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Family Caregiver Resources

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Living with late-stage dementia

By the late stage of dementia, the person you care for needs constant assistance. It's hard to know what to do to interact. Communication is challenging. We suggest activities, as well as options with music, the universal language. In addition, we include an article about nonverbal signs of pain so you can keep your loved one from suffering.

Visits and meaningful activities



How do you connect with a person who is unable to converse? For those who live far away, it can be especially challenging to visit and engage in a meaningful exchange. If you are the primary caregiver, you may find these tips helpful to share with visitors.

Research suggests that during late-stage dementia, a person's core self still remains. Much like

in our earliest, preverbal years of life, we perceive the world around us largely through touch, smell, sound, sight, and taste. We can get easily overwhelmed. We can experience comforts and pleasures. And we do generally respond well to the calm, reassuring presence of others.

In this light, visits are important! Bear in mind:

- Words may not be understood, but your facial expression and tone of voice may be.
- A quiet room away from noise and clutter is most reassuring. Make eye contact, but don't force interaction.
- Visits are best one person at a time, although an adult should accompany children.
- If your relative doesn't want to interact, it's about the disease, not you. Don't take it personally. Thirty minutes later, tomorrow, or next week, things may be very different.

Try these options for happy connection:

- **Brushing hair or rubbing lotion** on hands or feet. These simple gestures are reassuring and communicate love and care.
- **Playing music**—especially tunes from your relative's youth or favorite hymns.
- **Looking at photo albums**, you might retell a favorite family story. Or look at a simple, colorful book, reading aloud and pointing out pictures.
- **Sharing a favorite food.** Easy-to-chew food is best such as pudding or a soft cookie.
- **Cuddling a pet or stuffed animal.** The touch of fur and the unconditional love of an animal—alive or stuffed—is often very comforting.



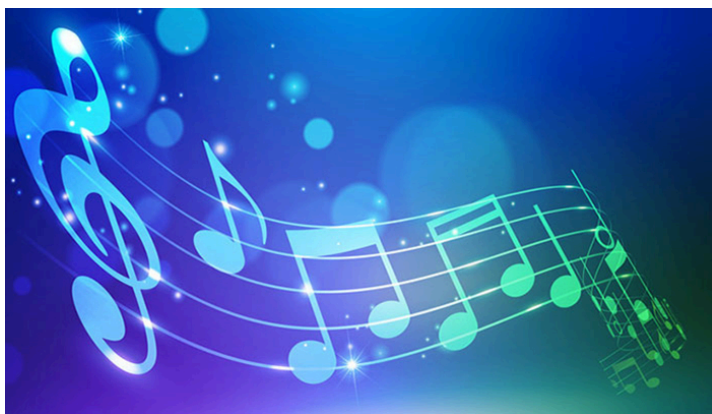
"My job at this point is to make sure that every day is the best day possible. I focus on things that make my sister happy. And on keeping her comfortable and pain free."

[YOUR PHONE]

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Music: The universal language



Music bridges the barriers of dementia and provides opportunities for joy and connection. Research shows that music is processed in parts of the brain that remain lively long after a person's ability to "name that tune" is gone. Hearing familiar songs brings up old memories, essentially reconnecting a person to his or her sense of self and to times past.

Music can be a fun and valuable part of your caregiving toolkit. For instance, you can

- **stimulate** with lively tunes, especially music with a pronounced beat. This can help motivate your relative to get through tasks, such as bathing and dressing.
- **calm** with soft, harmonious music that tends toward lullaby. Use quiet music to encourage them to take a nap or to soothe them at bedtime.
- **redirect** to address or avoid agitation. For instance, play favorite sing-along tunes at a time of day your relative is apt to pace or become irritable.
- **connect** with them through songs that prompt shared movement. Maybe dancing, or just toe tapping, swaying, or silly gestures.

You might collect some of his or her old records (or tapes and CDs) and play songs as needed. Alternatively, compile music on a smartphone or MP3 player and have your relative listen with headphones.

For most purposes, strive for music that your relative knows and loves:

- Songs from childhood, with happy lyrics
- Music from youth (age 18–25), for memories of a lively time in life
- Tunes of a favorite composer or performer that recall meaningful occasions
- Hymns and other spiritual music for comfort

Observe your loved one's response to the music and make changes as needed.

Nonverbal signs of pain

Dementia itself does not cause physical pain. But people with dementia still encounter pain, just like anyone else. They still get headaches or have arthritis. Their pain is real, but they may not be able to describe it. Late in the disease, they might deny having pain, even if you ask directly, because they don't understand what you are asking.

It falls on you to learn the nonverbal signs so your loved one doesn't suffer. Look for

- short, rapid breathing
- unexplained sweating
- grimacing, wincing, or frowning
- moaning, whimpering, crying, or shouting
- shielding a part of their body, curling up
- rocking or self-soothing movements
- tense or rigid body

Other signs include withdrawn behavior, increased confusion, trouble sleeping, inability to be comforted, restlessness or lashing out, refusal to eat. The more of these signs, and the more intense they seem, the more likely there is a high degree of pain.

If you don't see an obvious source of pain—a mouth sore, a reddened or sensitive area, a bleeding cut, or a fever—contact the doctor. Describe what you have been observing. Can you think of a likely cause? Are there patterns, such as time of day? Is there swelling somewhere? A particular location of the pain? Is your loved one constipated? Is he or she urinating frequently? What have you found that seems to help?

You and the doctor together can determine if there is a problem to be treated. And if not, what you can do to effectively manage your relative's pain. In the later stages of dementia, your loved one may not understand what's happening, but he or she understands comfort. Do what you can to provide comforting doses of pleasure and kindness. Perhaps try a foot rub, a sweet treat, or a favorite song.

Contact us at [Your Phone]



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