

**Ráiteas Oscailte don An Comhchoiste um Comhchoiste um Bás Cuidithe
Opening Statement to the Joint Committee on Assisted Dying**

October 17 2023

Dr Konia Trouton, Canada

Thank you for the opportunity to address you today. *Go raibh maith agat.*

My name is Konia Trouton. I'm a family physician and a Clinical Professor in the Department of Family Practice at UBC. I have worked in several provinces and territories in Canada and am cross appointed at the University of Victoria, University of Calgary and now live in Toronto. I hold a Master's of Public Health from Harvard and am a Fellow of the College of Family Physicians of Canada. I've been in practice for over 30 years, and involved in MAiD work since it was de-criminalized in Canada.

I am speaking to you today as co-founder and president of CAMAP- the Canadian Association of MAiD Assessors and Providers. CAMAP – Canadian Association of MAiD Assessors and Providers (camapcanada.ca). We are a charitable voluntary organization that supports the people who do this work. Our members are mainly nurse practitioners and physicians, but also includes nurses, care coordinators, social workers, researchers and pastoral care. We provide leadership on various educational initiatives and research and have recently launched the Canadian MAiD Curriculum to ensure a standardized and rigorous approach to assessments and provision of MAiD in Canada.

I hope to convey to you today that assessing and providing an assisted death is a humbling and intimate experience, that requires compassion, caution and diligence.

One of my more memorable patients died of motor neuron disease. He put in a request when he was diagnosed, and still living at home. According to the law, he had an independent person witness the government approved form, in which he personally attested to the criteria that he was informed of his incurable illness, that he was suffering intolerably and that he was in an advanced state of irreversible decline in capability. I met him alone in his home- and had to be sure that he was not coerced into signing the Request, and of having the private assessment with me. He described to me how he was an avid outdoorsman, used to trekking regularly and tenting in the hills. He said he noted foot drop, and clumsiness, leading to a series of medical tests. Within 6 months of his diagnosis, he was now wheelchair bound at home, and unable to hold a glass of water. He used the remote on his chair by flicking his wrist, as his fingers had lost any dexterity. A nurse came to help him in and out of bed, as his wife was unable to manage his weight alone. He needed help to toilet and was anticipating a feeding tube in the coming weeks, as chewing and swallowing a chicken dinner led to choking, spluttering and anxiety. His

respirologist had told him it was possible he may need breathing support in the months to come. He was sure he wanted to die at home, was sure he didn't want palliative care and would be in touch. I didn't hear from him for almost a year. At that point, I received a call from the Palliative Care Unit at the local hospital. He had been admitted a few weeks prior and was wanting an assisted death. I met with him again and was really shocked by the change. He had a tracheostomy and needed continuous breathing support. He was able to formulate only a few words at a time. He was confined to bed, and needed help to turn, and his wife and daughter were taking turns to be with him at all times, round the clock. He indicated that he wanted to have assistance to die in a few days- on his birthday, and with a blessing. When I asked what kind, he said to ask the spiritual care worker in the unit, with whom he had a good connection. In the months since I had seen him, his respirologist, who also knew him well, was his main clinician. He provided the second formal assessment for an assisted death, and encouraged him to seek palliative care. The palliative care physician was also involved, confirming that he consistently spoke of his request for an assisted death, and was accepting of the various measures that were in place to relieve his suffering. Both agreed that he maintained capacity and focus. I was able to engage the spiritual care worker, and he was blessed. The same day, I started the IV and with his wife and daughter present, he was able to say goodbye to both of them, knowing that he had explored life to the fullest, and tried his best to find solace in the palliative care services around him. He still wanted to be in charge, after having no say in the disease that took his life and independence.

What does this tell us about applying the law in Canada? An assisted death is requested by the patient, formally. It is not requested by a clinician, nor by the family. It is required that the assessment confirms that there is no coercion to make the request, and so part or all of each assessment needs to be done with the patient alone. And, an assessment cannot start until after the patient has put forward his or her request formally.

Next, it requires 2 separate and independent clinician assessments. I say clinician, because Canadian law allows for a nurse practitioner to provide one or both of the assessment and even to provide the assistance. Many of the clinicians who provide assistance in dying are not the treating clinician, but rather they are clinicians like me who care about choice, support autonomy and have added this to our other practice. The other assessment is commonly done by the one who knows them best- a family physician or a specialist. Between the assessments, however, the patient is generally looked after by others- whichever type of clinician is best suited to manage their needs and reduce suffering.

Third, it requires careful documentation. Those of us who do assessments and provide an assisted death must report this to our local health authority and to our federal government within 72 hours of the event. There is no exception. We must liaise with the pharmacy team who dispenses the medication and review our documentation with them before they release the medication. It's a carefully regulated process. If it's wrong, we risk discipline, court and jail time. If we get it

wrong, we can lose our license, our career and livelihood. We must prepare each case and each documentation as if we will be on trial.

Let me bring you another story. I was called recently to see a nurse who was diagnosed with metastatic lung cancer, following a thorough assessment and CT scans after a fall. She had worked in long term care for some years, and knew about MAiD but as a Catholic from the Philippines, was somewhat cautious about if and where it fit into health care. Once diagnosed with metastatic disease, she tried the chemotherapy that was recommended and hoped for the best. But she had a poor response, experienced many intolerable side effects, and continued to lose energy. Her tumor progressed through her bones and lesions were found in her brain. I was consulted by the palliative care physician, who was not able himself to assess her due to restrictive regulations at the facility. I was able to have a private consultation in the palliative care unit, which was lucky, as a transfer would have been very painful, and required medications to ease the discomfort of the journey. After a second visiting doctor also determined that she met the medico-legal criteria, she set a date. Because of the metastatic nature of the cancer, and the increasing narcotics for pain, I suggested she and I sign a waiver of advanced consent for that date in case of lost capacity. 3 days before the date, she called me. Her family was coming from overseas and she wanted a chance to say farewell and have a visit. We moved the date. A week later, I received another call with a similar request. More family was coming and she wanted another change. The waiver was no longer valid. I waited until she called again. And, to my surprise she did. She wanted a Monday morning, at a chapel, and wanted her family present. The facility that would not allow the assessment would also not allow the provision, so she was hooked up with sub-cutaneous (under the skin) infusion of medications for the 45 minute cross city journey to an apartment funded by a charitable organization. There, I was able to join her family in the Lord's prayer, and witness her final breaths as I administered the IV sequence of medications.

You will notice in this story that there are other elements about the MAiD legislation in Canada that are important. First, and most importantly, it is the patient/the person, someone we now call the Requestor, who directs everything. They can change their mind, they can opt out, they can cancel and they are in charge until the last minute.

Next, there is a possibility to integrate spiritual and religious beliefs and farewells into any event. Assisting death most often happens when there is an inevitable death. And death is both a natural event and a spiritual one. If a person believes in an afterlife, then meeting that next life with a blessing is still possible, even when there is assistance involved in the transition.

Thirdly, even those experienced in health care, those who have provided palliative care to others, may choose to have assistance to die. We cannot presume to know the mind, wishes, or dreams of another.

I'm not alone in finding this work professionally satisfying. Qualitative research studies and surveys have such findings. We are able to have intimate contact with patients and families, and bring an end to suffering while supporting the autonomy and choices of those I help.

What we are now working on, in our organization of CAMAP is to ensure a standardized approach to assessments and provisions across Canada. No clinician is required to do assessments or to provide assistance to die, but if they choose to do this work, it's important to be rigorous and consistent from one end of the country to the other. We have worked within the legislative framework of C14 since 2016, and under C7 since 2021, and throughout this journey, CAMAP has brought opportunities for networking for the professionals in our country who do the work of MAiD. We have established position papers and guidance documents. Over the last 2 years, we have developed a multi module comprehensive MAiD curriculum. To do this, we have engaged the input of all the national health care professional organizations, and representatives from the provinces and territories, because it is them who implement the services. The curriculum is completely accredited and requires 80 hours to complete all the modules.

To conclude, I'd like to leave you with the thought that there is a lot of distracting noise in some of the sensational headlines about MAiD in Canada. I believe it is done well, and it is done according to the law by hundreds of compassionate, careful and thorough clinicians.

References and resources:

- 1) CAMAP's website hosts a number of useful documents: [CAMAP Publications and Guidelines – CAMAP \(camapcanada.ca\)](#)
- 2) Beuthin R, Bruce A, Hopwood MC, Robertson WD, Bertoni K. Rediscovering the art of medicine, rewards, and risks: Physicians' experience of providing medical assistance in dying in Canada. 2020 SAGE Open Medicine Volume 8: 1–9 DOI: 10.1177/2050312120913452
- 3) An up to date and comprehensive listing of Publications on Canadian Experience with MAiD can be found here: [CANADIAN EXPERIENCE WITH MAID | Hemlock \(hemlockaid.ca\)](#)

Health Canada produces an annual report using the data submitted by assessors and providers. The report from 2022 data is expected in the coming weeks, which will identify any changes since Bill C7 [Third annual report on Medical Assistance in Dying in Canada 2021 - Canada.ca](#)

CAMAP

Canadian Association of MAID
Assessors and Providers

ACEPA

Association canadienne des évaluateurs
et prestataires de l'AMM



Konia Trouton
MD MPH FCFP
president@camapcanada.ca
tel: +1 250 661 0908