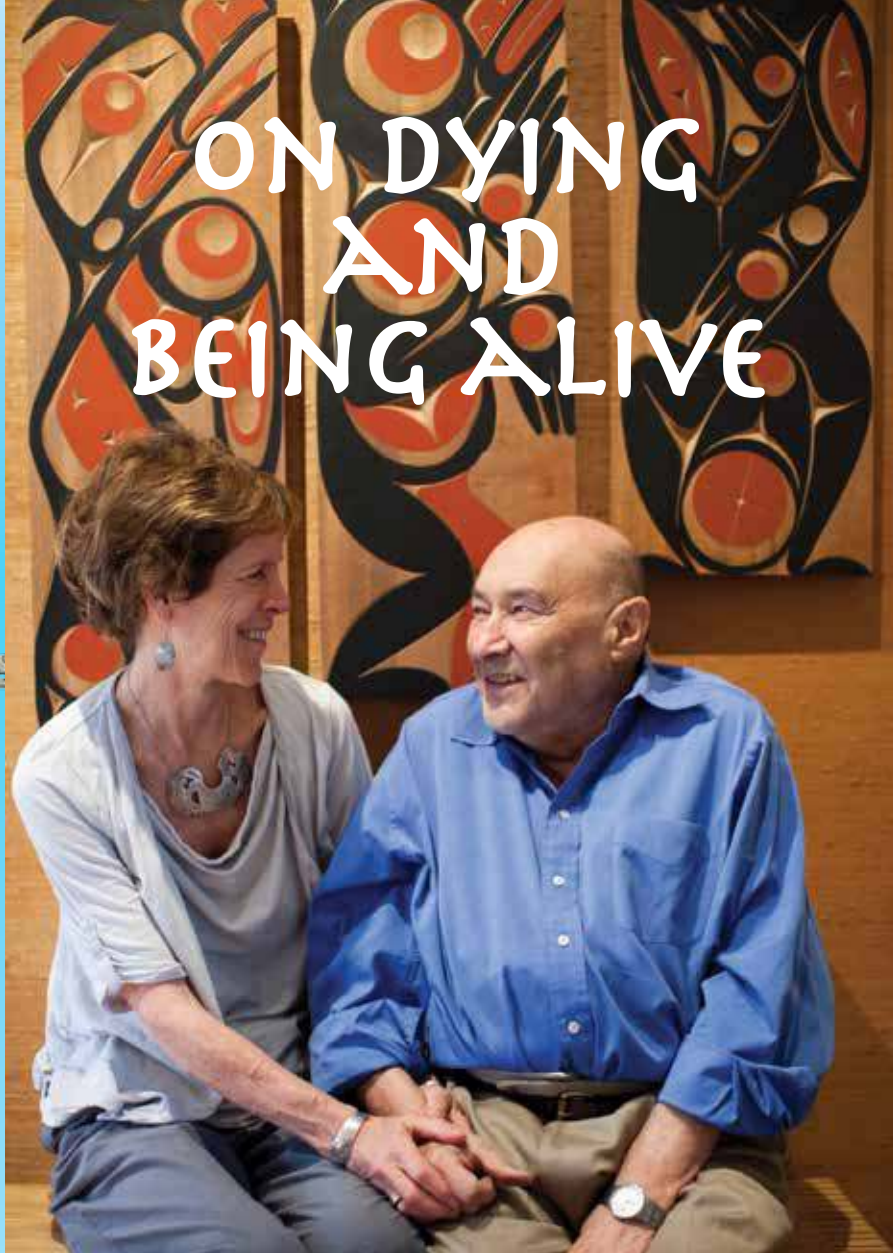


ON DYING AND BEING ALIVE



Courtesy of Dr. De Lancey

Nelson Fausto, MD, and Ann L. De Lancey, PhD

Dr. Fausto was professor in the Department of Pathology and Senior Advisor to the Dean at the University of Washington School of Medicine in Seattle. He died in April 2012.

Dr. De Lancey is Clinical Professor in the Department of Psychiatry and Behavioral Sciences at the University of Washington, and Training and Consulting Analyst at Seattle Psychoanalytic Society and Institute.

I'm dead, I'm gone."

"You couldn't be gone. I'm talking with you," said Ann.

"Oh, never mind. I know I'm dead."

My *annus horribilis* began in August 2010 after my return from a short trip

to Brazil to present a talk. On my arrival in the United States, I was diagnosed with H1N1 virus, despite having been vaccinated against it. No case had been diagnosed in the Northern Hemisphere in the new season, and being the first meant that the labs were not yet ready to give a rapid diagnosis.

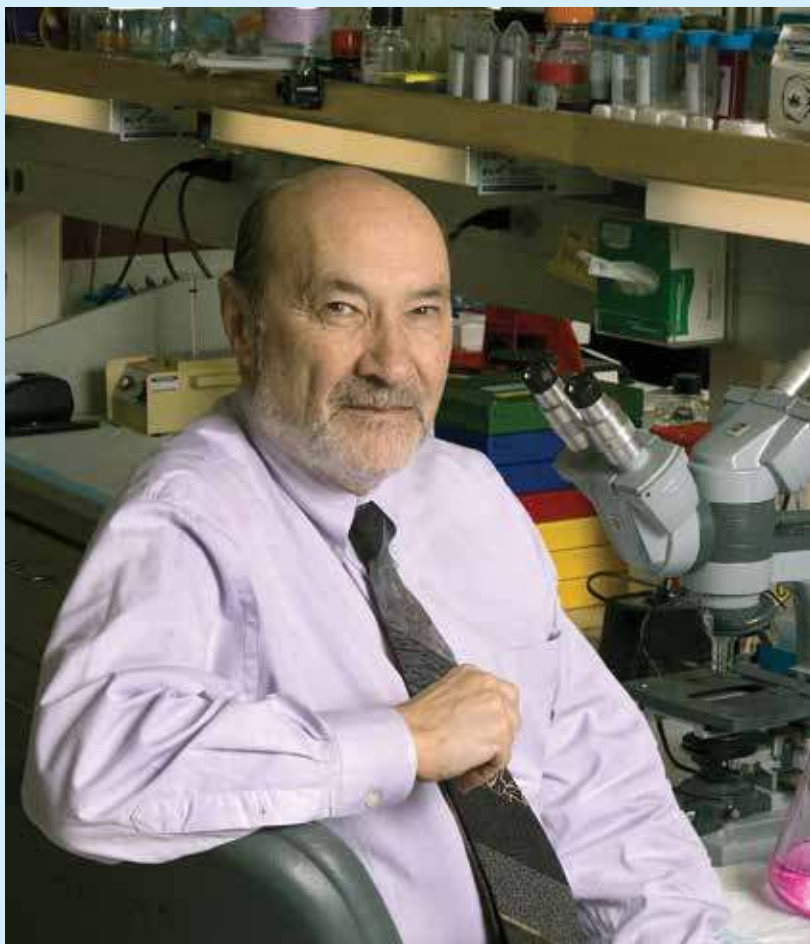
Worse news piled up on top of the bad: renal failure, first acute with a chance of recovery, then with chances diminishing as the weeks went by. We were anxious and waited for the daily report on creatinine levels. But since following the results in an obsessive manner did not improve them, we went "down the tubes" (so to speak) with three four-hour sessions of dialysis each week. Given the time required, I felt

that my professional life was finished.

A doctor insisted that the cause of the renal failure was excess ingestion of Aleve, which Ann had given me while keeping the much less toxic Tylenol for herself for an upcoming operation. Her feelings of guilt and selfishness were paralyzing until friends told her to get a grip and focus on what was important: taking care of me.

These difficulties came on top of my multiple myeloma, diagnosed in 2007 after several horrendously painful fractures. During this new hospitalization the multiple myeloma caused more fractures of thoracic vertebrae

Background: Tlingit soul catcher. Photo by Werner Forman/Universal Images Group/Getty Images.



Courtesy of Dr. De Lanczy

and unbearable bone pain. The pain required continuous application of methadone and Fentanyl “lollipops” for the acute episodes, which if not controlled produced pain so intense that I cried.

In October, during my recovery from these fractures, I began losing sensation in my legs. I asked for a neurology consult. On the third day after I requested the consult, I could not move my lower extremities. I called Ann to tell her I was paralyzed from my waist down. She immediately called my oncologist, who managed to get a neurologist there by 2:00 PM. The neurologist did not recommend an urgent intervention, but must have contacted orthopedic surgery, because late that night orthopedic residents recommended against operating because of the risks. Aware that the operation had to occur within twenty-four hours for any chance of success and knowing that I would not want to live paralyzed, my oncologist had been calling all around

town to find a neurosurgeon to operate. She found a neurosurgeon—who was not even on call—who was willing to operate and who appeared at 3:55 AM as if from nowhere. He told us that while there were grave risks with the surgery (generally a five percent rate of success), the choice was clear: paralysis of the lower extremities and lack of control of physiological functions if we did not proceed immediately. He assured us that he felt he could do the operation, but wanted us to be fully aware of the risks. I called my family in Brazil to say goodbye and then said goodbye, with much love, to Ann. Surgery began at 6:00 AM.

In the afternoon, the surgeon reported success to Ann. He explained in clear and understandable terms (a clarity much appreciated by Ann) that he had prevented the collapse of the spinal column using metal rods and pins and had removed a tumor from the cord. We were both overjoyed with the

unexpected success of the operation, but I realized that I could no longer walk.

About a month later, on Thanksgiving morning, the hospital called Ann and asked her to come in immediately because I had been transferred to the ICU. I expected her to arrive within twenty-six minutes. She arrived much later than that. I was frantic. The team greeted Ann with the news that my situation was grave. I had orders to be resuscitated, but they were quite sure I had had an intracranial bleed and that she should consider letting me go. Ann asked for time to take off her coat, trying to create some emotional and mental space. She asked them to contact my oncologist before they did anything. They wanted to do a CT scan and MRI.

I was later told I was profoundly delirious and by turns either somnolent or extremely agitated. When moved for the CT scan, I had appeared unspeakably terrified and violently agitated. It was excruciating for everyone to watch.

Having seen the consequences of moving me, Ann asked what was to be gained for the desired MRI?

More data.

But would the treatment change?

“No, not at this point.”

With her heart in her mouth, Ann asked them not to do the MRI.

The next four days I was delirious and never slept.

Ann's perspective

During the first forty-eight hours, Nelson pleaded with me every few minutes to not let him die. I did everything I could think of. I stayed by him and acknowledged his fear of dying. I tried to tell him what was happening, but of course he was delirious and his belief was that he was dying.

The next forty-eight hours he begged me to let him die. I reflected on all of the measures we were taking to keep him alive, and asked myself, What is for him, and what is for me? I felt inexpressible love, fear, tenderness, and

an overwhelming desire to support him. I also felt terribly responsible.

I now realized that the Living Will we had signed was utterly inadequate. I wanted any decision to be jointly discussed and ultimately Nelson's, not mine alone. They told me that he wouldn't remember all of this, but he remembered everything.

Nelson's perspective

I didn't see a way out.

"I'm dead. I'm gone."

"You couldn't be gone if I am talking with you," said Ann.

"Oh, never mind. I know I'm dead."

I was suffering from delirium and hallucinations—four days and nights of tremendous discomfort and furious mental activity. During this time, many friends passed through my head. Among the pleasant images, which were few, was eating freshly made donuts for breakfast on the porch of our house in East Alstead, New Hampshire. It became fixed in my mind that the Dean of the Medical School had sent a notice: "Dr. Nelson Fausto died of multiple myeloma the night before." I took this to be true: *I am dead. So I should not spend effort in trying to breathe or become comfortable.* I expected that I would finally be at peace.

But I could still see the monitor of the computer in my room. I thought, I am not completely dead, or I am dying slowly. What poor work people have done in not shutting off the oxygen or giving me an injection of potassium chloride so that I would die quickly!

And so the debate continued: Was I dead or not? I certainly thought that I was dead and tried to remember what one was supposed to feel once dead. I did not have peace, nor did I see angels who would pick me up for transport, or grab my soul for storage. I told myself that probably you see those things only if you believe in them. If you didn't, you would be dying alone.

As this near-death or after-death state continued, I saw myself in a European-style train station. Facing me

was a group of people attached to each other by their waists, with my friend, the Chair of Medicine, in front. He was tall and had on an East Coast-style raincoat. The people were not sad, but seemed instead to be laughing as they tried to have me join the group. I, on the other hand, was desperate, hoping for them to grab me. I could see the end of a train with a caboose and a red light behind it. Inside the train was my beloved sister-in-law who had died a few months before. She was saying, "Nelson, come in." The struggle to catch me went on, apparently, for a long time. Every time they tried, the group lost their grip on me and the train seemed closer. Finally, I recalled being in the hands of the group, looking at the train tracks below, and seeing only the red lights of the caboose, which was traveling far away. Next, instead of being on the train, I was at a lower level of the train station waiting with the group for transportation by horse and buggy to go somewhere where I could rest.

These memories coincided with my waking up and insisting that I was not alive. It took a long time for me to be convinced that I was alive, that I could speak, and that I could see earthly things. The hallucinations took place mostly over Thanksgiving weekend when we were reliant on a young group of residents and attending physicians who may not have been as experienced as the regular attendings. They certainly panicked when they saw my condition, and also realized I was a VIP, which meant that everything that could be done would have to be done. The pressure to find a diagnosis caused them to consider a cerebral hemorrhage and recommend that I have an MRI. As it turned out, the brain scan was entirely normal. After much debate, the consensus was that the whole problem had been caused by an adverse reaction to the drug Baclofen that I was given as an anti-spasmodic after the spinal surgery. Days after the episode, the residents who had given me the drug came to apologize. They told me how

badly they felt about the whole episode. I told them that those things happen, but that I hoped that the mistake would not interfere with their feelings about themselves. They had clearly learned from it.

After recovering from this Thanksgiving delirium, I entered a rehab program but was too weak to continue. When I finally recovered enough, I re-entered and completed the rehab program. I could, with great difficulty, walk with a walker. Still, what a luxury to be out of the hospital.

Several months later in a routine appointment my nephrologist discovered that I was in atrial fibrillation. He admitted me, supposedly only overnight for a cardioversion the next day. The hospital called Ann at 3:00 AM that morning to say that I had been found without pulse or breath, that they had performed CPR, that I was in the ICU, that I was intubated, and to come in. The nurse who had done the CPR told Ann that I had asked for a nebulizer treatment, but that since the orders were for nebulizer treatments only every four hours they had given me oral methadone. No one knew exactly what happened. Did I have a cardiac event? Did I aspirate? Did my panic at not being able to breathe trigger the PEA arrest? Ann got to the hospital in twenty-six minutes only to be told that she could not see me. They told her that she would not want to see me as I was. They did not want her in the way. She waited for an hour, alone, worrying.

The first cardioversion was unsuccessful, but the second worked. A friend whom I had not seen in seventeen years came in as I was waking up after the second cardioversion and the extubation. Ann told me I turned bright red. My friend and others in the room burst into tears of joy and relief. Doctors smiled from ear to ear. I had no recollection of any of this: just that at the time of the arrest everything turned black and a curtain closed. The nurse who did the CPR had been two rooms away at the time I stopped

breathing. She told us: "I was nearby for a purpose."

All of this seemed to be more than enough, but there was more.

Shortly after the cardiac arrest, I fell straight backwards on my head while on Coumadin, my caregiver three paces away and not at my side. I had a subarachnoid hemorrhage and went to the ICU trauma unit for two weeks. Everyone was amazed at my will to live and endure. I was annoyed by all the cognitive questions, which had nothing to do with my cultural background, my state of mind, or my educational background.

Reflections on the year

I'm glad to report that most of the physicians I encountered during my long hospital stays were open and communicative and were not afraid to approach me. Unfortunately there were a few others who came to "examine" me but stayed several steps from my bed with their backs flattened against the wall, or talked at me in meaningless generalities.

At one point I had terrible, intractable diarrhea that was both debilitating and demoralizing. What I needed at the time, but did not get, was human connection and even physical touch. I had terrible trouble breathing. I needed someone who understood the panic that accompanies gasping for breath; instead I got someone talking about generic algorithms, or nutty hypotheses of HIV. Some of the visits from distinguished individuals or young learners provided little or nothing for me, in spite of the visitors' great knowledge.

On the other hand my oncologist inspired me to go on when I needed it most. My nephrologist, who came to the house many times, called many times a day, e-mailed me from an island with a total population of 350, and conveyed a level of involvement and caring that sustained both me and Ann beyond words. And then there was the psychiatrist who I felt dropped out of the sky from nowhere and ultimately

enabled me to say what was in my heart. Instead of talking in hackneyed ways about going on my "journey," he joined me wherever I was—in my house in New Hampshire, in music. And from there I could find my way to telling him my deepest terrors and greatest hopes.

What do I make of all of this? Was it just plain suffering as I tried my best to survive, or was there more to it? For me as a patient/doctor there is the realization that there are many layers to treatment. In my semiconscious interior I saw friends and family that needed to be addressed; in my semiconscious exterior I saw Ann becoming incorporated into me. Can physicians understand that patients have an internal and exterior reality that begs to be dealt with?

Today I look back and say that I died twice. With all of the challenges that were thrown at me, it is quite remarkable that I was able to walk with my walker and function relatively well most days. Unfortunately, more continued to come; it appears to be a situation without end. The damage was both physical and psychological: why do I see my father who died many years ago closing a gate on me, telling me that no more people will be admitted? Is my father closing the door on me? Is there no room for me? Nevertheless I am here to tell you that I am very much alive and fighting to be alive because I like what I have. Out of all of this, new friends have come out of nowhere to join old friends and dear family. The old friends have always been here, but I never knew that I could relate so well to them. These old and new friends have given me a sense of being a person who could be desired and loved.

For the future, I will enjoy what I have, because it is just wonderful. We recently organized a barn contra dance at our house in New Hampshire and I was honored at a symposium at which I was ceremonially given a blanket by a Northwest Native American. I am not a religious person, but I do believe in spiritual things. I never thought a

spiritual experience would happen to me. In the blanket ceremony I felt protected and connected with something beyond what I have could ever have imagined. It defied description. Obviously bad thoughts come all the time, but I try to put them in a corner of my mind and let them escape as rarely as possible. I do not want to deny reality. I only ask to enjoy it.

Afterward

In an act of heroic courage and quiet dignity, Nelson decided to stop treatment. He died April 2, 2012. From the beginning of writing this manuscript to the end (three days before his death), working on it contributed to the meaningfulness of his life. As he grew sicker, his legacy and ways to continue contributing became more and more important to him.

Nelson was accomplished and loving, always with a particularity to the love that made it even more special, and with a unique use of language and authenticity of expression that commanded attention. In turn, he was beloved. Having loved and given, he was loved in return—especially by those with whom he worked closely, family, and friends. Nelson discovered his self in medicine, in pathology, and especially in the relationships he developed. But having lost his mother when he was one year old, and subsequently losing his country (becoming a political refugee in 1964 to escape retribution from the military dictatorship in Brazil), he had a hard time accepting the love everyone gave back to him. He kept giving and contributing. The disease never took away his desire to expand and expand others.

Nelson's biggest fear was of dying alone. He shared that terror, and in sharing was not alone. Several physicians, in particular, went where Nelson needed to go. One he called his brother. The other, as he said, "dropped out of the heavens from nowhere into his life" and changed him profoundly. A third also saved his life in more ways than

one. And another, thousands of miles away, was an anchor.

They knew how to treat a person's soul. They listened. They went wherever Nelson went—which often was to their own lives, or music, soccer, Native American art, or seemingly irrelevant details. But they were wise enough to know that the seemingly irrelevant hides the relevant. Soon enough, these conversational journeys led Nelson to talk about what mattered to him the most.

Nelson wanted his physicians' security, calmness, hopefulness, intelligence, authority, and charisma to serve as a retaining wall against his losses, his sense of aloneness, his anger that his body had betrayed him, his worry that his courage was flagging, and that the illness would grab him and kill him. Such a job is a heavy burden to carry, but some, especially these doctors, these friends, held the load when it was possible, and gave it back to Nelson when it was time to give it back.

The parachuter from the heavens picked up on and carried Nelson's sense that he was crossing a river, but terrified of it. He did not hide reality, but offered the hope that while he didn't know and wasn't religious, he could not help but think there was something good on the other side of the river. I believe that these words, uttered by someone Nelson deeply loved and who he knew loved him, carried him, even as he felt he was drowning.

These physicians had empathy. They knew that people yearn to surrender their defenses, their ways of protecting themselves, and wish to expose their deepest longings. They read Nelson's prose and poetry. They understood that underneath his surface bravery lurked the panic inherent in staring death and infinity in the eyes. While everyone talked about his courage, these friends knew more. They knew the keening aloneness of the critically ill. They joined him in his dark woods, but pointed out the ways to sequester the terrifying thoughts and look at other things, as they groped their way along. They were like landscape architects

who, looking at untended land, could see how to make the place tamable and even beautiful. They shared their agonies with Nelson. Together they wrestled with Nelson's fate. But while it was Nelson's immediate fate, they were strong enough to name, tolerate, and put into perspective their own.

What sick people want most is a capacious grasp of their situation, an ability to speak the truth, truth tempered with wisdom and perspective. Physicians who court dire statistics kill the soul. Physicians who illuminate the possibilities give hope. They know the sick need a good wind behind their sails.

A doctor-who-is-the-patient, in particular, is always thinking about the what-ifs. He needs a companion. Nelson wanted a doctor who could read him, speak to his worries, enjoy him, and appreciate him. These doctors made Nelson laugh and smile. They loved Nelson's smile and told him so. They helped Nelson smile and even laugh at the absurdity of it all. We all undervalue the importance of mirroring. Nelson had a wistful desire for a beautiful relationship with a brother, father, man. These physicians groped for his spirit, found it, and reflected it back. Without such recognition Nelson would have been nothing but his illness. Nelson wanted these special physician friends to be many things, but he also wanted them to admire him, which they showed; for there to be a place to meet and play together, which they did. They understood the importance of surprise and the value of the spontaneity and precariousness of play.

These physicians had something more—something that conveyed the prosody of their humanity, a grace, but mostly a willingness to be vulnerable and plunge themselves into the other, losing their own fears.

His doctors said that they never had seen anyone suffer as much as Nelson. During his five-year battle, in the words of his physician brother: "He showed such resilience, such desire to live, and such tenacious attachment to life that

he would endure almost anything." In asking himself why Nelson kept fighting and enduring, he found the answer in Nelson's quest for freedom: "Nelson was a freedom fighter. He fought for personal freedom in Latin America. He fought for social justice there and in his adoptive country, the United States, where he joined with those who were more vulnerable, who were marginalized, or who were from disadvantaged backgrounds. As he saw his body incarcerated by this devastating disease, his mind continued to fight for freedom, this time his own freedom."

I would add that I think Nelson wanted to continue to love and be loved and to go on fighting for others, which in part was the essence of this article. He wanted to give of himself; to render unto physicians something that might help them minister both to themselves and their patients.

All this says everything about what the physicians gave to me as well. I think Nelson and I spent most of the last two years of his illness in the hospital. When he was unconscious or delirious, they would speak with me at great length—at all hours of the day or night or weekend. I regard, as the most precious of gifts, that they shared their own experiences of family illness and how these life events and the meanings we ascribe to them take up residence. When I had to face critical decisions about Nelson's life, they were able to give perspective and their perceptions of Nelson's desires, creating a pathway for me to find a place of peace and relative tranquility.

As for what Nelson gave me—he gave me everything. He was everything.

Nelson asked me in his last days what a pilot does. I replied that a pilot takes us from one place to another and lands us safely in the new land. This is what these special physicians did for both of us. And Nelson did for me.

Address correspondence to Dr. De Lancey:
9125 View Avenue NW
Seattle, Washington 98117
E-mail: aldalancey@comcast.net