

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 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 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 with dementia to understand the purpose of hospital visits and medical intervention, and he or she will be unable 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 with the disease. This can be beneficial to those who are helping to coordinate care.

- **Hospital visitation form:** Hospitals in some states may enforce strict visitation laws and/or require special forms if a relationship, such as a domestic partnership, is not legally recognized in that state.
- **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 diagnosis of Alzheimer's or other dementia.
- If the person 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 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.

Medicare rights

A hospital must share a copy of the *Important Message from Medicare about Your Rights* (sometimes called the Important Message from Medicare or the IM) to all Medicare beneficiaries (Original Medicare beneficiaries and Medicare Advantage plan enrollees) within two days of admittance and prior to discharge. If you don't receive this notice, ask for it. This form indicates that:

- The patient has the right to receive all of the hospital care necessary for the proper diagnosis and treatment of the illness or injury covered by Medicare, Medicare Advantage or other Medicare managed care plan (if the patient is a plan enrollee).
- The patient has the right to know about any decision that the hospital, his or her doctor, Medicare health plan, or anyone else makes in regard to the hospital stay and who will pay for it.
- The patient's doctor, Medicare health plan or the hospital should arrange for the services needed after leaving the hospital. The patient has a right to know about these services, who pays for them and where he or she can get them.
- The patient is informed of their right to file complaints and appeal a discharge decision. They are provided with the name of the Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO) in their area. The BFCC-QIO is an outside reviewer hired by Medicare to review complaints and discharge appeals.

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, referrals to rehabilitation facilities, or outpatient services. Post-operational or discharge orders may involve several components, including new medication, therapy, wound care or monitoring.

The following questions may help the individual and their care team to prepare for discharge:

- Which activities may require assistance after discharge?
- When is it safe to engage in physical activity?
- What is the safest way to manage pain?
- Have medications changed and how often should they be administered?
- Which signs or symptoms are causes for concern? Who should be contacted if these occur?
- Is a follow-up visit necessary? If so, when will it occur?

Discharge home

If the person 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 with dementia and his or her care team may consider these questions:

- 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 facility

If the person with dementia is not able to return home and needs services from a residential care or rehabilitation facility, the discharge planner should identify local facilities 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 facility with any questions and make the final selection about placement. The discharge planner will follow up with the chosen facility to share medical information and discuss discharge status.

If there are no vacancies available at selected facilities, discharge planners are required to offer additional options. A hospital cannot force an individual to enroll in a facility 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 facility, a person with dementia and his or her care team may consider these questions:

- Does the facility have services designed specifically for individuals with Alzheimer's or dementia?
- What is the recommended length of stay? When will re-evaluation occur?
- What types of services and treatments will be conducted?
- How will the cost of treatment be covered?
- How are facilities evaluated in terms of safety, cleanliness and staffing?

Steps to appeal a discharge

1. You must contact the BFCC-QIO no later than your planned discharge date and before you leave the hospital. If you do this, you will not have to pay for the services you receive during the appeal (except for coinsurance and deductibles). You can file a request any day of the week. Once you speak to someone or leave a message, your appeal has begun. Ask the hospital for help if you need help contacting the BFCC-QIO.
2. You will receive a detailed notice from the hospital, your Medicare Advantage or other Medicare managed care plan (if you belong to one) that explains the reasons they think you are ready to be discharged.

3. The BFCC-QIO will ask for your opinion. You or your representative need to be available to speak with the BFCC-QIO if requested. You or your representative can choose to give the BFCC-QIO a written statement, but you are not required to do so.
4. The BFCC-QIO will review your medical records and other important information about your case.
5. The BFCC-QIO will notify you of their decision within one day after it receives all necessary information.
 - a. If the BFCC-QIO finds you are not ready to be discharged, Medicare will continue to cover your hospital expenses.
 - b. If the BFCC-QIO finds you are ready to be discharged, Medicare will continue to cover your services until noon of the day after the BFCC-QIO notifies you of its decision.
6. If you miss the deadline to appeal, you have other appeal rights. You can still ask the BFCC-QIO or your plan (if you have one) for a review of your case:
 - a. If you have Original Medicare: Call the BFCC-QIO listed in your IM.
 - b. If you belong to a Medicare Advantage Plan or other Medicare managed care plan: Call your plan.
7. If you do not appeal, or the BFCC-QIO finds you are ready to be discharged, but you decide to stay in the hospital past your planned discharge date, you may have to pay for any services you receive after that date.

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