DEMTIA MENTORS

Partners In Care Hospitalization Kit

CARE PARTNER HOSPITAL TIPS

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CARE PARTNER HOSPITAL CHECKLIST

When caring for a loved one living with cognitive impairment, a trip to the emergency room (ER) or hospital is almost a given. Even if you are fortunate not to ever go, being prepared is vital to your experience and the outcome. Receiving proper healthcare today has many problems, and hospitalization for a person with dementia and their family is especially difficult. Keep in mind that hospitals are not typically well-designed for patients with dementia. Below are recommendations for what to consider and what to do to make the experience for everyone, including the hospital staff, less stressful.

PLAN AHEAD

- [ ] Complete Medical Legal Form and Life Story forms included in the kit.
- [ ] Gather and make copies of legal papers such as Advance Directives, DNR, POLST, and organ donation documents.
- [ ] Keep a pad and pen to take notes.
- [ ] Pack an emergency bag with essentials for yourself, including a change of clothes, toiletries, personal medication, a phone charger, and cash.

TRIP TO THE ER

- [ ] Ask a family member or friend to accompany you if possible.
- [ ] Explain the symptoms and events leading up to the ER visit. Share pertinent information from the kit with the staff.
- [ ] Inform the staff about dementia and suggest effective ways to communicate with your loved one.
- [ ] Advocate for your loved one and help the staff understand their needs and behaviors.

IF ADMITTED TO THE HOSPITAL

- [ ] Have someone stay with your loved one at all times.
- [ ] Monitor all aspects of care and ask questions when needed.
- [ ] Ensure important information about dementia diagnosis and behavioral concerns is noted in the medical chart.

CARE PARTNER HOSPITAL CHECKLIST

IF ADMITTED TO THE HOSPITAL (CONTINUED)

- [ ] Request that physical restraints or medication to control behavior be avoided.
- [ ] Report any changes or worsening symptoms to the hospital staff.
- [ ] Be aware of delirium symptoms and their impact on patients with dementia.
- [ ] Recognize that an unfamiliar environment may increase confusion and the need for assistance.
- [ ] Employ strategies to reduce anxiety and agitation, such as removing personal clothing from sight, using reminders or cues, minimizing background noise, and providing comforting touch or distractions.
- [ ] Ask family and friends to keep others informed.

IF ENCOUNTERING PROBLEMS WITH THE HOSPITAL STAFF

- [ ] Contact the patient advocate or the Beneficiary and Family-Centered Care Quality Improvement Organization for assistance.

MAIN POINTS TO REMEMBER

- Hospitals are complicated and not designed for care of dementia patients. They are critically understaffed.
- There is a lack of understanding and knowledge regarding cognitive impairment by the hospital staff, even those that should know.
- Common medications used for pain, nausea, depression and psychosis are not safe for those living with dementia.
- Be prepared and use the above suggestions to get the best possible outcome for your loved one.

COMMUNICATION TIPS

People living with dementia or any cognitive impairment use behavior to communicate their needs. Yelling, agitation, and combativeness are only a few means they use to tell others that they may be overwhelmed, in pain, confused, or frightened. When you look at a situation from this point of view, you can better communicate in ways they understand. These tips will help reduce conflict and improve connection.

FUNDAMENTAL PRINCIPLES TO REMEMBER

- Empathy rather than explanations
- Reason WHY, rather than reasoning WITH
- Your goals should be: Validation and Reassurance
- Understanding THEM: how they see a situation and how they feel about it (NOT getting them to understand you)

FUNDAMENTAL PRINCIPLES TO REMEMBER (CONTINUED)

- Avoid trying to correct their reality or beliefs. Avoid arguing about what's true or accurate. Someone with cognitive impairment is losing the ability to see your point of view or even the reality of a situation — and that's the perfect set-up for lots of disagreements. Focus on helping them feel understood, or at least: accepted and loved.
- It's not always necessary to tell the whole truth. It is sometimes OK to fudge things or use a "fiblet" (therapeutic non-truth). Ask yourself, "Will my answer do more harm than good?"

WHAT TO STOP SAYING

- "Don't you remember?"
- "Why did you do that?"
- "But that's not true."
- "You've already asked that." or "We just talked about that."
- "Do you remember that...?"
- "I can't believe you did/didn't do that."
- "You need to accept/remember/understand that..."

HOW TO RESPOND TO RESISTANCE

It is often frustrating when a person living with dementia resists help. Acknowledge the challenge and then try to use it as an opportunity to connect and learn more about what matters to them. This connection and what you know will be invaluable later when you attempt to step in.

The 4-step connecting approach you can use:

- Consider how cognitive impairment plays into this.
- Make sure you've heard and validated their feelings.
- Probe to learn more about their fears, desires, goals, and priorities.
- Distinguish what YOU need from what THEY need.

USEFUL PHRASES

- "Hm, sounds like you don't like that idea."
- "Tell me more."
- "What I'm hearing from you is that it's really important that..."

For exploring desires:

- "Tell me more about what you like about ____."

For exploring fears:

- Fears will probably be hard for them to describe directly. Try listening to what they say and then venturing an interpretation: "It sounds like you're worried that _____. Does that sound right?"

Be careful about asking, "Why?" It makes people defensive, and they usually have trouble finding a good answer.

COMMUNICATION TIPS

CREATING THE BEST ENVIRONMENT FOR COMMUNICATION

Pick the right setting and time: Ensure you're not competing with the TV, radio, or a room full of people. If possible, choose a time when they are rested and alert.

Give it time: Many people living with dementia take a while to dive into a deeper conversation, especially if they have trouble with vision, hearing, or mobility. In fact, normal cognitive aging by itself means that older adults need more time to weigh complex issues, especially those that trigger negative emotions. You might ease in with small talk about the weather or your dog first. As you ask questions, allow plenty of space for answers; don't be in a rush to fill pauses or silences with chatter.

Assume nothing: This isn't about who's right and who's wrong. It's about exploring their feelings and value and how they see things. Best to go into this conversation expecting you won't see things exactly the same way because most people living with dementia and others don't. Conflicts and trade-offs are likely. Or what you hear may not be logical or wise.

USEFUL PHRASES THAT HELPS YOU FIND OUT MORE INFO

- "Hmmm, tell me more." (Both neutral and encouraging, this is one of the most valuable responses you can offer — especially if they've just said something that sounds a bit confusing).
- "Can you say more about that?" "What's the most important part of that for you?"
- "What else is on your mind?"
- "Would you like me to help you get some more information about that?"
- "What if things got worse; what would you like to see happen?"
- "Anything else?"

FORGET ABOUT INSISTING YOU CAN GET THEM TO "UNDERSTAND"

Insisting on the reasoning and logic behind a particular decision, especially one they might not prefer, won't work. Brain functions that support logic, judgment, and rationality are affected when cognitive issues are present. No matter how hard you try, no matter how patient your explanations, they may become upset, hold a decision against you, or behave in other uncharacteristic ways. Unfortunately, this is a common aspect of living with cognitive impairment that you can't do anything about. It's natural to want to explain, and OK to try to a limited extent. But don't beat yourself up if doing so goes nowhere. And definitely don't persist with getting them to understand if it's not working.

DON'T EXPECT A LOGICAL FLOW TO YOUR CONVERSATIONS

They may be unable to engage in thoughtful negotiations or follow lines of thinking that make perfect sense to you. Yet your auto-pilot impulse will be to fall back on the same logic and other ways of conversing with them that you've always used. Even if they seem "normal," brain changes can interfere with (or prevent) really productive, linear talks. If you find yourself feeling frustrated by their lack of logic, try to take a deep breath. Then focus on listening to them and accepting where they are at with their thinking, even if it seems to be going in circles or isn't logical.

TIPS FOR DISCHARGE PLANNING

Being prepared to leave the hospital is just as critical as entering. Hospitals and insurers require the shortest stay possible without considering the patient or the family. The discharge planning will begin as soon as you arrive.

A discharge plan indicates where the patient should go upon leaving the hospital but also must address various factors to ensure the patient recovers safely, with little chance of complications and potential hospital readmission.

The team making these decisions may include:

- A case manager
- Nurses
- Doctor(s).
- Physical, occupational, and speech therapists
- A social worker
- The patient's insurer

One of the most essential tips for hospital discharges is to get involved in the process! Your involvement is even more vital when there is a diagnosis of dementia. When family members participate in the planning process, they can ask questions about the diagnosis, expected progress, potential complications, the types of help their loved one will need, and more.

Your job is to explain the home situation and the availability of family support. This includes their ability to stay on top of their care, medication management, and other activities of daily living. If you or other family members are helping out, you should share any restrictions that would make any or all caregiving responsibilities difficult. If physical, financial, family, work, or other limitations could affect your caregiving capabilities, you must speak up during this planning process.

Transitioning from hospital to home can be dangerous for those with cognitive decline and their care partners. Sending home sick patients with complex medical needs increases the risk of dangerous complications and infections. Talk to the doctor(s) and discharge planner if having a "safe discharge" is impossible. Provide details about your concerns in writing.

Remember, you are your loved ones ADVOCATE!
Be prepared to speak up for them.

MY NOTES

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