

Hospitalization and discharge planning

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

A hospital visit or overnight stay can cause anxiety and discomfort for the person living with the disease. The change from home to an unfamiliar environment and the added stress caused by medical interventions 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 stage of the disease, the person living with dementia is able to make decisions on his or her own behalf 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.

As the disease progresses, it will become increasingly difficult for the person living with dementia to understand the purpose of hospital visits and medical intervention, and he or she will be less able to participate in the health care planning process. The 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 intervention; 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 in an envelope attached to the refrigerator. Some items to include:
 - A list of current medications and allergies.
 - Copies of legal papers (e.g., living will, advance directives, power of attorney, do not resuscitate (DNR)).
 - Insurance information.
 - Name and phone number of physician.
 - 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 the person with the disease 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 he or she is 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 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 facilitate a safe and comfortable experience:

- **Communication**
 - Make sure that all treating physicians and medical professionals are aware of the 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 possible.
 - 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 there is 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 the disease.

- **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 meal times if the person has difficulty feeding him or herself, 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 providers 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 his or her 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 his or her care team may 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 his or her 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, a person living with dementia and his or her care team may 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?

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](https://www.cms.gov/Medicare/Appeals-and-Grievances/MMCAG)).

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