

I recently began a course on Health Ethics, Law, and Policy at Queen's University. In the first month of the course, we discussed decision-making towards the end of one's life. We focused on the ethical issues surrounding this process stemming from the varying beliefs between different patients, their families, and healthcare professionals. To highlight this topic on a personal level, I completed an advanced directive for myself and my partner, Chloe. The template we used can be found at [Speak Up Ontario](#).

Part 1

"What were my feelings when completing and then discussing the form?"

When trying to answer these questions, I felt slightly frustrated and confused. It was extremely difficult to articulate my generalized wishes for end-of-life care in a couple short sentences. There were so many passionate feelings stirring inside me and there was no way to explain my preferred outcome in every possible situation that might arise.

This was further complicated due to the nature of my work. Over the last decade, I have spent 7 years as an infantry soldier in the Canadian Army and 4 years as a Search and Rescue Technician in the Royal Canadian Air Force. The threat of death has been a real possibility throughout my entire career, and I had never put that much thought into "how I want to die." This gave the eloquently worded questions a lot more weight as I began to imagine how real their answers might be.

How did Chloe react to the process? What questions or comments did she have?

Similar feelings were both expressed and amplified by Chloe when we attempted to complete the advance directive for her. She had an extremely hard time wrapping her head around several of the questions and I was often met with blank stares as she tried to find the words to express her intentions. She answered the questions using specific examples of her loved ones who died which made the process even more emotional. She asked me several times to explain the questions and her lack of understanding of how the healthcare system and medical interventions worked became apparent.

How did I respond to those comments?

Throughout our discussion, I aimed to calmly encourage her answers without ever putting words in her mouth. On my end it was a mixed bag on consoling the resurfaced grief for lost relatives and attempting to objectively explain the level of detail required by the questions. I tried to emulate the approach that I thought a doctor might take when having these conversations with their patients.

Do I think this experience was typical of discussions about end-of-life issues? Why?

Personally, I think this is an extremely typical example of conversations surrounding end-of-life issues. Most people, like Chloe, are not medical professionals and probably haven't given much informed thought towards the idea of how they want to die. While they might have a vague understanding of some things they want, they might not have clearly defined, well articulated wishes. This can make conversations with relatives or physicians confusing, overwhelming, and even convoluted.

Part 2

What are the benefits and limitations of the form?

This form asks open-ended questions, allowing an individual to formulate their wishes void of medical terminology. It allows individuals to walk through some difficult questions in a stepwise manner. It is fairly exhaustive including an area for individuals to add any other information they feel might not have been captured by the questions. One of the limitations can come from the examples it gives. While the examples can further explain the questions, they can also guide the response of the individual. Sometimes it's hard to truly explore your own thoughts and feelings when a specific prompt is provided. Another limitation is that it would be difficult for an individual without much medical knowledge (like Chloe) to complete on their own.

How understandable was the form to Chloe and I? How effective would the form be in different situations and for different people?

Although my education in the health sciences and my employment within the healthcare system allowed me to understand the form more easily, Chloe struggled to understand what some of the questions were asking her. I think the most effective use of a form like this would be its administration by a healthcare professional who could help clarify the questions. They would also be able to explain any in-depth medical procedures that the general population might not fully understand. Additionally, an informed individual might also be able to provide context to the questions or guide the individual down paths they may not initially consider relevant.

Does the framework of the form promote or confine free expression of preferences?

This semi-structured form has open-ended questions that promote free expression and allow the individual to discuss anything they deem relevant. The last section amplifies this by allowing individuals to include anything that they think may not have been captured by the previous questions. Although this form would be more easily completed

with an understanding of the various medical procedures, it's allowance for individuals to answer the questions in their own words encourages the autonomy outlined in the Health Care Consent Act. At the very least, it highlights the importance of having these conversations with a healthcare provider. This way, we can get back to doing the things we love with confidence that we will be taken care of in the way we deem best.

– Michael

References

Health Care Consent Act. (1996). Ontario. <https://www.ontario.ca/laws/statute/96h02>

Queen's University. (2021). BMED 373 – Health Ethics, Law, and Policy

Speak Up. (2021). Advance Care Planning Workbook – Ontario Edition | Speak Up Ontario. <https://www.advancecareplanning.ca/my-plan/>