

THE ILC FOUNDATION

Chronic Pain 🍁 Ehlers Danlos 🍁 HCTD

Hosting The Canadian Ehlers Danlos Syndromes Conference since 2013



How is it possible in 2022 that an entire population of primarily the female gender with Ehlers Danlos Syndromes continues to be ignored and MAiD is now a replacement for healthcare?

December 10, 2022

In response to: <https://www.who.int/activities/global-report-on-health-equity-for-persons-with-disabilities>

Letter to the Editor:

As the charity that has been working with the Ontario Ministry of Health (2012 to present) on the inequities of healthcare, of the one-in-five children and families with chronic pain and the one-in-three-hundred people with Ehlers Danlos Syndromes (EDS), we are overwhelmed with outcries for support due to the amount of media coverage on the use of Medical Assistance in Dying (MAiD).

Canadians living with EDS and heritable connective tissue disorders are affected by multiple comorbid conditions, such as cranial cervical instability (CCI), Chiari malformation, atlantoaxial instability (AAI), cranial settling and basilar invagination resulting in a variety of life-threatening symptoms. Specialists tell patients with these conditions that they need immediate surgery, but this country has no access to neurosurgery. From cases recently reported on in the media, there seems to be an overrepresentation of those suffering from EDS and related comorbidities (such as Postural Orthostatic Tachycardia Syndrome [POTS], Mast Cell Activation Syndrome [MCAS], Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) to name a few). While this has been shocking to watch unfold, at the same time, it is not surprising to organizations such as TheILC that support the EDS patient population.

The longstanding lack of neurosurgical and other care in Ontario has left many patients with no options for treatment within their province or country. This lack of healthcare forces those who can afford it to travel and leave the country for care; there are often no treatment options for those who cannot. Individual self-advocacy stories shared with TheILC, and the Ministry of Health highlighted the lack of access to specialized healthcare, including neurosurgery. These lived experiences describe neurosurgeons, saying, *"until the Ontario Spine Program addresses how EDS patients are going to be cared for, they are not able to offer the neurosurgical treatments that would help them have improved quality of life."*

After twelve years of advocating for and delivering healthcare education about the needs that EDS patients require, deplorably, there remains a lack of access; this has led to family physicians offering Medical Assistance in Dying (MAiD).

The criteria stated for eligibility for MAiD on the Government of Canada website include "experience unbearable physical or mental suffering from your illness, disease, disability or state of decline that **cannot** be relieved under conditions that you consider acceptable." It is unclear that the stated eligibility criteria concerning "**cannot** be relieved under conditions that you consider acceptable" has been met in many of these cases.

It seems that certain conditions would have been acceptable, which would have changed people's minds had the care and support been available. Our patient population also faces a lack of pain management and the financial burden of treatments when and if they can get access. In Ontario, OHIP covers some costs, but most modalities require payment over and above OHIP. If ineligible for private insurance, the cost of these treatments makes them out of reach for most. For those receiving disability support, these treatments are unobtainable. For example, recently, Ketamine Infusions, a beneficial treatment for Neurological pain that EDS patients suffer, are no longer universally covered by OHIP. Clinics are now charging between \$600-1,200 per treatment, forcing many patients who can no longer afford these monthly treatments to suffer from debilitating, severe nerve pain, leaving them unable to function and even bedridden (one patient reports that her care costs for 2022 will be **\$30K**).

In the case of EDS patients, acceptable conditions would include access to trained healthcare professionals that are as skilled and knowledgeable about treating EDS as they are about other patient populations, whether it be cancer, Parkinson's, or MS. MAiD is intended to end needless suffering due to a "grievous and irremediable medical condition."

TheILC Charitable Foundation provides resources to help people cope with what is known and not known by hosting The Canadian Ehlers Danlos Syndromes Conferences (since 2013), which has educated the patient population and medical professionals.

Through the experiences of the population we serve, we know that having timely access to trained neurosurgeons with the skills to address the issues that happen when a patient has weak connective tissues can result in the prevention, or the correction of, severe symptoms. Surgeries of any kind aim to preserve and improve quality of life and prevent unnecessary hospitalizations in advancing disease. By doing that, the healthcare system can relieve the burden in emergency departments and hospitals.

As a charity, we see the daily disparities in individual health and health care in a patient population composed primarily of women with EDS. For example, family physicians are challenged to refer these patients to neurologists or neurosurgeons because these practitioner groups and hospitals refuse to accept EDS patients. These specialists and hospitals do not want to absorb the costs of caring for EDS patients' complex, chronic health problems. Yes, Ontario does have an EDS Clinic, but this has only added another roadblock to care. These severe barriers to accessing care are causing increased disability.

Canada can no longer afford to sacrifice a significant portion of its citizenry for inadequate, substandard access to health care. For all the scientific and technological innovations that represent the best attributes of the Canadian healthcare system, there is a consensus that the system is broken, is not improving, and is hurting the rising number of people who cannot gain consistent access to its services. This lack of access is increasing health and healthcare disparities, as well as healthcare costs.

In the recently publicized case of Jennyfer Hatch, the National Post reported that after her EDS diagnosis ten years ago, Jennyfer's treatment had primarily consisted of a chaotic and ineffective stream of specialist appointments, none of whom had any background in her condition. An extract of the MAiD approval issued to her stated, "There were no other treatment recommendations or interventions that were suitable to the patient's needs or her financial constraints." The article highlights Jennyfer's wish to live and that her decision to end her life was largely influenced by her inability to obtain medical care. As we supposedly live in a country with universal health care, it is unsettling to see the term "financial constraints" used in this context. The strength that Jennyfer, as a 37-year-old woman, has portrayed is admirable and respected, but we have seen many patients living with EDS dismissed in the current healthcare system, where the offering of MAiD is the only option.

The social determinants of health, such as housing, mental health, community support, financial resources, education, equality, inclusivity, and diversity, impact the vulnerability of the EDS population; and the isolation experienced by this population has been further affected by COVID. These challenges are exacerbated by the side effects of many medications prescribed, which can increase depression and cause suicidal ideation. Living with chronic pain with little care and being offered MAiD becomes an option not otherwise considered. MAiD was not intended, and should not be used, to end life in cases where the major contributing factors to an individual's decision to use it are socioeconomic or due to lack of care options and treatments that one could or should reasonably expect to be available and are open to managing other conditions of comparable complexity. The data on the healthcare costs for EDS patient care are available in other countries, for example, in the USA, Spain, and India, but are not tracked nor available in Canada. Without this valuable data, how can funding be adequately allocated for research and improving clinical care?

In our meetings with the Ontario Ministry of Health and patient letters to MPPs, we have asked for legislation to be created with policies that support mandating hospitals, neurosurgeons, and multidisciplinary specialists to meet the comprehensive care requirements of these patients.

MAiD is not healthcare.

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