They didn't follow my father's advance care plan

I live in a regional centre in Victoria, and have a strong health focus in both my personal and professional life, being married to a GP and having worked previously as a nurse, and for the last 17 years in our local primary health network (previously Medicare Local / Division of general practice).

We are very fortunate in our city that we have a local hospital that funds a very accessible advance care plan program that operates out of a number of general practices.

With ageing parents living in a medium size town (population approx 10,000) 1 ½ hours drive away, and with no on the spot family support, I was especially keen to ensure they had the benefit of an advance care plan document in place.

Having first discussed the idea with my siblings, it was agreed that I would speak to my parents about this potentially uncomfortable topic to gauge their interest.

In fact the conversation turned out to be a very easy one, as they were also concerned about the possibility of being on the receiving end of unwanted interventions, and had been increasingly dwelling on these fears. In other words they welcomed this topic being raised.

As a result they both completed a ‘Statement of Choices’ document, and appointed me as having enduring medical power of attorney, to be evoked in the event of them being unable to make a decision. Copies of both documents were circulated to all of their children (my siblings), and to both their GPs (of 30 years).

It is important to note that the strong theme of my father’s statement of choices was that he did not want to be treated actively unless there was a certainty of a good outcome and continuing independence. His main fear was in regard to the process of dying, and not in death itself. He also asked to be allowed to die at home.

Given that their local hospital is run by the local GPs, we felt confident that their wishes would be respected.

My father’s health continued to decline to the point that he was put on home oxygen. It was clear that he was on borrowed time. A number of times over a period of weeks he articulated to me that he had “had enough”. My GP husband had expected him to die at any time over the previous 5 years, and had raised it with me a number of times in order to help me prepare.

Over one weekend my father became ill with a gastro type of illness. He needed to seek medical help, but unfortunately the GP practice was closed. The local hospital was our only option. My father was very reluctant to attend, pleading with me not to let them admit him. Unfortunately for him, his illness coincided with a gastro epidemic in the town (confirmed as unrelated later on), so they would not let Dad go home for fear he would spread the gastro to others in the community. His own GP was the admitting GP.

After admission Dad again asked me to do everything I could to get him home and to prevent him being sent to the nearest regional hospital- a very likely reality giving his complex and deteriorating medical conditions.

I tried (unsuccessfully) to contact the GP to remind him of Dads Advance Care Plan and to inform him of Dads frequent words to me that he had “had enough”. I also left a message via a short note on the ward (with the encouragement of the nursing staff) to this effect, suggesting that active investigations / treatment was not in Dads interests.

Unfortunately I never succeeded in having that conversation with the GP, and Dad was of the generation and personality type that found it very hard to refuse anything the doctor suggested. As a result investigations were undertaken that revealed that Dad in all probability had some kind of leukemic process developing. The GP told Dad that he needed a bone marrow biopsy and Dad (as usual) consented.

I was absolutely appalled! He had suffered enough and I was desperate to spare him the acute pain of a bone marrow biopsy and the absurdity of chemotherapy. I wanted to say to the GP that Dad was dying and to please let him go peacefully.

I tried all day to contact the GP, leaving several messages at the practice and feeling increasingly desperate. My call was finally returned at 10pm that night, by which time the bone marrow biopsy was already booked for early the following morning. I expressed my incredulity and asked what the point of this useless and extremely painful intervention would be. The GP replied that it was required in order to establish an appropriate chemo regime. I responded that as my father was dying, he would not want or need any chemo.

My father died that night.