



HOSPITALIZATION HAPPENS



A Guide to Hospital Visits
for Individuals with Memory Loss

For more information about
Alzheimer's disease, contact:



**Alzheimer's Disease Education
and Referral (ADEAR) Center**

1-800-438-4380 (toll-free)

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

A service of the National Institute on Aging, the ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. Go to the ADEAR website, www.nia.nih.gov/alzheimers, to get information and resources in English and Spanish, sign up for email alerts, and search for clinical trials.



Contents

Introduction	1
Hospital Emergencies: What You Can Do Now	2
At the Emergency Room	7
Before a Hospital Stay	8
Working with Hospital Staff	14
Make Contact with Helpful Resources	17
Additional Resources	18



Introduction

A trip to the hospital with a person who has memory loss or dementia can be stressful for both of you. This brochure can relieve some of that stress by helping you prepare for both unexpected and planned hospital visits.

Inside, you will find: steps you can take now to make hospital visits less traumatic; tips on making your relative or care partner more comfortable once you arrive at the hospital; and suggestions on how to work with hospital staff and doctors.

Share this information with family and friends, keep this brochure in a convenient location, and begin preparing now for what will happen in the future.

Hospital Emergencies: What You Can Do Now

Planning ahead is key to making an unexpected or planned trip to the hospital easier for you and your care partner. Here is what you should do now:

- **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.
- **Register your relative for a MedicAlert® + Alzheimer's Association Safe Return® bracelet** through your local Alzheimer's Association chapter. People who are lost may be taken to an emergency room. This bracelet will speed up the process of reconnecting you with your care partner. Learn more about safety-related programs such as Project Lifesaver International (www.projectlifesaver.org).
- **Know who you can depend on.** You need a family member or trusted friend to stay with your care partner when he or she is admitted to the emergency room or hospital. Arrange to have



at least two dependable family members, neighbors, or friends you can call on to go with you or meet you at the hospital at a moment's notice so that one person can take care of the paperwork and the other can stay with your care partner.

Pack an Emergency Bag Containing the Following:

Personal Information Sheet

Create a document that includes the following information about your care partner:

- Preferred name and language (some people may revert to native languages in late-stage Alzheimer's disease)
- Contact information for doctors, key family members, clergy and helpful friends (also program into cell phone, if applicable)
- Illness or medical conditions
- All current medicines and dosage instructions; update whenever there is a change

- Any medicines that have ever caused a bad reaction
- Any allergies to medicines or foods; special diets
- Need for glasses, dentures or hearing aids
- Degree of impairment and amount of assistance needed for activities
- Family information, living situation, major life events
- Work, leisure and spiritual history
- Daily schedule and patterns, self-care preferences
- Favorite foods, music and things your care partner likes to touch and see
- Behaviors of concern; how your relative communicates needs and expresses emotions

Paperwork

Include copies of important documents such as:

- Insurance cards (include policy numbers and pre-authorization phone numbers)
- Medicaid and/or Medicare cards



- Durable Power of Attorney, Health Care Power of Attorney, Living Will and/or an original DNR (do not resuscitate) order

Supplies for the Care Partner

- A change of clothing, toiletries and personal medications
- Extra adult briefs (e.g., Depends), if usually worn. These may not be available in the emergency room if needed
- Moist hand wipes such as Wet Ones; plastic bags for soiled clothing and/or adult briefs
- Reassuring or comforting objects
- An iPod, MP3 or CD player; earphones or speakers

Supplies for the Caregiver

- A change of clothing, toiletries and personal medications.
- Pain medicine such as Advil, Tylenol or aspirin. A trip to the

emergency room may take longer than you think. 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. Keep a log of your care partner's symptoms and problems. You may be asked the same questions by many people. Show them what you have written instead of repeating your answers.
- A sealed snack such as a pack of crackers and a bottle of water or juice for you and your care partner. You may have to wait for quite a while.
- 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.



At the Emergency Room

Have an emergency bag prepared for your trip to the hospital that includes items like over-the-counter pain medication, sealed snacks and bottled water.

A trip to the emergency room may fatigue or even frighten your care partner. There are some important things to remember:

- **Be patient.** It could be a long wait if the reason for your visit is not life-threatening.
- Recognize that results from lab tests take time.
- Offer physical and emotional comfort and verbal reassurance to your relative. Stay calm and positive. How you are feeling will get absorbed by others.
- Realize that just because you do not see staff at work does not mean they are not working.
- Be aware that emergency room staff often have limited training in Alzheimer's disease and related dementias, so try to help them better understand your care partner.

- Encourage hospital staff to see your relative as an individual and not just another patient with dementia who is confused and disoriented from the disease.
- Do not assume your care partner will be admitted to the hospital.

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

Before a Hospital Stay

If your relative is going to the hospital for a planned stay, you have time to prepare and get more information from your doctor. Ask your doctor if the procedure can be done as an outpatient visit. If not, ask if tests can be done before going to the hospital to shorten the hospital stay. Ask if your doctor plans to talk with other doctors. If so, find out if your care partner can see these specialists before going into the hospital.

You should also ask questions about anesthesia, catheters and IVs. General anesthesia can have side effects. Ask if local anesthesia is an option and ask to be allowed in the recovery room. Insist that regular Alzheimer's medications be



Before your hospital visit, prepare a list of questions and concerns for your doctor.

continued throughout the hospital stay unless contraindicated. Discourage stopping cholinesterase inhibitors (Aricept, Exelon, Razadyne).

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. Medical facilities are not typically well designed for those with dementia, and advance planning and preparation can make all the difference.

Build a team for care and support during a hospital stay. Develop roles for each person (spokesperson, hands-on caregivers, comfort people, home and personal affairs manager, communication center person). Do not try to do it alone. Now may be the time to have one-on-one caregivers on site if money or resources permit. They can help make sure medications and/or physical restraints are not used to control behaviors that can

be managed with redirection or distraction.

Before Going to the Hospital

- If your insurance allows, ask if a private room is available. It will be more quiet and calm. Request a reclining chair or bed for you or a companion/respite provider.
- Shortly before going to the hospital, decide the best way to tell your care partner that the two of you are going to spend a short time in the hospital.
- Involve your care partner in the planning process as much as possible.
- Do not talk about the hospital stay in front of your care partner as if he or she is not there. This can be upsetting and embarrassing.
- Plan ahead. Make a schedule with family, friends and/or a professional respite care provider to take turns staying with your care partner while in the hospital. This is particularly important if your relative needs continuous supervision.



Pack comfort items
—things to help your care partner feel safe and secure such as favorite clothes, blankets and/or photos.

During the Hospital Stay

- Ask the hospital staff to avoid using physical restraints.
- Have a family member, trusted friend or hired caregiver with your care partner at all times if possible—even during medical tests. This may be hard to do, but it will help keep your care partner calm and less frightened, making the hospital stay easier.
- Use a “telephone tree,” email or online tools to keep others posted of progress. This can greatly reduce stress and make sure that you do not receive calls just as you get your care partner settled down. You may need to turn the ringer on the phone down or off during rest times.
- Ask doctors to limit the questions directed to your relative, who may not be able to answer accurately. Instead, arrange to answer questions

from the doctor in private, outside your care partner's room.

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



Give your care partner something to hold such as a book, photos or a favorite comfort item.

Be aware of acute or sudden confusion or delirium, which can be caused by serious medical problems such as fever, infection, medications and/or dehydration. Inform the doctor as soon as possible if your care partner seems suddenly

worse or different. Make sure you advocate for the person you are caring for... others may not recognize the difference in your relative's condition.

If Anxiety or Agitation Occurs

Try some of the following:

- Remove personal clothes from sight.
- Post reminders or cues if this comforts your care partner.
- 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 your care partner with offers of snacks and beverages.
- Consider “unexpressed pain” (i.e., furrowed brow, clenched teeth or fists, kicking). Assume your relative has pain if the condition or procedure is normally associated with pain. Ask for pain evaluation and treatment every four hours without your care partner having to ask for it—especially if he or she has labored breathing, loud moaning, crying or grimacing, or if you are unable to console or distract your care partner.
- Listen to soothing music or try comforting rituals such as reading, praying, singing or reminiscing.
- Slow down; try not to rush your care partner.
- Avoid talking about subjects or events that may upset your care partner.

Working with Hospital Staff

Remember that not everyone in the hospital knows the same basic facts about memory loss and Alzheimer’s disease or related dementias. You may need to help teach hospital staff what approach works best

with your care partner, 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 your care partner'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 your care partner's "baseline" is (prior level of functioning) to help differentiate between dementia and acute confusion or delirium.

You should:

- Make the personal information sheet easy to read with headings and short, simple statements. Place a copy with the chart in the hospital room and at the nurse's station.
- With the hospital staff, decide who will do what for your care partner. For example, you may want to be the one who provides assistance with bathing, eating or using the bathroom.

- Inform the staff about any hearing difficulties and/or other communication problems your relative may experience and offer ideas for what works best in those instances.
- Make sure your care partner is safe. Tell the staff about any previous issues with wandering, getting lost, falls, suspiciousness and/or delusional behavior.
- Not assume the staff knows your care partner'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 for your relative.
- 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.

What is possible and reasonable are two different things... Which would your care partner want?



Make Contact with Helpful Resources

The following agencies can provide you with information about Alzheimer's disease and related disorders and connect you with community programs and services such as support groups and respite care:

- **Alzheimer's Disease Education and Referral (ADEAR) Center**
1-800-438-4380 (toll-free)
www.nia.nih.gov/alzheimers
- **Alzheimer's Association**
1-800-272-3900 (toll-free)
www.alz.org
- **Eldercare Locator**
1-800-677-1116 (toll-free)
www.eldercare.gov
- **Family Caregiver Alliance**
1-800-445-8106 (toll-free)
www.caregiver.org
- **Caregiver Action Network**
1-800-896-3650 (toll-free)
www.caregiveraction.org

Additional Resources

University of California, San Francisco Memory and Aging Center

Partner With Me Project

<http://memory.ucsf.edu/caregiving/hospitalization>

See the video "Partnering with Family Caregivers: A Guide for Hospitalization When Your Loved One has Dementia"

This brochure was originally designed and produced by the North Carolina Division of Aging and Adult Services (NCDAAS) in conjunction with the Joseph and Kathleen Bryan Alzheimer's Disease Research Center through the U.S. Administration on Aging grant #90AZ2246. It was revised in August 2008 by NCDAAS through grant #90AZ2782 in conjunction with the Joseph and Kathleen Bryan Alzheimer's Disease Research Center, Alzheimer's Association – Eastern NC Chapter, Duke Aging Center Family Support Program and Positive Approach, LLC. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

Distributed by:

**NIA Alzheimer's Disease Education
and Referral Center**

www.nia.nih.gov/alzheimers

1-800-438-4380

adear@nia.nih.gov



December 2008 (Reprinted January 2013)