



Palliative Care Approach and End-of-Life

FACT SHEET | WWW.ALS.CA

ALS is a progressive and life-shortening neurodegenerative disease that does not yet have a cure. When caring for you, your healthcare team will strive to maximize quality of life from the time you are diagnosed, all the way through to the end-of-life.

People with ALS are faced with many choices that will influence the course of their illness and the type of death they experience. Choices about symptom management, feeding, and ventilation devices can all help a person with ALS to have a dignified death. Early discussion and planning for the end-of-life stage of ALS can help ensure your wishes are respected as much as possible. Communication can often be maintained, using eye-pointing to answer closed-ended questions.

People with ALS have the right to a peaceful, dignified death, and to know and understand advance care planning and end-of-life options. Your healthcare team will support and respect your decisions about your life, body, and death based on your preferences, values and beliefs.

A skilled healthcare team, along with modern medicine can offer excellent pain and symptom management during the end-of-life stage of ALS. Most people with ALS experience a peaceful death.

During the end-of-life stage, healthcare providers aim to provide good symptom control of pain, breathing, swallowing, drooling, anxiety, depression, bowel and bladder function, all of which can help improve quality of life and minimize suffering.

WHAT ARE PALLIATIVE CARE AND END-OF-LIFE CARE?

Palliative care provides comfort and aims to relieve distress for someone with a life-shortening illness, such as ALS. Palliative care is provided by a team of doctors, nurses and other specially trained people who work with you, your family and your other doctors to provide specialized support. Many people think that palliative care is only offered in the end stages of life. When they are introduced to a palliative care team, they may worry that it signals it is the end of their life. A palliative care approach can be introduced and applied early in the disease trajectory and delivered alongside active management of your ALS.

Palliative care includes managing pain and other symptoms as well as helping with emotional, psychological, and spiritual needs. The quality of life of the person with ALS is maintained by looking after the wellbeing of both the individual and their family. Studies have shown that early palliative care contributes to

increased quality of life and some studies have shown that it may prolong life.

End-of-life care addresses the needs of anyone in the final stage of life, providing support to help them live as long as possible, as comfortably as possible and to die with dignity. End-of-life care includes palliative care and can be provided at home, in a hospice, hospital and long-term care home.

HOW DO PEOPLE DIE OF ALS?

Some people with ALS worry about death from choking. It is important to know that this kind of death is very rare among people with ALS. People with ALS typically die of respiratory failure following infection. This can be a difficult thought to contend with, but it may be helpful to know that healthcare providers are able to offer excellent management of shortness of breath, pain, anxiety, or other forms of distress.

In the end-of-life stage, healthcare teams typically use opioid medications to manage pain and dyspnea (difficulty breathing). These medications very effectively reduce the sensation of shortness of breath and choking. They do not speed up death.

One study found that between 88 and 98% of people with ALS die peacefully. A peaceful death was defined as the kind of death they would have chosen if they had the choice.

CHOICES

People with ALS have the right to a dignified death that unfolds according to their own wishes as much as possible. Many of the choices a person makes throughout the course of the illness can affect the end-of-life stage.

Respiratory support

As ALS progresses, the muscles responsible for breathing weaken, which makes breathing more difficult. People with ALS can choose between non-invasive (BiPAP) and invasive ventilation (tracheostomy and ventilator), which may help to prolong life and are intended to improve quality of life.

Feeding support

Bulbar symptoms which affect a person's ability to swallow may make eating food a challenge. People with ALS may choose to have a feeding tube inserted. Some people with ALS choose not to have a feeding tube as it may not align with their goals of care.

Advance care planning

Advance Care Planning (ACP) is a process that enables individuals to make plans about their future healthcare. Advance care plans provide direction to healthcare professionals when a person is not in a position to make or communicate their own healthcare choices. This may include writing down your wishes or can also just involve speaking to your family, friends, or loved ones about your values and wishes around your healthcare decisions. This does not need to be a legal document.

The important part of ACP is that you think about how you want your healthcare to unfold and that you communicate this openly with the individuals involved in your care and your support.

It is very important that you begin these conversations in the early stages of your disease. If you wait until the

end stages of your disease you may have more trouble communicating your wishes and a sudden health event may rob you of the chance to have these discussions. Participating in ACP will help you feel a sense of control and can ultimately contribute to an end-of-life experience that respects your wishes.

An excellent resource on advance care planning is the My Speak Up Plan, www.AdvanceCarePlanning.ca/.

DISCUSSING END-OF-LIFE

Talking about end-of-life is difficult. Most people do not like to think about the prospect of death. It can make you and others feel uncomfortable. You might worry that the discussion will upset your loved ones and they might worry that it will upset you too. But planning and talking in advance means that when someone is faced with difficult decisions on your behalf, they will know what you would want them to say about your care and what your instructions would have been.

It is important for all of the important people in your life to be aware of your wishes. It is quite common for families to experience significant conflict when some members are left out of these discussions and or don't agree with decisions made on your behalf. This may be avoided if you share your values and wishes with all the people most affected by your end-of-life decisions.

Here are some suggestions for having these discussions with your family.

- Consider talking to one or two people at a time, instead of a large group.
- Find a quiet place to talk, and make sure there is enough time for the discussion.
- Make a list of the topics you want to discuss so you don't forget anything.
- There is a great resource called Go Wish, a card game activity that helps make it easier to talk about what is important to you. You can find this at www.gowish.org.
- It may help to begin the conversation by discussing one aspect of the end-of-life, such as what music or flowers you would like at your funeral. You can expand the conversation from there.
- You could also discuss what information you and your caregivers/Substitute Decision Maker will need to make decisions.
- It can help to revisit the topic once you have enough information and are closer to making decisions.

There are two ways people are selected to represent you when you are unable to represent yourself:

1. Your substitute decision maker, or SDM, is the person who is entitled by law to make health decisions on your behalf should you be incapable (and only when you are incapable and not before). In most provinces there is a formal SDM hierarchy that determines who will make decisions on your behalf if you have not specifically identified someone by completing a document naming them your Power of Attorney (POA).
2. You can select the person whom you would want to speak on your behalf should you be incapable, your Power of Attorney (POA) for Personal Care, using a form which is available online. Whenever possible be open and clear with everyone about whom you have chosen as your POA, be sure to discuss your wishes and values with your POA and ensure that the individual is prepared to carry out your wishes.

MEDICAL ASSISTANCE IN DYING (MAiD)

Medical assistance in dying (MAiD) is a difficult topic that can bring up a lot of different reactions among people affected by ALS. Some people feel strongly that people with ALS should have access to MAiD, while others feel it puts pressure on people with ALS to choose the option. A person's religious and spiritual beliefs often factor into how they feel about the issue.

In 2016, the Supreme Court of Canada ruled to make MAiD legal in Canada. This means that people with ALS have access to MAiD, should they wish to pursue it. People with ALS can access both palliative care and MAiD.

People must be evaluated by two healthcare professionals to ensure eligibility. MAiD legislation in

ADDITIONAL RESOURCES

[Advance care planning in Canada](#)
[Physician-assisted death](#)
[Supreme court of Canada ruling](#)

[Promoting excellent in end-of-life care in ALS](#)
[End-of-life management in patients with ALS](#)
[A guide to ALS patient care for primary care physicians](#)

[ALS fact sheets](#)
[A guide to ALS](#)

Canada contains a number of safeguards to protect vulnerable persons from pressure to end their lives.

Canadians living with ALS can find province-specific information about MAiD laws and regulations on the following [website](#).

If MAiD is something you want more information about ask your healthcare team to connect you with the right people.

HOW TO GET SUPPORT

It can be challenging to have to think about the end of your life, or of a loved one's life. The ALS Society of Canada is here to help. We can connect you to support groups, where you can discuss these aspects of the disease with others who understand.

SUMMARY

- People with ALS are supported from diagnosis to end-of-life, with the goal of maintaining a good quality of life.
- A palliative care approach can provide comfort and support physical, emotional, psychological and spiritual needs.
- People with ALS have the right to a peaceful, dignified death, and to feel that they have choices leading up to it.
- Most people with ALS die of respiratory failure following an infection.
- Advance care planning is an important process for people to discuss their wishes about how they would like their end-of-life to unfold. It is important for people in your life to know what your values and wishes are.

KNOW THAT WE ARE HERE TO HELP | For people and families living with ALS in Ontario, ALS Canada can assist in connecting you to support services, equipment, and ALS clinics. Whether you are a person living with ALS, a family member or a caregiver, we will strive to support you along this journey. If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region. Learn more at www.als.ca.

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