The UCLA Inpatient Dementia Guidebook

Presented by the UCLA Alzheimer's and Dementia Care Program
Introduction

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When someone with dementia is admitted into the hospital, it can be a stressful experience for the patient and their caregivers. This book was developed with this unique situation in mind. It is meant to help persons with dementia and their caregivers navigate the hospital and improve their hospital experience.

If you have any questions or concerns, please do not hesitate to speak to one of the health care providers looking after your loved one. Thank you for trusting UCLA as your partner in health.

Sincerely,
The UCLA Alzheimer’s and Dementia Care Program
200 UCLA Medical Plaza, Suite 365A
Los Angeles, CA 90095
310-319-3222
uclahealth.org/dementia

Our Team

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PEOPLE WITH DEMENTIA FACE A HIGHER risk of being hospitalized than those who do not have dementia. Packing items that are necessary and familiar to your loved one may be helpful in making the hospital stay more comfortable. Make sure to label items with your loved one’s name. Please keep valuables at home.

HOSPITAL ESSENTIALS
- List of medications. Leave medication bottles at home and instead bring the list of medications. Include the dose and time your loved one normally takes these at home.
- Advance Directives and POLST forms

ASSISTIVE ITEMS
- Eyeglasses
- Hearing aids
- Assisted listening devices (such as a pocket talker)
- Dentures
- Cane
- Walker

CLOTHES
- Bathrobe
- Comfortable non-skid slippers
- Tennis shoes
- A change of clothes for when they are ready to go home

COMFORT ITEMS
- Blankets
- Family pictures
- Music player with earphones
- Books / magazines
- Religious items

CAREGIVER ITEMS
- Change of clothing, toiletries, cell phone charger and other necessities for yourself
It's important to communicate your needs and concerns with the care team. We are counting on your involvement and partnership to provide the best care possible.

When your loved one is admitted into the hospital, we ask that you designate one person to serve as the primary contact person. Please leave that person’s name and phone number on the white board in the patient’s room.

UCLA is a teaching hospital, so it is not unusual for patients to have several team members taking care of them. Attending and resident doctors will usually visit each patient before 10 am. Between 8 am and 11 am each day, the care team will meet at rounds to discuss events that happened overnight, new information on the plan of care, any concerns from patients and their caregivers, and any needs after leaving the hospital. Here are the main people you need to know:

**ATTENDING PHYSICIAN**

The attending physician is a UCLA faculty member in charge of the care. He or she leads the care team. Attending physicians change weekly on Saturday mornings. Each time this change occurs, the new physician will introduce himself or herself to you and your loved one as the current attending physician during the hospital stay. Team members communicate regularly with each other to coordinate care.

**CONSULTING PHYSICIAN**

Specialty physicians may work in collaboration with the attending physician and provide consultations, if necessary. These doctors are specialists in a specific practice area and partners in care.
“Our commitment is to deliver acts of kindness with every patient encounter and to provide an exceptional patient experience.”

—Valerie Yeo, MSN, RN-BC, NEC-BC

RESIDENT PHYSICIAN

Resident physicians are doctors who have completed medical school and are undergoing further training. They are supervised by attending physicians and coordinate the plan of care with the team and other services with consulting physicians, as needed. Resident physicians rotate every two to four weeks. Each time a new rotation begins, the new resident will introduce himself or herself to you and your loved one.

NURSE PRACTITIONER

Nurse practitioners work closely with the doctors to manage your loved one’s care. He or she writes orders and can assist in coordinating discharge needs with the unit case manager.

REGISTERED NURSE (RN)

Registered nurses will be assigned to care for your loved one in 12 hour shifts. These nurses work with the team to implement the care plan, give medications, monitor progress and inform the doctors of any important changes.

CLINICAL NURSE SPECIALIST (CNS)

A clinical nurse specialist is an advanced clinical expert in the nursing profession. He or she provides specialized ongoing education and training to staff to ensure all patients receive the highest quality and most advanced care available.
CHARGE NURSE
Charge nurses are registered nurses responsible for co-managing the unit with the unit director and for acting as an additional resource to all staff members providing care.

ADMINISTRATIVE CARE PARTNER (ACP)
Administrative care partners staff the front desk on each unit. They are the people who answer call bells and relay messages to the primary nurse or clinical care partner. Please feel free to call them when you need assistance.

CLINICAL CARE PARTNER (CCP)
Clinical care partners assist our nurses with tasks such as bathing, feeding and taking vital signs. CCPs are assigned to work for 12-hour shifts, similar to nurses. Your loved one’s CCP and RN work closely to ensure all care needs are met.

CLINICAL SOCIAL WORKER
Our clinical social workers can support you and your loved one with social and emotional adjustment to illness and injury. They also assist in locating helpful community resources, such as referrals for senior or in-home services. Consult your loved one’s nurse if you would like to meet with a social worker.

CASE MANAGER
Case managers help coordinate needs after the hospital stay. They facilitate discharge-related services, including insurance coverage, and work collaboratively with an interdisciplinary team to tailor a plan of care for patients. They can help arrange home health care or a stay at a skilled nursing facility after discharge if needed. Case managers assist with transitioning patients to the next level of care needed.

REHABILITATION SERVICES
When someone has been admitted to the hospital, they may need therapy to return to their previous level of function. Physical, occupational and speech therapists serve as key members of our care team, providing the rehabilitation services needed during the hospital stay. Their goals are to perform an evaluation and to provide treatment recommendations. They also help doctors determine if your loved one will need additional therapy after leaving our hospital.

PHYSICAL THERAPIST
A physical therapist will evaluate a patient’s strength, range of motion, endurance, balance, and ability to perform functional mobility, such as getting into and out of bed, transferring, walking, stair climbing, and wheelchair skills, if appropriate. They will also recommend any durable medical equipment that a patient may need to be safe at home, such as a cane, crutches, walker or wheelchair.

Team members are distinguishable by their color-coded scrubs
Registered nurses  Patient care partners  Administrative partners
Lift team  Physical/occupational therapists
**OCCUPATIONAL THERAPIST**

An occupational therapist (OT) may assess how a person performs their daily tasks, such as bathing, dressing or grooming by evaluating their strength, balance, vision and cognition. They might suggest adaptive equipment or home modifications to improve performance and safety. OTs may also assess how a patient is able to transfer to and from the bathroom or shower, and may recommend equipment to make these tasks safer.

**PHARMACIST**

A pharmacist works with the care team to ensure that each patient receives safe and appropriate medication therapy. They reconcile all medications upon admission and prior to discharge. The pharmacist also provides education and training to patients and members of the UCLA Health system about medications.

**SPEECH THERAPIST**

A speech therapist performs evaluations on patients with communication, language, cognitive and/or swallowing problems.

**LIFT TEAM**

The lift team works with any patient who presents a high risk of injury for nursing staff when helping with physical movement. They assist patients on transferring in and out of chairs as well as repositioning in bed. The lift team members collaborate with the nursing staff and perform rounds on each unit.

**OTHER IMPORTANT TEAM MEMBERS**

Nutritionists, respiratory therapists, housekeepers, food service workers, spiritual care specialists and other health professionals work with our team to provide essential services to patients during their hospital stay. If you would like to inquire about these services, please consult the nurse for your loved one.
Visiting your loved one

When you visit your loved one in the hospital, it's important to stay calm and optimistic. Persons with dementia often respond to or mirror what their caregivers are feeling. Since the hospitalization is likely causing them distress, your loved one will be looking for reassurance.

**Sharing with your care team**
- Be ready to explain the events leading up to the hospitalization to the hospital staff, likely more than once.
- Tell the medical staff your loved one has dementia and what name they would like to be called.
- Help hospital staff learn how your loved one normally behaves and functions. Explain how to best deal with your loved one when he or she is upset and share your loved one’s home routines so that staff can try to follow the same routine in the hospital.

**Tips for visiting**
- The hospital can be a confusing and stressful place. Make sure that someone familiar stays with your loved one at all times.
- One visitor may stay overnight with your loved one. There is a sleeper chair available in each room.
- Depending on the therapeutic diet prescribed in the hospital, you may bring food from home. Prior to doing so, please consult your nurse to make sure your loved one is not scheduled for a test that requires him or her to have an empty stomach. Please note that unit staff are not able to accept food once it has entered the patient’s room and unit refrigerators are not able to store leftovers.
- Assume your loved one will need help using the telephone, finding the call button and adjusting the hospital bed.
- If your loved one has difficulty hearing, please notify the nurse and ask for a hearing assistance device called a “pocket talker.”
- Prepare yourself for discharge early in the hospitalization, as many hospital stays are shorter than expected. Be prepared for your loved one to need help at home, and speak to the case manager about what services you may need. Consider hiring professional caregivers.

**Discharge time**
- UCLA Health - Santa Monica Medical Center geriatric unit:
  - 11 am
- Ronald Reagan UCLA Medical Center: 4 pm
Hospital activities and services

UCLA HEALTH OFFERS MANY ENJOYABLE and uplifting activities for our patients and caregivers. These are complimentary during the hospital stay. If you are interested in any of these special activities for your loved one, please speak to your nurse so that he or she can place an order.

PEOPLE-ANIMAL CONNECTION (PAC)

If your loved one likes dogs, you can consider asking your nurse about the People-Animal Connection program, or PAC, which is one of the most comprehensive animal-assisted therapy and activity programs in the nation. These teams include canines and their human partners, and are able to offer companionship to children and adults in the UCLA medical centers.
MUSIC THERAPY
Music therapy has been found to be beneficial in reducing stress and anxiety for many patients in the hospital. There are different music-therapy techniques and instruments, and each one is tailored to the needs and preferences of each person. Music therapy visits are conducted at the bedside for patients and their caregivers.

SPIRITUAL CARE
Our Spiritual Care staff tends to the spiritual and emotional needs and concerns of all patients and caregivers. Chaplains participate as full members of our care team and provide support and reflection during hospitalization. Patients of any faith tradition (or none) may request a chaplain visit for support and assistance in finding serenity, trust, strength and hope.

SPOTIFY
Each patient room has an iPad with a Spotify application. You may set this up for your loved one if you have an existing Spotify account.

COMPANION CARE PROGRAM
Hospitals can be a lonely place. The Companion Care Program provides trained volunteers to engage our patients in activities such as art therapy, reading, playing games and coloring. They can also assist with feeding and accompany patients on walks under a nurse’s supervision. Our volunteers are also trained to provide appropriate activities for patients with memory loss. Please note that this program is only available in the geriatric unit of UCLA Health - Santa Monica Medical Center.
Behavioral issues

There are several issues that are unique and common in patients with dementia. If your loved one is behaving differently from the person you knew, please discuss your observations with the care team. Understanding how an illness can affect a person with dementia is important, as this will help you and the care team take better care of your loved one.

Behavioral issues can sometimes occur when the person with dementia is experiencing distress or discomfort. Being away from his or her normal environment can cause your loved one to feel frightened and angry. These behaviors can be difficult for caregivers and staff to deal with, but it is important to try to understand the reason behind them. Oftentimes, there is an explanation for your loved one’s distress.
Emotions and behaviors in persons with dementia

**AGITATION**
Repetitive questions, shouting or pulling out IVs and tubes. “Where am I? I'm scared and don't know what is going on.”

**AGGRESSION**
Hitting or pushing. “Who are these strangers and why are they touching me?”

**CONFUSION**
Wandering or repeated efforts to get out of bed. “Where am I? I want to go home.”

**DEPRESSION + ANXIETY**
Afraid, sad and crying. “I’m scared and don’t understand what is going on. Where is my mother?”

**Video guidance**

The UCLA Alzheimer's and Dementia Care Program Caregiver Training Videos focus on the following topics:

- Aggressive language and behaviors
- Agitation and anxiety
- Depression/apathy
- Hallucinations
- Home safety tips
- Refusal to bathe
- Refusal to take medications
- Repetitive behaviors
- Repetitive phone calls
- Repetitive questions
- Sexually inappropriate behaviors
- Sleep disturbances
- Sundowning
- Wandering
- Paranoid thoughts
- Lack of eating

Watch the videos here: uclahealth.org/dementia/caregiver-education-videos
Delirium is a common medical condition that occurs in sick older people in the hospital. It is particularly common in persons with dementia.

Delirium is characterized by a sudden change in a person’s cognitive function, which might cause a change in their behavior or personality. Delirium can be a frightening experience for the person with dementia and their caregivers.

Delirium can be caused by an infection, disturbances in blood chemicals, certain medications, pain, unfamiliar faces, change in routine, surgery, excessive noise, or a change in environment. Although most episodes of delirium last a few days, some may take weeks or months to resolve. Complications of delirium include falls, a prolonged hospital stay and greater needs after the hospitalization. Treatment is focused on addressing the cause of delirium, preventing complications and keeping your loved one safe.
Chapter 2  Behavioral & Emotional Concerns

- If at all possible, make sure that there is a family member or caregiver present with your loved one at all times. If you are planning on leaving, please consult the nurse first before you leave.

- Provide frequent reassurance to your loved one about where they are and what they are doing there.

- Make sure your loved one is wearing his or her hearing aids or eyeglasses.

- Avoid overstimulation, such as multiple visitors or loud noises from electronic devices.

- Give your loved one comforting items, such as blankets, family or pet photographs, or magazines.

- If your loved one is anxious, try to distract him or her by playing soothing music, reading a book together, or praying.

- Recognize that he or she may need more help with personal care.

“Because you know your loved one best, please share your knowledge of his or her preferred activities and routines so that the care team can provide a more personalized experience.”

—Maristela Garcia, MD

Types and common signs

There are two types of delirium, both characterized by increased confusion. Below are the other signs:

1. HYPERACTIVE DELIRIUM
   - Increased energy
   - Aggressive behavior
   - Agitation
   - Hallucinations
   - Anxiety

2. HYPOACTIVE DELIRIUM
   - Low energy
   - Sleepiness or drowsiness
   - Difficulty concentrating
   - Withdrawal

- Consider if your loved one is having any pain. Discuss this with his or her care team.

- Encourage your loved one to maintain a regular schedule of being awake in the daytime and asleep at night.

- Encourage mobility, and as soon as your loved one is cleared by their care team, help him or her get out of bed and sit in a chair. You can also consult with your loved one’s nurse to see if it is appropriate to help them walk. This is one of the best ways to prevent delirium.
The importance of mobility

Mobility is a person’s ability to move around, whether that means walking independently or using a cane or walker. Mobility is also the ability to transfer from one position to another, such as moving from the bed to a chair. Persons with dementia have a high risk of developing worsening cognitive and physical decline in the hospital, but the risk is even higher if they are not able to maintain mobility.

Ideally, your loved one should get out of bed on Day 1 of their hospitalization. Although he or she may be tired and want to rest, it’s important for your loved one to maintain their mobility while they are in the hospital. As soon as your loved one is cleared by his or her care team, consult your nurse about ways of helping your loved one increase his or her mobility.

If a patient is not able to perform certain tasks they previously performed before the hospitalization, the care team may order a consultation with our rehabilitation team, who can perform an evaluation and provide treatment recommendations. The rehabilitation team can also help physicians determine if your loved one will need additional therapy after leaving the hospital, which can be done at home or in a rehabilitation facility.
The risk of falls

People with dementia are 10 times more likely to fall compared to people without dementia. Falls occur because of cognitive impairment, an unfamiliar environment, illness, medications and balance problems. Injuries from falls can cause longer hospital stays, disability and loss of independence. It is important that you partner with the care team to prevent your loved one from falling.

Patients who are deemed high risk for falling will have a yellow armband placed on their wrist and a yellow sign with the symbol of a falling star placed outside their door. If your loved one is using the commode or toilet, staff will stay within visible sight of him or her, and within arm’s reach.

Tips for preventing falls

- Eliminate environmental hazards, such as clutter or equipment on the floor.
- Always consult the care team about helping your loved one transfer into a chair or walker.
- Make sure your loved one is using their assistive device, such as a cane or walker, during their walks.
- Help your loved one with food, water and toileting needs often.
- Make sure that the call light, telephone and other necessary items, such as water and a tissue box, are within reach.
- Provide well-fitting non-skid footwear.
- Notify the nurse before you leave the hospital. While each hospital bed and chair has an alarm system, the alarm must be turned on by nursing staff to work.

Risk factors for falls

- History of falling
- Elderly
- Dementia
- Use of an ambulatory aid, such as a cane or walker
- Impaired balance or weakness
- Overestimates or forgets limitations
- Intravenous (IV) access

“Mobility is one of the strongest indicators of overall wellness within the geriatric population. Even the slightest movement can make a huge difference and help the patient on their road to recovery.”

— Tina Mamais, MSN, GNP, NICHE coordinator
Getting ready for discharge

To ensure a smooth and timely discharge from our hospital, the care team begins planning your loved one's discharge needs soon after admission. It is important for you to be involved in these discussions, since this will help you make preparations after your loved one is discharged from the hospital.

RETURNING HOME

If your loved one is returning home, the nurse will provide written discharge instructions that will include a list of follow-up appointments and necessary medications. Please ask any questions of your physician or nurse before leaving the hospital.

NURSING OR REHABILITATION FACILITY CARE

If your loved one requires care at a nursing or rehabilitation facility, we will coordinate ambulance transportation and communicate with the facility's physicians and nurses to ensure continuity of care.

The goal of care at a rehabilitation facility is to optimize your loved one's functional abilities. While a physician will oversee this care and be available on-call, physicians are not available on-site 24/7. Licensed vocational nurses (LVNs) will be responsible for providing the nursing care, while RNs will often be present to supervise. Therapeutic treatments may include physical, occupational and speech therapy. We encourage you to participate in these treatments and ask how to best help your loved one at home.

Tips for a smooth discharge

■ Get an early start in planning for discharge.

■ Expect that your loved one will need more help with their daily activities. Consider hiring a caregiver and ask the unit case manager for a list of home care agencies.

■ Determine how your loved will be transported to their next destination. Consult the unit case manager if you have questions or concerns.

■ If your loved one is going home, prepare the environment prior to his or her arrival. If you have not already done so, consider installing grab bars around the toilet and shower. Speak to the care team about needs for shower chairs, hospital beds, wheelchairs, walkers and other medical equipment.
In some cases, people with dementia who are in the hospital are approaching the end of their life. Discussions about end of life care are often complex, and caregivers may find themselves faced with difficult decisions. During these challenging times, it is important to know that UCLA Health is here to support you and your loved one.

If your loved one is too ill to leave the hospital, the care team can make arrangements to make your loved one more comfortable in the hospital. If your loved one is discharged back home or to a facility, your care team will make arrangements for you to speak with palliative care and hospice care.

Palliative care is specialized interdisciplinary medical care focused on relieving the pain, symptoms and stress of serious illness.

Hospice is a medical service provided to a terminally ill patient at home or wherever he or she may reside. Hospice care usually involves relieving troublesome symptoms for the patient and providing psychological and social support for the patient and family.

If you have any questions or concerns about this issue, please make sure to speak to the care team taking care of your loved one.

“Hospice treated my mom and my family with dignity, care and respect. It helped me feel emotionally present and at peace.”

Suanne, daughter and caregiver of UCLA patient
Chapter 4  Community Resources

Adult day care centers for people with dementia

Adult day care centers are daytime facilities that provide social, physical, emotional and nutritional support for patients with dementia. These centers also provide relief for caregivers, while allowing their loved one to participate in supervised activities. The following are some local adult day care centers to consider:

1. **ONE GENERATION ADULT DAY CARE**
   17400 Victory Blvd.
   Van Nuys, CA 91406
   Phone: 818-708-6625
   Web: onegeneration.org/seniors/adult-daycare

2. **OPICA ADULT DAY CARE**
   11759 Missouri Ave.
   Los Angeles, CA 90025
   Phone: 310-478-0226
   Web: opica.org

3. **SENIOR CONCERNS ADULT DAY CARE**
   401 Hodencamp Rd.
   Thousand Oaks, CA 91360
   Phone: 805-497-0189
   Web: seniorconcerns.org

4. **WISE & HEALTHY AGING ADULT DAY CARE**
   1527 4th St., 2nd Floor
   Santa Monica, CA 90401
   Phone: 310-394-9871
   Web: wiseandhealthyaging.org

More Information

For further assistance in finding adult day health care facilities closer to your home, please consult the California Association for Adult Day Services (CAADS)
Web: caads.org/find_program/find_program.htm
Chapter 4  Community Resources

Community resources for caregivers

Caregivers are the foundation of care for the patient with dementia. Your involvement, knowledge and partnership are crucial to your loved one’s health.

UCLA Health salutes all our caregivers and we thank you for everything you do. Being in the hospital can be stressful for you and your loved one. In order for you to be a good caregiver, you need to take care of your health and well-being. The following are some resources you might consider:

1. **THE UCLA ALZHEIMER’S AND DEMENTIA CARE PROGRAM**
   - **Address:** 200 UCLA Medical Plaza, Suite 365A, Los Angeles, CA 90095
   - **Phone:** 310-319-3222
   - **Web:** uclahealth.org/dementia
   - The UCLA Alzheimer’s and Dementia Care Program provides comprehensive dementia care to address the complex medical, behavioral and social needs of people with dementia and their caregivers. If your loved one is not enrolled in the program, please speak to his or her UCLA Health primary care physician about a referral.

2. **UCLA ALZHEIMER’S AND DEMENTIA INFORMATION SERVICE (ADIS)**
   - **Phone:** 310-824-8447
   - **Hours:** Monday – Friday: 8 am – 5 pm
   - This service is focused on patients with mild dementia. The care coordinator provides telephone assistance to help patients and their families by providing guidance about UCLA and community-based resources for patients and caregivers.

3. **UCLA ALZHEIMER’S AND DEMENTIA CARE PROGRAM/EASTON CENTER SUPPORT GROUP**
   - **Phone:** 310-794-3914
   - **Web:** eastonad.ucla.edu/index.php/patients-caregivers/caregiver-support-groups

4. **ALZHEIMER’S GREATER LOS ANGELES**
   - **Address:** 4221 Wilshire Blvd., Suite 400, Los Angeles, CA 90010
   - **Phone:** 844-HELP-ALZ
   - **Web:** alzheimersla.org
   - Alzheimer’s Greater Los Angeles provides programs in English and Spanish to help people with dementia, their families, caregivers and care professionals. Programs include free counseling on care issues, care planning, support groups and education programs.
Chapter 4  Community Resources

5  ALZHEIMER’S ASSOCIATION
Phone: 800-272-3900 (24-hour hotline)
Web: alz.org
The Alzheimer’s Association, a non-profit committed to finding a cure for Alzheimer’s disease, offers care and support for those living with Alzheimer’s disease and those who care for them.

Services include:
- A toll-free, 24-hour helpline
- Support and educational groups for people in early stage and their care partners
- Individual care management and counseling sessions for caregivers
- Peer and professionally-led support groups for caregivers
- Advocacy to encourage legislative reform
- Training and community educational presentations
- Memories in the Making art programs

6  LEEZA’S CARE CONNECTION
501 South Buena Vista St.
Burbank, CA  91505
Phone: 818-847-3686
Web: leezascareconnection.org

Services include:
- Caregiver resources
- Health and wellness programs
- Information and referral services
- One-on-one family meetings
- Preserving family memories/scrapbooking
- Support group

7  WISE AND HEALTHY AGING
1527 4th St., 2nd Floor
Santa Monica, CA 90401
Phone: 310-394-9871
Web: wiseandhealthyaging.org

Services include:
- In-home care management services
- Caregiver support groups
- Caregiver Training Academy
- Peer counseling
- Legal clinics in conjunction with the Legal Aid Foundation of Los Angeles
Chapter 4  Community Resources

8 SENIOR CONCERNS
401 Hodencamp Rd.
Thousand Oaks, CA 91360
Phone: 805-497-0189
Web: seniorconcerns.org

Services include:
- Caregiver support center and management services (information and education)
- Caregiver support groups
- Legal, financial and advocate services
- Volunteer and community activities
- Assisted living consultation

9 OPICA
11759 Missouri Ave.
Los Angeles, CA 90025
Phone: 310-478-0226
Web: opica.org

Services include:
- Support groups
- Counseling for caregivers and the general public
- Educational programs for caregivers

10 JEWISH FAMILY SERVICES (LOS ANGELES)
3580 Wilshire Blvd., Suite 700
Los Angeles, CA 90010
Phone: 323-761-8800
Web: jfsla.org

Services include:
- Counseling
- Case management
- Homebound meals

11 ONE GENERATION
18255 Victory Blvd.
Reseda, CA 91335
Phone: 818-705-2345
Web: onegeneration.org

Services include:
- Care management
- Caregiver support groups
- Homebound meals

Notes