
Hospitalization and discharge planning

A planned hospitalization or unexpected health emergency can occur at any point during the progression of Alzheimer's or another dementia, and the reason for hospitalization may or may not be due to the disease.

A hospital visit or overnight stay can cause anxiety and discomfort for a person living with dementia. Being in an unfamiliar environment and the added stress caused by medical treatment may lead to increased confusion or disorientation. Knowing what to expect during a hospital visit can help make the experience more comfortable for everyone.

Plan ahead

In the early stages of the disease, a person living with Alzheimer's or another dementia is able to make decisions and should be included in all conversations about medical care. It is important to address wishes for health care, including emergency medical treatment, as early as possible so that family and care team members can confidently implement the plan in the event the person is no longer able. Be aware that even in the early stages, a person living with dementia may need additional support during a hospitalization, so advanced preparation is critical.

As the disease progresses, it will become increasingly difficult for a person living with dementia to understand the purpose of hospital visits and medical treatment, and they will be less able to participate in the health care planning process. A care partner or a member of the care team should always be present to explain, as much as possible, the reason for the hospital visit or medical treatment; provide support; and act as an advocate on the person's behalf. Consider the following:

- Prepare an emergency kit with legal paperwork and current medical information. This information should be available in an easily accessible place, such as a secure electronic file on a phone or app, or in an envelope attached to the refrigerator. Some items to include:
 - A list of current medications and allergies.
 - Copies of legal papers, such as a living will, advance directives, power of attorney and do not resuscitate (DNR) order.
 - Insurance information.
 - Names and phone numbers of the person's doctors.

- Names and phone numbers of the emergency contact and additional care team members.
- Request for brain autopsy or organ donation.
- Review current legal documents stating preferences for health care, including life-sustaining treatment. The following documents help provide assurance that the wishes of a person with dementia are upheld:
 - **Power of attorney for health care:** Names a health care agent to make health care decisions on behalf of the person with dementia when they are unable.
 - **Living will:** A type of advance directive that includes preferences for medical treatment, including life-prolonging treatments.
 - **Medical release of information:** Ensures that a doctor can share information with a family member or friend of the person living with the disease. This can be beneficial to those who are helping to coordinate care.
 - **Do not resuscitate (DNR):** A physician order to prevent attempts at revival, particularly CPR or defibrillation. Without it, medical professionals are required to perform resuscitation.

Prior to hospitalization

- Share information regarding the person's diagnosis, other medical conditions or allergies with the entire medical team.
- Provide information about personal habits, dietary preferences or any environmental needs, like a private room, that would make the experience more comfortable.

Ask questions

- Which procedures will be performed and how? What are the risks and benefits? What are the expected results? What is the expected length of recovery?
- Is assessment or treatment available at an outpatient clinic?
- How long is hospitalization required?
- If anesthesia is used, how will this affect cognition?
- What are the visiting hours? Are extended hours available?

During hospitalization

Some of the most common concerns during hospitalization include communication, safety and nutrition. The following suggestions may help ensure a safe and comfortable experience:

- **Communication**
 - Make sure that all treating physicians and medical professionals are aware of the person's dementia diagnosis.
 - Remind medical staff that the person living with dementia may not be able to respond appropriately or correctly to questions. Ask to be included whenever any important decisions are being made.
 - If the person living with dementia has difficulty communicating, offer suggestions to medical staff about what the person may want or need.
 - Be present when a test or medication is administered to offer support or to answer questions from the medical team.
 - Consult with members of your care team. Who is able to stay during preadmission testing? Medical procedures? How often will someone be able to visit during the hospital stay?

- **Safety**
 - Confirm that important information, including dementia diagnosis and any behavioral concerns or allergies, is noted on the medical chart.
 - Inform medical staff if the person has a history of wandering or getting lost.
 - Bring familiar items from home to make the room feel more secure and comfortable for the person living with dementia.

- **Behaviors**
 - Alert the medical staff of any triggers that may cause unpredictable thinking or behaviors.
 - Offer suggestions on approaches that may help reduce these behaviors.
 - Inform medical staff of a history of behavioral reactions to certain medications.
 - Discuss limiting the number of visitors if the number of guests or medical staff visiting the room becomes too stressful.

- **Nutrition**
 - Share any dietary preferences with medical staff.
 - Arrange to be present during mealtimes if the person has difficulty feeding themselves, or alert hospital staff to this need.
 - Offer suggestions to encourage good nutrition and hydration.
 - Notify medical staff of any difficulties chewing or swallowing.

Hospital discharge planning

At the end of a hospital stay, health care professionals will make recommendations for long-term care needs and recovery following hospitalization. A member of social services or a discharge planner may also be involved if the care plan calls for in-home services or referrals to rehabilitation or outpatient services. Post-operational or discharge orders may involve several components, including new medication, therapy, wound care or monitoring. Be sure that the discharge team is aware of the dementia diagnosis in order to address needs for additional support services.

Discharge home

If the person living with dementia is able to return home, the discharge planner will assess the personal and community support available. If the person or members of their care team have concerns about the feasibility of providing care at home, this should be discussed with the discharge planner. When planning for in-home discharge, a person living with dementia and their care team should consider these questions:

- Is the primary caregiver able to provide the types of services the person living with dementia will need?
- Are there family and friends available to help?
- What type of care is needed?
- Which activities can the person safely manage without assistance?
- Which community service agencies are available to assist? What services do they provide?
- How will the cost of in-home services be covered?

Discharge to a residential care or rehabilitation community

If the person living with dementia is unable to return home and needs services from a residential care or rehabilitation community, the discharge planner should identify local care communities with vacancies and provide the family and individual with information to help make the selection. Typically, it is the responsibility of the family to contact the care community with any questions and make the final selection about placement. The discharge planner will follow up with the chosen community to share medical information and discuss discharge status.

If there are no vacancies available at selected care communities, discharge planners are required to offer additional options. A hospital cannot force an individual to enroll in a community that does not meet their needs; is not Medicare/Medicaid certified; or is at too great a distance from family. A patient cannot be forced to be discharged without consent from a legal representative.

When planning for discharge to a residential care community, consider these questions:

- Does the community have services designed specifically for individuals with Alzheimer's or dementia?
- Is this expected to be a temporary or long-term stay?
- What types of services and treatments will be conducted?
- How will the cost of treatment be covered?
- How is the community evaluated in terms of safety, cleanliness and staffing?

Explore the Alzheimer's Association & AARP Community Resource Finder (alz.org/CRF), a database of dementia and aging-related resources, to find local care services and communities.

If you disagree with the discharge:

- Ask to speak with the patient advocate or nurse supervisor.
- Contact the Beneficiary and Family Centered Care Quality Improvement Organization (cms.gov/Medicare/Appeals-and-Grievances/MMCAG).

Resources

Alzheimer's Association & AARP Community Resource Finder
alz.org/CRF

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