

**Self-care**

- It is important to take care of yourself.
- Get out, walk, breathe fresh air, cry, eat, and try to relax.
- Consult often with your hospice nurse.
- Explore options for respite, in-home care, home health aides, etc.
- You, or the patient, have selected Stillwater Hospice to support you during this journey with the aim of providing comfort and dignity to your loved one as they experience the end-of-life process. The treatment will generally focus on managing pain, education on nutrition, safety and fall prevention, skin health, and medication intervention for emotional components such as anxiety, agitation, sleep, or mood health. The Stillwater team of nursing, aides, social worker, and chaplain will work with the patient and family to help develop a plan of care and provide support so the "journey" will not be traveled alone. It is recommended that family also reach out to the Alzheimer's Association for any other information that may be helpful to you.



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## End of Life Management When a Loved One Has Alzheimer's

**Understanding Alzheimer's**

- Alzheimer's is a degenerative disease of the brain. The causes are unknown but unfortunately it is progressive, and no cure is available. It affects the patient physically, mentally, and emotionally. Think of the disease as each person's brain as a computer. It takes in and stores information and can be retrieved with a "click" of a key to use at any time. With this disease, the "computer" no longer recognizes any stored or new data, and the information pathways no longer work.

**Some expected symptoms**

- The effects of the disease can also affect the other body functions. It is usually diagnosed or, established as being in a particular "stage". New onset with slow progression, onset with rapid progression, the gradual or rapid loss of everyday functions. When another illness is also present, such as heart disease, lung disease, diabetes, kidney function, or any other illness, there may be a more recognizable decline in these areas as the brain controls the physical function of the body. Your family member may not recognize the need for food, not recognize thirst, not recognize fatigue, or need to sleep or rest. They may also not be aware of the need to toilet or where to toilet, eventually losing that ability to control their bladder or bowels. The outcomes can be weight loss, dehydration, loss of muscle mass with weakness and increased risk for falling. This is relative to a loss of strength that previously allowed the patient to sit, stand, walk from one location to another. Additionally, the eye-hand coordination can be affected, and they may be unable to understand the process of using a toothbrush, comb, brush, putting on/off clothing, etc., as they can not process what these are or why.



- This disease also greatly affects the mental ability of each patient. Most common is the loss of memory of family, friends, their home, time, place. These components usually become more pronounced as the disease progresses. Emotionally, they may not recognize sadness, happiness, laughing, and speech may become garbled, words jumbled, or say yes or no with opposite meanings. Observing these changes, or living with the changes, is a tremendous challenge for the patient and family. One of the most common components for both the patient and family is anxiety. The patient may feel, on some remote level, that “something is not right” but cannot express what it is. This can result in increased anxiety, agitation, restlessness, change in sleep/awake cycles. They may be very active for three days and then suddenly sleep for two days. Unfortunately, this is one of the most challenging disease processes, not only for the patient, but also for family or caregivers.

#### **Sleep changes**

- May have drowsiness with increased sleep, confusion when they first wake up, or continual fatigue.
- Worries or concerns may keep person up at night.
- Continue to talk openly about loved one while they sleep.
- Trazadone or melatonin may be suggested by your hospice nurse.

#### **Pain control**

- Provide pain medication regularly. Seek advice from hospice nurse.
- Offer other methods for pain relief, such as massage and relaxation.
- Pain medication regimen may need to be adjusted frequently.
- Look for signs of pain like grimace to face, rigid body posture, moaning, restlessness, etc.
- There are many options of narcotic and non-narcotic medications to try. The nurse may also suggest introducing small doses of morphine.

#### **Appetite changes**

- As the body naturally shuts down, the need or want for food often decreases. This may be caused by the body's need to conserve energy and decreased ability to digest.
- Let your loved one choose if, when, and what they would like to eat or drink.
- Because chewing may become difficult, soft or blended foods may be appetizing.
- If ability to swallow is compromised, offer moisture for lips and mouth.

#### **Awareness**

- May be episodes of confusion or hallucinations near end of life. Gently remind your loved one of their surroundings and who is with them.
- If agitation should occur, don't attempt to restrain the person. Reach out to the hospice nurse for guidance.
- Hospice nurse may suggest an anti-anxiety, such as, Ativan in these instances. Haldol is often used for end-of-life hallucinations, agitation, or anxiety.
- Some people report seeing loved ones who have died. They may talk about things they are seeing that are not real. As long as these visions are not disturbing the person, it is okay to encourage the person to share these experiences.

#### **Withdrawal from family and friends**

- Focus turns inward. This doesn't always mean the person is depressed or angry. May be caused by lack of oxygen to brain or mental preparation for dying.
- May lose interest in things they previously enjoyed.
- Caregivers should offer continued support and love.

#### **Emotional Support – “How can I best support my loved one?”**

- Keep your loved one company—talk, watch movies, read, or JUST BE WITH them.
- Allow the person to express their fears and concerns—dying, leaving family, etc.
- Reminisce about life.
- Avoid being secretive—talk openly about disease and symptoms with loved one
- Include person in decision making.
- Reassure your loved one that the advanced directives will be honored and clarify any concerns.
- Respect person's privacy and/or silence.

