

PALLIATIVE CARE AND END-OF-LIFE PLANNING IN ALS

ALS is a progressive and fatal 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 until end-of-life.

People with ALS are faced with many choices that will influence the course of their illness. You will be able to make decisions about symptom management throughout your illness. Early discussion and advance care planning can help ensure your wishes are respected. Communication can often be maintained, using a variety of methods and devices.

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 can be expected to support and respect your decisions about your life, body, and death based on your preferences, values and beliefs.

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



What is palliative care?

Palliative care is an approach to care aimed at optimizing quality of life for people facing life-threatening illness such as ALS. It treats physical symptoms in order to reduce discomfort and distress and provides support for the psychosocial and spiritual needs of patients and their families. Palliative care is provided by a team of doctors, nurses and other healthcare providers 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 and worry that it signals that end of life is near. However, a palliative care approach can be introduced and applied early in the disease trajectory and delivered alongside active management of your ALS.



What is end-of-life care?

End-of-life care addresses the needs of anyone in the final stage of life, providing support to help them live as comfortably as possible and to die with dignity. End-of-life care includes palliative care and can be provided at home or in a hospice, hospital or 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. It may be helpful to know that healthcare providers are able to offer symptom management in order to minimize discomfort and distress.

At end-of-life, healthcare teams typically use 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.



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 able to make or communicate their own healthcare choices. This may include writing down your wishes or simply speaking to your family, friends, or loved ones about 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 often recommended that people with ALS begin these conversations early. If you wait until later in your disease progression you may have more trouble communicating your wishes and a sudden health event may prevent you from having adequate time to make decisions.

You might worry that this discussion will be upsetting for you or your loved ones. But planning and discussing your wishes in advance means that your family and healthcare team know what you would want them to say about your care and be able to carry out your wishes. 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, [AdvanceCarePlanning.ca](https://www.advancecareplanning.ca)

WHO CAN MAKE DECISIONS ABOUT YOUR CARE?

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 Ontario 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, through a legal representative, or by 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)

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 must be evaluated by two healthcare professionals to ensure eligibility.



Canadians living with ALS can find province-specific information about MAiD laws and regulations at <http://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>

If MAiD is something you want more information about, ask your healthcare team to refer you to a specialist.

KNOW THAT WE ARE HERE TO HELP

The ALS Society of Canada can assist in connecting people and families living with ALS in Ontario to support services, equipment, and ALS clinics. We also invest in the most promising Canadian ALS research, advocate federally and provincially for the needs of people affected by ALS, and provide information to empower Canadians affected by the disease. Learn more at www.als.ca where you can also find more resources in the “What is ALS?” section.

If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region.

References

- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5027804/>
- <https://www.justice.gc.ca/eng/cj-jp/ad-am/scc-csc.html>
- <https://www.tandfonline.com/doi/abs/10.1080/14660820510028647>
- <https://www.sciencedirect.com/science/article/abs/pii/S1474442214702212>
- <https://www.gowish.org>
- <https://www.dyingwithdignity.ca>

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