



Visiting a Friend or Loved One with Dementia

Dementia is a progressive disease that is measured not in months, but in years. As the disease progresses it may become difficult to visit the patient—he may not recognize you, she may not be able to converse with you, or you don't know if the person even realizes you are there.

WHY VISIT?

You may question if there is any reason to visit any more. With dementia it can be hard to know how to be supportive, especially at the end of life.

There is a good reason to visit—you can make a difference. The focus of visits shifts; instead of expecting an exchange of pleasantries, your motivation becomes, "What can I do to improve quality of life?"

Your visit really begins with you, at home. You may want to think about your feelings. Am I frightened I too will end up with dementia? Am I afraid of the end of life? What do I want to accomplish in my visit?

PLANNING THE VISIT

Visiting a person with dementia can be frustrating and unrewarding when you feel as though there is nothing you can do. You may be able to make the visit more meaningful with some preparation.

Gather together some supplies so that you are prepared for whatever the situation is when you arrive. A few ideas are:

- Knitting, a crossword or a book to read if the patient is sleeping
- A picture book with large colorful or interesting images
- Interesting photos someone has sent you in an email
- Music you know the patient likes
- A newspaper column, such as Dear Abby or the sports page to read aloud
- A photo album
- A special memento
- A letter from a mutual friend to share
- A nail file and polish for a manicure
- The patient's favorite perfume
- A favorite food
- Lotion for a hand or foot massage
- A pet, if allowed

*"We can do no great things, only small things with great love."
—Mother Teresa*

The sky is the limit. Use your imagination and everything you know about the person to come up with ideas of things to share. The resident may want to listen to news about her book club, his former poker buddies or the doings at church.

THE VISIT

Begin with the basics. The visit will be more successful if the resident is clean and dry, not hungry, and comfortable. Ask for help if needed.

Pain can sometimes appear as negative behavior. People with dementia may withdraw, strike out or display other "bad" behaviors when in pain. If you have seen behavior changes that you suspect may be due to discomfort, you may want to ask the caregiver for a trial of pain medicine.

Think about providing comfort through the senses.

TOUCH

We all need to be touched, but seniors are often deprived of this essential element to wellbeing.

- Our society is youth-centered and may look at wrinkled skin as ugly, not weathered with experience.
- Among hospitalized patients, the only ones touched less than the elderly were people who were psychotic.

Touch can be "instrumental;" that means required to carry out activities such as bathing or dressing. But research shows that people with dementia can tell the difference between this and "expressive" touch. Expressive touch is when we hold hands, put an arm around the person, or give a back rub or hug. This conveys acceptance, nurturing and caring.

Expressive touch helps the elderly feel less isolated, dependent and depressed.

- One researcher found that it also made the toucher feel better. They felt this non-verbal communication conveyed trust, reassurance, and love, and that it instilled hope.
- Others described touch as making a person feel psychologically worthy and have a sense of being cared *for* and cared *about*.
- It is no coincidence that the ultimate form of punishment is solitary confinement—no touching.

Caring touch can trigger the brain to release endorphins and serotonin—natural chemicals that suppress pain and depression. This is one reason massage can lower the perception of pain.

- Massaging a loved one's hands or back can help significantly while waiting for pain medicine to work.
- Brushing the resident's hair or applying lotion have the same affect.

HEARING

We know that hearing seems to remain intact until the very end of life. This gives us an opportunity for providing comfort.

- Soft music can be very soothing to an agitated resident.
- If the resident has been religious, he may appreciate hearing hymns and spiritual music. Bring in CDs or tapes of his favorites and a CD player to play them on.
- You can even sing or hum a familiar tune.
- Bring in a music box.

COMMUNICATION

If you are not close, calling residents with Alzheimer's disease "sweetie," "dear," "cookie," or "honey" may cause more resistance to care. Experts have known for a long time that mentally competent elderly residents in nursing homes are irritated by being "talked down to." Recent research shows people with dementia are more agitated when talked to this way.

What they found was that residents were more resistant if the communication was what they dubbed "elderspeak."

- Saying things like, "Are we ready for dinner?" implies that the person isn't able to act independently. An alternative would be, "Are you ready for me to help you with your dinner?"
- The tendency of caregivers to use "elderspeak" increases with the caregivers perceived level of infirmity of the resident.
- We need to remember that residents were high functioning adults. The more we remember their earlier lives, the more we respect them as people than as a disease.

Just chatting can be very reassuring. "I spoke with Michael today, back in Virginia. He says he and Alice are going to take a trip to Vermont. They are going as soon as the snow melts. It's February now, so it may be a couple of months."

Maintain the resident's dignity in small ways: use terms like "disposable briefs" instead of "diapers." Remember to speak slowly. People with dementia take longer to process what you have said.

SENSE OF SMELL

This sense is so basic that when we smell a certain odor, it can bring back memories from decades ago.

- Aromatherapy takes advantage of this by providing pleasant smells that might bring back pleasant memories.
- Bring a rose, a lavender sachet, or a scented candle that smells like pumpkin or apple pie.
- A favorite perfume or aftershave can brighten spirits.

TASTE

- Bring in a favorite food or drink. The resident may love Fritos or M&Ms and they won't be on the menu in assisted living.
- Cleaning the mouth with minty toothpaste or mouthwash on a 4x4 may be refreshing.

We have to be very careful about anything in the mouth at the end of life. With dementia, all the muscles get weaker and weaker—including the muscles for swallowing.

- Food or fluids can easily get into the airway, causing aspiration pneumonia.

TEXTURES

- A resident in a facility has little chance to experience unusual textures, such as soft fur or a smooth, cool stone. A pet or even a stuffed animal may provide comfort.
- Wrapping someone's hands or feet in a hot, wet towel might feel very soothing and relaxing—the spa treatment!
- Find a way to warm a flannel blanket to wrap the resident in.
- Smooth the sheets or put cool, clean sheets on. Change the pillow case or turn over the pillow.
- Open a window to feel a breeze.

IMAGINATION

Use your imagination. Think about what would bring you comfort. What would feel good to you? For each visit plan a simple, new, creative way to bring pleasure, serenity or comfort. Quality of life will improve for both of you.

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