

**SIGNATURE** healthcare
at home

care where you are

COPING AND COMMUNICATING

Dementia patients and their families undergo a difficult process as patients progress through their illness. Many family members report difficulty in visiting their loved one with dementia or memory concerns. It is hard to have your loved one not remember you, or to try and carry on a conversation that seems to go nowhere. This handout was created to provide families and patients with information on the dementia process, and to suggest ways of interacting with your loved one so that visits are less stressful and instead are simply an opportunity to share each other's company.

ANTICIPATORY GRIEF

Often, for families and patients, there are many losses along the way that go unrecognized, even as they continue to affect daily life. Grieving loss is a process, it is not an event. There are physical, emotional, spiritual, and psychological effects of grief. For both patients and families, grief usually begins at diagnosis, not after death. Family and patients experience tangible and intangible losses along the way. Both patients and families often experience conflicting emotions including guilt, resentment, anger, shame. Finally, the many losses experienced by both parties are often not recognized or acknowledged because the patient is still living.

WAYS THAT GRIEF MAY BE AFFECTING YOU

Grief affects people differently. Physical effects can include disturbed sleep, intestinal or respiratory distress, and fatigue. Psychological effects can include difficulty thinking and concentrating, anxiety. Another important effect of grief is forgetfulness, which can be very distressing to families of dementia patients. Something to note for patients is that loss of cognition does not equal loss of emotion. Dementia patients often know on some level that something is not quite right, but are unable to identify it, which can cause anxiety.

AT HOME

If you are the primary caregiver for your loved one, the most loving thing you can do is GET HELP. A caregiver who is exhausted or overwhelmed is more likely to make mistakes. Find caregiver support groups, seek respite care. The importance of self

care cannot be emphasized enough. Families often experience secondary losses as care giving needs increase. Less time for rest, nutrition, exercise and socializing means that your ability to function at full capacity decreases. There are many options for support. If you're struggling and don't know what to do, please let your hospice team help you.

VISITS A CHANGE IN EXPECTATIONS

As the stages of dementia progress, your time together will look different. While early in the disease process you may be able to carry on conversation. This will change as the disease progresses. Be flexible. If your loved one does not live with you, call the facility before leaving. If it's a bad day, make a decision about whether or not to go. Don't force yourself to stay if the visit isn't going well, but enjoy the time if it is. When you arrive at the facility, sign the visitors log and encourage other visitors to do the same. Upon arrival, view the visitors log. This gives you a more accurate account of your loved one's social opportunities when they tell you no one is visiting, and can relieve your own guilt about "not visiting enough". You will probably find that if you can let go of specific expectations (conversation content, length or frequency of visits, etc), visits will be less stressful for both of you.



COPING AND COMMUNICATING (CONTINUED)

Hopefully this information will be useful to you and your loved one as you navigate this illness. Please remember that hospice is as much for you as it is for your loved one.

COMMUNICATION STAGES OF DEMENTIA

There is a current research to suggest that repeating stories, living in the past, and seeing the deceased are very important processing functions for patients who are dying, including dementia patients. It can be uncomfortable at first, but try to go with the flow and have patience with these conversations. Skills used in communicating with dementia patients are similar to those used in communicating with children. This is not to say patients should be treated like children, but that it's important to communicate in a way that matches their skill level, which changes as the disease progresses.

- If the patient is still verbal and able to communicate clearly, try to meet them where they're at in time. For example, if they speak of being on a bus when you are clearly in their room, get on that bus with them and ask where you're going!
- If the patient is still verbal but uses nonsensical language, mirror the feelings (except anxiety) that are being expressed even if words don't string together in a logical way.
- If the patient is non verbal, speak to them with a calm voice, use images, objects, and sound. Use body language such as touching or pointing as appropriate.
- If the patient is non responsive, appeal to the senses. Use colorful objects with pleasant textures such as soft blankets. Bring in flowers or other pleasing scents. Touch them if they are comfortable with this. Speak to them quietly or play music you know they enjoy.

AGITATED BEHAVIOR

One of the common symptoms of dementia is restless agitation. If your loved one is becoming agitated, step back and check out the environment. Perhaps they are cold or not feeling well. Perhaps there is noise or light in the room that is disturbing. You may try redirecting them to a repetitive task such as folding towels or picking flowers. Try to engage them on pleasant topics such as favorite hobbies or family pictures. Approach the person from the front, introduce yourself, and try to use quiet speech with simple words. Sometimes modeling calm behavior can encourage the patient to do the same.



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