End-of-life care

Why is end of life care important with Alzheimer's disease?

It can be very difficult to think of someone reaching the end of life. People have a range of emotions even thinking about it. This is important for people with Alzheimer's disease because there is no cure for this disease and it is a life-limiting condition. If someone is in the late stage of Alzheimer's disease, their symptoms will get worse over many months and it will eventually lead to the end of his or her life.

End-of life planning is important to do as early as possible so that the person with Alzheimer's can have some input. This would normally include what his or her wishes are for care, who will make decisions for them and any issues at the time of their death. Some questions that may want to be talked about include:

- If given a choice, would the person prefer to die where they are living (e.g., at home or in a long-term care home), in a hospice or in the hospital?
- What medical interventions, if any, such as cardiopulmonary resuscitation (CPR) or feeding tubes, would the person want?
- Does the person have any special wishes at the time of death, such as family and friends nearby, music playing, or specific faith or cultural rituals?

How do you talk about end-of-life care?

It can be very difficult to have a conversation with a person with Alzheimer's disease and the family regarding end-of-life care. This is still very important and can make the decisions near the end of the person's life much easier. The Alzheimer Society of Canada has provided some tips and suggestions that may help with this conversation.

Tips for talking about end-of-life care

- Choose a time and place where you and the person with Alzheimer's disease are comfortable
- Feel free to acknowledge the difficulty of talking about end of life. Using humour, when appropriate, may relieve pressure
- If the other person refuses to talk or changes the subject, try saying "*That's okay, we don't have to talk about it right now, but it is something I would like to talk about soon. I want to be sure I know your wishes so I can act on them when the time comes.*"
- It is okay to express your emotions, including your sadness. Talking about a person's end of life can be upsetting
- If you find the discussion overwhelming, suggest continuing the conversation at another time. You do not have to talk about everything all at once
- This is a conversation about you and the person you support, so encourage the person with dementia to be involved in it as much as they are able
- Once done, consider sharing the person's thoughts with other family members so that everyone is aware of these wishes

What happens to the person when they approach the end of life?

People in the final months of dementia will have a major decrease in their mental and physical abilities. When the person reaches this stage, they need to have intensive 24-hour care. At this point, the person will lose their ability to communicate through speech, but nonverbal communication through touching, smell, vision and hearing become important.

As the person approaches the end of his or her life, he or she will:

- Become more frail
- Sleep more
- Eat and talk less
- Have more frequent falls or infections
- Have poor blood circulation
- Have irregular breathing
- Experience skin problems
- Show loss of mobility and an inability to sit up

How do you care for people at the end of their life?

Caring for a person at the end of life can be difficult and is likely very emotional. Even though the person has communication and physical challenges, there are still many things that you can do. The table below gives you some tips for helping a person at the end of his or her life.

Strategies to care for someone at the end of life	

Communication changes	– The person will have problems with verbal communication
	– He or she is more likely to use body language, gestures, sounds and facial expressions to express feelings and needs
	– People should:
	  – Use non-verbal communication such as gestures, facial expressions, body language and touch
	  – Take time and make eye contact
	  – Even if you don't think the person understands or is listening, keep talking to them. They connect with your voice
	  – Talk about things that are relevant from their past (like pictures or stories)
	  – Speak in a calm and reassuring way

Physical changes	– You may want to help the person eat and drink – Make sure that they are given at least sips of liquids to prevent dehydration – Use a lip balm to keep the lips moist – Use a cotton swab moistened with water or glycerine to dampen the lips and to keep the inside of the mouth moist
Spiritual changes	– Play/sing/recite favourite songs, scripture, prayers, readings – Arrange for a faith leader to visit, if appropriate – Some individuals need permission to die. As well, some family members need permission to let go.

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