



Comfort Care at the End-of-Life

for Persons with Alzheimer's Disease or
other Degenerative Diseases of the Brain

This guide is intended for caregivers of a person whose health has been severely affected by Alzheimer’s disease or by another type of degenerative disease of the brain, such as Parkinson’s disease, the effects of multiple strokes, or even certain forms of multiple sclerosis.

A common element in all these diseases is that people increasingly have difficulty speaking and understanding reality in terms of what is happening around them, thus making it difficult for them to participate in medical decisions that concern them. Consequently, when a complication or a new health problem occurs, either the spouse, child or someone close to the sick person must represent them during discussions with the caregiving team when decisions are made about how much care should be provided. This is a sensitive task for which you, and most family members or next of kin may not be prepared.

The purpose of this guide is to provide you with basic information so that you can have a better understanding of how the illness progresses toward the final stages of life. As well, it provides you with information about an approach to care which ensures above all a comfortable end-of-life. We hope that this information will be helpful and give you peace of mind during this difficult period.

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Natural Evolution of the Illnesses

1 What is the path leading to the end-of-life like for those suffering from the above-mentioned conditions?

In the later stages of life, the two main medical problems connected to these illnesses are trouble swallowing and repeated infections.

The most frequent cause of death is pneumonia, for which there are multiple causes. First, most of these illnesses are accompanied by increasing swallowing problems. Affected persons often choke on their food because it enters the wrong passage. More particularly, saliva or food enters the lungs instead of the stomach, and while the person requires less food, they are fed the same amount leading to coughing spells and trouble breathing. Some people who are very ill may not have the strength to cough and will have tremendous difficulty breathing. Eventually, most people will develop what is called aspiration pneumonia. Even if the pneumonia is treated successfully, it will likely re-occur if the individual continues to have difficulty swallowing.

At the same time, the individual will lose weight and become increasingly dehydrated, meaning that the body will have a lower volume of liquid because of difficulty swallowing. As a result, the individual will become weaker and increase the likelihood of developing further complications such as pneumonia or urinary tract infections.

2 What can caregivers do when the sick person can no longer eat or drink?

The first thing that health care providers do, is look to see if there are any causes for the eating and swallowing difficulties that could be corrected (e.g., a mouth infection). However, in the later stages of life, some individuals refuse to swallow for a number of reasons. They may not be hungry, or their food might not taste very good. They may also be afraid of choking, may simply be unable to open their mouths, or may have lost the ability to swallow.

The caregiving team uses a number of approaches when dealing with eating problems. If there are no causes that can be corrected, health care providers must make modifications based on the person's needs and preferences. There is a natural progression to eat less at the end-of-life. Health care providers must meet hunger needs and provide comfort. To simply meet hunger needs, food supplements are also provided (i.e., Ensure, Resource, and so on). These supplements are usually accepted by people and can replace a portion of the meal.

However, as the illness progresses, these strategies become less and less effective. The question then arises as to whether the person should continue to be fed and hydrated (provided liquids) orally or through a feeding tube inserted directly into the stomach. Feeding tubes are sometimes brought up as a solution to a person who is no longer eating. This approach, however, is not recommended for individuals who are at the advanced stages of degenerative brain diseases for the following reasons:

- The process of inserting a tube into the stomach requires anesthesia and is uncomfortable and distressing for the person;
- Feedings with a tube can lead to severe diarrhea;
- The feeding tube can sometimes become blocked and therefore have to be changed;
- Individuals who are confused will often try to pull out the feeding tube;
- The pleasure of tasting food provided through a feeding tube is eliminated, and the individual misses out on the social contact that they normally would have with the caregiver at mealtime;
- Moreover, the use of a feeding tube has not been found to lead to a longer life in the advanced stage of dementia. This is because aspiration pneumonia frequently occurs at this stage, even among people with feeding tubes. Feeding tubes can sometimes be used to provide nutrition but they often do more harm than good.

For the above-mentioned reasons, it is not recommended that health care providers insert a feeding tube in an individual with a degenerative illness, whose condition realistically is not expected to improve, or for whom this procedure is likely to cause more discomfort than relief.

Often, people with advanced dementia can experience problems with their oral health or may develop dental disease. When someone eats and drinks less than usual, good mouth care is important to make sure that their mouth feels as comfortable as possible. Oral hygiene is very important, even for those people who may wear dentures.

- Try to keep the mouth moist through regular gentle teeth cleaning or, if appropriate by providing small sips of water.
- You can clean the mouth with some water-moistened gauze.
- Lip balm, or a similar lubricant can be used to reduce the risk of your relative developing dried or cracked lips.
- Remember that with advanced dementia many people will need help to clean their teeth or look after their dentures. Try to make this part of your regular routine.
- If your relative wears dentures try to ensure that they are a good fit (particularly if they have lost weight) and make sure they are washed and stored correctly.
- Try to get into a good oral healthcare routine where mouth hygiene is considered after every meal or at least before bedtime.

Good oral hygiene will make your relative feel a lot more comfortable.

3 What can the caregiving team do when the person develops pneumonia?

When a person develops respiratory problems and food or saliva enters the respiratory tract, it is necessary to clear the back of the throat and the breathing passages. To make someone feel more comfortable, it sometimes helps to provide them with oxygen. Health care providers can prescribe an antibiotic if the individual develops a fever and if it is judged, from a medical standpoint, that the individual has pneumonia. However, as mentioned earlier, the chance of recovering from pneumonia in the advanced stages of these types of neurological diseases is limited, and the possibility of this problem re-occurring shortly thereafter is elevated. Antibiotics are useful sometimes, and not helpful in other times. Again, the decision to treat with an antibiotic depends on different factors, including where in the illness journey the person is and what their wishes are believed to be. Early in the illness, it may be helpful to treat a pneumonia that is believed to be caused by bacteria with an antibiotic. The goal being to have the person comfortable

Each situation is evaluated on a case-by-case basis. The health care provider and the person's substitute decision-maker must decide whether a curative or palliative approach is to be taken, while taking into account the person's goals of care, values and wishes.

4 Should the person with this problem be transferred to hospital?

Transferring a person in an advanced stage of dementia to a hospital may, at times, cause them a great deal of distress. If the person is agitated and is not placed in an environment that is adapted to the person's needs (i.e., in an emergency room), the individual will likely be given tranquilizers and perhaps even be restrained to limit movement. Such people will often refuse to eat food and may return to the long-term care setting with other issues such as bedsores and contractures because hospital staff are not aware of the person's goals of care. For these reasons, a transfer to an acute care hospital should only be made when it is absolutely necessary, and only for the shortest possible time period. A short hospitalization period is justified under some circumstances, such as for painful fractures that can be stabilized through surgery. Nevertheless, it is generally preferred not to transfer the person if the problem can be dealt with within the long-term care home with a palliative approach and good symptom control.

5 Do health care providers always carry out cardiopulmonary resuscitation?

(a procedure to get the heart beating again)

Most long-term care settings are not equipped for cardiopulmonary resuscitation (CPR), raising the question of whether to carry out this procedure. However, for argument's sake, let's assume that the individual is in a facility that is equipped to carry out this procedure. Would CPR be appropriate under such circumstances? The general consensus is that more harm than good results from this procedure. First, the likelihood of successfully resuscitating a person in a poor state of health, such as we have described, is extremely limited. Second, the risk of causing injury to the person is quite elevated (i.e., fracturing the ribs). The likelihood of the person remaining in a coma for the rest of their life is extremely elevated after conducting such a procedure if the individual was unconscious for a long period of time. Those are some of the reasons why it is not recommended that resuscitation procedures be carried out on individuals who are at the advanced stages of brain deterioration.



Decisions About the End-of-Life

1 Who makes medical decisions about end-of-life—the health care provider, the person, or the person’s substitute decision-maker?

It is common practice for caregivers to be faced with the dilemma of preserving life (curative treatment) or ensuring a comfortable end-of-life (palliative care). It is recommended to take the necessary time to have an open discussion with the health care providers and the family. The question that needs to be considered is: “What is the most appropriate thing to do for this person at this time in their life?” The ideal situation is one in which everybody agrees on the appropriate course of action for the person. The family should not be left alone with the burden of having to make such a difficult decision. Ideally, positive relations have been established between the family or substitute decision-maker and the caregiving team well before the terminal stage. Family members tend to feel more confident when they have been well informed and that their point of view has been respected on past occasions.

2 What is the role of the substitute decision-maker in the decision-making process?

The role of the substitute decision-maker is to discuss care options with health care provider’s and make a decision taking into account persons’ values and preferences when they are no longer capable of making those decisions. The substitute decision-maker must act according to what they believe is in the person’s best interest and consistent with what the person previously said they wanted or wished for. If the person’s wishes have not been written down or expressed verbally, decisions will need to be made based on the person’s lifelong desires and values and what you think the person would want.

You may have to weigh the risks and benefits of the decision and assess how it will affect the person’s quality of life and well-being. Consent must be informed and provided voluntarily and without constraint; the substitute decision-maker must be informed of treatment options and must not feel that any choice is being imposed upon them.

The laws regarding the roles of a substitute decision-maker vary from province to province across Canada.

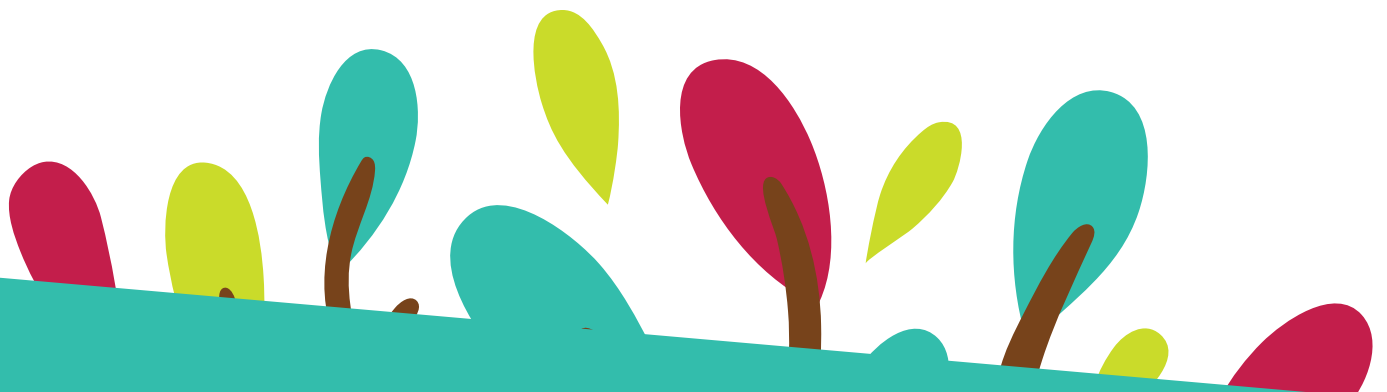
You should never hesitate to share your questions with staff! When questions or concerns are not expressed, family members or next of kin are left with unnecessary distress.

3 What to do in case of conflict or doubt?

Family members occasionally disagree with health care providers' advice or among themselves on deciding upon the appropriate course of action for the person. Health care providers do not have the power to impose a solution upon the family. At the same time, the preferred choice of the substitute decision-maker can also be contested if it is not in the person's best interest. What can be done under such circumstances? It is sometimes necessary to arrive at a compromise. For example, one can try out a treatment and evaluate its effects. One can also get a second opinion from another health care provider or an ethics committee, which is composed not only of health professionals but also of ethicists, jurists and members of the general public. Fortunately, differing points of view between the medical team and the family are rarely settled in court. It is preferable to find a friendly solution before resorting to tribunals.

4 If it is decided not to resort to curative treatment, does this mean that the person is left on their own?

In the past, health care providers would often tell the family that "nothing more can be done" during the terminal phase of the illness. Family members often considered this as abandoning the person, and in spite of good nursing care, viewed it as a very uncomfortable or painful period at the end-of-life. This way of thinking no longer exists. Inspired by the success of palliative care teams working with cancer patients, today's caregiving team plays an important role in providing maximum physical and psychological comfort to the dying person and their family. A number of ways are now available to make this possible, as will be described herein.



5 Under such circumstances, are religious authorities in agreement with the decision to withdraw or not provide life-prolonging treatment?

To the best of our knowledge, all religious authorities who have addressed these questions consider it morally acceptable to refrain from using life-prolonging measures if there is little or no significant hope of improving the person's quality of life. If questions should arise, it is recommended that family members take the necessary time to discuss this matter with a representative of their religious or spiritual denomination. Spiritual leaders who are all aware of person's problems and the concerns of the caregiving teams, are available in most long-term care facilities and hospitals to address family concerns.

6 Medical Assistance in Dying (MAiD) is legal in Canada. Can people with advanced dementia have it?

MAiD is a procedure occurring when a health care provider administers a medication that intentionally causes the death of a person, at the person's request. Although MAiD was legalized in Canada in June 2016, in order to qualify for MAiD, a person needs to meet certain criteria or conditions. To qualify for MAiD the person must have the ability to understand and give consent for MAiD (be capable). Therefore, people with advanced dementia cannot have MAiD. Substitute decision-makers are not able to consent to MAiD on behalf of those with advanced dementia. As legislation evolves this may change, but for now, the answer is no.

7 If someone cannot have medical assistance in dying (MAiD), what else can be done to alleviate suffering?

A palliative approach to care aims to improve the quality of life for people with a life-limiting illness, such as dementia, and to support their families throughout the illness. Medical Assistance in Dying (MAiD), and a palliative approach to care are very different and distinct practices. A palliative approach to care provides medical and comfort care to people and their families to help them live as fully and comfortably as possible until their natural death. A palliative approach does not seek to hasten or postpone death.

8 How might spirituality be integrated into care at the end-of-life?

Spiritual care may be important as the person approaches the last days of life. Providing person-centered care means that it is just as important to meet someone's spiritual needs as it is to meet their physical needs.

Spirituality is a term used to describe a set of core beliefs that people use to gain a greater understanding of their lives and those things that give their life a deeper meaning, value or sense of purpose. For some people spirituality may be expressed through their religious or cultural beliefs. Other people may not believe in an organized religion and their values, sense of purpose and significance may be influenced by other things such as nature, being outside, family, friendships, music or art.

Religion or spirituality provides a set of beliefs that allow someone to make sense of their lives, cope with their experiences and maintain a sense of hope and peacefulness during their life, particularly during difficult times such as illness. These may include traditions, rite of passage, or rituals. You may find it helpful and comforting to talk to a leader in their religious community. Alternatively, some people may feel more comfortable talking to friends who are aware of their beliefs. It is important that the healthcare team is made aware of any important rites or rituals or spiritual beliefs.



Relief of Symptoms

1 What are the most frequent symptoms at the end-of-life?

The most frequent signs at the end-of-life are reduced functional status, loss of appetite, loss of weight, pain, and discomfort. Other symptoms include restlessness, agitation and difficulty breathing.

2 How does the caregiving team look after breathing problems?

Breathing difficulties can have many causes (lung infections, cardiac failure, aspiration of food into the lungs, and so on). Treatment will vary according to the cause of the problem. Opioids, such as morphine are generally used to reduce the person's distress. Certain medications, which can be inhaled through a pump, an inhalor or a mask, can reduce spasms of the breathing tubes or bronchi. Diuretics may also be necessary when there is heart failure or to eliminate excess water that has accumulated in the lungs.

3 Should the person be given antibiotics when they have an infection?

In the case of pneumonia, antibiotics can sometimes be used if the person has high fever and purulent secretions (with pus). The dilemma that then arises is deciding whether giving antibiotics for the pneumonia would improve comfort or not. Through discussions with the family, the person's wishes need to be identified in order to decide upon the most appropriate care to administer. In case of doubt, or when the substitute decision maker cannot be located, some health care providers may decide to implement a treatment, and then stop it if it is not effective or if it is no longer desirable.

On the other hand, in the case of certain infections which result in discomfort (i.e., bladder infection), antibiotic therapy may be the best way to provide the person with rapid relief.

4 How are secretions controlled when they cause difficult and noisy breathing?

When there is a large quantity of secretions at the back of the throat, caregivers position the person correctly and administer medications to decrease the formation of new secretions. The medications are usually helpful at the beginning; however, the secretions often become too plentiful or thick, and the person continues to have noisy breathing (called rales). To those near the person, this type of respiration may seem uncomfortable; however, if they are in a coma or if they are receiving enough medication to keep them comfortable, they are unlikely to be aware of the way they are breathing. In rare cases it can be necessary to use a suction machine to remove large quantities of secretions from the mouth. Since this can be an unpleasant procedure, it is only carried out when necessary.

5 Is it helpful to provide oxygen?

When the person has difficulty breathing, oxygen may help reduce certain breathing problems. However, when the end-of-life is near or if the person is in a coma, it is reasonable to remove the oxygen so as not to prolong life with the use of technology.

6 What are the signs of pain in someone who is unable to express themselves?

Pain is often difficult to evaluate in someone who is unable to express themselves. Thus, one has to observe facial expressions, vocal sounds and body movements. Do not hesitate to inform nursing staff if you feel that the person needs pain relief.

7 How can pain be relieved?

There are many possible causes of pain, thus it is important to identify the right one. It is especially important that the person be properly positioned in a comfortable bed. Various medications are available for different types of pain, and sometimes they have to be combined in different ways to be effective. Opioids, such as morphine, are definitely the most effective medications to relieve moderate to severe pain. In order to effectively control pain at this stage of the illness, it is preferable to regularly administer opioids (i.e., every four hours). Additional doses are occasionally prescribed by health care providers within the four-hour period so that the person doesn't wait too long to receive adequate pain relief. Because the body becomes accustomed to certain doses of opioids, the dose has to be increased by the health care provider in order to keep it effective.

8 Can morphine kill the person?

Many people wrongly believe that it is the last dose of morphine that the person receives that causes breathing to stop. People can tolerate higher doses of morphine if the strength is gradually adjusted. It is possible that high doses can sometimes lead to death prematurely. Under such circumstances, it is generally understood that if the intent was to provide relief and not to end life, it is morally acceptable to administer the necessary doses.

9 How can anxiety or agitation be relieved?

It is not always easy to distinguish pain from anxiety when someone who has limited ability to communicate is agitated or unable to rest. That's why experts in palliative care prefer to administer medications for anxiety, in addition to morphine. Other treatments for anxiety include a calm environment or a gentle or soothing touch.

10 What if the person is in distress and no medications or treatments are helping?

In certain circumstances, palliative sedation can be used to manage specific, distressing, non-reversible symptoms such as agitated delirium, seizures and intolerable shortness of breath (dyspnea). Palliative sedation uses medications (sedatives) to decrease a person's level of consciousness so the person does not feel the distressing symptoms, to relieve suffering. Palliative sedation is considered during the end-of-life when the person is close to death (hours to weeks of life), no longer eating or drinking, and continued until death. The goal of palliative sedation is not to hasten death. This is a last resort when other treatment options have been ineffective. Palliative sedation is implemented only after discussions between the healthcare team and the substitute decision-maker.

11 Is it necessary to administer other medications or to verify blood pressure, temperature, blood sugar levels, and so on?

The caregiving team also has decisions to make regarding other types of care and treatments for the person. Towards the end-of-life, when swallowing difficulties become problematic, it is often preferred and even necessary to stop taking medications orally. Instead, necessary treatments are administered through injections or suppositories. In order to reduce the discomfort of repeated injections, nursing staff insert small catheters under the skin which people can easily tolerate.

It becomes less relevant to take the person's temperature and blood pressure or to verify blood sugar levels as end-of-life approaches, especially when the interventions disturb the person who is sleeping peacefully. On the other hand, nursing care, aimed at maintaining hygiene and care of the skin (to prevent skin breakdown), needs to be carried out until the end-of-life because this contributes to the comfort and the dignity of the dying person.

12 How do people feel when they are no longer drinking or eating?

People who are lucid and who are suffering from cancer or degenerative, neurological diseases say that the feeling of thirst and hunger is not common near the end-of-life. Most people refuse all or even small amounts of food that are offered to them. Forced feeding does not help. It is important to provide people with what they enjoy.

Some say that they feel a sensation of dryness in the mouth. That is why experts in palliative care have developed products that are effective for treating dryness of the mouth, lips and throat. In terms of nursing care, management of this symptom is given high priority.

On the other hand, an overall lowering of body-fluid levels (dehydration of the body) is not painful in itself. The blood becomes more concentrated, and the kidneys gradually operate less and less, eventually stopping their function. All these changes are generally positive for the person because the perception of pain is lowered as well. In addition, having a lower volume of fluids in the body also means a reduction in the quantity of secretions, thereby making it easier to breathe.

13 Should an intravenous be started for hydration?

Some families believe that the person would be more comfortable with an intravenous. Evidence suggests the total opposite, as IV results in more secretions in the breathing passages, puts off the onset of the coma, and prolongs the duration of the discomfort.



14 What to do if the person already has a feeding tube?

Even though some might have trouble understanding this concept, experts in the field of ethics consider that the decision to stop tube feedings is essentially the same as not inserting a feeding tube. Thus, after discussing with a substitute decision-maker, it is possible to stop the tube feeding at any time that it is judged to be in the best interest of the person. The tube does not need to be removed because the procedure is usually uncomfortable.

15 How long will a person who is no longer drinking live?

When a person is no longer drinking, they will usually keep on living for a few days. However, people who are physically stronger or ingesting liquids when they are receiving mouth care, may live one or two additional weeks. Each case is different, and it may be difficult for the caregiving team to estimate the amount of time remaining at the onset of the terminal phase.



The Final Moments

1 How can you engage with someone who appears to be unconscious?

The kinds of interventions which appear to help the person who is dying are simple. Touching and holding the person, speaking with a soft voice, or playing music that the individual enjoyed are some of the ways in which the person can be comforted and helped to feel more secure. Whenever possible, family members should make arrangements so that the person is not left alone during the last days of life. Institutions are increasingly helpful in accommodating family members so that they can spend the night with their loved one. When the family member is elderly or unwell, or few family members are available, alternate services can be used, such as volunteers, who can stay with the dying individual and inform nursing staff if the person appears to be uncomfortable.

2 What are the final moments like?

When the dying person receives comfort care, as described in this guide, death is usually peaceful. Breathing can become shallower and irregular. The pauses between breaths become longer and longer. Eventually, the unconscious person will take one or two deep breaths before exhaling the final one. Many family members and friends who have been present at this time have said that these final moments were much less difficult or upsetting than they had anticipated, and in turn they became reassured about their own eventual death. Most were content to have been with their loved one right up to the end.



After the Death

1 What happens after death?

A health care provider will confirm the death and nursing staff will then prepare the body before the body is taken to the funeral parlour in accordance with the family's wishes, religion and culture. The health care provider may even seek your approval for an autopsy, although this will usually have been discussed prior to the death. If the person suffered from an illness whose cause was uncertain, it may be useful to carry out an autopsy of the brain. This seldomly happens.

The results of the autopsy could be of significant importance if the person had an illness that can be traced to their relatives, especially if a treatment becomes available for the disease. In universities, where research is carried out to discover the roots of such diseases, "brain banks" serve an important role. Discussions regarding such donations will usually have been carried out at an earlier time. When an autopsy is to be conducted or a brain is to be donated to a university "brain bank", the body will be sent to the appropriate hospital before being delivered to the funeral parlour.

After the death of the person for whom you have cared, you will experience grief in various forms. These reactions can be very different from one person to another. Some people will be surprised to find that they feel more relieved than grief-stricken. This is a normal reaction when death is "timely" after a long illness. You may also feel angry, alone, exhausted and even guilty and need to give yourself some time or obtain support during this period. If you need counselling or support, certain community services can be of assistance, such as the local Alzheimer's society.



In this guide we have tried to provide some answers to the sensitive questions that arise at the end-of-life of people suffering from degenerative brain diseases. In order for this stage of the illness to take place in a serene manner, it is important that family members and next of kin have a good understanding of what the caregiving team must do. It is also essential that health care providers be available to provide the necessary information and take the time to agree about the treatment that serves the best interest of the person and respects their wishes. Given that the wishes of the person are not always clearly expressed orally or in writing, we have recommended that in case of doubt, a palliative care approach, based on physical and psychological comfort, be deployed. That's because the majority of people perceive that advanced and prolonged dementia is worse than death.

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