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As a rehabilitation specialist physician, I have 23 years of clinical and research experience with people with spinal cord injury who I follow from acute care, through rehab, transition to community, and lifelong follow up to manage symptoms and prevent complications, to help improve quality of life. Most people with SCI live for years, some up to normal life expectancy. My concern with MAID since bill C7 has passed is the removal of the criteria that one is expected to die in the foreseeable future. So, people with a new, severe neurologic disability are now able to ask to end their life after only 3 months.

Imagine this: waking up after a severe car accident for example, learning you have a spinal cord injury and not being able to move your legs, and maybe not even your arms. Many of you may think "wow I wouldn't want to keep on living if I was like that." And yes, that is what many people with new spinal cord injury think in the early months. Many of the acute care health care providers that person meets early on may have the same viewpoint, not having ever cared for someone with a significant neurologic disability living a full life in the community. Many of their friends and family might also have the preconceived view that their loved one won't have much of a life going forward. The person with new SCI will spend many months in hospital, between acute and rehab care, and in the first few years will still be adjusting to their new life. In those early months, even years, suicidal thoughts and wishes to die are held by many – people can go through some very dark times after SCI. However, I can verify from my group's research, the current evidence and my clinical experience, that most people who have chronic SCI, that is, at least a few years, rate their quality of life as very good, equivalent or better than those that are able bodied. In a research paper I recently published with colleagues (Tchajkova et al.), it was found that most people with chronic spinal cord injury admit that early after their injury they had a wish to die. But all of the people we interviewed declared they no longer wished to die and would not accept MAID after they adjusted and had lived real life experiences with their SCI, and they were in agreement that offering MAID early after SCI was wrong, that a person in the early months could not make an informed choice on whether they should die as they had not at that point lived the life experience with a spinal cord injury. Literature supports this applies to others with new neurologic disabilities such as stroke, and that people really cannot adjust to their "new normal" for at least 2 years. (Kishi et al.)

I do not believe that people with a new, severe, neurologic disability such as spinal cord injury will have the ability to make this informed choice until they have had the opportunity to have lived with their new impairments and disabilities, reintegrate into the community, and realize the excellent quality of life that is experienced by most with such disabilities.

I want to tell you about a story, reflective of many scenarios I have witnessed. I was asked to see a young man in intensive care. He was on a ventilator and had a high spinal cord injury. I was asked to discuss prognosis. Patient and mom were so relieved when I reported that he had a chance of getting significant improvement based on my neurologic exam. Mom came to me crying and reporting to me that the ICU MD was advising them they should turn off the ventilator, that his life would be terrible and not worth living. I went back to my clinic where I was seeing a patient who had a high SCI years before. He had little use of his arms and no use of his legs. He was very happy to report to me that his job was going very well, he had married the year before, and was expecting his first child! And guess what? that young man in the ICU? About 4-5 months later, he walked out of the rehab to go home! My point is not to suggest that many people get such excellent recovery, but rather to reinforce that we cannot let our preconceived notions of what we think life with a disability would be like to cloud our judgement or care decisions as we have not lived that life. MAID now being part of care choices early on in these times when a person is vulnerable, struggling to accept their new disability, before they realize what excellent QOL their future may hold, is a grave failure to those patients.

References

Kishi, Yasuhiro, Robert G. Robinson, and James T. Kosier. "Suicidal ideation among patients with acute life-threatening physical illness: patients with stroke, traumatic brain injury, myocardial infarction, and spinal cord injury." *Psychosomatics* 42.5 (2001): 382-390.

Tchajkova, Natalja, Karen Ethans, and Stephen D. Smith. "Inside the lived perspective of life after spinal cord injury: a qualitative study of the desire to live and not live, including with assisted dying." *Spinal Cord* 59.5 (2021): 485-492.