



# Palliative care and legacy creation

A medical student's journey in understanding death.

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**A**s the global COVID-19 death toll hits a new high every day, our hearts sink together with those of the families and friends of the deceased. For most of us, thinking about death is not a daily practice. It is in times like this that the thought of death could strike us as we watch the grief and pain behind each addition to the death toll. I remember receiving news about my aunt's cancer prognosis a few years ago and how shocked I was, for the first time, at the thought of someone close to me dying. Death is such a taboo topic and it is feared in many cultures. In my culture, talking

about death is considered ominous and it is avoided whenever possible. No one in my family talked about what dying entails, even when one of our own was reaching the end of life. Eager to understand death, I started my own journey of exploration by participating in palliative care and legacy creation.

I was nervous when I started volunteering at the palliative care unit in a hospital. What if the people there cry? What if I can't control my emotions? What if someone dies in front of me? The list of what-ifs was endless. Nevertheless, I walked into the unit and started talking to

patients and their families. After a while, I was surprised to discover that I actually felt at peace. It was calming on the ward, almost as if I had unloaded the burden I carried. But I couldn't name what it was about the ward, the patients, and their families that calmed me down.

During my time there I befriended many patients and their families. Some patients passed away before I got to know them, and some I got to know very well. It was never easy to learn about a patient's death, but as time went on, I found myself feeling relieved when I knew that a patient spent their last moments with dignity, great care, and no pain. I learned how a holistic approach to care near the end of life could benefit patients and families and noticed a shift in my perception of death. It was no longer a scary and unknown concept but rather a normal part of life. The volunteering experience sparked my interest in the field. During medical school I was fortunate to have the opportunity to work on a palliative care project, the Legacy Project, through UBC. This project involved pairing a medical student with a patient at the end of their life to create an item of the patient's discretion that would be left behind for their loved ones.

I first met Ms Betty Bains\* through her counselor, who introduced her to the program. "I was diagnosed with an incurable disease and I just don't know how much time I have," she told me. Betty has many children and grandchildren, and they are the reason for her participation in the Legacy Project. She loved the idea of leaving something meaningful behind for them. While talking to Betty and getting to know her more, I felt fortunate to be able to participate in the creation of her legacy. I was about to enter a vulnerable space to learn about her life, values, hardships, and wishes for her loved ones. It was a privilege to have such an opportunity.

We decided to create a video and use questions from the RecordMeNow app ([www.recordmenow.org](http://www.recordmenow.org)) to guide us. RecordMeNow is a free application that allows people to create a lasting video legacy and has approximately 40 questions to help create a legacy. The creator of the RecordMeNow app, Gaby Eirew, surveyed 100 people who were younger than 16 years of age when their parents died to find out what questions they wish their parents could have

answered for them. The app was built around these questions. We thought it was a good place to start as Betty's main audience to her legacy would be her children and grandchildren.

We worked together on the recording over a couple of weeks. I learned about where Betty grew up, her childhood stories, the most romantic date with her spouse, and some of their favorite family recipes. Then, I watched her talk about her diagnosis, her struggles, and how she coped with them. As we got to the final phase of recording, the questions became more difficult to answer. "What's your advice for your children about living after you die?" I asked after returning to meet with her for our last recording session.

"Be strong," she said. "Lean on each other for support . . . and try to be happy when finally the pain of it goes away." I could see that Betty was trying hard to hold back her tears and started getting choked up. I passed some tissues to her while she said to me, "Just as a parent, I just wish that they never, never, never, ever have to go through anything like that . . . but unfortunately, it's part of it . . . I hope doing this helps."

After we finished recording, I edited the plethora of content we generated to create a video full of Betty's stories, thoughts, values, and wisdom. We then watched the final product together. "I feel like I have no regrets and I can just go anytime now. I have said everything I wanted in there," Betty said to me after we finished watching the video. It was one of the most satisfying and meaningful moments I have ever experienced.

My aunt lost her battle to cancer in February of this year, right when the world was starting to see an increasing number of fatalities due to COVID-19. I wonder if it would have been easier for her, or if it would at least have relieved some of the pain that my family had to go through, if she had created a legacy item like Betty's. I wonder how my aunt would have reminisced about her life while going through this process and if it would have brought her

more peace at the end of life. Similarly, for those who unexpectedly lost their lives due to COVID-19, I wonder how many of them had opportunities to say goodbye to their loved ones and to say what they needed to say to leave the world with no regrets.

Finally, I started to understand the peace I felt on the palliative care unit when I volunteered there. It came from the collective awareness of our final destination—death. No matter who we are, where we are from, or what titles we hold, we can rest assured that our final stop will be the same. Death is inevitable and unpredictable. No one can hold onto the gift of life forever, and no one knows when death will knock on their door. Who could

have known that a viral illness would change how our world operates and take away over 800 000 lives globally (as of August 2020) in merely a few months?

*Shanzhong* is a concept in Chinese culture that praises an ideal death. It is about coming to wholeness, and it is what people wish for their loved ones at the end of life. We often talk about living a good life, but how do we die a good death? While the idea of a good death may be different to different people, some commonalities exist regardless of someone's cultural background. Love, acceptance, peace, dignity, and comfort are just some of the things that both the living and the dying strive for. Perhaps living a good life and dying a good death are really two sides of the same coin. Dying a good death starts while we are still alive. ■

*\*The patient's name and identifying details have been changed for confidentiality.*

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