

KNOWLEDGE IS POWER...

PALLIATIVE CARE AND ALS

We often think of palliative care as the end of life where those nearing death can be admitted to die peacefully, surrounded by loved ones, rather than dying at home.

This may be Palliative Care for some, but it can be so much more. The World Health Organization (WHO) defines Palliative Care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care can be initiated early in the course of an illness, while people are still being actively treated. To quote the WHO, "palliative care is not passive care. It does not ask patients to give up on care. It is not reserved only for the imminently dying...."

Palliative Care can start soon after diagnosis. In fact, the earlier you start Palliative Care, the better. To access Palliative Care does NOT mean that you have given up. There is a distinct difference between Palliative Care and Hospice Care*. You can receive Palliative Care while you are still receiving treatment or actively searching for a cure for your illness.

So if Palliative Care is not for those facing imminent death, what can it offer you, the person (and family) diagnosed with ALS? Why sign up for yet another healthcare team? So, here are a few reasons why you should consider a referral to Palliative Care earlier rather than later.

Palliative Care may include:

- Help with decision making around treatment options
- Expert medical assistance to help with pain and other symptom control at home or in hospital
- Social, psychological, emotional and spiritual support
- Occupational therapy, physiotherapy and social work
- Support for family, friends and caregivers
- Information about financial, legal and other services
- End of Life care
- Bereavement Support

Palliative Care does not need to be provided by a team that only becomes involved at end of life. It is best provided by people who know you best, working together with experts when needed.

NEW BRUNSWICK

Palliative Care can be provided in different settings in New Brunswick, including a clinic or doctor's office, person's home, hospital, nursing home, special care home or at a hospice.

To access Palliative Care in New Brunswick, speak with your family physician or nurse practitioner, or contact the Extra-Mural Program Care Coordination Centre at the toll-free number 1-844-982-367.

All hospitals offer Palliative Care, including end-of-life care. Contact your doctor about accessing Palliative Care in a hospital. For residents of special care homes or adult residential facilities, Palliative Care can be supported by the New Brunswick Extra-Mural Program in this setting.

NOVA SCOTIA

To access Palliative Care in the province of Nova Scotia, call 1-800-225-7225. A Care Coordinator will set up an in home visit to complete an assessment. If you already have a Care Coordinator, talk to them about accessing this service. It is important to note that services may vary between NSH Zones within the province.

Remember that Palliative Care is not the same as Hospice Care. A Hospice is a special facility for persons for whom death is imminent. Hospice Care is for people who are nearing the end of life. The services are provided by a team of health care professionals who maximize comfort for a person who is terminally ill by reducing pain and addressing physical, psychological, social and spiritual needs. To help families, hospice care also provides counseling, respite care and practical support.

Unlike other medical care, the focus of Hospice Care isn't to cure the underlying disease. The goal is to support the highest quality of life possible for whatever time remains.