American Journal of Otolaryngology and Head and Neck Surgery

Perspective
Published: 17 Mar, 2026

A Cancer Surgeons Journey- Searching for End-of-Life Clarity

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Perspective

Recently the passage of a law allowing Medical Aid in Dying in New York led me to reflect once more on the challenges faced at the end of life's journey. Many caring for patients with cancer have the ability to compartmentalize and rhetorically close the door on those patient encounters that proved to be the most disquieting.

This week's journey opened many of those doors that I had closed. In all candor writing this has been challenging, disruptive and at the same time enlightening. Yet when I finish the last word and push the submit button, I will close those doors for good.

We all know at some level that life has finality but for most it is abstract in concept until facing death. Some religions believe in an afterlife, while others refer to the soul in each of us that in one way or other lives on. Yet still there is the abstract concept of a force in the universe that will provide for the best of us. Dealing with cancer, I have long believed that death is finite.

"Live each day as if it is your last because one day it will be." (Steve Jobs), More importantly to me, acknowledging no after life in any form, is the question, do I have the absolute right to choose the manner and time of my death, given the concepts of autonomy and capacity? The opinions on this vary from country to country, among religions, politicians, philosophers and ethicists. In attempting to answer the latter, I have spent hours reflecting on the issues at hand. Some reflections will be controversial and I am sure potentially unacceptable to some but I hope my considerations move the ball down the field, if not into the end zone.

It was a cold end of a fall day as I walked the two miles to the VA hospital at 6:00 am. This was the last day of my three-month rotation and as such my last two encounters with Joe. He had been hospitalized at the VA for more than a year. Approaching the door of his small isolation room that had been his for months, the pungent odor of pseudomonas was present. His frail body and sunken face were reminiscent of photos of liberated prisoners of Auschwitz. Worse yet was his right eye -pyroptotic, conjunctiva engorged, cornea opaque giving a visage that couldn't possibly be human. The sarcoma leading to his current level of decline had failed to respond to all therapeutic modalities. It was understandable why he had no visitors including family. He was in a narcotized stupor most of the day. We were both the same age 28. I would see him for five minutes on morning rounds and spend 15 - 30 minutes on evening rounds before leaving every day. I knew his life story. Our formative years were very similar but where I had been given direction, he hadn't. It was now evening and this was my farewell. He would be all alone. As I rose to leave, I held his hand for the last time. I shared that I would never forget him and I haven't. Looking into his good eye, I said I will miss our conversations my friend and then asked if there was anything I could do for him? His response "help me die-I want to die."

After contemplating for a moment, I said I couldn't. I was a doctor and it simply wasn't possible. He made the same request again. This time I had a brief discussion of end-of-life issues as limited as my understanding of such were at the time. It gave him a modicum of control.

From that day on death has never been abstract for me. I knew what intolerable death was. I knew it wasn't fair. It could be associated with inhumane suffering unless physicians were able to help when appropriate. My only regret looking back is that laws weren't in place enabling me to suggest medically assisted death as an alternative at the beginning of my rotation three months earlier.

Before reflecting on ethicists and philosophers' points of view, some rethinking of the implications of verbiage used in the discussion of physicians assisting death is germane. The word

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Received Date: *03 Mar 2026*
Accepted Date: *14 Mar 2026*
Published Date: *17 Mar 2026*

Citation:
Strome M. A Cancer Surgeons Journey- Searching for End-of-Life Clarity. Am J Otolaryngol Head Neck Surg. 2026; 8(2): 1270.

suicide has negative connotations for many of the public, religious leaders and politicians. As such I believe should not be used in the context of physician's involvement in end-of-life issues. Suicide to me represents an otherwise physically healthy individual with the prospect of years of life in the future taking his/her life. It is often associated with a severe situational depression or an untoward event. If suicidal ideation is recognized, therapies and counselling can be lifesaving and have remarkable positive life altering effects. The latter differs greatly from what I prefer to refer to as Medical Aid in Dying (MAID) *versus* Physician Assisted Suicide (PAS). Patients considered for MAID even today in most instances have limited life remaining, usually less than six months and have concluded that continuing to exist would be problematic on many levels.

Using MAID, I believe removes much of the stigma associated with the word suicide and as such eases the patients and family's angst during a more than difficult time frame. Further the patients are in control and can change their mind at any time prior to taking the prescribed medication. Many patients in Oregon receiving prescriptions never used them [1]. Having such preserved their autonomy which surveys has shown to be of foremost concern to those with a terminal illness. Some have raised the consideration that having a prescription might lead to guilt if action wasn't taken. Having a background in psychiatry, I find this argument to be circumspect.

Voluntary Active Euthanasia (VAE) is conflicting for me. It is a direct intervention on the part of a physician being actively involved in taking a patient's life. It is an option in Canada and two other countries. I understand that for some having that option given some religious considerations might tend to help absolve guilt. Yet the ultimate choice to end one's life is a personal and difficult decision. Others may disagree but philosophically for me there is a stark difference between giving the patient end of life options versus direct intervention on the part of the physician. Once made the patient should assume ultimate responsibility and not request a physician to consider violating the Hippocratic oath-"neither will I administer a poison to anybody when asked to do so."

A patient is considered "terminally ill" in my paradigm when all therapeutic options have been exhausted, the disease process isn't controlled and death will occur. Time has relatively little impact on my musings e.g., a six-month death window which many states require for intervention. Alzheimer's is one such consideration. Death will inevitably occur as the patient's cognitive ability wanes leaving at the end a human visage with no humanism. I believe as long as the latter has cognitive ability in the early stages of illness a dehumanizing death is inevitable and they have a right to choose MAID.

Joe's story took place more than 50 years ago. Sadly, religious and political efforts continue to prohibit MAID. It should have a place. The newest programs will be discussed as we progress but for Joe, given the magnitude of his situation, even today I believe MAID would have been the best option. Joe was catholic and perhaps that is why he never raised the consideration of assisted death earlier. Pope Francis, despite being considered a liberal and a reformer, rejected MAID. He referred to the concept as "false compassion" [2] and as a consequence of our 'throw away "culture that dehumanizes the sick. Catholic organizations are often the leaders in attempting to block pending legislation for legalizing death with dignity.

Of interest in the philosophers brief Dworken states "it is a form of tyranny to force someone to suffer needlessly at life's end for the sake of someone else's values."

Today there are approximately 1.4 billion Catholics worldwide. As some observant catholic women choose oral contraception against the wishes of the church, it is my hope that none would choose to suffer the way Joe did. It is not lost on me that many reproductions of Jesus depicted on the cross show him with a tortured expression. He was on the cross for an estimated 6 hours before a roman soldier plunged his sword into his side. I have often wondered if this was in reality an act of compassion. If so, it might be considered VAE and have implications for today for those believing in the concept. Young people are less religious and more are unaffiliated with religion. Further the majority of Americans believe that religious institutions should stay out of politics. MAID is an individual choice at the end of life and in my paradigm need not fall under the umbrella of religion or politics.

Politically, options favouring some active form of assistance in dying remain controversial but the tide is slowly changing. Since 1942 Switzerland has allowed assistance in dying. There are eight independent groups that provide this service. They must report when they have assisted in a death and then its relevance is assessed. Physicians write the prescriptions after assuring that the patients have capacity. Then members of the selected group, chosen for their compassion and caring, bring the medication to the individual and provide support. The person seeking this service must self-administer the medication. Medical tourism for this purpose is allowed. It's very existence serves to illustrate the concerns of some about their tolerance for loss of autonomy and the ravages of impending death.

Canada in 2016 adopted a federal law legalizing MAID and VAE. Of interest is that only a small percentage of Canadians favour VAE. Importantly the Canadian statute does not require that there be a fatal or terminal condition to be eligible for assisted death. From my perspective this is an important step forward in the right to die concept. An elderly individual, for example, diagnosed with early dementia while still having autonomy and capacity could direct that at a certain stage of decline assisted death would take place. The indignity of a mindless viable body persisting for potentially years would be prevented. I realize the small risk posed by this scenario, that at a future time the patient may have considered changing the directive and didn't. My mother never would have changed her mind.

Taking things, a step further, euthanasia is legal in the Netherlands as young as age 16 and parental consent is not a requisite [3]. The law's directives are relatively few and loosely written. The physician must be satisfied that two conditions are met: there must be unbearable suffering without any likelihood of improvement and there are no reasonable alternatives to treat it. As in Canada there is no directive in the law that the patient must be close to death. The Dutch system is purported to give deference to physician's experience etc. It is said to value the physician patient relationship. In this setting, it could be argued that the latter is given too much weight and a series of dedicated checks and balances might be warranted. Further some in the USA, including the ethicist Arras, would probably consider this evidence of the slippery slope concept. For me the inevitable question arises; how expansive is any consideration of an individual's right to die? I pose the question here as I side with the Dutch. It is a decision to be reached solely by a patient with capacity, respecting individual autonomy, and a physician schooled in the nuances of dying. I recognize there is considerable resistance to this view. My answer to the religious issues has been addressed. Further consideration will be given to political concerns but I include the Dutch program as being supportive.

In the USA, Oregon adopted its death with dignity act in 1997. At its inception the Oregon law provided the ability for residents to end life voluntarily with self - administered medication provided by a physician. State residency was required at the laws inception to be eligible for such but that has been officially eliminated. There have been other revisions since. However, it is the basis for models currently adopted by the 12 states and Washington DC at this time. The last one to adopt such was New York in 2026. Currently requisite in all states are capacity, self - administration and a terminal illness. Yet with the countries recent shift to the right, evidenced by the supreme court's current composition, this enlightenment could come under intense scrutiny.

Data from Oregon show there has been an increase in recent years of written prescriptions for assisted death but the number of deaths from taking such actually decreased a small amount and the number relative to total deaths remains small. The aforementioned tends to negate some of the ethicist Arras' concerns that such laws would almost certainly lead to increased MAID and VAE. He contends that both should be prohibited. Given the latter, it is interesting that in some exceptional circumstances where pain and suffering are extreme, he tacitly acknowledges that physician's assistance in death could be meaningful. However, he infers that any such measures be kept under the radar. Given that small concession, one could conclude that at some level he and Dworkin agree on managing pain and suffering. Also, there may be some element of agreement on the necessity to act on other motivations; continuing emotional and psychological degradation and loss of autonomy.

Arras presents two major objections. MAID is an option without limits and there is a likelihood of abuse. He believes that highly predictable shifts will occur from "predictable to merely incurable, from contemporaneous consent to best interests, and from PAS to active euthanasia [4]. Yet remarkably from my perspective he acknowledges that they aren't patently immoral or unjustifiable. These acknowledgements also seem to bring him somewhat closer to Dworkin [5]. They again bring into question the slippery slope issue. Going from PAS to euthanasia would seem to infer a slippery slope consideration- going from passive to active, but if they aren't patently immoral or unjustifiable is that a slippery slope?

To strengthen his second consideration, the potential for abuse, Arras raises concerns about the efficacy of the safeguards established in the Oregon law to protect patients. He contends many requests would not be truly voluntary because of subtle coercive influences of family and physicians. In my experience the family in most cases has been consulted prior to seeing a physician. As such patient motivations and capacity can be independently judged by the physician. In addition, Oregon requires two independent physician evaluations. Hospitalized patients requesting intervention usually get a psychiatric consult. Further, I have never observed coercion by a physician interacting with a patient with capacity when discussing end of life issues. I certainly never did. However, when a patient is totally incapacitated and unresponsive with no prospect for recovery, I believe it both moral and ethical to discuss end of life alternatives with family.

Arras further incorrectly imputes physician's diagnostic skills, stating there is a highly predictable failure of MOST physicians to reliably diagnose and treat reversible clinical depression, particularly in the elderly. The Oregon data refutes the latter. Oregon physicians have very high rates of attendance at courses in palliative care and end of life decision making. Such courses have a large part of the content dedicated to the recognition and management of depression. In addition, the vast majority of physicians treating primarily cancer know that the minute a patient hears the word cancer their level of anxiety increases. Further they recognize in the days following the diagnosis for many there is some element of depression and appropriate medications are prescribed early.

An additional assertion he makes is that reporting systems would not properly monitor MAID procedures. There is nothing that I could find in any of the available information reviewed that suggests this assertion has legs. However, it would be reasonable to consider that to protect patient requested confidentiality, limited underreporting could occur.

Arras also "confidently predicts that all reasonable alternatives will not have been discussed" relating to pain and suffering. The latter and many of his other unfortunate comments noted above and refuted regarding physician's diagnostic skills and practices are factually inaccurate and are patently biased. These transgressions are sufficiently significant that dismissing his essay as irrelevant, I would not find to be objectionable. One might also suggest that he is on a slippery slope to philosophical and literary irrelevance.

In fairness Arras is correct about "the new turn style medicine" potentially limiting the depth of discussion. Many of us have vociferously rejected the time limiting patient interaction and other constraints attempted to be placed on physicians by profit driven hospital executives. Every one of my new cancer patients had an hour allotted on their second visit to address all questions and allay fears. More time is typically allotted to patients with recurrent disease. I don't believe turn style medicine promotes discrimination as alleged. My practice from day one has never charged a patient who claimed an inability to afford my services.

Dworken 5 addresses some of Arras' concerns in the philosophers brief stating "the state may declare that it is unable to provide adequate protection for the ill-informed, unstable, foolish or sufficiently independent from mistakenly choosing death".

I have pointed out some small areas of potential agreement between the 2 philosophers.

However, although open to pushback, I found Arras' major points and concerns to not be sufficiently factual, biased and less than forthright. Dworkin's thought sequencing was nuanced, documented and inclusive. From my perspective, they seem to exist on different planets.

Before focusing on the present, let me summate with further considerations that weren't covered or others warranting additional support. As stated, I believe that life and death decisions are best handled by the physician patient relationship. Some would see physician assisted death limited to the terminally ill. In that consideration life is beyond salvage and that gives some potential comfort. That is considered by many but certainly not all to be moral and ethical. Both the Netherlands and Canada are more inclusive in their views. A life threating illness isn't disqualifying. The Netherlands and Swiss systems prioritize the physician patient relationship. One can philosophize about such decisions but when faced with a patient expressing in real time with incredible emotion, uncontrollable pain, suffering, profound mental fatigue, family stressors, financial issues that hurt, ongoing loved one's angst, physical deterioration and the creeping loss of autonomy, the abstract goes out the window. If you haven't been in the room, decisions should be left to those who have. No one knows for certain what lies beyond deaths door. Yet as an agnostic, if something does exist irrespective of the way life ends, the way life was lived will determine access.

My final considerations will reflect years of successfully extending life with the understanding that those pleasant memories merge into one confluence. The deaths on the other hand remain individual, personal lasting memories of people who despite my best efforts died horrible deaths e.g., Joe. MAID for many years was the only alternative- a single prescription designated to relieve pain and so directed, yet potentially if abused giving the patient autonomy.

This last week I have spent seemingly most of my available waking hours considering end of life.

This time was dedicated not only to reflection but attempting to integrate the best modern options available to making the last journey as pain free as possible and memorable for those remaining. It has become clear to me that one has to reflect on the totality and meaning of one's life, if the best choices are to be made at its closing. Each life is individual and must be treated as such. Those differences can be stark. I recall an Asian American citizen having been herded into a camp in his own country during the second world war; several Nazi holocaust survivors; a vice president of GM who fought in the rice fields of Vietnam with exposure to agent orange with an incurable agent orange induced malignancy. His country never acknowledged the obvious carcinogenic effects of that deadly product. The 48-year-old African American woman dying of metastatic tonsil cancer after all she endured, living an impoverished life, experiencing prostitution, physical and mental abuse, drug addiction and aids. Let me reiterate- being in the room changes your concepts of how life should end. In those years all I had to give these folks was my time to listen, to empathize, to let them know that I was doing my best to understand, to hold their hand, tell them I cared and provide pain medication. Praying didn't relieve the pain. Political machinations didn't relieve the pain. Philosophizing didn't relieve the pain. Being in the room with them helped.

Thankfully 20-30 years later we are more enlightened and the landscape has changed. The two most dramatic and welcomed advances are hospice care and palliative care. At the moment the difference between the two relates to ongoing care. Palliative care physicians and units will accept patients with a terminal illness still receiving life prolonging medications. Many of the best hospitals now have dedicated palliative care units staffed with palliative care physicians. The latter care primarily for end-of-life patients and they are remarkable. They are expert in pain management, depression in the terminally ill and managing the differences and intricacies of a body slowly shutting down.

The palliative care unit at the Cleveland Clinic was a welcoming space, spacious and bright with areas for congregating. Families were welcomed and importantly came because of the environment which was anything but depressing. Hospice does not currently as a rule accept patients on life extending medications even though terminally ill. They do provide home care services which are exceptional with individuals trained to do such. As the inevitable decline proceeds, patients are offered the opportunity to transition to a hospice facility. Then care is very similar to that in palliative care units. Most of the costs for either are covered by insurance and for those incapables of paying hospice care is usually covered. Autonomy is respected in both as long as there is capacity. These units decrease the need for MAID, yet for some fearing hospital environments and not trusting the system as unfortunately happens far too often in our underserved communities, it still is needed. Further terminal illness patients with entities such as ALS and Parkinson's disease with Lewy body dementia may opt for MAID earlier in the course of their illness. As an alternative, patients may choose to stop eating and drinking, death although variable, usually coming in about two weeks. Home hospice can provide comfort measures during this interval if requested.

My most recent paradigm for patients with a terminal illness was as follows:

Several patient encounters during which I tried to understand their life's journey, there short-term goals and priorities. These sessions were interactive with family present if requested.

Then all options would be discussed. My suggestion was always that hospice or palliative care should be tried first when appropriate. They were informed that their pain would be for most part controlled and that anxiolytics and or antidepressants should be started.

If they were uncomfortable with the latter, then the alternatives of MAID and cessation of food and drink were discussed. VAE was the last consideration as I have philosophical issues with it but acknowledge the Canadian data. My personal concerns were not shared unless requested.

After this recent immersion in self-reflection, end of life and all I learned in preparation for writing this paper, dying with dignity still prevails. I feel blessed to live in a world where I have the option to choose the time, place and circumstances of my death.

In closing it gives me comfort to believe If one's life is well lived, selfless, moral, ethical and hopefully in some small way having contributed to the betterment of all, footprints left in the sand can become indelible.

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