

ADVOCACY

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Being an advocate means helping to articulate your loved one's needs and desires. To do that, you should be prepared to take the initiative and work actively alongside the health care team.

Use these tools to help your loved one get the necessary information, support, and care.

- 1) Become educated.
- 2) Discuss your loved one's personal wishes.
- 3) Prepare for doctor's appointments.
- 4) Schedule regular discussions with all care team members.
- 5) Take steps to prevent medical errors.
- 6) Get "backup."

1) Become educated.

Research suggests that patients who educate themselves on their condition get better results from doctors. As a caregiver, you may need to step in for your loved one in this regard, so learn all you can in order to explore treatment options knowledgeably.

- | Ask the doctor for books, videotapes, or other materials that explain your loved one's condition and treatment.
- | Get information from condition-specific organizations, such as the Alzheimer's Association and the American Heart Association.
- | Speak up if you have questions or concerns. You have a right to question anyone involved with your loved one's care.
- | The National Caregivers Library web site offers articles designed to address the specific concerns of caregivers, and can help narrow your search for relevant information.

2) Discuss your loved one's personal wishes.

Before meeting with the doctor, get firm answers to the following questions. Go over these issues as early as possible, and consult a lawyer about living wills, durable powers of attorney for health care, and other documents that can formalize your loved one's wishes.

- | Who should make medical decisions if your loved one cannot?
- | What kind of medical intervention does your loved one want? Under what circumstances should heroic measures not be taken?
- | What medications or procedures should be avoided?

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- | What is your loved one's attitude toward pain management? What are his or her preferences when it comes to procedures like long-term sedation?
- | What worries or fears does your loved one have?
- | What type of end-of-life care would your loved one prefer?
- | What are his or her spiritual needs or requests?

3) Prepare for doctor's appointments.

Before each meeting with the doctor, make a list of issues you want to discuss. Write down questions in advance and make sure you have a pen and paper handy to take notes and record the doctor's answers.

Consider asking the following types of questions:

- | Can you explain the illness in non-medical terms? Where can I find more information?
- | How has the situation changed since the last appointment?
- | Are more tests required? A second opinion?
- | What treatment options are available? What do you recommend? Are there alternatives?
- | What are the side effects of these treatments?
- | What would occur without any treatment?
- | What changes do you expect in the next three months? Six? A year?
- | What are the side effects of prescriptions?
- | Is there a home health agency you can recommend? When would a referral be necessary?
- | How can you be reached? If you are unavailable, who should we contact?
- | What steps should we take in case of emergency? What is the likelihood of such an event?
- | What are the next steps in the procedure or diagnosis?

The following techniques can also help you get the most out of encounters with your loved one's

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physician:

- | Keep in mind that most appointments are scheduled for 15 minutes. Ask for more time in advance, adding that you are willing to pay if necessary.
- | Continue the discussion until you are sure about the diagnosis, treatment plan, medications, and the next appointment.
- | Consider repeating something back to the doctor and asking, "Is that right?" This helps ensure mutual understanding, and it may also help the doctor realize that he or she has left something out.
- | If you're feeling rushed or uncomfortable, make sure that the doctor understands this.
- | Follow up with a phone call or even a quick return visit if there's anything you forgot to ask, or if you think of additional questions.
- | Keep a record of all discussions by making copies of the **Appointment Information** forms and the **Caregiver's Log** at the end of this section.

See the www.CaregiversLibrary.org web sites for more information about developing questions related to your loved one's condition.

4) Schedule regular discussions with all care team members.

A health care team may include: a primary doctor, specialists, assistants, nurses, health aides, therapists, family, and friends. In cases of complicated illness, you may want to draw these people together for a "health care conference" that will get everyone on the same page. In any case, take advantage of opportunities to address the following questions about the functions of the health care team.

- | Who are the specialists involved in your loved one's care, and what is the process of referral?
- | Who can be contacted with questions and concerns?
- | In emergencies, who should be contacted first?
- | What about alternative care (including acupuncturists, chiropractors, massage therapists and herbal remedies)? Does the doctor work with these kinds of services? Does insurance cover them?
- | Can your loved one be admitted to the hospital of his or her choice? (Certain doctors, specialists, and nurses only work with certain hospitals.)

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- | What relationships does the health care team have with home health agencies, hospice services, or long-term care facilities? Who can make recommendations?
- | Are there problems or symptoms that the doctor hasn't asked about?

Also make sure that everyone is aware of your loved one's important health information. Don't assume all members of the health care team know everything they need to. Make copies of the **Caregiver's Log**, and encourage the health care team to use it. This will help information pass from member to member.

5) Take steps to prevent medical errors.

The following steps can help reduce the chances of medical errors. The most important step, of course, is to be as active and involved in decisions as possible.

- | Make sure the doctors know about all medications your loved one is taking, including over-the-counter drugs, vitamins, and herbs.
- | Make sure the doctor knows about any relevant allergies.
- | When the doctor writes a prescription, make sure you can read it. If you can't, a pharmacist might not be able to either.
- | When picking up a prescription, make sure it's the right medicine.
- | If you have any questions about the directions on medicine labels, ask.
- | If possible, choose a hospital where many patients have had the procedure or surgery your loved one needs.
- | Ask all health care workers who have direct contact with your loved one whether they have washed their hands.
- | When your loved one is discharged from the hospital, ask the doctor to explain the treatment plan that he or she will use at home.
- | It's a good idea to find out why a test or treatment is needed and how it can help. Your loved one could be better off without it.
- | If your loved one had a test, and you haven't heard back from the doctor, don't assume that no news is good news. Ask about the results.
- | Ask the doctor if your loved one's treatment is based on the latest medical studies and evidence.



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Portions of the above have been adapted from "20 Tips To Help Prevent Medical Errors," AHRQ Publication No. 00-PO38, developed by the United States Agency for Healthcare Research and Quality, February 2000.

6) Get "backup."

If you are unable to make headway on your own, look for professional advocates within the system. Most health care facilities have resource persons such as social workers, patient advocates, chaplains, and nurses who will work on your behalf and help clarify any concerns.

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CHOOSING A DOCTOR

Consider the following questions and steps as you and your loved one evaluate physicians.

What to find out:

- | Has a consumer group rated doctors in the area where your loved one lives? How reliable are these ratings?
- | Does the doctor accept your loved one's health insurance?
- | In what areas does the doctor specialize? Do these areas match our loved one's needs?
- | Length of time in practice?
- | Where did the doctor receive his or her degrees and training?
- | Which hospitals does the doctor use?
- | What are the office hours (when is the doctor available and when can you speak to office staff)?
- | Does the doctor speak the language you and your loved one are most comfortable speaking?
- | How many other doctors "cover" for the doctor when he or she is not available? Who are they?
- | How long does it usually take to get a routine appointment?
- | What happens if your loved one needs to cancel an appointment? Will you have to pay for it anyway?
- | Does the office send reminders about prevention tests?
- | What do you do if your loved one has an "after hours" emergency?
- | Does the doctor give advice over the phone?
- | Is the doctor aware of relevant community resources?
- | How long or difficult is the trip to the office?

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CHOOSING A DOCTOR

If possible, accompany your loved one on his or her first visit. Did the doctor:

- | Give you and your loved one a chance to ask questions?
- | Really listen to these questions?
- | Answer in terms you understood?
- | Show respect for you and your loved one?
- | Ask you both questions?
- | Make you both feel comfortable?
- | Address the health problem(s) your loved one came with?
- | Ask about treatment preferences?
- | Spend enough time with you?

When evaluating a doctor, trust your own reactions but also give the relationship some time to develop. It will take more than one visit for you, your loved one, and the doctor to get to know each other.

And keep in mind:

- | Give information. Don't wait to be asked.
- | You know important things about your loved one's symptoms and health history. Tell the doctor what you think he or she needs to know.
- | It is important to tell the doctor personal information—even if it makes you feel embarrassed or uncomfortable.
- | Take your loved one's "health history" list with you (and keep it up to date). You can use the form found at www.CaregiversLibrary.org.
- | Make sure the doctor is aware of any medicines your loved one is taking. Talk about any allergies or reactions to medicines.
- | Tell the doctor about any natural or alternative medicines or treatments.
- | Bring other medical information, such as x-ray films, test results, and medical records.
- | Ask questions. If you don't, the doctor may think you understand everything that was said.
- | Write down questions before your visit. List the most important ones first to make sure they get asked and answered.
- | Take notes.



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- Browse our library containing thousands of articles on all aspects of family caregiving, and congregational and organizational Caregiving Ministries.



APPOINTMENT INFORMATION

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This form is designed to help you keep track of doctor's meetings and the information shared during treatment.

Appointment

Date/Time: _____

With: _____

Where: _____

Phone: _____

For: _____

Insurance

Coverage: _____

Changes in Condition? Treatment Progress? _____

Procedures/Tests Performed? Results? New Tests Scheduled? Time, Date, Location of these tests? _____

Outcomes from Current Medication? New Medication? Reason for Prescription? Side Effects? _____

Support Services Recommended? Name, Address, Phone? _____

Next Appointment: _____



CAREGIVER'S LOG

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Use copies of this form to monitor daily changes and help with communication among care providers working in shifts.

Caregiver Name:

Title/Association:

Phone:

Day and Date:

Hours:

Changes Noted:

Food	Amount	Time	Comment
Activities	Duration	Time	Comment
Medication	Dose	Time	Comment



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Rate the following from 1–10, with 1 being the lowest and 10 the highest.

Pain & Discomfort: 1 2 3 4 5 6 7 8 9 10

Energy Level: 1 2 3 4 5 6 7 8 9 10

Sleep Pattern: 1 2 3 4 5 6 7 8 9 10

Nausea/Constipation: 1 2 3 4 5 6 7 8 9 10

Miscellaneous:
