother and the doctor for an active discussion.

*For **Kate**, the doctor followed her lead and slowed down his questions to allow Dave time to respond. Kate held off asking her questions until Dave had a chance to speak for himself. They are both pleased with these changes and feel they are better partners in his care.*

It may take a little time for you, your family member, and the doctor to get used to this new way of communicating. But it is worth the effort to achieve this type of open and useful conversation.

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