

ALZHEIMER'S CAREGIVING

Going to the Hospital: Tips for Dementia Caregivers

A trip to the hospital can be stressful for people with [Alzheimer's disease](#) or [another dementia](#) and their caregivers. Being prepared for emergency and planned hospital visits can relieve some of that stress. This article suggests ways to help you prepare and tips for making your visit to the emergency room or hospital easier.

Hospital Visits during COVID-19

Due to COVID-19, hospitals continue to update appointment and visitor policies to comply with state department of health guidelines to protect the health and safety of patients, visitors and employees. For example, visitors may be required to wear a face mask or cloth face covering. Or, they may not be allowed to accompany patients in clinics, hospital departments or the emergency room, with exceptions in certain cases. Before you plan a visit, call or check the hospital's website for information on their policies. Get the latest public health information on the coronavirus at [coronavirus.gov](https://www.cdc.gov/coronavirus).

Hospital Emergencies: What You Can Do

A trip to the emergency room (ER) can tire and frighten a person with Alzheimer's or other dementia. Here are some ways to cope:

- Ask a friend or family member to go with you or meet you in the ER. He or she can stay with the person while you answer questions.
- Be ready to explain the symptoms and events leading up to the ER visit—possibly more than once to different staff members.
- Tell ER staff that the person has [dementia](#). Explain how best to talk with the person.
- Comfort the person. Stay calm and positive. How you are feeling will get absorbed by others.
- Be patient. It could be a long wait if the reason for your visit is not life-threatening.
- Recognize that results from the lab take time.
- Realize that just because you do not see staff at work does not mean they are not working.
- Be aware that emergency room staff have limited training in Alzheimer's disease and related dementias, so

try to help them better understand the person.

- Encourage hospital staff to see the person as an individual and not just another patient with dementia who is confused and disoriented from the disease.
- Do not assume the person will be admitted to the hospital.
- If the person must stay overnight in the hospital, try to have a friend or family member stay with him or her.

Do not leave the emergency room without a plan. If you are sent home, make sure you understand all instructions for follow-up care.

2 people holding hands in a hospital bed

What to Pack

An emergency bag with the following items, packed ahead of time, can make a visit to the ER go more smoothly:

- Health insurance cards
- Lists of current medical conditions, [medicines being taken](#), and allergies
- Healthcare providers' names and phone numbers
- Copies of healthcare [advance directives](#) (documents that spell out a patient's wishes for [end-of-life care](#))
- "Personal information sheet" stating the person's preferred name and language; contact information for key family members and friends; need for glasses, dentures, or hearing aids; behaviors of concern; how the person communicates needs and expresses emotions; and living situation
- Snacks and bottles of water
- Incontinence briefs, if usually worn, moist wipes, and plastic bags
- Comforting objects or music player with earphones
- A change of clothing, toiletries, and personal medications for yourself
- Pain medicine, such as ibuprofen, acetaminophen, or aspirin—a trip to the emergency room may take longer than you think, and stress can lead to a headache or other symptoms
- A pad of paper and pen to write down information and directions given to you by hospital staff
- A small amount of cash
- A note on the outside of the emergency bag to remind you to take your cell phone and charger with you

By taking these steps in advance, you can reduce the stress and confusion that often accompany a hospital visit,

particularly if the visit is an unplanned trip to the emergency room.

Before a Planned Hospital Stay

With Alzheimer's disease and [related dementias](#), it is wise to accept that hospitalization is a “when” and not an “if” event. Due to the nature of the disease, it is very probable that, at some point, the person you are caring for will be hospitalized. Keep in mind that hospitals are not typically well-designed for patients with dementia.

Preparation can make all the difference. Here are some tips.

- Think about and discuss hospitalization before it happens, and as the disease and associated memory loss progress. Hospitalization is a choice. Talk about when hospice may be a better and more appropriate alternative.
- [Build a care team](#) of family, friends, and/or professional caregivers to support the person during the hospital stay. Do not try to do it all alone.
- Ask the doctor if the procedure can be done during an outpatient visit. If not, ask if tests can be done before admission to the hospital to shorten the hospital stay.
- Ask questions about anesthesia, catheters, and IVs. General anesthesia can have side effects, so see if local anesthesia is an option.
- Ask if regular medications can be continued during the hospital stay.
- Ask for a private room, with a reclining chair or bed, if insurance will cover it. It will be calmer than a shared room.
- Involve the person with dementia in the planning process as much as possible.
- Do not talk about the hospital stay in front of the person as if he or she is not there. This can be upsetting and embarrassing.
- Shortly before leaving home, tell the person with dementia that the two of you are going to spend a short time in the hospital.

During the Hospital Stay

While the person with dementia is in the hospital:

- Ask doctors to limit questions to the person, who may not be able to answer accurately. Instead, [talk with the doctor](#) in private, outside the person's room.
- Help hospital staff understand the person's normal functioning and behavior. Ask them to avoid using physical restraints or medications to control behaviors.
- Have a family member, trusted friend, or hired caregiver stay with the person with Alzheimer's at all times if possible—even during medical tests. This may be hard to do, but it will help keep the person calm and less frightened, making the hospital stay easier.
- Tell the doctor immediately if the person seems suddenly worse or different. [Medical problems](#) such as fever, infection, medication side effects, and dehydration can cause delirium, a state of extreme confusion and disorientation.
- Ask friends and family to make calls, or use email or online tools to keep others informed about the person's progress.

- Help the person fill out menu requests. Open food containers and remove trays. Assist with eating as needed.
- Remind the person to drink fluids. Offer fluids regularly and have him or her make frequent trips to the bathroom.
- Assume the person will experience difficulty finding the bathroom and/or using a call button, bed adjustment buttons, or the phone.
- Communicate with the person in the way he or she will best understand and respond.
- Recognize that an unfamiliar place, medicines, invasive tests, and surgery will make a person with dementia more confused. He or she will likely need more assistance with personal care.
- Take deep breaths and schedule breaks for yourself!

If anxiety or agitation occurs, try the following:

- Remove personal clothes from sight; they may remind the person of getting dressed and going home.
- Post reminders or cues, like a sign labeling the bathroom door, if this comforts the person.
- Turn off the television, telephone ringer, and intercom. Minimize background noise to prevent overstimulation.
- Talk in a calm voice and offer reassurance. Repeat answers to questions when needed.
- Provide a comforting touch or distract the person with offers of snacks and beverages.
- Consider “[unexpressed pain](#)” (i.e., furrowed brow, clenched teeth or fists, kicking). Assume the person has pain if the condition or procedure is normally associated with pain. Ask for pain evaluation and treatment every 4 hours—especially if the person has labored breathing, loud moaning, crying or grimacing, or if you are unable to console or distract him or her.
- Listen to soothing music or try comforting rituals, such as reading, praying, singing, or reminiscing.
- Slow down; try not to rush the person.
- Avoid talking about subjects or events that may upset the person.

Working with Hospital Staff

Remember that not everyone in the hospital knows the same basic facts about [memory loss](#), Alzheimer’s disease, and related dementias. You may need to help teach hospital staff what approach works best with the person with Alzheimer’s, what distresses or upsets him or her, and ways to reduce this distress.

You can help the staff by providing them with a personal information sheet that includes the person’s normal routine, how he or she prefers to be addressed (e.g., Miss Minnie, Dr. James, Jane, Mr. Miller, etc.), personal habits, likes and dislikes, possible behaviors (what might trigger them and how best to respond), and nonverbal signs of pain or discomfort.

Help staff understand what the person’s “baseline” is (prior level of functioning) to help differentiate between dementia and acute confusion or [delirium](#).

You should:

- Place a copy of the personal information sheet with the chart in the hospital room and at the nurse’s station.

- With the hospital staff, decide who will do what for the person with Alzheimer's disease. For example, you may want to be the one who helps with bathing, eating, or using the bathroom.
- Inform the staff about any hearing difficulties and/or other communication problems, and offer ideas for what works best in those instances.
- Make sure the person is safe. Tell the staff about any previous issues with [wandering](#), getting lost, [falls](#), suspiciousness and/or [delusional behavior](#).
- Not assume the staff knows the person's needs. Inform them in a polite, calm manner.
- Ask questions when you do not understand certain hospital procedures and tests or when you have any concerns. Do not be afraid to be an advocate.
- Plan early for discharge. Ask the hospital discharge planner about eligibility for home health services, equipment, or other [long-term care options](#). Prepare for an increased level of caregiving.
- Realize that hospital staff are providing care for many people. Practice the art of patience.

For more information on dealing with dementia and hospitalization, see the University of California, San Francisco, Memory and Aging Center's [Tips for Hospitalization](#).

For More Information About Hospitalization and Alzheimer's

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center

800-438-4380

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

The NIA ADEAR Center offers information and free print publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Alzheimers.gov

www.alzheimers.gov

Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

Eldercare Locator

800-677-1116

eldercarelocator@n4a.org

<https://eldercare.acl.gov>

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