SURGERY FOR PERSONS WITH DEMENTIA



Just-in-Time Tip Sheet for Caregivers

Introduction

People with Alzheimer's disease and other related dementias (ADRD) often go through changes in thinking and physical abilities after surgery and while in the hospital. It can be a stressful and confusing time for them and for you. These changes could be due to their daily routines being disrupted, being in an unfamiliar place, and dealing with medical staff they don't know.

Just-in-Time

This *Just-in-Time* tip sheet for caregivers gives some helpful advice on how to communicate with hospital staff during this time. It includes tips on what questions to ask and what information to have ready.

Remember, caregivers play a crucial role in the care of someone with ADRD, especially during transitions in care (moving from one care setting to another, like hospital to home or nursing home). By working together, we can improve the quality of care for these individuals.

Vital Information to Communicate with Surgery Staff

- Let the surgery staff and bedside nurse know that your loved one has dementia. Give them details about the stage (early, middle, or advanced) and other important characteristics like how they communicate and understand things. Share any words or phrases you use that help your loved one feel validated and understood. Ask the hospital staff to pass this information along during shift changes.
- Make sure to confirm your relationship with your loved one (husband, wife, partner, family member, friend) and let the surgery staff know if you'll be leaving and when you'll be back.
- Mention aids the person uses (glasses, hearing aids, dentures, cane, walker) and request that they be available before and after any medical procedures. If possible, keep possession of expensive equipment like hearing aids or custom durable medical equipment when the patient isn't using them.
- **Explain daily activities where the person may need extra help** (eating, bathing, toileting, walking) and share any tips that work for you with the bedside staff.

Communication Tips

As a key member of the care team for someone with ADRD, don't be afraid to ask medical providers to slow down if they're talking too fast or if you're unsure about what's going on. Let them know if you're having trouble hearing or understanding. This will help you better understand the care being given. It will also help you make sure that your loved one is well taken care of.

If you're feeling overwhelmed or unsure about caring for them at home, reach out to a discharge planner, hospital ombudsman, or patient advocate for help and advice.

Critical Questions to Ask Surgery Staff

If you're scheduled for surgery, chances are you've already planned for this activity before heading to the hospital. But if you still have questions about the procedure, don't hesitate to ask to talk with the surgeon beforehand. Here are some questions to ask.

How can the surgical team help minimize anesthesia and drug interactions that might lead to cognitive decline and delirium in individuals with ADRD?

Talking about this ahead of time allows the anesthesiologist and team to explain their anesthesia plan and how they'll work to prevent side effects that could cause problems in the person's cognition (thinking, understanding, reasoning) or cause delirium (a temporary, treatable change in mental abilities). It also helps them get important information from you about the person with ADRD before the surgery.

How will the team help with pain the person might feel after surgery if they can't tell us?

Persons with ADRD often express pain physically by rubbing a body part, moaning, or yelling. It's helpful to ask the team how they check for and handle a person with ADRD experiencing pain. This gives you a chance to share how you manage your loved one's physical pain, anxiety, and tough behaviors. You can also identify specific triggers to avoid (some things that cause someone to feel upset and frightened) that could cause challenging behaviors and how to handle them when they occur.

How long will the surgery last, and how long will it take for the person to recover?

The surgical team will give you an idea of how long the surgery will last and how long the person will need to recover. This info can help you plan your time at the hospital. If it's a long surgery, you might want to run some errands or take care of things at home. If it's a quick surgery, it's best to stick around so you're there when the person wakes up.

What information can be shared with me about the person I care for? I understand the importance of patient confidentiality and privacy.

Before hospitalization or upon admission, the hospital will try to identify a dedicated decision-maker, such as a Durable Power of Attorney (DPOA) agent, if there is one. Because caregivers are a vital link in the information chain, it's important to share relevant legal documents and information with staff. For more info on DPOA and other legal documents go to Family Caregiver Alliance: www.caregiver.org.

Additional Information Caregivers Should Have on Hand to Share with Hospital Staff

- A brown bag containing all medication bottles or a medication list with information on when and how to take each medication for a person with ADRD.
- List of allergies.
- List of other health conditions (such as diabetes, congestive heart failure, chronic obstructive pulmonary disease, and psychiatric conditions) and how the person is managing them.
- Insurance information.
- Primary care physician's name and phone number, advance directives, and signed POLST form.
- Name and number of caregiver and other emergency (ICE) contacts.

Help surgery staff understand what matters most from the person's perspective. If the person could communicate with the staff, what would they want to tell them? Helping the care team confirms that you want to make their job easier and that you are part of the care team.

What should I know about discharge from the hospital?

Before the person with ADRD is discharged, be sure to ask the following questions:

- What is the diagnosis, and what does it mean?
- Are there any new medications or care that should start upon discharge? When and how?
- Is there new medical equipment I need to learn to use before going home?
- What should I look for at home and do if my loved one is having a medical problem?
- When is the next follow-up appointment?

If the person is being transferred to another floor in the hospital or to another facility, ask about their diagnosis, care plan, and how long they will be there. Stay informed and be prepared!