

Communicating With Your Health Care Team

Physicians and other medical professionals are a central part of the care team of a person living with dementia. Along with other members — which may include family, friends or others — they work to provide support throughout the course of the disease. Effective communication with other care team members — particularly health care providers — is critical to ensure that the person living with dementia receives the best possible care.

Advice for the Person Living With Dementia

Prepare for visits

The following tips can be helpful as you prepare for a visit with a health care professional:

- Document any changes in your health, including your mood, memory and behaviors.
- Bring a list of your current prescriptions and over-the-counter medications (including any vitamins or supplements).
- Consider bringing your care partner, family member or friend with you.
- Make a list of questions you and/or your care partner wants to ask.

Ask questions

It's normal to have many questions about the disease and your personal circumstances and common to forget what you'd like to ask a doctor. Consider bringing a list of questions to each appointment so you're prepared to discuss your questions and concerns. Also, be sure to let the physician or other medical professionals know if you need additional information or clarification.

The Alzheimer's Association® National Early-Stage Advisory Group — comprising individuals from across the country living with early-stage Alzheimer's or other dementias — helped develop a list of questions to help others make the most of doctor visits. These questions may be helpful as you create your own list to share with the doctor.

Diagnosis

- What is my official diagnosis?
- Which test(s) or tools were used to determine my diagnosis?
- What were you measuring with the tests performed?
- Can my symptoms be attributed to any other causes?

Alzheimer's disease

- How might the disease progress?
- What is my prognosis?
- What can I expect in the future? How can I best prepare?
- How will my diagnosis affect my overall health?
- How will this disease affect how I manage my other health conditions?
- When do I have to stop driving?
- Can I still work? If so, in what capacity?
- How do I decide how and when to disclose my diagnosis to friends and family?
- Are there any daily practices that may help me continue to live well with the disease?
- Is there support available to help me sustain these daily practices?

Treatments and coverage

- Which treatments are options for me?
- Will this medication target symptoms of the disease or the disease itself?
- How will the effectiveness of each treatment be measured?
- Are there any possible side effects? How will they be monitored and managed?
- Is one treatment option more likely than another to interfere with medications for other conditions?
- Will this treatment be covered by my insurance? If not, what are my options?

Clinical studies

- Am I eligible to enroll in any clinical studies?
- Is published information about clinical treatment studies available?
- What are the possible risks and benefits for participation in a clinical study based on my medical history?
- What are the eligibility requirements for these clinical studies?

Health care team

- How familiar are you with Alzheimer's disease?
- Who will be responsible for overseeing my care moving forward?
- Will you coordinate with other members of my health care team?
- If hospitalization is necessary, will you be able to provide care in this setting?
- How frequently will follow-up appointments be scheduled?
- Under what circumstances should I contact you?
- Who else might be recommended as a member of my care team (e.g., specialist or counselor)? What would their roles be?
- At what point will you consider me unable to make my own health care decisions?
- How will you work with my care team during the course of the disease? What information will be shared?

Care and support

- What care planning services do you provide?
- Are there support services and other resources where I can learn more about my diagnosis so I can live a fulfilling life for as long as possible?
- Are any of these support services in my community?

Advice for Members of Your Care Team

In the early stage

In the early stage of Alzheimer's, the person living with the disease should be included in all conversations regarding care and encouraged to independently share any health-related observations with the physician and other members of the medical team. If the person appears to need help communicating his or her needs, you may want to ask permission before interjecting.

This is a good time to ask the person living with dementia to sign a release of information so that you can freely communicate with the doctor on the person's behalf when the disease becomes more advanced.

As the disease advances

Over time, as the person's needs change and ability to communicate declines, the care team should consider which adjustments to make in order to ensure good health care. The team will also need to provide any updates on behalf of the person with dementia in order to maintain accurate health records that are accessible in case of an emergency.

Insurance coverage of care planning

Medicare and some other forms of health insurance cover care planning services for people recently diagnosed with cognitive impairment, including Alzheimer's and other dementias. Care planning allows individuals and their caregivers to learn about medical and non-medical treatments, clinical trials and services available in the community, and additional information and support that can contribute to a higher quality of life.

Under this coverage, physicians, physician assistants, nurse practitioners, clinical nurse specialists and certified nurse midwives can provide detailed care planning that includes:

- Evaluating cognition and function.
- Measuring neuropsychiatric symptoms.
- Medication reconciliation.
- Evaluating safety (including driving ability).
- Identifying caregivers and caregiver needs.
- Identifying and assessing care directives.
- Planning for palliative care needs.
- Referrals to community services for both the beneficiary and their caregiver.

Experts note that care planning for individuals living with dementia is an ongoing process and that a formal update to a care plan should occur at least once per year.

Talk to your health care provider about care planning services. If your provider is not familiar with Medicare coverage of care planning, your provider can visit alz.org/careplanning for more information.

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