Getting into Harvard or being admitted to palliative care

By Marlyn Silverstone

We live in a society in which getting a place in Harvard is an enormous accomplishment, one for which candidates compete with all their strength. Palliative care, on the other hand, compassionate care for those with terminal illnesses, is not, supposedly, in great demand. And yet you have to compete for a bed in a palliative care unit as well. I should know. I'm in went to palliative care. I call it my Harvard.

Even when I was young and strong, I knew that I'd accept death when it came my way without heroic measures. I wouldn't take the counsel of the poet Dylan Thomas but would instead "go gently into that good night." (1)

When the Quebec government produced a document in 2014 (2) that asked how we wished to be treated if very ill, I duly filled mine out and sent it to the ministry. But that didn't mean I wanted to die if a cure was possible. Four years ago, in 2016, I had open heart surgery to repair a leaky valve. Two years previously I had a lump removed from my breast. And I carried on gratefully.

When I was diagnosed with lymphoma, in November 2020, my doctor suggested chemotherapy. Six monthly sessions and I'd be cured. I was reluctant nonetheless. "Try it once," said the hematologist/oncologist. And I did.

The outcome was disastrous. I was allergic to one of the two chemotherapy drugs. My internal organs, including my kidneys, shut down. I couldn't breathe. I might have died. I was a mess. They hospitalized me on the eighth floor of the Jewish General Hospital with the intent of bringing me back to where I was before chemo. I felt like a chemistry set, each of whose items had to be modified. I'll give them a chance. I decided on two weeks to get me back to pre-chemo condition.

In those two painful weeks, despite the physicians' efforts, I didn't get better at all. On January 2nd, two weeks after chemo, they told me my blood was infected, a very dangerous development that could, along with my failed kidneys, cause death. They gave me blood transfusions and intravenous antibiotics and water to flush out the kidneys. My legs were so inflated that I could barely walk. Then they gave me Lasix, which was supposed to dry up the water. A little counterproductive, one might say, even for a layman.

I knew that I had to get out of the hospital, and I talked to anyone who would hear me about palliative care — one palliative-care doctor and a nurse. They both supported my claim, but nothing was being implemented. Meantime my fragile veins were having more difficulty to accommodate intravenous tubes. It often took three attempts by the most skilled nurses on the floor to insert them.

On Saturday, January 2nd, I knew I had to stop the merry-go-round. When the first nurse arrived at 3 a.m. to apply intravenous, I pronounced a strong "no." Two hours later, another nurse came by on some other mission, and I made the same response. Then I waited.

In the afternoon, Dr. Schwarz, the internist, and his team came to evaluate. They had a hard time believing that a person whose lymphoma might be cured, would opt for death. They thought I must be depressed. Of the depression theme I'd heard from other professionals, including nurses. One actually said I didn't eat lunch because I was depressed. Nothing was farther from the truth. I resented this bedside quackery. My oncologist/hematologist took a different line: According to one of her colleagues, who served as her advocate, she "really liked me" and didn't want me to die. My only response was that I liked myself even more than she did.

The afternoon crept on. The debate continued. Another hematologist came to discuss my situation, as did a palliative care nurse who was compassionate but couldn't give me an answer without consulting her team. I just knew that I couldn't go home alone and couldn't stay in treatment.

Then the tide turned. I was interviewed very thoroughly by a psychiatric resident summoned by internal medicine. She approved my choice of palliative care. She also interviewed my friend who had taken care of me for a few days when I was home.

The next day, the transfer was disgraceful. I was left in my room until 2 p.m. after one early morning visit by a nurse. Nobody looked to my needs for food or water. By noon, I was so hungry that I managed to climb out of bed. I asked for and received a soup, taken from a passing trolley, from a benign orderly. And I scolded the resident who came to apologize on behalf of his team. Even then there were two more hours to wait. (3)

Arriving at the palliative care unit in another facility, I thought I'd gone to Heaven. Nurses and doctors interviewed me, getting to know me, feeding me, making me a cup of tea. I was so glad, feeling that I'd made it to Harvard.

In time, however, I've discovered that it's not perfect here. There's a shortage of staff in the early morning, and there's not always a response when you press the button. I know I can't blame the PABs (préposés aux bénéficiares, i.e. orderlies or nurses' aides), especially on the morning shift when two of them are responsible for the whole third floor. I could opt for sleeping pills and sleep all day long, but that's no life.

I still believe in palliative care and am making this, my last effort in this life, to promote it by writing this article. When it is completed, there will be nothing left for me to do. The advent of COVID has made palliative care less humane. But I'd still opt for palliative care while we wait for better days.

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1. Dylan Thomas, ”Do Not Go Gently into that Good Night,”(1947)

2. Act Respecting End of Life (Quebec,2014)

3 The less-than-ideal conditions at the hospital were doubtless because of the attention required by Covid patients.