Progression

Alzheimer Society

END OF LIFE

This document is one in a five-part series on the stages of Alzheimer's disease and is written for the person with the disease, their family and caregivers. The end of life stage of the disease is featured in this sheet. For information on the other stages of the disease, please see the following sheets in the series: *The Progression of Alzheimer's Disease – Early Stage; Middle Stage;* and *Late Stage*. For a general overview of the disease, its stages and the approach to care, please see *The Progression of Alzheimer's Disease – Overview* sheet.

What is Alzheimer's disease?

Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgment and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to work, maintain relationships or carry out everyday activities.

Alzheimer's disease is the most common form of dementia. Other forms of dementia resemble Alzheimer's disease in that they also involve a progressive degeneration of brain cells that is currently irreversible. They include Vascular Dementia (the second most common dementia after Alzheimer's disease), Frontotemporal Dementia, Creutzfeldt-Jakob Disease, Lewy body Dementia, Huntington disease, and Parkinson's disease.

Alzheimer's disease is a disease of the brain, characterized by deterioration of thinking ability and of memory, caused by the progressive degeneration of brain cells. The disease also affects mood and emotions, behaviour and one's ability to perform activities of daily living. There is currently no cure for Alzheimer's disease nor can its progression be reversed. However, present treatment options and lifestyle choices can often significantly slow the progression of the disease.

Alzheimer's disease typically follows certain stages which will bring about changes in the person's and family's lives. Because the disease affects each individual differently, the symptoms, the order in which they appear and the duration of each stage vary from person to person. In most cases, the disease progresses slowly, and the symptoms of each stage may overlap, often making the move from one stage to another quite subtle.

End of life – what to expect

Dying is a unique experience for each person, coming in its own time and its own way. However, the process often follows a somewhat predictable path and there are a number of physiological changes that signal that death is near. Knowing what to expect during this difficult time can lessen some of the fears and apprehensions. When a person with Alzheimer's disease is in the very late stages of the disease, the focus should be on quality of life and comfort, rather than on length of life and treatment. Palliative (or comfort) care focuses on the whole person's needs - physical, emotional and spiritual.

At the end of their lives, many people with Alzheimer's disease are being cared for in a long term care home. The care required is extensive and is very difficult for family members to undertake on their own. It is certainly more than one family member can manage alone. If the decision is made to have the person die at home, it is important that the physician refer the person to home support services so that a community nurse can assist the family in determining the care required, teach the family how to undertake it, and provide support and direction as needed. Under the best circumstances, the family will be assisted by a palliative care team.

The following are some common changes and possible strategies for this stage of the disease. These strategies are not intended to be substituted for medical advice and should be discussed with the health care team before being undertaken.

Common Changes	Possible Strategies
Physical changes:	
Circulation - extremities may feel cold or cool to touch - blood pressure goes down - lips and nails become bluish	- Gently massage hands and feet with lotion
Skin breakdown and pressure sores	- Get direction on how to position the person and prop with pillows - Change the person's position every two hours, or more frequently if the person is thin or has persistent reddening over bony areas - Keep the skin clean and dry; do not massage over bony areas - Relieve pressure on heels, elbows and other bony areas by placing a pillow or foam wedges under them - Consult a physiotherapist about range of motion exercises
Person no longer accepts food and drink due to body shutting down	- Realize that the person is not starving to death, as the body no longer needs the same amount of energy. This is part of the disease process - Use a cotton swab moistened with water or glycerine to dampen the lips - Get direction for how to provide mouth care including cleaning the teeth, tongue and inside of the mouth
Possible build-up of secretions in the lungs or back of throat; dry mouth	- Speak to your health care professional for assistance in these matters
Sleepiness increases; the person may experience pain or discomfort but awareness of pain decreases	- Watch for signs of pain e.g., grimaces, crying out, moaning, changes in behaviour, increased agitation, anxiety, sleep problems. Speak to your health care provider about pain relief strategies such as changing the person's position and using medication.

Common Changes	Possible Strategies
Physical changes continued:	
Fever may appear	- Consult your health care provider on ways to keep the person cool, without having the person get chilled
Breathing may sound congested; may change in rate, depth and rhythm; may be periods of not breathing for 5-30 seconds	- No intervention is usually necessary
Senses start to change: - vision may become blurred or appear to be distant - sensitivity to noise, lights etc; may react positively to familiar voices, such as singing or someone reading aloud	- Keep connected through touch - Continue to talk quietly, tell stories, reminisce about past events, play music that the person likes, read - Do not talk about the person, as if they are not there. Leave the room if you need to discuss something - Observe the person for signs of stress; keep lights low and noise to a minimum; consider visiting in smaller numbers
Irregular pulse, agitation and restlessness	- Reassure the person - If this persists, look for causes of the behaviour such as pain or thirst
Emotional issues:	
Emotions are still experienced and sensed by the person	- Speak soothingly, reassuringly; remind the person that they are safe and cared for
Spiritual issues:	
Spiritual connections may remain important. The person may seem to choose their time of death.	- 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.

Making decisions

There will be many decisions to be made at this stage of the disease.

- Refer to and follow any documents that the person with the disease has established to address his or her wishes.
- If plans are not already in place, establish who will be responsible for making financial, legal and care decisions.
- Follow the person's wishes, if you know them. Otherwise, decisions will need to be based on the person's lifelong values and desires and what you think the person would want.
- Advise the health care team of any expressed medical wishes and include the team in the decision-making process on medical issues.
- Much can change during the course of this stage. Keep informed of any changes in the person's condition that may prompt the need for additional decisions.

It can be challenging for family members to agree on a course of action but with discussion and understanding, conflict can be reduced and crisis decision-making avoided. The Alzheimer Society can connect you with professional support from counsellors, social workers and family mediators.

Medical care decisions

There is a range of life-prolonging medical care available for people in the terminal stages of an illness. When and if to use these measures depends on the type of medical care that the person has specified or, if explicit directions have not been given, the best decision based on the person's values and desires. The following are some of the measures that commonly need to be addressed.

- *Cardiopulmonary resuscitation or CPR* is a group of treatments used to restore function when a person's heart and/or breathing stops.

CPR:

- may be painful and traumatic for the person
- may leave the person in worse condition
- is not likely to be effectively successful
- may not prolong life
- is not recommended by many experts when a person is terminally ill and is often not desired by persons when they are competent to make such decisions

A "Do not resuscitate" (DNR) or Do not attempt resuscitation (DNAR) order tells the medical professionals not to perform CPR if the person's breathing or heartbeat stops.

- *Feeding tubes* are sometimes suggested if a person has a difficult time eating or swallowing, which is common in the later stage of Alzheimer's disease. Tube feeding has not been proven to benefit or extend life and can result in infections and discomfort to the person. However, sometimes it is considered for a fixed time period. Talk to your health care team about any specific plans for use of feeding tubes.
- *Intravenous (IV) hydration* is liquid administered to a person through a needle in a vein. Lack of hydration is a normal part of the dying process and allows for a more comfortable death over a period of days. Using IV hydration can draw out the dying process for weeks and physically burden the person. If IV use is being considered, there should be specific goals with a limited time period agreed to by you and the health care team.
- *Antibiotics* may be prescribed for common infections but may not improve the person's condition.

Palliative Care

Deciding not to use extreme measures to prolong life does not mean withholding all treatments. A person may continue to receive any necessary medications, for example, those for chronic conditions such as diabetes or high blood pressure as well as those that prevent pain and discomfort. Generally these medications are reduced in end-of-life care with the health care team providing advice on these issues. The goal of palliative care should be to provide comfort, quality of life, dignity and pain control. Aggressive interventions that

produce fear and discomfort may not be in the person's best interest and may do more harm than good. It is important to have ongoing monitoring and discussion between you and your health care team to ensure the best care for the person.

Taking care of yourself

This stage of the disease can be particularly challenging. It is important to take the time you need to care for yourself, too. Try to:

- take time to acknowledge that you may be grieving even before the person dies
- take care of your own health by taking breaks from caring for the person. Consider if there is someone you trust to spend time with your family member while you get some rest. Develop a "visiting schedule" with other family members and friends.
- confide in friends and family or consider a support group
- seek professional help if feelings become overwhelming

What's next?

At the time of death you may feel a variety and range of emotions – from relief and guilt to sadness and peace.

These are all normal feelings and it is common to feel some guilt at experiencing a sense of relief at the person's death. Grief is a normal, natural, expected response to the loss of a significant person in your life and will be a different experience for everyone. Even if the relationship was a difficult one, the loss of the person can still be felt very deeply.

You now need to take care of yourself. Give yourself time to grieve. You have likely been grieving since the start of the disease and have experienced losses throughout. Be kind and patient with yourself. You may not be able to return to your previous routines quickly or feel as energized as before. Grief can affect all areas of our life - physical, social, emotional, psychological and spiritual.

Here are some suggestions for working through your grief:

- Do what comes naturally to make you feel comforted - there is no right or wrong way to grieve.
- Give yourself permission to feel whatever you feel.
- Feel free to express yourself - write, cry, dance, tell your story over and over again.
- Express yourself in your own way - don't compare yourself to others – everyone grieves differently at different times.
- Share your feelings with someone you trust.
- Allow yourself to learn - grief is a process that can teach you many things about yourself and about the relationship you had with the person.
- Caring for someone for months or years can become a primary focus in one's life. It is not uncommon to neglect other relationships and activities during this time. Take some time to rebuild the connections that are important to you and discover old or new passions.
- Consider joining a bereavement support group. Anniversaries (including the anniversary of the person's death), birthdays and holidays are all special occasions that may create fresh feelings of grief – even years later. Plan ahead for how you will

manage these occasions. Only you will know if it is more helpful to be with others on these days or spend quiet time alone. Sometimes it is hard to know how you will feel until the time comes. Consider having a backup plan – such as a friend who might be available to meet on the spur of the moment if being alone is difficult.

Help and support from the Alzheimer Society

You have been on a difficult journey and it is normal to feel grief and loss as well as a variety of other emotions.

It is important to acknowledge your feelings, care for yourself and seek the practical help and emotional support that you need.

The Alzheimer Society in your community can provide educational resources, support, and referrals to agencies that can help you with the grieving process. Contact your local Alzheimer Society or visit www.alzheimer.ca

Useful resources

The Progression of Alzheimer's Disease - *Overview; Early Stage; Middle Stage; Late Stage*; and *End of Life* information sheets. Alzheimer Society of Canada (2013)

Guidelines for Care: *Person-centred care of people with dementia living in care homes*, Alzheimer Society of Canada (2010)

Ambiguous loss and grief: a resource for healthcare providers. Alzheimer Society of Canada (2013)

Ambiguous Loss and Grief for family members. Alzheimer Society of Canada (2013)

All About Me. Alzheimer Society of Canada (2013). This fillable PDF booklet gives information about the individual's needs, preferences, likes, dislikes and interests

Day-to-Day Series - Communication. Alzheimer Society of Canada (2010)

The Alzheimer Society of Canada offers a wide variety of free information sheets and brochures. To learn more, please visit our resources section at http://www.alzheimer.ca/en/We-can-help/Resources/Alzheimer-Society-brochures-and-publications

Note: This information sheet provides guidance but is not intended to replace the advice of a health care professional. Consult your health care provider about changes in the person's condition, or if you have questions or concerns.

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