



**Paralyzed Veterans
of America**

New England Chapter

July 6, 2020

Secretary Marylou Sudders
Massachusetts Office of Health & Human Services
1 Ashburton Place, 11th Floor
Boston, Massachusetts 02108

Secretary Sudders:

Paralyzed Veterans of America is privileged to be a part of the coalition meeting with you on July 8, 2020 to further the discussion of the Massachusetts Crisis Standards of Care. I write to you today in support of coalition's efforts and to ensure the voices of our paralyzed veterans, in their own words, are a part of this discussion.

In times of extreme crisis, many legal restrictions can be loosened to meet unique demands and maximize resources. For example, the Department of Health and Human Services (HHS) recently waived a number of federal regulatory requirements enabling hospitals to respond to Covid-19 with State guided Crisis Standards of Care (CSC). Even though Officials' emergency powers can be wide-ranging under CSC conditions, the ability to discard anti-discrimination protections is not among them. To ensure these protections remain untouched, HHS's own Office for Civil Rights (OCR) issued a bulletin stating "entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion".

Roger Severino, OCR Director stated in this bulletin, "HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal". Additionally, Severino added, "Persons with disabilities, should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism".

What concerns me the most are the difficult choices that will arise when triaging patients under these CSC conditions. These choices will put life-threatening pressure on HHS's commitment, and ultimately that of the local healthcare systems. They concern me because although a Veteran may primarily receive their healthcare through the Veterans Affairs Healthcare System, under COVID-19 conditions they may find themselves seeking immediate treatment at a local public community care facility. In this circumstance, there is no differentiator in determining the services provided and/or received by a Veteran. More importantly, there is no medical history with which the community care facility can refer to in determining any underlying or pre-existing conditions and their treatment status. Given the unique needs and requirements for treating Veterans, having this information is critical to properly diagnose and treat them.

Massachusetts CSC policies state, "To the extent resources become scarce, maximizing benefit will involve saving the most lives and saving life-years. This will involve determinations of eligibility for critical care resources based on a combination of prognosis for immediate and near term survival." As part of this prognosis it additionally states, "Healthcare providers making allocation decisions should not consider



Paralyzed Veterans of America

New England Chapter

characteristics that have no bearing on the likelihood or magnitude of benefit. Factors including but not limited to race, disability, gender, sexual orientation, gender identity, ethnicity, ability to pay, socioeconomic status, perceived social worth, perceived quality of life, immigration status, incarceration status, homelessness or past or future use of resources have been taken into account in development of this framework. These will not be used to limit care, and efforts must be made to ensure that the application of the framework does not result in disproportionate negative impact on individuals from these groups or with these characteristics.”

Yet, this policy also states, “Patients who do not have a severely limited near-term prognosis due to advanced underlying medical conditions are given priority over those who have such advanced conditions that they have a very limited near term prognosis even if they survive the acute critical illness.” The nearly 1000 members I represent, including myself as a paralyzed veteran, all fall into this category of having “advanced underlying conditions” which could be viewed as having a “limited near term prognosis” as compared to some abled-bodied persons.

Determining a person’s life expectancy after an injury or illness is simply impossible, and one might say to attempt it is just an educated guesstimate at best. For example, after I sustained a catastrophic spinal cord injury my prognosis was extremely uncertain. By some indications, it was thought I might not survive the next 24 hours, but thankfully, 20 years later I’m still here. In these 20 years I’ve never been hospitalized for any injury related conditions, illnesses or otherwise. Other than my spinal cord injury, I have, and continue, to live a very healthy and productive life. I’ve gotten married, raised a daughter, work fulltime and regularly volunteer my time.

Incorporating one’s life expectancy into any equation leaves out the intrinsic value of the experiences and knowledge gained over their lifetime. In speaking specifically of Veterans, these are our Nation’s greatest treasures, having selflessly suffered and sacrificed so much for our country. Their lives are inherently part of the fabric that makes our country what it is.

“Our veterans left everything they knew and loved and served with exemplary dedication and courage so we could all know a safer America and a more just world. They have been tested in ways the rest of us may never fully understand...let us show them the extraordinary gratitude they so rightly deserve...” – President Barack Obama.

Limiting the lives of these men and women, in any manner, is just unconscionable. In doing so, you’re not only robbing them of any opportunities to experience the life that still remains ahead of them, however long or short that may be, but also the opportunities of others to share in that life with them, as well.

As another example, I had a close friend who sustained a severely catastrophic spinal cord injury. At the time of his injury his anticipated life expectancy was ‘determined’ to be from 1 to 5 years. His Physicians actually gave him the choice of whether or not to be removed from the life-support he was currently on. Thankfully he chose life, and in making that choice, he lived for another 10 years. It was more than ample time for him to see his children graduate from high school, get married, have families of their own, and experience the birth his grandchild. Had someone predetermined his outcome through a ‘Points System’ and only provided



Paralyzed Veterans of America

New England Chapter

him the palliative care allowed, and not the lifesaving treatment he did, he would've missed all these life enriching experiences, and more importantly, so would the rest of his family with him.

In prematurely ending anyone's life, you also break the chain of knowledge and experiences handed down and shared from person-to-person, family-to-family, generation-to-generation. For Veterans, telling their service stories is a time-honored tradition for sharing these experiences and knowledge. Once that life is extinguished, the knowledge and experience it held is irretrievably lost forever. I often think of the passing of my own mother 6 years ago, who I still have so many questions to ask of but will sadly never know the answers to them.

HHS OCR Director Roger Severino summed it up best when he said, "Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism".

Paralyzed Veterans of America was founded in 1946 by wounded heroes who made a decision not just to live, but to *live with dignity as contributors to society*. Since then, we have been tirelessly working to change lives and build brighter futures for our seriously injured heroes. We have had a single-minded mission—to empower our brave men and women to regain what they fought for: their freedom and independence.

Sincerely,

Michael G. Negrete
National Director, Chapter President and Paralyzed Veteran
United States Marine Corps and Coast Guard Veteran

New England PVA member statements:

Dr. Samuel Jay Keyser

Mr. Michael Guilbault

Mr. Peter Falcione

Mr. Mark Murphy, Executive Director



Statement from Dr. Jay Keyser

I was seventy-eight years old when I had my accident—a fall while exercising that injured my spinal cord and paralyzed me from the chest down. In a nanosecond, I had left the “normal” world forever and entered the world of tetraplegia. First things first. I underwent an operation, a laminectomy, that relieved the pressure on my spinal column. I spent 9.5 hours in an operating room. A week after the operation a postoperative infection meant another three hours under the knife. This time around the surgeons discovered a hole in the membrane surrounding my brain. Fluid was leaking out and my brain was sinking inside my skull. The doctors patched the hole with muscle tissue. When I returned to the ICU, the word was my 78-year-old body would probably not survive. They were almost right. My heart stopped beating. Then, unwilling to take no for an answer, it started again. A few days later, a doctor I hadn’t seen before—I think he must have been a resident—stood at the foot of my bed and armed with all the accoutrements of medical authority, a clip board, a white coat, a stethoscope, a pocket protector filled with pen-shaped gadgets declared that while my operations had been a success, he was sorry to inform me that I would never walk again.

Given my background—I have a PHD in linguistics—I suspected he was basing his judgment on aggregate information; that is, on probabilities. But probability is just another name for ignorance. When he made his pronouncement, I said to myself “F**k you.” What I said to him was, “I’m sorry to hear that.” The truth was I didn’t believe him for an instant. He knew nothing about me, my character, or what made me tick. He didn’t know what I was capable of. My injury was “incomplete.” That means my spinal cord was bruised but not severed. It’s an odd name for an injury, as if the accident hadn’t done its job properly. But it also meant that whether or not I would walk again was up to me, my body and luck.

My rehabilitation began at MGH and continued at Spaulding Rehabilitation Center in Charleston, Massachusetts. Spaulding, though one of the best rehabilitation facilities in the country, was focused on the bottom line. When I entered Spaulding, I immediately came down with *Clostridioides difficile* (C-diff), a highly contagious bacterial infection that frequently accompanies major operations. The heavy dosage of antibiotics upsets the balance of intestinal flora and allows C-diff to run wild. It is a dangerous infection. One in eleven sufferers OK over the age of 65 die of related infections. Clearly, Spaulding had to quarantine me. I remained in my room for a month unable to take advantage of the magnificent facility I had entered. And then I ran into the “length of stay” problem. When I emerged from C-Diff, Spaulding focused not on rehabilitating me, but on getting me out of there. Why? My insurance was about to run out. If I couldn’t pay, I couldn’t stay. I will be forever grateful to the case manager at Spaulding who discovered that I had been in the Air Force a century earlier. She thought I might qualify for admission to the VA hospital in West Roxbury. She was right. I entered the VA Hospital in West Roxbury on my 79th birthday. That case manager couldn’t have given me a better birthday present. The VA didn’t care about money or my age. All they were concerned about was how much they could do to bring my body back to whatever potential lay within it. In other words, being completely unfettered by insurance companies, they were able to focus all their attention on healing me.

I was an inpatient at the West Roxbury VA for over four months, then an outpatient. (I still am. Once in the VA family, you never leave it.) It was as an outpatient that I took my first step. Within six months I was able to walk a mile a day. But that number is not the important thing. I have written two books since my rehabilitation ended. I am currently working on another. But even that is not the most important thing. The



**Paralyzed Veterans
of America**

New England Chapter

most important thing is that my wife is not the widow of a husband who is still alive. She is completely untethered from me because, thanks to the VA, I am independent in my home.

Life is incredibly precious. To protect it and make it as livable as possible ought to be a primary goal of every government. The VA did that for me. I hope the State of Massachusetts will do as much for its citizens.

Dr. Samuel Jay Keyser, Professor emeritus, MIT

Member New England Paralyzed Veterans of America

United States Airforce Veteran

The Mental Life of Modernism, MIT Press, 2020

Turning Turtle: Memoir of a Man Who Would 'Never Walk Again,' amazon.com, 2020



**Paralyzed Veterans
of America**

New England Chapter

Statement by Michael Guilbault

Predictions of five-year prognoses should be eliminated from state guidance. Five years is a significant amount of life. Much can occur in that timeframe, such as graduations or new births. It would be incredibly unfair to use a five-year prognosis to exclude any patient from receiving medical care.

After my accident, the diagnosis was that I would not make it through the night. When someone was called in to ID my body, I was still alive and although they were told I wouldn't survive, I'm still breathing twenty-five years later. There is no way to adequately predict a patient's chance of survival; especially, when a spinal cord injury (SCI) or other serious preexisting condition is present.

Due to my SCI, I have respiratory issues which puts me at an increased risk of COVID-19. I've also had my spleen removed, so my immune system is further compromised. I don't feel that should decrease my chance to receive treatment should hospitals become overwhelmed.

The need for visitors able to assist in the care of patients is also a very important point. I have a friend with Wilson's Disease and another with ALS. They are both non-verbal and rely completely on their caretakers to communicate on their behalf. It would be totally unacceptable to deprive them of those they trust to speak for them, especially in a medical emergency. The caretaker's knowledge can also educate the medical team that is caring for the patient.

I've been spoiled with great care at the VA and have only had to go outside the VA System once, for a medical issue that occurred when I was traveling in another state. I have no desire to go outside of the VA for medical care, but if in an emergency the VA was full, I would seek care at a non-VA facility for COVID-19.

Michael Guilbault
Vice President, New England Paralyzed Veterans of America
United States Air Force Veteran



**Paralyzed Veterans
of America**

New England Chapter

Statement from Peter Falcione

I'm seventy-seven years old and have Multiple Sclerosis (MS). According to this document, if hospitals were to become overwhelmed then I would not be eligible for life saving treatments because of my age and medical condition.

This policy insinuates that I am a perishable item not worthy to save because I'm near the end of my life. I may be feeble but that doesn't mean it's okay to bypass me for someone else. The government cannot decide when it's my time, only God can. The Crisis Standards of Care guidance reminds me of the Nazi death camps. Those who can't be a worker, or who are too old and aren't of use, are eliminated.

I may be feeble, but I have a mind like a trap and can advocate for myself. I also spend a great deal of time advocating for others, as I'm a director on several boards. I push myself as much as I can and try to impart that to anyone else who has this disease.

I began serving this country when I was 25 years old. I went through infantry school and basic training, all while suffering from the beginning of MS. No one even knew of it at the time. I then got through Vietnam and was awarded a Purple Heart and a Bronze Star. I returned home to have people throw tomatoes at me. I've been through it all and persevered. I knew I could never give up, and I won't now.

I believe that states should follow the path of New York and focus on dual-purpose facilities (for example warehouses, arenas, or ships) to be readily available for medical responses during crises and non-medical usage for the community during the steady state. This would help with overflow issues in a much more effective way than determining who should receive life-saving care.

Peter Falcione

Board Member, New England Paralyzed Veterans of America

Vietnam Veteran, Purple Heart and Bronze Star recipient



**Paralyzed Veterans
of America**

New England Chapter

Statement from Mark Murphy

As Executive Director of the Paralyzed Veterans of America, New England Chapter (New England PVA), and as an Army veteran myself, I take very seriously our mission of health care advocacy and our work of breaking down barriers encountered by paralyzed veterans and all persons with disabilities. Especially in these challenging times and the impact of COVID-19 on so many vulnerable people and communities, the health care needs of our members have become even more urgent.

The spinal cord injury and disease (SCI/D) population is one of VA's most susceptible populations to this pandemic. Our members with SCI/D are not only in a high-risk group for the virus, but also for other health issues and the disruption of daily life, including the ability to access essential services and supplies. Many of these needs are immediate, and some will have a significant and long-term impact. Those with SCI/D are one of most susceptible populations to COVID-19 because they inherently suffer from two of its major underlying risk conditions – compromised immune and respiratory systems.

At New England PVA we are very concerned about our members who have been falsely labeled as having major co-morbid conditions with substantial impact on long term survival when they are treated in community hospitals, rather than at VA facilities. With the rationing of ventilators and other essential equipment and supplies, from an ethical standpoint this reality has become even more alarming. If our members were to seek treatment outside of the VA system, especially with their underlying health conditions, their lives could be in danger. Finding ways to protect their access to specialized services within the VA, including the SCI/D system of care, is of paramount important for us at the New England PVA as we advocate for our members well-being. Fighting for this will make a significant difference in the lives of our seriously injured members, who truly are heroes.

Mark Murphy
Executive Director, New England Paralyzed Veterans of America
Army National Guard Veteran