

Hi Samantha,

February 13, 2020 (December 2019 letter)

Simon Yates died on Monday January 13, 2020. It was the date he chose for his Medical Assistance In Dying (MAID) action. I was amazed how joyful the last week was—especially in comparison to what my Aunt Rose-Emily and Dad had to go through to die.

Since the law about MAID had not been established in Canada when Aunt Rose-Emily and Dad decided they wanted to die, the only dignified option for them was to stop eating. It was a long and difficult process for them by comparison to Simon. I was not around for Aunt Rose-Emily but the reports were similar to Dad's experience so I will tell you about his.

Dad suffered for many years with back problems that meant he was severely limited in what he could do. Once it got to the point that he needed full-time care, Mum had become more limited in her ability to help out, and he was diagnosed with bladder cancer, he decided that the best option would be to die. He didn't like being so dependent on others and felt that he was too much of a burden for Mum. He had also seen how his brother (Dick) had died from bladder cancer so did not want to go through the same suffering, lack of control, and indignity.

Once Dad decided to stop eating, the first action of his doctor and the health services was to determine whether this was simply a case of depression and would pass. They got a psychologist to meet with him for a few sessions. Eventually, they decided that it was not depression and that Dad was fully capable of making such a decision. The medical supports then swung into "geriatric" mode and provided some wonderful supports throughout the process.

They assigned a team to Dad and discussed with him and Mum what he should expect to happen. According to the law at that time, they could not contribute to his death, but they could act to make him more comfortable throughout. They informed him, for example, that at times he may wish to have a bit to eat, but that he should not have too much since his body would be shutting down and ordinary food would just make things worse. They suggested that under these circumstances, he should have a small amount of a drink like Ensure.

They also arranged for someone to come in to the apartment on a regular basis and to provide supports for both Dad and Mum. Both Mum and Dad told us how wonderful they were, and how they provided special equipment and psychological services along the way.

When the doctor assessed that the end was near (a week or so at most) they moved Dad to a hospice in Vancouver (the St. James Hospice). It is a beautiful building in a lovely location—overlooking the North Shore mountains and the inner part of Vancouver harbour. It's also located in the middle of a park, providing views of children playing, people walking their dogs, and the usual bird activity.

You can see details of Dad's final days—with photos—by checking out the blog I prepared via the following link.

<http://billreimer.net/personal/documents/MumDadJournal20070916.pdf>

The final few days were pleasant, but difficult for Dad as he waited for the end. We enjoyed our visits but the uncertainty of the end and Dad's failing capacity made the experience stressful for everyone.

These experiences contrasted sharply with Simon's. Visiting him at home was pleasant, but he was often unable to participate fully because of his low energy, occasional problems with breathing, pain medication, and multiple trips to the hospital to deal with each crisis related to his lung cancer. It was after he was admitted to the hospital to deal with one of these crises that he confirmed his decision that his time was up. He was moved to the palliative care unit of the Montréal MUHC hospital. There, he met with the doctors, filled out the forms, provided the necessary tests, and got the permission for a MAID response. He had to wait 10 days before his death could be arranged according to the law. It was decided that January 13th would be the day, so we all settled in to a few days of visits.

The period of time when Simon was in the palliative care unit was wonderful. Because all the equipment and personnel were accessible at a moment's notice, the crises he experienced at home disappeared. It was easy for them to provide him with oxygen, pain management, appropriate food, physical care, and any other services he required. As a consequence, a huge amount of the stress was removed and both his physical and emotional condition improved.

At each visit I was amazed how well he looked and how much energy he had by comparison to his last days at home. It made us all wonder whether this was a reason for calling off the MAID, or just a reflection of the changed circumstances. In any case I was very thankful for this period since it meant that conversations with Simon were animated, humorous, engaging, and sometimes profound. Madeleine expressed it as Simon "holding court" as he gave instructions, answered questions, debated multiple topics, told stories, and took time to pass on personal thanks and appreciations to his visitors and staff. We later learned from the volunteer staff at the hospital how he was seen and appreciated as a special person on the ward. He wrote them a letter of thanks which was framed and put up at the nurses' station.

Fran and I made several visits to see him—not simply because he was dying, but because the event was so uplifting. I think that the clarity of the process made a big contribution to this positive result. The time of death was fixed, the negative side-effects of Simon's cancer were well controlled, he was fully cognisant of his surroundings, and was keen to settle the issues that most mattered to him. Instead of MAID creating a focus on death, it was very much a celebration of life!

For the other dying people we have visited (without the MAID option) the experience was quite different. In most of those cases (e.g. Dorothy, Richard Drapeau) there was always a conflict between controlling pain and keeping them mentally clear. To minimize pain, they would receive morphine, but this reduced their mental capacity. To increase the mental capacity, they would experience more pain.

I don't know if Simon's choice for MAID made the difference, but my impression was that the responses of the doctors and staff were different because they knew he had a death date. Perhaps they focused more on keeping him cognisant and using pain medication that had addiction or long-term negative effects (e.g. morphine or steroids) since they knew he would be dead on the 13th. It would be interesting to know if this is a pattern or not. I'll check the research that emerges since to this point my evidence is just anecdotal.

These experiences have made me a big fan of MAID. I love how it gave Simon control of his death in a respectful and life-affirming way.

Love,