

Medical Aid-in-Dying Diary by Barbara Garlock

***What follows is a diary kept by Barbara Garlock, chronicling the year and a half leading up to her husband, Gayle's, death via Medical Aid-in-Dying (MAiD) in Victoria, Canada in 2019. Gayle had been diagnosed with Lewey Body Dementia in 2014, and lived relatively unhindered by the condition until 2017, when he took a sharp decline.**

Barbara was kind enough to allow us to publicly share her diary on the Completed Life Journal. We hope that it will serve as a helpful resource to demystify the process of pursuing MAiD.

We initially shared Gayle Garlock's story on our podcast, *Voices of the Completed Life*. To listen to the two-part episode, which features Barbara, her son Geoff, and Gayle's MAiD provider, Dr. Stefanie Green, click [HERE](#). It provides additional insight into who Gayle was as a person, what the process was like from a legal and medical perspective, and the impact the death has had on Gayle's family in the years since.

It was Gayle's wish that his story be told. So we encourage you to share this journal and the podcast, to continue the conversation in your community.*

March 12, 2018

Gayle and I went to see Dr. Stefanie Green this afternoon. She lists her practice as specialising in newborn babies... so she deals with the beginning and end of life. She is very direct and open; we both like her. After reviewing Gayle's medical information and the application he submitted, she made it clear that she cannot risk going to jail or losing her license to practice. She said she would think about his situation but likely would be unable to approve his application because his diagnosis was only Lewy body dementia. He does not want MAiD soon or perhaps ever; he just wants the option.

Stefanie did say that we could pursue another avenue if we chose and Gayle would be the perfect candidate. She said we could challenge the law in court. She claimed that there would be several lawyers who were anxious to try such a case and they might possibly work pro bono. She felt the chances of winning such a case were high. The timing might be tricky because Gayle might have to appear in court and would have to be competent during the case as well as when and if he chose to end his life. We told her we would go home and think about it.

March 13, 2018

We told Chris, Geoff and Bernadette about yesterday's appointment with Stefanie. They were supportive and didn't seem to be terribly surprised. Geoff saw it as I do, as a kind of legacy which might give thousands of Canadians (including Gayle) a choice. Chris was concerned about the demands in terms of time, energy, privacy and money. We will talk with Mike about it when we see him in May. I sent an email to Stefanie requesting information so that we would understand exactly what is involved.

March 15, 2018

We received an email from Stefanie. As expected, she could not approve Gayle's application. She had spoken to the CEO of [Dying with Dignity Canada](#), Shanaaz Gokool.

We are down to three choices:

1. Do nothing further.
 2. Try to find another provider in Victoria. She doubted that anyone would consider doing this during the next six months. Why six months?
 3. Pursue the court case. She would be willing to testify on Gayle's behalf.
-

March 19, 2018

Stefanie phoned today and gave us the contact information for Shanaaz Gokool. I asked her whether Gayle would have a better chance of being approved for MAiD if the diagnosis was Parkinson's. She listened to my line of reasoning and found it interesting. She looked at the report summaries from early 2014 by Dr. Pai, Dr. Henri-Bhargava and Dr. Friesen. All of them mentioned Parkinsonian features. None of them made a definitive diagnosis of Lewy body dementia. Words like "suspected" were used and it was acknowledged that Gayle's various scores were within the normal range or above. They guessed that there might be dementia based on their expectations of a man with his educational background. Stefanie offered to consult with Dr. Henri-Bhargava about this.

March 27, 2018

Stefanie phoned today. She will phone on a regular basis to talk to Gayle to assess whether he is still competent in her opinion. She sent the consultation request to Dr. Henri-Bhargava on March 19 and that is likely why he wants to see us in early April.

I received an email from Shanaaz. She will phone us tomorrow.

March 28, 2018

We just had a phone call from Shanaaz. She is lovely. She confirmed that a competent adult with dementia and with a second diagnosis causing physical suffering could be eligible for MAiD and she seems to think that this would be the easiest approach. When Gayle sees Dr. Henri-Bhargava on April 6 she would like us to obtain an opinion about Gayle's competence and to ask whether Gayle's Parkinsonian traits are sufficient for a Parkinson's diagnosis. There has been at least one person with Parkinson's who has received MAiD approval and whose "foreseeable death" was within five years. If Gayle is competent then the problematic areas are that he may not be in an "advanced state of decline" and he is not yet willing to say that he is "suffering intolerably." That suffering can be defined by him.

The "advanced state of decline" is tricky. Two weeks ago I had suggested to Stefanie that a 61 year old man who ran the Boston Marathon was in an advanced state of decline at age 74 when he could only walk around the block. She commented that she supposed that one had to consider the starting point when determining an advanced state of decline. If the starting point was very high then a moderately low point might be considered an advanced state of decline. At least she was open to that line of reasoning. Shanaaz made a similar comment when I asked whether an advanced state of decline was a relative thing depending on the person. At the time I was only thinking of a physical decline, and the application does not specify that the decline must be physical. I could argue more easily that a man who earned a PhD in English literature was in an advanced state of decline when he could only manage magazine articles. Isn't the mental decline advanced when Stefanie feels that she has to check on the competency of a man who earned a PhD?

Shanaaz will be talking to Stefanie about our conversation. Stefanie may possibly help us if there is a Parkinson's diagnosis. If Stefanie cannot help us then Shanaaz will try to find a doctor who will. She apparently had someone in mind. If none of that works then she will try to find a lawyer who might take the case pro bono. She said it might not have to be a challenge to the existing law but could be a statutory declaration. I now understand the difference. We would not have to appear in court in any case; a video would be sufficient if required at all.

It's interesting. Shanaaz is more concerned with helping Gayle as an individual than in furthering her "cause." A court case, if successful, might do more for her "cause." I think it is surprising but admirable that she put Gayle's interests first.

March 31, 2018

Yesterday, Gayle and I had a hard conversation. He will not lie about suffering intolerably but he would like to be approved for MAiD. We decided to sit down and talk about where he is and how he is suffering, if at all.

We started out with what he finds frustrating. There is surprisingly little. Most of it had to do with communication: his struggle to write, his inability to use the computer independently and his unclear speech. He also gets frustrated when he has to make a decision if there are several alternatives. He can put up with the extra time it takes to do everyday tasks—to dress or towel off after a shower, to put on a jacket or to prepare breakfast, for example. The list could go on and on. His patience is endless.

Then we listed how Gayle is suffering (not suffering intolerably) and the list got longer. He suffers no physical pain, only discomfort from Raynaud's syndrome. However, he suffers because he is unable to be independent—cannot drive a car so cannot go outside the neighbourhood unaccompanied, cannot cook on the stove safely, cannot manage his pills. He cannot be alone at home for more than a few hours. He struggles to use a credit card which he can use only when I am with him. He suffers because he cannot surprise me with a gift. He suffers because he cannot read novel length books. He is limited to magazine articles and newspapers. He suffers because he cannot play with his grandchildren. Board games are too confusing and physical play is out of the question. He suffers social embarrassment because his nose drips, his body smells when he has a cold sweat, he cannot keep up with a conversation, he cannot find words, he is slow to express thoughts. He is embarrassed when his friends are overly kind; he suffers when he senses their pity. He suffers because his health has hurt mine.

Gayle suffers intolerably in two ways. First, he is unable to think as he once did; he is aware that his mind is failing. Second, he suffers intolerably in the present when he thinks about what his future will be.

After a conversation like this we needed a reason to smile. I reminded Gayle about a letter that, coincidentally, I had written to him exactly fifty years ago yesterday. In it I expressed a longing just to be able to touch him while he was asleep beside me. And so, last night, we held one another for a very long time before we fell asleep, and cuddled when we woke this morning. I am grateful that we still have each other.

Puppy Dog Eyes

*My husband looks at me with puppy dog eyes,
Eager and full of trust,
Asking for affection, affirmation and love.
There was a time when those eyes were an invitation to intimacy.
Now they lead to a long, warm, gentle hug.
My husband's mind is failing
But he still looks at me with puppy dog eyes,
And he remembers.*

April 6, 2018

Gayle's appointment with Dr. Henri-Bhargava went as expected. He has no issue with Gayle's competence. He would not give an additional physical diagnosis (Parkinson's) but said that it might not be necessary for MAiD. This is different from what we are hearing from Stefanie and Dying with Dignity Canada (Shanaaz). He mentioned that a court case would help greatly in clarifying the MAiD law in this regard. We need to talk to Shanaaz more about this. Stefanie and Dr. Prinsloo (our GP) will receive the consultation report in the next few days.

April 10, 2018

We had an appointment with Dr. Prinsloo for Gayle. He read Dr. Henri-Bhargava's consultation report to us and it said what we expected. The word "capability" rather than "competence" is used by medical professionals. We brought him up to speed on what has happened in regard to Gayle's application for MAiD and I asked whether he would even consider being the second doctor if a provider can be found. To our surprise, without hesitation he said he would be that second doctor. He said that I could pass that information on to Shanaaz. We have an appointment with him in a month.

After emailing Shanaaz about Dr. Prinsloo, she replied by saying that this was good news. The provider who she has in mind will not be available for an appointment for a month or more. She and we feel there is no rush because Gayle is capable and should remain so for a while (we hope). So right now everything is on hold.

May 24, 2018

While we were in Toronto we told Michael about where we are in the MAiD process. As expected he was supportive and will tell Pam.

When we returned home from Toronto yesterday there was a phone message from Stefanie. She was simply keeping in touch and presumably evaluating Gayle's capability. We updated her on where we are and she had a couple of interesting things to tell us. She doubts that any provider will approve Gayle's application until the BC coroner releases her report on the MAiD case from late 2017. Ironically, we believe that this MAiD case was an acquaintance whose only diagnosis, as far as we know, was Alzheimer's. If the coroner has no finding of wrongdoing then Stefanie would likely approve Gayle's application and could be his provider. Otherwise we would pursue the statutory declaration route.

I sent an email to Stefanie today updating her on Gayle's recent physical and mental decline. I did not want to be so blunt yesterday with Gayle listening to our conversation on the phone.

Transitions

*I take his hand when we cross the street
Or as he goes carefully down the stairs.
I help him get dressed, tickling as we go.
I remind him when it is time for his nap.
And I tuck him in at night with hugs and kisses.*

*Is this one of our sons?
(We are blessed with three)
Or one of our grandsons?
(More blessings. We have five)*

*No, this is their father and grandfather
And my husband.
And just as I did with our sons
So many years ago,
I tuck him in at night with hugs and kisses.*

June 20, 2018

Still no word from Stefanie or Shanaaz about the BC coroner's report.

Today was not a good day for Gayle and I wondered about his capability. He got up from a nap, took off his underwear, put on a diaper and tried to have a bowel movement in the diaper rather than going to the toilet. When nothing happened he sat down on the toilet with the diaper still on and urinated into the diaper. He was very confused about what he should have done when we talked about it. It astounds me that he just accepts these incidents with equanimity. I suppose that's better than getting upset.

August 14, 2018

Stefanie phoned today. I told her that I was becoming more and more concerned about Gayle's capability. She did not ask to speak to him.

Stefanie told me that the BC coroner had turned the case over to a panel of doctors from the BC College of Physicians and they seem to be taking their time about making a decision. It is a decision which might set a precedent for people with dementia who are

still capable. Their decision will not be announced publicly but Stefanie will quickly know what it is. Until then we will have to remain in a holding pattern and hope that Gayle remains capable. If he has a choice I am not sure what it will be (nor is he). I just want him to have a choice.

September 29, 2018

Still no word from Stefanie. Three days ago we spent three hours in the research department at the hospital to see if Gayle would qualify for the COMPASS-ND study. He scored 22 on the MOCA screening test (13 was the minimum acceptable score) so perhaps my concerns about capability are not valid at this point.

During the past three days we have filled out the questionnaires that are part of this study. Among other things, there were detailed questions for Gayle about how he communicates verbally and for me in strategies that are helpful or not during our conversations. At the hospital they recorded a 20 minute conversation between the two of us and Gayle held up his end pretty well. We talked about our extended trip to Chile. Good memories.

October 4, 2018

Gayle had his six month check-up with Dr. Henri-Bhargava. I told him about the June 20 incident and he said that there are good and bad days with Lewy body dementia and perhaps this was one of Gayle's bad days. He does not question Gayle's capability. He feels that the mental processing is there, just very slow, which is why Gayle talks so little.

We spoke about MAiD and referred to the case which is being reviewed by the panel of doctors. He said that the problematic aspect of that MAiD case was that the patient's "intolerable suffering" was what she anticipated for her future, not her situation in the present. He did not think that the Alzheimer's diagnosis, as her only diagnosis, was the most troubling aspect of the case for the panel of doctors.

October 13, 2018

Last night was not a good night. At around midnight I awoke to hear Gayle calling "ona" about every five seconds, at first quietly but gradually louder and louder. I finally figured out that he was trying to say "Sonja." When I asked if there was a problem he told me that his diaper was wet. When we got to the bathroom I asked him why he was calling his sister and he said that he could not remember my name (although he did when we were in the bathroom). After cleaning him up I tucked him in bed, waited until he fell asleep and

went into the living room to have a good cry. He had two more wet diapers during the night, the first time that has happened. I don't know what is going on.

A Promise

*We made a promise fifty years ago
And now our world has turned upside down.*

*How do I love a man who is no longer himself?
How do I desire a man who does not desire me?
How do I accept who he has become
When I see so little of who he once was?*

*The answer to those questions is devotion,
An unselfish and giving kind of love.
Is this what I am supposed to learn from his disease?
Will I ever see devotion as a gift?*

March 12, 2019

Yesterday I sent an email to Shanaaz asking if she could help us with a statutory declaration since I fear that Gayle's capability will not last much longer. She replied today, saying that she was at a conference in Europe. Stefanie is also there and last week they spoke about Gayle's situation. Shanaaz said that there has been a "development" which may influence Stefanie's ability to help Gayle—nothing more specific than that. There have been no relevant MAiD related changes reported in the newspaper and no public report from the BC College of Physicians. She said that Stefanie will contact us.

March 15, 2019

Gayle had his usual every six month check-up with Dr. Henri-Bhargava today. At the end of the appointment I asked him, as I always do, whether Gayle was still capable. Every other time he has immediately replied in the affirmative. This time he said he would need another appointment to do an assessment. I am afraid that we are running out of time.

April 15, 2019

Stefanie phoned a few days ago when I was out and Gayle took the call. He knew who she was, what the call was about and took the message that she would phone me back today.

Stefanie began the conversation by saying that Gayle still seemed capable based on their short phone conversation. She asked me what changes I had seen in him in the past year. Then she took me completely by surprise by saying that she was open to offering MAiD to Gayle if indeed he was still capable. What had changed? She did not specifically answer that question but I suspect that the B.C. College of Physicians found no wrongdoing in the case they had investigated. Stefanie asked me to explain to Gayle what she had said and to get back to her at any time. She certainly did not expect an immediate reply from us.

When Gayle returned from the day centre, I told him what Stefanie had said and asked him to say it back to me so I knew that he understood. He asked a few questions and we then let the matter drop. I do not want to influence his decision.

April 25, 2019

At lunch today, out of the blue, Gayle said, "I want to go ahead." I actually had to ask him what he was talking about because this was out of context. He wants me to contact Stefanie for an appointment to assess his capability.

May 9, 2019

We spent two hours with Stefanie today. She and Gayle first spoke for an hour without me being present. She needed to assess his capability and also to ascertain that MAiD was something that he truly wanted. I do not know what was specifically discussed but among other things there was something about a Groucho Marx joke.

Stefanie invited me to join them. I asked why she now felt that she could offer MAiD to Gayle and she vaguely mentioned the B.C. College of Physicians' report, which will not be made public.

Stefanie also said that a number of MAiD providers agree with her that nothing in the law should prevent a capable person with dementia from receiving MAiD. A position paper stating as much is to be published in the near future and Stefanie guesses that it will create discussion as well as controversy. She wants this issue brought out into the open. We said, as we did a year ago, that we did not want her to risk going to jail or losing her license to practice medicine in order to help us. She smiled and said that this was her choice and her responsibility, not ours. She is one gutsy lady.

Stefanie estimates that Gayle will remain capable through the summer but likely not until Christmas. He does not want MAiD yet; I believe that he is hoping for one last vacation

with the whole family at Buckhorn in late August. She warned me that he may never be ready and his opportunity to have MAiD may just slip by.

However, Stefanie is being very careful. If Gayle wants to go ahead at the end of the summer, then she would like Dr. Henri-Bhargava to assess his capability. She will also reassess his capability and will ask another MAiD provider to do so as well. All of this would happen in mid September if it happens at all.

June 18, 2019

We have had several awful days and I am hoping so hard that this is not the new normal. Gayle fell off the toilet on Friday morning, falling to the bathroom floor but not injuring himself. His body was so stiff and he was so confused that he could not walk or even crawl. I eventually got him sitting on a bathmat and pulled him sled-like to the bed. I do not know how I got him into bed. All of this took about half an hour. I stuck to him like glue for the rest of the day because he kept trying to get out of bed. His blood pressure was ridiculously low from the orthostatic hypotension.

Since then he has been in a wheelchair or in bed. Blood pressure still very low. More hallucinations than before. Sleeping 18 hours a day. I don't think he is capable. There is no way that we are going to Ontario in August if he remains like this. It is possible that the fall sent his whole system out of whack and Dr. Prinsloo said he may mostly recover within two weeks. That is our best hope.

June 28, 2019

It's been two weeks since Gayle fell and he has improved somewhat, but not enough to get on an airplane and fly to Ontario. He can walk and seem fine; moments later he gets dizzy and would fall if I wasn't there to push him into a chair. We have had two falls when we both went down. He wakes me several times a night with hallucinations. I cannot leave him alone in the house except when he naps and then I briefly go outside to garden to keep my sanity. The occupational therapist thinks that we need to consider long term care. He had two dizzy spells during her hour-long visit today.

Sleep. Blessed Sleep

"What time is it?" This at one in the morning.

"Are you still there?" at two.

"We have to rescue three pods of whales," at three.

"I need the bathroom," at four.

And so it goes all night

*As I desperately try to sleep
And he makes requests
Which prevent that from happening.*

*Sometimes he shouts out
Or thrashes in his sleep,
Startling me awake
My heart pounding.*

*I know he can't control this.
I know it is his disease.
I also know that
I can't keep doing this forever.*

July 3, 2019

Yesterday Gayle's case manager came by, likely prompted by the occupational therapist. She recommended beginning the long term care process which put Gayle on waiting lists of six to nine months at three different facilities.

Today Gayle said that he wanted to go ahead with MAiD. I believe that the spectre of long term care, his inability to fly to Ontario and his awareness of his failing mind all contributed to his decision. I contacted Stefanie and we have an appointment for her to assess his capability on July 18. She arranged for Dr. Henri-Bhargava to assess him on July 26. This is not standard MAiD procedure but Stefanie is being extra cautious. Another MAiD provider will have to assess him, which is standard procedure, at a later date.

July 9, 2019

This afternoon and evening Gayle did not know my name or that I was his wife for about four hours. Looking straight at me he said things like, "My wife is in the other room" or "You need to tell my wife about my chipped tooth." I was devastated. I hope he knows me in the morning.

Who Are You?

*A car door slams at our neighbour's house.
"It's just someone at Karen and Robert's," I whisper.
Gayle starts to get out of bed saying,
"I must tell her I am not Karen."*

*True, he was not Karen.
But who did he think he was?
He did not know who I was
For several hours that day.*

*"I think, therefore I am."
Descartes' essential principle.
Did Descartes truly mean
That you are defined solely by your mind?*

*I cannot accept that.
I believe that goodness is innate,
That love defies explanation
And that the soul is at least a possibility.*

*Yet, I cannot help wondering.
If you are unable to think
Exactly,
Who are you?*

July 10, 2019

Upon waking this morning Gayle knew who I was. I started crying with relief and he asked me why I was crying. I explained what had happened the day before. He remembered some aspects of those four hours but not that he hadn't known me.

July 18, 2019

Gayle had his appointment with Stefanie today. It started out badly. Gayle wanted to walk into her office (at home his blood pressure had been reasonable) rather than be pushed in the wheelchair. After about thirty steps in the parking lot it was clear he would go down. A woman saw us struggling and together we pushed him against a truck to help support him. The truck owner, a big guy, ran over and held Gayle up while I got the wheelchair out of the car.

Once inside things went well. As before, I was not allowed in the room for their first hour of conversation. Stefanie then called me in and told me that she was completely confident that he was capable and qualified for MAiD. He had even told her about the incident in the parking lot and about not knowing me nine days earlier (which he described to her as "shattering"). She was not fazed; she said that people have good and bad days as they are losing capability, much as Dr. Henri-Bhargava had said months ago. We have hidden nothing from her.

July 26, 2019

This afternoon Gayle had his assessment with Dr. Henri-Bhargava. His role was not to show that Gayle met the qualifications for MAiD (advanced state of decline, intolerable suffering, etc.). Rather, Dr. Henri-Bhargava had to assess whether Gayle had the capacity to understand his decision to have MAiD. Again, Gayle did well.

August 13, 2019

Gayle had his final assessment with a second MAiD provider, Dr. Trouton. She was satisfied that he met the criteria for MAiD and that he was capable. I asked her why she had become involved in MAiD and she answered that she believed in choice as a general principle. More personally, her father-in-law had died from Lewy body dementia and she wanted to help people avoid that kind of suffering. She briefly described what his final years had been like and Gayle was listening very carefully.

August 24, 2019

This morning on waking Gayle did not know my name. This has been happening with greater frequency. He was very confused although he did know that our sons would be arriving shortly after noon. He wasn't sure about their names. Mike, Chris and Geoff arrived while he was napping. When he woke at least Gayle knew everyone's name.

August 25, 2019

We had a wonderful day. Last week Gayle and I had made a list of memorable or funny or special incidents during our life together including those while raising children. On the flight here our sons had done the same. We talked about them, smiling and laughing together. I had hardly heard Gayle laugh for many months. Chris took a few short videos while this was happening. I will treasure them.

August 26, 2019

Gayle was very quiet this morning. He knew what would happen in a few hours. After breakfast we all sat outside on the deck, watched birds and talked quietly. There were some tears. I laid next to Gayle and held him while he napped. When he woke we talked for a short time and then each of our sons had a few minutes alone with their father.

Stefanie arrived accompanied by a nurse promptly at one o'clock. She went into the bedroom to assess Gayle's capacity one last time and to confirm that he truly wanted this. She also explained the procedure to him. Stefanie then came into the living room and told us what to expect. She told us that once the procedure had begun it could not be stopped, as she had explained to Gayle. We all went into the bedroom and I crawled into bed next to him. Our sons were at the foot of the bed, touching him. Stefanie asked Gayle if she should begin and he assented.

Gayle fell asleep in less than a minute. I was whispering to him that I loved him, again and again. For another minute or so his breathing was normal and regular. Then it slowed markedly, still regular with no sign of struggle, for a few minutes. His breathing stopped but his heart kept beating. By then our sons and I were weeping. Stefanie continued to take his pulse for a few minutes, then took out her stethoscope to check for a heartbeat. Gayle was gone.