Care at the End of Life
for People with Alzheimer’s Disease
or Other Diseases of the Brain

A Guidebook for Caregivers
As diseases of the brain progress, the person affected begins to have more and more trouble communicating and understanding what is happening to them and around them. As the person’s health worsens or new health problems arise, a family member or friend must become involved in making decisions regarding their plan of care. This is a difficult task that many of us are not prepared for.

We hope this guidebook provides you with a better understanding of how diseases of the brain progress toward the final stages of life. Our goal is to ensure that every person affected by Alzheimer’s disease or other disease of the brain is well cared for and comfortable during the final stages of their lives. We hope this information is helpful and gives you peace of mind during this difficult time.
Contents

The natural journey to the end of life
- What is the journey like to the end of life? 
- What can be done when the person no longer eats or drinks?  
- How about a feeding tube?  
- What can be done when the person gets pneumonia?  
- Should the person be cared for in a hospital?  
- If the person’s heart stops, will we try to restart it?  

Decisions about the end of life
- Who makes medical decisions at the end of life - the doctor or the substitute decision-maker? 
- What if you are not sure what actions are most appropriate?  
- Is it right to stop treatment that could prolong life?  
- Is ‘euthanasia’ the same as withholding or withdrawing treatment?  

Relief of symptoms
- What symptoms are often present at the end of life? 
- How does the care team look after breathing problems?  
- Is it helpful to give oxygen?  
- How is noisy and wet-sounding breathing treated?  
- If the person has an infection, should we give antibiotics?  
- How can pain be relieved?  
- Can opioids kill the person?
Relief of symptoms, continued

How can anxiety or agitation be relieved? ............... 17
Why do we continue bothering the person with medications and repeated checks? ............... 17
How does the person feel when they stop drinking or eating? ................................. 18
Should we try and prevent dehydration with intravenous fluids? ................................. 19
What to do if the person already has a feeding tube? ... 20
How long will a person live at this stage? ............... 20

The final hours

How should you behave when the person appears to be unconscious? ...................... 21
What are the final moments like? ...................... 21

After the death

What about organ donation? ...................... 22
Caring for yourself ...................... 23

Summary ...................... 24
What is the journey like to the end of life?

In the later stages of life, the two main health problems related to brain diseases are difficulty eating and repeated infections.

The journey begins with the person having more difficulty with swallowing. This can result in the person choking on food. If food or saliva goes down the wrong way and into the lungs, the person can have coughing spells and trouble breathing. When a person cannot cough well enough, a lung infection or pneumonia occurs.

During the later stages of life, the person naturally does not want to eat or drink very much. This is either because the person cannot remember how to eat, or loses interest in food. The person loses weight. When the person does not drink, they become dehydrated (meaning the body does not have enough fluid). With weight loss and dehydration, the person becomes weak and may develop bladder infections or pneumonia.
What can be done when the person no longer eats or drinks?

The first thing is to see if we can find the reason for the eating problem. We can treat the problem, if it is related to an infection in the mouth or changing the type of medication. However, sometimes the person refuses to swallow for any number of reasons. For example, it could be that the person:

- is not hungry
- does not like the taste of food
- is afraid of choking
- cannot open his or her mouth
- cannot swallow at all

To help the person get the nutrition they need, we can:

- purée the food and thicken fluids, which makes it easier to swallow
- give food supplements such as Ensure®, or Resource®
- make sure the person is sitting up while eating
- make sure the person is fully awake while eating or drinking
- make sure food or drinks are given very slowly

As the disease progresses, these strategies become less effective. Then, we have to question whether we should continue to feed the person by mouth.
How about a feeding tube?

Insertion of a feeding tube may be considered when the person is aware and still enjoys different activities, or when there is a chance they could return to normal eating habits. At this stage, feeding through a feeding tube will not prolong life because there is a greater chance the person would develop pneumonia or bladder infections.

We do not recommend a feeding tube for people who are in the later stages of their brain disease because:

- inserting the tube can be uncomfortable and upsetting to the person
- tube feeding can cause diarrhea
- the feeding tube can become blocked and need to be changed
- people who are confused often try to pull the tube out
- the person loses the enjoyment of tasting food
- the person misses the social contact that occurs at mealtime

We do not recommend a feeding tube for any person with a brain disease whose health is not expected to improve, or when the procedure is likely to cause more discomfort than relief.
What can be done when the person gets pneumonia?

In this situation, the goal is to keep the back of the throat and the airways as clear as possible, so it is easier to breathe. We might use suction to clear the airways and give oxygen, so the person is more comfortable. If the person has fever, chills or other signs of pneumonia, we might give antibiotics.

In later stages of brain disease, the chance of the person recovering from pneumonia is low. Even if there is improvement, it is very likely the infection will happen again. This is why we prefer not to give antibiotics for pneumonia at the end of life.

Each situation and person is different. Together with the care team, a family member or friend who is speaking for the person can make decisions regarding the plan of care that will be in the person’s best interest.

Pneumonia may very well be the elderly person’s best friend because it can bring his suffering to an end.

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Sir William Osler, MD
Should the person be cared for in a hospital?

The best place to care for a person with a brain disease is where they know the environment and the caregivers. Moving the person to a hospital during the later stages of brain disease could be upsetting and confusing for them.

We move people to the hospital only when it is necessary for what they need. For example, if the person needs surgery to repair a broken bone, we would move that person to the hospital for a short stay.

If the person is taken to an unfamiliar environment, such as the hospital, they may become agitated. Hospital staff may give medications to sedate the person, or restrict the person’s movement to keep them and others safe.

If the person’s heart stops, will we try to restart it?

“Would cardiopulmonary resuscitation (CPR) be the right action for this person?”

The chances of the CPR bringing the person back to life are quite low. On the other hand, the chances of injury (such as broken ribs) during the CPR are high. If the person survives, the person might return to the

Cardiopulmonary Resuscitation (CPR) is an attempt to restart the heart and breathing when one or both have stopped.
state of health they were in before, but it is more likely that their health would decline. CPR will not improve the person’s health or brain disease.

These are some of the reasons that explain why we believe CPR should not be considered for a person in the later stages of Alzheimer’s or other brain disease.

Decisions about the end of life

Who makes medical decisions at the end of life - the doctor or the substitute decision-maker?

It is common to be faced with the question of whether the goal is to prolong life or make sure the person has a comfortable and peaceful end of life. This is the time for family members, friends and the health care team to talk frankly about goals of care for the person.

Consider the question: “what is the most appropriate care for this person at this time in their life?” Ideally, everyone agrees on the best plan of action for the person. We would not leave you and your family alone with the burden of making such difficult decisions.

Substitute Decision-maker is someone who makes decisions for a person who cannot speak for themself.
The substitute decision-maker can accept or refuse the doctor’s or the care team’s advice. If you are the substitute decision-maker, you must act according to what you believe the person would want and what is in the person’s best interest. We make sure you have all the information you need to make a decision. We welcome your questions and want to know your concerns.

**What if you are not sure what actions are most appropriate?**

Sometimes, family members disagree with the doctor’s advice or disagree with each other on the best plan of care for the person. The doctor does not have the power to decide for the family. At the same time, the decision made by the family or substitute decision-maker can be questioned by the doctor and the care team if it is not in the person’s best interest.

These situations call for a compromise. For example, we may try out a treatment for a short time and see what effect it has, before it is decided to continue that treatment. Another option might be to get a second opinion from another doctor or an ethics consultant. We will work with you to find a compromise that works for everyone.
**Is it right to stop treatment that could prolong life?**

In the past, doctors would often tell families that “nothing more can be done”. Families often thought this meant abandoning the person. We are now inspired by the success of palliative care and focus on providing the best physical and emotional comfort we can to the dying person, their family and friends.

It is acceptable to stop treatment to prolong life if:

- there is little or no hope of improving how long the person lives
- there is little or no hope of improving how well the person lives
- any treatment and its side effects will cause the person more pain or discomfort than any positive effects from the treatment

If any family members have questions about what is right or wrong, we suggest you talk with someone of the person’s religious or spiritual faith. If you do not have someone to talk to, we can ask our Pastoral Care team to talk with you about your concerns.
Is ‘euthanasia’ the same as withholding or withdrawing treatment?

‘Euthanasia’ is when someone knowingly and intentionally performs an act that ends a person’s life. Euthanasia is currently against the law.

Withholding or withdrawing treatment is different from euthanasia. Under Canadian law, it is acceptable to withhold or withdraw treatment if it is thought to be ineffective or cause suffering.
Relief of symptoms

What symptoms are often present at the end of life?

The most common symptoms at the end of life are breathing problems and pain. The person might also be anxious, agitated, and confused (more than what is normal for that person).

How does the care team look after breathing problems?

We treat breathing problems based on our understanding of its cause. Breathing problems can be caused by lung infections, heart failure, or brain disease. We might change the person’s position, clear the saliva from their throat, or give medications.

To help ease breathing, we give **opioid** medications. To help open airways in the lungs, we give medications that are inhaled through a pump, an inhaler, or a mask. We can give **diuretics** to help remove fluid in the lungs or from the body when there is heart failure.

**Opioids** - medicines made from opium, sometimes called ‘narcotics’

**Diuretics** – medicines that increase the amount a person urinates (goes ‘pee’).
Is it helpful to give oxygen?

Generally, the feeling of breathlessness is not helped by oxygen at the end of life. If we have been giving oxygen for other medical reasons, we might continue the oxygen along with giving medication to help ease the breathlessness.

When the end of life is near, or when the person is not conscious, it is reasonable to either not give or to remove the oxygen.

How is noisy and wet-sounding breathing treated?

When the person has a lot of fluids at the back of the throat, the person’s breathing can become noisy. People who are in the same room might feel uncomfortable with this sound or think this is uncomfortable for the person.

If the person is not conscious and is getting medication to be comfortable, they are probably not bothered by noisy breathing.

We will position the person and give medications to help reduce the amount of fluid in the throat. Sometimes, we will use suction to remove fluid. This can be an unpleasant procedure for the person, causing mild gagging and coughing. We only do this when it is necessary.
If the person has an infection, should we give antibiotics?

If the person gets pneumonia with a high fever and coughs, we may give antibiotics. The antibiotics may help reduce the amount of mucus, but might not cure the infection. When a person cannot swallow pills, the only way to give antibiotics is through an **intravenous**. The question is whether it is beneficial to move the person to the hospital to give intravenous antibiotics, or to not treat the pneumonia at all. A trip to the hospital can be frightening to a person with Alzheimer’s or other disease of the brain, especially at the later stages of life.

We discuss with the family and friends about what would be in the best interest of the person. If you are not sure, we sometimes go ahead with intravenous antibiotics. Later, we can stop the antibiotic if it is not working or if, together with the family and friends, we decide it is preferable not to treat the pneumonia.

If the person gets an infection that makes them feel uncomfortable (such as a bladder infection), antibiotics may be given to relieve their symptoms. If the infection spreads beyond the bladder into the bloodstream (called sepsis), we would talk with you about further treatment, just like we would if the person had pneumonia.

**Intravenous** - *intra* meaning ‘into’ and *venous* meaning ‘vein’, commonly called an ‘IV’
How can pain be relieved?

When the person is not able to tell us they have pain, we watch the person’s face, the way they move, and the sounds they make. If you see the person grimace, hear them cry or moan, or see them change positions or move often, they could be in pain. If you think the person is in pain, let us know. We will try and find the cause and make sure the person is kept as comfortable as possible.

We use different medications to treat different types of pain. Sometimes we combine medications to get the best effect. The best way to control pain near the end of life is to give opioids regularly throughout the day and night. If there are times when the person has more pain than usual, we can give what we call ‘top up’ doses to make sure the person is comfortable.

Medications are not the only way to relieve pain. Making sure the person is lying in a comfortable position can help. We might add extra padding or cushions to make the person more comfortable. Some people find gentle massage or warm blankets helpful. Talking about things that were of an interest to the person could help take their attention away from the pain.
Can opioids kill the person?

Many people think that opioids cause breathing to stop. Opioids do not cause breathing to stop when the appropriate amount is given to ease breathing or pain. Opioids help the person breath more easily and reduce the work of breathing. Research studies show that opioids do not shorten life. The person dies naturally from their brain disease, and they die comfortably.

How can anxiety or agitation be relieved?

It is not always easy to tell the difference between pain and anxiety when the person is agitated or not able to rest comfortably. Because of this, we often give medications for anxiety or delirium along with opioids. When given regularly, these medications can help the person relax and feel more comfortable.

Why do we continue bothering the person with medications and repeated checks?

We keep checking the person to see how comfortable they are and what treatments are needed. Our care is focused on making sure the person is as comfortable as possible.

If the person can no longer swallow, we switch to giving medications in different ways. We might choose to give medications by injection into an arm, leg, or other muscle. To reduce the discomfort of repeated injections, we can place a small flexible tube under the skin and give medications this way.
As well, everyone feels better when they are clean, dry, and in clean clothes. This is just as true when a person is near the end of life. We will continue to wash the person regularly, changing clothes and bed linens as needed. We check to make sure their skin is in good condition.

As the person nears the end of life, we do not need to take the person’s temperature, blood pressure, or check blood sugar levels. We especially don’t want to do this if the person is resting comfortably or sleeping peacefully.

**How does the person feel when they stop drinking or eating?**

People who do not have a disease of the brain and that are near the end of life say they do not feel thirsty or hungry. Most people near the end of life refuse to eat or drink and say their lips, mouth, and throat feel dry. We believe these feelings would be the same in a person who cannot communicate due to a disease of the brain.

We might offer small sips of water or small amounts of food, but we do not force the person to drink or eat. Our priority is to treat the dry lips, mouth, and throat. We have products that work well for this.
With the person not drinking, they will slowly become dehydrated. This is not painful. The blood and urine get more concentrated. You might notice the person’s breathing is less noisy and wet-sounding. This is because the person is not producing as much saliva or mucus, making it easier to breathe.

**Should we try and prevent dehydration with intravenous fluids?**

Some families and friends believe the person would be more comfortable with some fluids given intravenously. Our experience is the opposite. We believe dehydration is part of the natural process of the body preparing for death.

If we give fluids through an intravenous, it means there is more fluid in the person’s body. When the body’s systems are naturally slowing down, this can result in more saliva in the throat and fluid in the lungs, making it harder for the person to breathe. Sometimes giving intravenous fluids can overload the body, causing more discomfort.
What to do if the person already has a feeding tube?

The person or the substitute decision maker can choose to stop the tube feeding at any time if they believe the feeding is not in their best interests. To help decide if tube feeding should be stopped, it is helpful to consider the same reasons used to decide whether the feeding tube should be put in (see page 6). Remember that a person near the end of life does not usually feel hunger.

At this stage, we usually do not remove the tube because it is uncomfortable and it might be used to give medications.

How long will a person live at this stage?

Each person is different. It is difficult to estimate how long the person will live from this point on. It could be several days to several weeks. Regardless of how long it takes, we continue to give care focused on keeping the person comfortable, giving appropriate medications through the tube or by injection.
The final hours

How should you behave when the person appears to be unconscious?

There are a few simple things you can do to comfort the person and help them feel secure. You can touch the person or hold them. You can speak to the person in a soft voice or play music that you know they enjoyed.

You may want to arrange to have a family member or friend stay with the person at all times, so they are not alone at the end of life. Our nursing homes and other care facilities can help you if family members or friends wish to stay the night. You may consider other options if you are worried there would be times when the person could be alone. Our care teams can assist you with your decisions.

What are the final moments like?

When the dying person is cared for the way we have described in this guidebook, death is usually peaceful. The person’s breathing pattern changes, becoming shallow and irregular. The time between breaths becomes longer. Sometimes you will hear a moaning-like sound when the person breathes out. This is just the air passing over relaxed vocal cords. The person is usually not conscious at this point. Eventually, the person takes one or two deep breaths before breathing out one final time.
Those families who have been present when someone with brain disease dies tell us these final moments were not as hard or as upsetting as they thought it would be. Most were comforted that they had been with their loved one right up until the end. For more information on the final hours, please ask for the guidebook called: ‘Preparing for the Death of a Loved One’.

After the death

What happens after death?

Traditions or rituals for after death are important. Please let us know before the person’s death if you have plans for any traditions or rituals. It helps to know so we can help you make arrangements or simply give you what you need.

After the person dies, one of our nurses confirms the death, informs the doctor and prepares the body to be moved to the funeral home of your choice.

What about organ donation?

If the person is under 75 years of age and meets other conditions, the person might be able to donate their corneas (the front lens of the eye) to someone with damaged corneas. Please ask us for more information about this.
Caring for yourself

Each person experiences grief in a unique way. Some people are surprised to find they feel more relieved than sad. This is a normal reaction when death happens after a long illness. You may also feel alone, exhausted, angry and even guilty. Give yourself some time to experience these feelings. It is okay to ask for help and support during this time. There are a number of community services that can offer you support, such as the BC Bereavement Helpline

BC Bereavement Helpline
1-877-779-2223
www.bcbereavementhelpline.com

For more information and guidance after the death, ask for ‘When Someone Dies…’ and ‘A Guide for What to do When Someone Dies’.
Summary

In this guidebook, we have tried to answer the sensitive questions that come up at the end of life of people suffering from diseases of the brain. Please let us know if you have questions or need us to clarify anything.

We hope you have a better understanding of what to expect when someone you know is nearing the end of life. We also hope you understand our approach to caring for people who are affected by Alzheimer’s or other diseases of the brain.

We are always available to answer your questions and to discuss the plan of care. We will make sure the people close to the person are aware of what is happening and can take part in their care. We will work with you to make a plan of care that is in the best interest of the person and respects what that person would want at the end of life. We realize it is not always clear what the person would want. If that is the case, we always suggest that care be focused on making sure the person has a natural, dignified, and comfortable death. We think that prolonging the life of a person with brain disease could be worse for them than death.
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