

GET THE MOST FROM YOUR HEALTH CARE TEAM

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Whether you are the primary caregiver for a family member, or even taking care of yourself, it pays to ask questions in a clear and assertive manner. Don't assume, "the doctor will let us know if ..." The best patients work actively with the health care team.

Use these suggestions to take the initiative:

Stay educated on each condition or treatment

Discuss personal wishes

Prepare for doctor's appointments

Schedule regular discussions with all care team members

Call in "the cavalry" when necessary

1. Stay educated on each condition or treatment

Research suggests that caregivers and patients who educate themselves get better results from doctors.

- Learn all you can to explore treatment options and alternatives knowledgeably.
- Ask the doctor for books, video tapes 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.

2. Discuss personal wishes

Before meeting with the doctor, get firm answers to the tough questions. Review these issues as early as possible, before there is a crisis. And consult a lawyer about living wills, durable powers of attorney for health care, and other documents that can help ensure your loved one's wishes are carried out.

- 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?
- What worries or fears does our loved one have?

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? Are there alternatives? What is likely to occur without any treatment?
- What are the side effects of these treatments? Of prescribed medications?
- How can you be reached? If you are unavailable, whom 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?

4. Schedule regular discussions with all team members

A health care team may include a primary doctor, specialists, nurses, health aides, care professionals, 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. Don’t assume all members of the health care team know the full picture; ask the primary care physician to take charge as “quarterback” to make sure everyone is clear about their roles.

5. Call in “the cavalry” when necessary

If you are unable to get the results you want on your own, find professional assistance: If you are dealing with an eldercare situation, consider hiring a geriatric care manager. Most health care facilities have resource persons such as social workers, patient advocates, chaplains, and nurses who will work for you and help clarify any concerns. If you are battling the “system”, enlist the help of your state ombudsman for managed or long-term care.

EVERY PATIENT NEEDS A MEDICAL TEAM

Effective treatment should include a “**team approach**” with **medical specialists** according to the patient’s organ involvement. It is common for a WG patient to regularly see the following Doctors: Nephrologist (Kidney), Otolaryngologist (Ear, Nose/Sinus, Throat), Ophthalmologist (Eye), Pulmonologist (Lung), and **always a Rheumatologist or Immunologist**. Other specialists are involved as needed.

Patients should ask their doctors if they have experience treating vasculitis.

Each medical team needs a “leader” - someone who is going to coordinate with the other team members about medications the patient is taking and the tests/procedures the patient is having.