



ALS and the treatment landscape

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ALS is a progressive, terminal disease that does not have a cure. While treatments exist, most focus on symptom relief and do not significantly alter the progression of the disease. However, researchers are working every day to uncover new potential treatments for ALS.

There is a lot of information and misinformation out there about treatments for ALS. It is therefore important to educate yourself about valid treatment options.

WHAT ARE APPROVED TREATMENTS FOR ALS?

There are currently two Health Canada-approved treatments for ALS:

- Riluzole is marketed under the brand name Rilutek® and is also available as a generic. It has been shown in clinical trials to increase survival by approximately 6 – 19 months.¹
- Edaravone marketed under the brand name Radicava® was approved in 2018. It has been shown to slow disease progression among certain people early in their ALS progression. Additional data is being collected to better understand its effect in the wider ALS population.

All other treatments target a person's symptoms and try to help them live more comfortably with the disease. Doctors may prescribe other medications and therapies to help treat symptoms of ALS. These include pain medications to treat pain, antidepressants to help with the emotional aspects of living with ALS, Nuedexta® to treat pseudobulbar affect, and physical therapy to maximize existing capabilities and prevent further loss of motion or prevent pain that may develop from stiff joints.

WHAT ARE COMPLEMENTARY THERAPIES?

The term “complementary therapies” describes a variety of non-medical treatments that are used in combination with conventional medicine in a holistic approach involving body, mind, and spirit that attempts to heal or to relieve the symptoms of disease. These therapies are typically

designed to help patients cope with symptoms and live better with the disease. These therapies are not aimed at affecting disease progression.

Complementary therapies include aromatherapy, acupuncture, massage therapy, and meditation.

Aromatherapy is the use of essential oils to promote health and wellbeing. Certain scents are thought to evoke different sensations, which may prove beneficial to the recipient.

Acupuncture is an ancient Chinese medical technique of inserting and manipulating thin needles through the skin at specific points of the body to promote healing. Many studies have shown that acupuncture has an apparent beneficial effect on the human body, but none have definitively explained how it works. Health conditions that affect the muscles often respond well to acupuncture, as do pain, itching, constipation, fatigue, anxiety, and depression.²

Massage is a physical therapy that applies pressure to the soft tissues of the body, including muscles, connective tissue, tendons, ligaments, and joints. Massage can help relieve psychological stress, manage pain, improve circulation and relieve tension.

Meditation is a mind-body technique used to enhance relaxation and awareness. Meditation often uses the act of breathing as an anchor to the present moment. The benefits include relaxation, feelings of wellbeing, a clear mind, and an elevated mood.

WHAT ABOUT STEM CELL THERAPY?

Stem cells represent only one type of treatment in a vast array of clinical trials aimed at slowing ALS disease progression. None of the clinical trials are aimed at using stem cells to replace motor neurons and recover function, but rather to use them as a means of delivering support to degenerating motor neurons. As such, there is cautious optimism that stem cell therapies could have some effect on ALS, but not more than exists with other experimental treatments.^{3,4}

There are some private clinics in Canada and around the world that offer people the opportunity to pay for stem cell therapy as a treatment for ALS and other diseases or health conditions. Health Canada has issued an advisory to Canadians clarifying that with a few exceptions, stem cell therapies are still experimental and can be administered only by health care practitioners who are conducting clinical trials authorized by Health Canada.⁵ Private clinics offering stem cell therapies as approved treatments for ALS should be approached with caution. When in doubt, ask your ALS clinician for guidance.

HOW ABOUT VITAMINS AND SUPPLEMENTS?

Some vitamins and supplements may contribute to living well with ALS, but none are proven to affect the disease progression. Many people with ALS find certain vitamins and supplements increase their quality of life or help control symptoms. Speak to your ALS clinician to understand what may or may not be best for you.

HOW CAN I FIND GOOD INFORMATION ABOUT THE NEWEST THERAPIES?

It is important to have a critical eye when reading news articles about ALS, especially on the internet. If you would like more information about something you've seen in the news, you can contact your ALS clinician or the ALS Canada Research Team.

REFERENCES AND ADDITIONAL RESOURCES

[1 Real-world evidence of riluzole effectiveness in treating amyotrophic lateral sclerosis](#)

[2 ALSUntangled No. 28: Acupuncture](#)

[3 ALSUntangled 56: "ten red flags"-things to be wary of in alternative or off-label products](#)

[4 Complications from "Stem Cell Tourism" in Neurology](#)

The global ALS community is a small but dedicated group that keeps up to date on developments in ALS research. The global ALS community communicates frequently through scientific meetings, the internet (e.g. www.clinicaltrials.gov), and newsletters.

ALS Untangled is an initiative promoting information and patient safety surrounding treatments for ALS. On the ALS Untangled Twitter page, ALS patients can ask questions and receive answers about alternative, or off-label therapies for ALS.

The ALS Society of Canada also maintains an informative, engaging website and blog covering the latest ALS research as well as other topics relevant to people affected by ALS in addition to webinars focussed on the latest therapies. You can also follow us on social media for the latest news on ALS research.

SUMMARY

- There is currently no cure for ALS, but researchers are working every day to uncover new treatments and therapies.
- There are two treatments for ALS that have been approved by Health Canada: Rilutek (riluzole) and Radicava (edaravone).
- Alternative and complementary therapies, including the use of vitamins and supplements, acupuncture, aromatherapy, meditation, and massage, can be effective at improving quality of life among people living with ALS.
- There is a lot of misinformation about ALS available on the internet. Before starting any new treatment or therapy, it is always a good idea to speak with your doctor.

[5 Health Canada is advising Canadians about the potential health risks associated with unauthorized cell therapy treatments such as stem cell therapy](#)

[Stem therapy for ALS: hope and reality](#)

[Phase II trial of CoQ10 for ALS finds insufficient evidence to justify phase III](#)

[Creatine monohydrate in ALS: Effects on strength, fatigue, respiratory status and ALSFRS](#)

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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Special thanks to everyone who helped write and review this fact sheet.

* Last updated 10/2020