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HOSPICE

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Caring for Someone with Dementia

If you are caring for someone with dementia, you are not alone. The Alzheimer's Association reports that more than 16 million Americans provide unpaid care for people with Alzheimer's and other types of dementia.

As a caregiver to someone with dementia, the goal is to keep the person safe, calm, and active for as long as possible. In some cases, this may help to slow symptoms such as mood swings, confusion, and trouble with memory or speech.

Below are tips which can be adapted to match each unique situation. Make adjustments based on the stage of the person's illness. You can also check for resources in your community that provide support and special care for those with dementia and their caregivers.

Tips for Caregivers

- **Avoid overstimulation.** If sights, sounds, smells, or touch are overwhelming to the person:
 - Switch bold linens to muted, solid colors.
 - Keep the person's space neat and clutter-free.
 - Allow plenty of time for meals, and eat with them.
- **Label cabinets and doors** to remind the person where to find things. Secure items such as medicine, cleaning supplies, and sharp or dangerous objects.

- **Help prevent falls** that can cause serious harm:
 - Remove area rugs and secure cords; keep the home well lit.
 - Keep a cane or walker nearby, and make sure the person wears their eyeglasses and hearing aids.
- **Prevent wandering.** Use safety gates and limit access to attics, basements, or cramped areas. Avoid leaving the person alone. Consider buying medical ID jewelry.
- **Do daily tasks around the same time each day** (such as bathing, dressing, and eating) but be flexible, if needed.
- **Talk about what you are going to do before you do it.** Walk the person through the steps of each task first.
- **Think of the phrase, "Do with, not for."** Be present, but offer help only when needed.
- **Create an "activity kit"** that includes puzzles, cards, matching games, sorting beads/blocks, or soft toys.
- **Help the person stay socially connected.** Hold hands, look at photos, or listen to music together. Recite familiar prayers if the person is religious.
- **Adapt your communication style:**
 - Approach the person from the front, get eye level with them, and make eye contact.
 - Do not speak to the person as if they are a child.
 - When you ask a question, give the person more time to respond — count to five before you speak again.
 - Don't interrupt the person, but let them interrupt you; they might forget what they want to say.
 - Do not argue with the person, and try not to take angry outbursts to heart — the person may be trying to cope with their own sense of fear and loss.



Source: "Living with Dementia: A Caregiver Guide to Memory Care," published by Quality of Life Publishing Co., www.QOLpublishing.com.

How Compassionate Doctors Approach Difficult Discussions

At a certain point during most serious, life-limiting illnesses, patients can get discouraged with the treatment process and results. The patient and family may find the symptoms of the disease are becoming very hard to manage as the patient's condition gets steadily worse. The patient may start losing a lot of weight, getting repeated infections, taking more trips to the hospital, having trouble breathing, and/or having pain that is hard to control.

It can be tough for doctors to start a conversation with these patients and their families about the illness and treatment options moving forward. When there are no other treatment options to cure a disease, doctors should work towards a compassionate shift in care goals. They can offer an option for ongoing care that includes emotional support and symptom management.

"This conversation is best done in bits and pieces...and it must start early," says Toby Campbell, MD, from the University of Wisconsin Carbone Cancer Center. He often tells his patients and their families about nursing and social work services that are available to relieve pain and manage symptoms at home.

Dr. Campbell also works with his patients to redirect hope. He reminds them of earlier conversations about their goals of care and their choice to focus on living well and being at peace with the time that is left. At a meaningful point in these discussions, he describes the multi-disciplinary care he is recommending as "hospice care."

"How does that sound to you?" he checks with his patients, allowing time for them to process their emotions and not rush to a decision. Many of his patients eventually come to realize they are tired of more treatments and ask to learn more about hospice care.

Patients trust their doctors to provide all the necessary details so the patient and family can make an informed choice

about the patient's end-of-life care plan. Patients searching for hope may find relief in information that is explained openly, honestly, and thoughtfully.

"Giving bad news is never easy, and receiving bad news is extraordinarily difficult," notes Joel Zivot, MD, associate professor of anesthesiology and surgery at Emory University School of Medicine. He recommends conversations that are sympathetic, unhurried, without distractions, and in words that are easy to understand.

"I pull up a chair, sit down, and take my time. I ask the same of the people who receive the information. Together we can generally come to an understanding."

These doctors stress that a referral to hospice or comfort care is not giving up. The goal of these difficult discussions is to *prevent* patients and families from feeling abandoned. Dr. Leslie Scheunemann of the University of

Pittsburgh Medical Center adds, "Good communication can provide people time to say goodbye, to participate in religious or spiritual rituals, to complete items on a 'bucket list,' and sometimes even to die at home."

Early Referral to Hospice Can Help Patients By:

- Addressing the patient's physical, emotional, spiritual, and social needs, as well as providing support for caregivers
- Delivering care, medications, and medical supplies wherever the patient calls home
- Allowing the patient to have a dignified death
- Offering bereavement support for loved ones



Some people mistakenly think hospice care is just about dying...nothing could be further from the truth. Hospice helps patients and families focus on living. Angels Grace Hospice, LLC, brings comfort, dignity and peace to help people with a life-limiting illness live every moment of life to the fullest. We also provide support for family and friends.

We are licensed in the state of Illinois, Medicare Certified, Joint Commission Accredited and are locally owned and operated by experienced professionals dedicated to providing excellent end-of-life care for Will, Cook, DuPage, Kendall, Grundy, and Kane counties. Please contact us for more information.

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To comfort always... this is our work

