

Not If, When: Preparing for a Hospitalization with Dementia

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On any given day, I can think of at least fifty other places I'd rather be at than a hospital. The post office? Let's buy some stamps. Holiday shopping at Kohl's? I'll grab my coupons. The DMV? Bring on those long lines. It's not that hospitals themselves are inherently bad; doctors, nurses, social workers, and other healthcare professions make up the backbone of our society. It's the crisis, new symptoms, long waits, fear of high medical costs, and pain that make a hospital trip not so pleasant. The reality is, that while many of us wouldn't choose to visit the hospital, most of us will at some point, either as a patient, or as a caregiver. When we add a disease like dementia to a hospitalization, the situation quickly becomes more complex and challenging. Below are some tips to help empower dementia caregivers to ease the stress of a hospitalization for themselves and the person they are caring for. I've also included some tips titled "*Be proactive*" that are helpful suggestions to begin before a crisis or hospitalization. Dementia is a very reactive disease in general, meaning it's challenging to predict what progression or new symptoms may arise. It's nice to have opportunities to be as proactive as possible!

Be an advocate

Depending on severity of dementia, the person you're caring for might not be able to accurately represent what symptoms they have experienced and for what duration. Delirium, which is a sudden change in cognitive functioning, can often accompany a dementia hospitalization, and adds to the confusion and impairment. Make sure the healthcare team knows the dementia diagnosis as soon as possible, and that you are there to help. Ask to speak with the healthcare team outside the room if you are more comfortable sharing information privately and not in front of the person living with dementia. As a hospitalization can add to the current level of cognitive impairment, it's important that there is a person able to listen and take in all important information, as well as be a reporter for the healthcare team.

Be proactive: Keeping a daily journal as a caregiver to log changing behaviors and symptoms, severity of pain, etc. can be a helpful guide for the healthcare team. Start by noticing what the 'normal' routine is, and noting any changes or unusual activity.

Make a hospital bag

This tip is all about being proactive! Having a hospital bag ready to go in case of a crisis can help prevent extra stress in the future. Dementia expert Teepa Snow lists everything you need to pack in her tip sheet "Dementia Hospital Bag: What to bring when going to the hospital". The items range from important documents such as power of attorneys and advance directives to a personal information sheet containing their health history, medication list, and level of support to complete the daily routine. The tip sheet also suggests sharing important behavior triggers, redirection techniques, and calming

strategies to help ease the anxiety a person living with dementia might be feeling. Find more direction to make your hospital bag at www.pineseducation.org/hospital.

Be proactive: Give copies of important documents and the completed personal information sheet to close family or friends who are part of your emergency contacts.

You are the expert

Don't expect every member of the healthcare team to understand dementia or how it manifests in the person you're caring for. Dementia itself is complex, and with all of the duties of the hospital staff, it can be challenging for them to completely understand their needs. You are the expert on the person you're caring for – feel confident in your role as a caregiver!

These tips describe central themes to reflect on; for more specific recommendations and ideas, check out the National Institute on Aging's tip sheet "Going to the Hospital: Tips for Dementia Caregivers".

For more information about Memory Moment articles & Effingham Area Alzheimer's Awareness, check out their website at www.effinghamalz.org. If you are a caregiver & have specific questions or situations you would like information on, please feel free to call Shannon Nosbisch at 217-663-0010 or Amy Sobrino at 618-363-8372.