Perspectives

The Legacy: An Interview with Ryan Farnsworth

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Abstract: This paper recounts the author's conversations with Ryan Farnsworth, a 30-year-old ALS patient who consented to be interviewed for the purpose of improving communication between physicians and patients. Under the California End of Life Option (ELOA), the patient had been prescribed medication that would allow him to end his life at a time of his choosing. He describes coping with the challenges of the illness, how he will make the decision when to take the drugs and what he hopes will be his legacy.

Keywords: ALS; end-of-life; EOLA; physician-patient communication

This paper recounts the author's conversations with Ryan Farnsworth, a 30-year-old ALS patient who consented to be interviewed for the purpose of improving communication between physicians and patients. What follows is his story.

In the Spring of 2015 I was diagnosed with motor neuron disease; but by the end of October, the official diagnosis had become ALS. My symptoms began with a loss of dexterity and strength in my hands. I was a server in a restaurant and I started noticing difficulty with gripping items, holding onto plates and saucers, or lifting a pitcher of water to pour for customers. That loss of strength moved to the rest of my arms and then included the entire loss of movement in my fingers. From there, I began losing leg strength as well. For me, it was primarily a case of the upper half of my body being affected first and then moving to the lower half. I thankfully did not suffer pain, and it is my understanding from speaking with other ALS patients, that pain—physical pain at least—is not a common problem.

In reflecting on how I view my life now, there are many possible ways of answering; but in general, I'm quite satisfied with my life as it is today and appreciate the multiple ways in which ALS actually has enriched my experience, by allowing me to appreciate how short and precious life can be. At the same time, my breathing difficulties have increased and lately, the situation has worsened to the point that continuing to breathe after falling asleep is difficult. I find myself in a strange dichotomy: I love my life and I want it to continue; but it's becoming more and more challenging.

Although my satisfaction level is high, I am still considering leaving life behind because my experience has become challenging to such a degree that I am on the fence as to whether I would like to continue. Where I live in California, an End-of-Life Option Act (ELOA) was passed. It's a law permitting terminally ill adults with decision-making capacity to request Aid-in-Dying medication from their attending physician. My family and I read articles about the bill, and about six months ago, we started talking to my physician to get more information. She has always been upfront with me about options, and a month ago, at

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my request, we started the process. Yesterday she gave the final signature officially prescribing the medication, and I believe my mother picked it up earlier today.

A provision of the law is that the drugs be self-administered. I believe that there needs to be a reexamination of the law to allow for ALS patients who have lost the ability to move on their own to also receive the medications. Why should the disability of patients in a certain disease group cause them to be denied access to medical benefits afforded to others? Should care that could ease suffering be based on levels of physical function?

In my own case, I am able to drink the drugs on my own, and—however difficult it will be for them—I am fortunate to have a family who will prepare the medication for me. They feel as I do; their number one priority is not wanting me to suffer when life no longer seems worth it. They are willing to take this journey with me, and without their support, everything would be much more difficult. I recognize that some ALS patients would need help with the whole process; but for me, I'm deeply grateful to have the personal connection with my family, and know that this is a family process.

At one point, the law was actually overturned, and then later reinstated. Although my family and I think it's less likely that it would be reversed now, we remain very much concerned that the right could be taken away again. If it looked like that was going to happen, it could very well hasten my decision to take the drugs. The nature of my challenges now are pretty intense, and if things do not change, I may decide to take the medication within the next few weeks. However, I am definitely open to the miraculous and if something should occur, I would look forward to continuing. However, ELOA has allowed me to be prepared for the worst, and ease the fear of suffering.

When you receive a diagnosis of a terminal illness that is typically fatal in three to five years, the future can literally become your worst enemy. You go from thinking that you might have 70, 80, or more years to just thinking: "Oh crap." The time window suddenly collapses, and the time left becomes more valuable. In your head, you are constantly replaying self-torturing questions: "What will happen next? How much worse will it be? How will this impact my life, my family members?" For me, the source of the torment came from asking "How bad can this get?" and "How long will I need to suffer?" What is essential about ELOA is that it offers some relief from envisioning the worst-case scenarios, and drowning in the hardships. You can replace the old negative fears with: "How long do I want to live? How long does it feel worthwhile for me to live?" This is a very different narrative, and one that has allowed me to handle this challenge with a far greater degree of grace than otherwise would have been possible.

People wonder if I'm depressed. I've known depression my whole life, and for much of the time, I was on antidepressants. As hard as my experience is now, it does not feel like the earlier depression I once knew. At that time, the depression was coming from a mental state of feeling that I was not good enough, and my life didn't account for much. Medication blunted those feelings of a lack of self-worth. I don't suffer from those thoughts now. It's difficult to say whether I'm depressed because you might say that the sheer difficulty and challenge of my current experience could cause depression. I guess it just depends on how you define depression.

I do fear for the future and more reduction of physical function and the

ability to breathe. Asking for the medication has been empowering for me. Without the medication, my whole experience would be worse. For me, the ELOA medication is an insurance policy that I do not need to suffer, should my circumstances become too challenging. If I did not have the medication, I would worry that I might have to suffer by living in a body that no longer feels worth it. For me, it's been an emancipation to have what started as an option, but is now looking more like a decision. I strongly believe these are important choices for everyone to have, especially in a situation like mine.

I don't believe that I would always have thought this way. Looking back, I believe my lack of knowledge and awareness of what this kind of experience could actually feel like, would probably have caused me to say "Oh well, life is good, why should anyone really have the choice to die?" but having lived through this experience I now see that from a totally different reality. People who are not experiencing a progressive loss of function, and an awareness that it is going to lead to death in these sorts of circumstances, cannot understand how valuable it is to make the choice for ourselves. We consider it completely natural to make decisions to prevent our pets from suffering; why shouldn't it be our right to choose similarly for ourselves?

I feel sadness and deep concern for patients who live in places where they are not protected by Aid-in-Dying laws. I do believe that in the future, the right for persons with terminal illness to choose will become more common. That is why it is so critical for those not affected by a disease such as ALS—especially health providers—to understand the viewpoint of people, like myself, going through this challenge. I want my story to help promote that awareness. Life with ALS is a delicate balancing act and I've been through the whole spectrum. Sometimes I want to sugarcoat my experience, not wanting to know the dirty details of the loss of physical function, and pretend that everything is OK. At other times, when I'm deep into a difficult emotional experience, I want to know about options like the ELOA. I want my physician to be sensitive to what cycle I'm in, and the nuances of where I am in my journey so as to be more adept at navigating our discussions.

I used to fear death. Now, I've been familiarizing myself in a personal way with the idea of death and what it means. It's not something that most of us typically do, but I find that just like anything that you're afraid of, when you consciously come to face it, you come to see that your fears were either blown out of proportion, or may not have been quite as warranted as you thought. I wouldn't say that I'm a religious person, but I do have spiritual beliefs. I don't think that this "here and now" life is "it," but that there are likely to be other experiences. This way of thinking allows me to be not too "clingy" to life, and has reduced much of my fear, but I would be lying if I said that I was not afraid on some level. More than death, as I've always told my family and friends, my worst fear is having to suffer unnecessarily. This is why I believe the ELOA is so important.

As surprising as it seems, ALS has given me a gift. Personal growth has happened in so many areas, especially in the area of perspective. Recognizing that we have the choice of how we view our experience is essential. If we're constantly telling ourselves stories like "I've been dealt a bad hand and everything is over because I have ALS," all we are doing is affirming a story of limitation. Early on, I learned that changing my narrative to "This is really hard

but I'm learning, and growing, and sharing, and coming to appreciate life to a greater degree than ever before." The challenge of ALS is reframing this experience for me in a positive way that I think, in many ways ironically enough, has reduced the depression that I once felt before my diagnosis.

Coming close to the end of my life, I look back on those earlier years of never feeling fulfilled because of a lack of accomplishment. I am grateful now to see how far I've come, since I had this very challenging disease situation placed upon me, and I made the absolute best out of it. I resolved to learn and grow from it. The person that I am now is not the same person I was 5 years ago. I am totally different. I am lighter, clearer, and brighter, and I am grateful for the new perspective this challenge has given me. Today, I feel that even with ALS—or in some ways because of it—my life is complete and rewarding. ALS is an essential part of the story that makes me who I am today.

Death is just as intimate as life, and I think that people need to have the choice of assistance-in-dying if their bodies are breaking down, and to choose when to exercise that option. And in my own life, knowing that I have that option has brought a great deal of peace and tranquility that I would not have had otherwise. We all think about our legacy, what we want to leave behind. I want mine to be that my ALS experience played a part in expanding the general understanding of what it means to face the existential challenges of this disease, and will prove valuable in strengthening the communication between physicians and their patients when it's time to talk about the hardest questions.

Five days after the last conversation, the patient wrote to say that he decided to take the medication later that day; and asked that his story be shared to encourage more open communication between ALS patients and their physicians.