Comfort Care

at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain

A Guide for Caregivers

Centre de santé et de services sociaux –
Institut universitaire de gériatrie
de Sherbrooke

A Guide for Caregivers

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 the person increasingly has difficulty speaking and understanding reality in terms of what is happening around him, thus making it difficult for the individual to participate in medical decisions that concern him. Consequently, when a complication or a new health problem occurs, either the spouse, child or someone close to the sick person must represent him 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.

Natural evolution of these illesses

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 eating 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 eating 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, 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 patients 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 his 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 nursing and medical staff do is trace the cause of the eating problem and attempt to correct it. In some cases, the individual can be helped (i.e., when there is a mouth infection or a problem with a medication). 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. The most frequent strategy is to provide food in a thickened form, such as purées (food that has been mashed up or put through a blender) and thickened liquids, which are easier to swallow. To enrich the diet or simply to meet hunger needs, food supplements are also provided (i.e., Ensure, Resource, and so on). These supplements are usually accepted by patients 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 patient should continue to be fed and hydrated (provided liquids) orally or through a gavage tube inserted directly into his stomach. A gavage tube is helpful for people who are lucid and who still enjoy a certain quality of life or

who hope to recover their normal eating habits after a period of rehabilitation. 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 is uncomfortable and can cause distress;
- Feedings with a gavage tube can lead to severe diarrhea;
- The feeding tube can become blocked and therefore have to be changed regularly;
- 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 he 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.

For the above-mentioned reasons, it is not recommended that physicians insert a feeding or gavage 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.

3 What can the caregiving team do when the patient 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 the person feel more comfortable, it is also helps to provide him with oxygen. The doctor can prescribe an antibiotic if the individual develops a fever and if it is judged, from a medical standpoint, that he has pneumonia. However, as mentionned 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-occuring shortly thereafter is elevated.

William Osler, a well-known early 20th-century doctor, said that pneumonia may very well be the elderly person's best friend because it can bring his suffering to an end. That is why many doctors prefer to abstain from prescribing antibiotics for pneumonia at the end of life, and select a palliative care approach such as the one described further on in this document.

Each situation is evaluated on a case-by-case basis. The physician and the patient's representative (mandatory) must decide whether a curative or palliative approach is to be taken, keeping in mind the patient's best interest.

4 Should the individual with this problem be transferred to a hospital?

Transfering a person in an advanced stage of dementia to a hospital may, at times, cause him a great deal of distress. If the person is agitated and is not placed in an environment that is adapted to his needs (i.e., in an emergency room), the individual will likely be given tranquilizers and perhaps even be restrained to limit his movement. Such people will often refuse to eat food and will return to the long-term setting with bedsores and contractures because hospital staff are unable to respond to their needs. 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 patient if the problem can be dealt with in the long-term care centre with a palliative care approach and good symptom control.

5 Do doctors 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 majority of physicians are of the opinion 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. On the other hand, the risk of causing injury to the patient is quite elevated (i.e., fracturing the ribs). The likelihood of the person remaining in a coma for the rest of his life is extremely elevated after conducting such a procedure if he 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 at the end of life, the doctor or the mandatory (the patient's representative)?

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 doctor 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 his or her life?"*. The ideal situation is one in which everybody agrees on the appropriate course of action for the patient. 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 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 mandatory or the representative of the patient in the decision-making process?

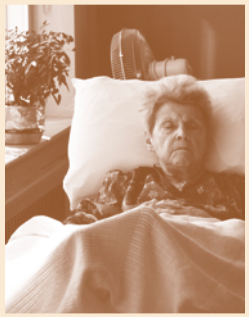
The role of the mandatory or the patient representative is essentially to accept or to refuse the doctor's advice. The person who is the mandatory must act according to what he believes is in the patient's best interest. Consent must be informed and provided voluntarily and without

constraint; the mandatory must be informed of treatment options and must not feel that any choice is being imposed upon him.

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

3 What to do in case of conflict or doubt?

Family members occasionally disagree with the doctor's advice or among themselves on deciding upon the appropriate course of action for the patient. The doctor does not have the power to impose a solution upon the family. At the same time, the preferred choice of the patient's representatives can also be contested if it is not in the patient'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 physican 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 much 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 patient is left on his own?

In the past, doctors 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 patient, 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 his 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 patient'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. Priests, ministers or spiritual counselors, who are all aware of the patients' problems and the concerns of the caregiving teams, are available in most long-term care facilities and hospitals to address family concerns.

6 Is euthanasia an acceptable option?

Many of us feel that ending the suffering of an individual who is in great discomfort may be the best alternative in the final stages. Many ethicists and moralists would support such an approach so long as certain conditions are met in order to prevent the misguided use of euthanasia. At the same time, in most countries, including Canada, it is believed that laws regarding euthanasia result in more negative consequences than positive ones. That is why euthanasia is formally prohibited. At the same time, to refuse to administer or to stop providing a treatment that is judged to be useless or ineffective, (i.e., a treatment that will not lead to the desired goal) or to withhold a treatment (not to begin it) is acceptable in our Canadian legal system.

Relief of symptoms

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

The most frequent symptoms at the end of life are dyspnea (breathlessness) and pain. Other symptoms include anxiety, agitation and vomiting.

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. Morphine is the drug that is generally used to reduce the patient'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. This type of breathing problem is similar to an asthmatic reaction. Diuretics may also be necessary when there is heart failure or to eliminate excess water that has accumulated in the lungs.

3 Should the patient be given antibiotics when he has an infection?

In the case of pneumonia, it may be necessary to administer antibiotics if the patient has high fever and purulent secretions (with pus). The dilemma that then arises is deciding whether the pneumonia should be treated or whether the focus should be on ensuring a comfortable end of life. Through discussions with the family, the patient's wishes need to be identified in order to decide upon the most appropriate care to administer. In case of doubt, or when the next of kin cannot be located, some doctors 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 patient 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 patient 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 patient continues to have noisy respirations (called rales). To those near the patient, this type of respiration may seem uncomfortable; however, if the patient is in a coma or if he is receiving enough medication to keep him comfortable, he is unlikely to be aware of the way he is breathing. It may sometimes 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 patient has difficulty breathing, oxygen may help reduce certain muscular pains and breathing problems. However, when the end of life is near or if the patient 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 himself?

Pain is often difficult to evaluate in someone who is unable to express himself. Thus one has to observe facial expressions, vocal sounds and the way the patient moves. Do not hesitate to inform nursing staff if you feel that the patient has not received enough pain killers.

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 patient be properly positionned 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. Narcotics (also called 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 narcotics (i.e., every four hours). Additional doses are occasionally prescribed by doctors within the four-hour period so that the patient doesn't wait too long to receive adequate pain relief. Because the body becomes accustomed to certain doses of morphine, the dose has to be increased by the doctor in order to keep it effective.

8 Can morphine kill the patient?

Many people wrongly believe that it is the last dose of morphine that the patient receives that causes breathing to stop, especially if it is stronger than the others. Patients can tolerate heavier 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. Failing to respond to the patient's needs would ultimately be immoral.

9 How can anxiety or agitation be relieved?

It is not always easy to distinguish pain from anxiety when an individual is agitated or unable to rest. That's why experts in palliative care prefer to administer, in addition to morphine, medications for anxiety or hallucinations. These medications, which are highly effective in providing a more comfortable end of life, are usually administered at regular intervals.

10 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 patient. 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 patients can easily tolerate.

It becomes less relevant to take the patient's temperature and pressure or to verify blood sugar levels as he approaches the end of his life, 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.

11 How does the patient feel when he or she is 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 prevalent near the end of life. Most patients refuse all or even small amounts of food that are offered to them and say that they feel a sensation of dryness in the mouth. That's 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 patient 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.

12 Should an intravenous be started?

Some families believe that the patient would be more comfortable with an intravenous. Our experience is 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.

13 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 the a family representative or mandatory, it is possible to stop the tube feeding at any time that it is judged to be in the best interest of the patient. The tube does not need to be removed because the procedure is usually uncomfortable. Although this may seem inhumane, as ethics experts point out, why should people suffer for a longer time than before the advent of current technological advances?

14 How long will a person who is no longer drinking or eating live?

When a person is no longer eating or drinking, he 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 calculate the amount of time remaining at the onset of the terminal phase.

The Final Moments

1 How should you behave 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 his life. Institutions are increasingly helpful in accomodating 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 patient 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 becomes more shallow and irregular. The pauses between breaths become longer and longer. Eventually, the unconscious patient 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 doctor 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. The doctor 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 patient had an illness that can be traced to his 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 to 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 the doctor and nursing staff 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 his wishes. Given that the wishes of the patient 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.

Notes

Marcel Arcand, MD,
Head of the Long-term Care Programme
University Institute of Geriatrics of Sherbrooke

Chantal Caron, nurse, Ph.D.,
Researcher at the Research Centre on Aging
Assistant Professor at the Nursing Department of the Faculty of Medicine and Health Sciences of the Université de Sherbrooke.

This guide is based on the results of a research project sponsored by the Alzheimer Society of Canada on the experience of natural caregivers in the end-of-life phase of people suffering from Alzheimer's disease. We wish to thank our colleagues and members of the ethics committee of the University Institute of Geriatrics of Sherbrooke for revising this text.

ISBN 2-923465-01-6

A Guide for Caregivers

pictures : Claude Croisetière • **design :** Tatou communication visuelle www.tatou.qc.ca

ISBN 2-923465-01-6