

Reducing the Stress of Hospitalization for Patients with Dementia and their Family Caregivers: A Provider's Guide

You are home watching TV, you get up to go to the bathroom, and suddenly you are on the floor screaming in pain. Then strangers are lifting you onto a stretcher and asking you questions. Now you are in a vehicle with a mask over your face and all you can hear is a loud siren. When you are lifted out of the vehicle, more strangers bend over you and ask you more questions.

Don't shout, you want to tell them. I can hear you. I just don't understand what you are saying.

The bright lights and loud sounds are terrifying. You see a familiar face in the background. Who is she? And why isn't she helping me? Now someone sticks a needle into your arm – it hurts – but some of the pain is going away. You think: What is happening to me? Am I dying? Am I already dead?

This is not a nightmare. It is the way a person with dementia might experience an emergency trip to the hospital.

Let's say she is an 85-year-old woman. You might encounter her in the Emergency Room, unable to answer any questions about her medical history or even her level of pain. Or you might meet her on the hospital floor, when she doesn't stay in bed as directed and confuses the closet and the bathroom. She might pull out the IV line or refuse to take her medications.

Your initial reaction might be annoyance. But if you recognize that she might have some form of dementia, you will think about her differently.

No one can take away her fear entirely or make her easy to deal with. But there is a lot that you as a health care provider can do when you work with this patient.

In this important task your main resource is often the family caregiver –the person who has critical information you need to treat this patient appropriately, to reduce the stress of hospitalization for the patient and her or his family, and to make your job a little easier.

Purpose of the Guide

The guide contains information about:

- ▶ Some symptoms of dementia and some other possible reasons for the patient's behavior,
- ▶ A communication approach that builds trust between care professionals and family caregivers, and
- ▶ Specific actions to reduce the patient's and family caregiver's anxiety and prevent errors and safety lapses.

Why people with dementia are particularly vulnerable

Dementia will generally not be identified as the reason your patient has been brought to the ER or has been admitted to the hospital. The primary reason is usually another medical problem such as congestive heart failure (CHF), a fall, burns, or chronic obstructive pulmonary disease (COPD). But consider these statistics:

Based on Medicare data, about 25% of all hospital patients aged 65 and older have dementia.

Compared with other older people, older people with dementia have:

- ▶ Three times as many hospitalizations
- ▶ Four times as many hospital days
- ▶ Almost three times as many ER visits.

Their hospital stays are likely to be longer than usual for their primary diagnosis and to result in adverse outcomes such as:

- ▶ New delirium
- ▶ Pressure ulcers
- ▶ Incontinence
- ▶ Functional decline
- ▶ Physical restraints
- ▶ Psychotropic medications
- ▶ Untreated pain
- ▶ New feeding tubes

It is especially important to be aware of these vulnerabilities during an inpatient stay and to take steps to prevent these poor outcomes, which may lead to further decline and avoidable readmissions.

Does this patient have dementia?

It is not always clear which patients have some form of dementia. Consider, for example, the following three hypothetical patients.

- ▶ Mrs. A is 85 and has COPD. She was cooperative and pleasant on admission but on the second night of her stay she suddenly starts hallucinating and striking out at everyone who comes near her.
- ▶ Mr. B is 90 and has CHF. He is agitated and confused. He won't stay in bed and thinks the closet is the bathroom.
- ▶ Ms. C is 70 has diabetes. She keeps forgetting where she put her glasses and how to use the phone. She yells at everyone, including her daughter and grandson, but whispers to the nurse that the aide is stealing the cash she keeps for her newspaper.

All of these patients – or none of them – may have some form of dementia.

Mrs. A. may be suffering from **delirium, a sudden, acute, often unrecognized but treatable onset of confusion**. This may be the result of new medication she is taking, dehydration, or infection. She may also have some underlying dementia – the chronic process of changes in the brain that affect memory and behavior. Older people with dementia are more likely to develop delirium in the hospital.

Mr. B's behavior suggests **dementia**. His agitation and his inability to locate the bathroom are typical signs of a chronic brain disorder. **But he may be disoriented because of the inpatient stay itself**, particularly if he has a fever or is on new medications.

Ms. C's behavior also suggests dementia. But it is also possible that she is a generally suspicious and demanding person. **Not every behavior can be reduced to a medical label.**

Here are some common signs of dementia. The patient:

- ▶ Seems disoriented
- ▶ Is a "poor historian," that is, can't recall medical or personal history
- ▶ Defers to a family member to answer questions
- ▶ Repeatedly and apparently unintentionally fails to follow instructions
- ▶ Has difficulty finding the right words or uses inappropriate or incomprehensible words
- ▶ Has difficulty following conversations

Source: Mathy Mezey, and Katie Maslow, "Recognition of Dementia in Hospitalized Older Patients," *Try This, D5* available at <http://consultgerim.org/uploads/File/trythis/finRecog.pdf>

Family Caregivers: Vital Links to Patients

Family caregivers may be spouses, partners, adult children and grandchildren, friends, or neighbors. They may or may not live with the patient. Family caregivers of patients with dementia or other kind of cognitive impairment have probably been dealing with this situation for quite some time. They may not openly acknowledge that there is a problem with the patient's memory or judgment beyond "a little forgetfulness" or "occasional confusion." **They may not even think of themselves as caregivers.**

Whatever they understand about their family member's condition, they are your vital link to the medical and psychosocial information you need to provide quality care.

The family caregiver is likely to be your primary source of information on your patient's medical history, social circumstances, and daily routine. If you are a physician, nurse or social worker or other professional evaluating the patient, the responses of the family caregiver to the following questions can give you a starting point. Family caregivers can also verify or clarify information collected about medications during the intake process. Assuming that there has not been a diagnosis of dementia, you might ask:

- ▶ Is this behavior typical of your family member?
- ▶ Has your family member been experiencing memory loss, confusion, poor judgment, disorientation, personality changes, or other unusual behaviors?
- ▶ Does he or she take all prescribed medications?
- ▶ Does he or she take other nonprescription medications?
- ▶ Have any new medications been added recently?

For **all** cases, it's important to ask:

- ▶ What do you as the family caregiver do regularly to assist in the patient's care?
- ▶ Who else is involved in the patient's care?

The special expertise of the family caregiver

As a health care professional you have special training and expertise that allow you to work with many different kinds of conditions and patients. Many family caregivers have learned a lot about the patient's disease but their special expertise lies in their long history with this particular patient. You can use this expertise to supplement yours—a benefit for you as well as the patient.

Based on their previous experiences, some family caregivers may come to the ER or hospital lacking trust in doctors, nurses, social workers, or the health care system. Many family caregivers feel that only they understand this person and know how to meet his or her needs. They see themselves as the patient's advocate and protector, and they may be afraid that you won't be able to provide good care. This is reinforced every time someone makes a critical remark or scolds the patient. Many caregivers won't tell you about their distrust directly. You may have to read between the lines as you develop a more effective kind of relationship.

A family caregiver who gives you an overly positive description of the patient's behavior, cognitive status, and overall condition may be trying to make sure you accept the patient as a person and not simply as a difficult case. Or it could be a way to convince herself that the situation is not so bad. Or putting a positive spin on bad events may be the habit of a lifetime.

Similarly, a family caregiver who paints a particularly miserable picture may have found you to be the first person who is willing to listen. The immediate reason for the hospitalization or rehab stay is disruptive and frightening for the family caregiver, and it may also raise questions about the future. How will I manage now? Is it time for a nursing home? How could I even think about that? Will I have to quit my job?

This hospital experience may be the transition that changes the family caregiver's perception of what to expect in the future.

Building Trust

Building a trusting relationship with the family caregiver is essential for effective diagnosis, treatment, and discharge of the patient.

You need to listen to the caregiver and probe for unspoken fears and concerns. This is time well spent because you will have a better grasp of the patient's history and condition and can develop a more effective plan for the inpatient stay.

Ask the family caregiver what he or she considers the best ways of dealing with the patient. Most family caregivers have a set of "best practices" – approaches and techniques that are most likely to get the desired response from the patient. Frequently these best practices maintain a familiar routine and recreate a familiar environment. Sometimes they are not "best" in the sense of professional nursing protocols, but they are "good enough" practices that build in individual preferences and realistic processes for care at home.

Practical steps toward safety and less stress

Here are some things staff can do to minimize the stress of the inpatient stay:

- ▶ Ask the family caregiver how the patient likes to be addressed (first name, Mrs. Jones) and whether he or she likes or dislikes terms like "Dearie" and "Honey."
- ▶ Watch for grimaces, clenched teeth or fists, kicking or other nonverbal cues that may be typical ways the patient expresses pain. Family caregivers are often alert to these signs.
- ▶ Remember that the patient's behaviors are attempts to communicate. They may be difficult to interpret but they are the only ways a patient with advanced dementia has to express fear, pain, distress, isolation, and confusion.

- ▶ Ask doctors and others on your team to limit the questions or instructions directed to the patient who will probably not be able to answer correctly or remember what was said.
- ▶ Approach the patient from the front so that he or she can see you.
- ▶ Speak calmly and reassuringly to the patient (and the caregiver).
- ▶ Don't say, "Don't you remember?" This only reinforces the patient's feelings of loss and inadequacy.
- ▶ If the patient needs help eating, make sure someone is there to help. An untouched food tray is a signal that something is wrong.
- ▶ Put personal clothes in the closet, so that the patient is not tempted to get dressed and leave.
- ▶ Alert the family caregiver to upcoming tests or procedures when the patient will be taken out of the room. Every change is disruptive and confusing for the patient, and it will help if the family caregiver can be present. People with dementia often wander out of the ER or test area if unsupervised. They should not be left alone in these situations.
- ▶ Give the family caregiver test results as soon as they are available.
- ▶ Keep noise and distractions to a minimum. Check with the family caregiver about whether television should be on or off, lowering the telephone ringer, and using the intercom.
- ▶ At the first sign from the patient that what you are doing is unacceptable to him or her, stop and redirect your efforts.

Here are some tips to give family caregivers:

- ▶ Encourage family caregivers to take time to sleep, shower, eat, and attend to their own needs.
- ▶ Suggest that family caregivers ask another family member, friend, or hired aide to be with the patient when they cannot be present. Explain your facility's policies about "companions" hired through the nursing office or independently. This is especially important when the patient is in the ER or is being taken for tests or other procedures.
- ▶ Suggest that family caregivers create a "telephone tree" or email list to keep others informed about progress and discharge. This minimizes the time caregivers have to spend bringing others up to date.
- ▶ Ask family caregivers (or substitutes) to fill out the menu requests, and note preferences.

Adapted from "Hospitalization Happens: A Guide to Hospital Visits for Individuals with Memory Loss" National Institute on Aging, Dec. 2008 <http://www.nia.nih.gov/Alzheimers/Publications/happens.htm>

Preparing for Discharge

Preparing this patient and family caregiver for discharge can be particularly challenging if the patient's condition has deteriorated while in the hospital (see *Hospital to Home Discharge Guide* at http://nextstepincare.org/uploads/File/Guides/Hospital/Discharge_Checklist/Discharge_Checklist.pdf) The short-term impacts of the inpatient stay may lessen in time, or this may be the start of a different and more serious phase of dementia.

In planning the discharge for the patient with signs of dementia, it is essential that you inform the family caregiver well in advance about the transition plans, including the day, time, transportation plan, and destination. **Long delays and missed communication will affect this patient and caregiver more than others.** The family caregiver or someone known to the patient should accompany him or her home or to the next setting to reduce the patient's confusion and to speak for him.

You can also help prepare the family caregiver with advice, support, and information:

- ▶ Information about the next care setting and the services that are likely to be available that will be particularly appropriate for the patient (see Planning for Inpatient Rehabilitation (Rehab) Services at http://nextstepincare.org/uploads/File/Guides/Rehabilitation/Guide/Complete_Rehab.pdf and Home Care: A Family Caregiver's Guide at http://nextstepincare.org/uploads/File/Guides/Home_Care/Guide/Home_Care.pdf).
- ▶ Referrals to the local chapter of the Alzheimer's Association and other community support services for the caregiver
- ▶ A person and a number to call with questions about the inpatient stay and instructions

A call to the receiving agency or facility to discuss the patient's condition and the caregiver's needs will help make the transition as smooth and welcoming as possible.

A Challenge With Rewards

There is no question that taking care of a patient with dementia can be difficult, but the rewards of knowing that you have made the inpatient stay as stress- and complication-free as possible are also great. Family caregivers are particularly grateful to a professional who has demonstrated compassion, confidence, and respect when caring for their family member with dementia.

The United Hospital Fund is grateful for the efforts of the advisory group who generously shared time and expertise in the planning and development of this guide: Marsha Berry and Katie Maslow of the Alzheimer's Association (national), Della Frasier-Rios of the Alzheimer's Association-New York City Chapter, Jan McGillick and Maggie Murphy-White of the Alzheimer's Association-St. Louis Chapter, and Nancy Smith-Hunnicuttt of Mission Hospitals (Asheville, NC).