Testimony of Gloria S. Bent to the US. Senate Permanent Subcommittee on Investigations

May 17, 2023

Senators, thank you for the opportunity to tell my family's story of the impact of Medicare Advantage practices on our lives in the midst of my late husband's significant health crisis.

Please meet my husband of 56 years, Dr. Gary Dean Bent, father, teacher, research physicist, mentor. For six years he was in treatment for cancers at the University of Connecticut Health Center - first Hodgkin's Lymphoma treated with aggressive chemotherapy and then metastatic melanoma, treated with surgery, radiation therapy and two years of immunotherapy.

This time last year my family was celebrating with Gary that one year after the conclusion of his immunotherapy, MRIs and CAT scans continued to show no evidence of melanoma's return. We rejoiced! Then, the morning of Memorial Day 2022 Gary asked to be taken to the emergency room at the Health Center. "Something is not right in my head,“ was his diagnosis. "I'm bumping into walls, I can't remember how to tie my shoes." Within half an hour of our arrival at the emergency room a CAT scan confirmed his diagnosis; what was not right in his head was the presence of a lesion in his brain that was bleeding.

On June 1, 2022 the lesion and a hematoma were removed surgically and the ER suspicion that it was a melanoma was confirmed by pathology. Gary came out of surgery with significant cognitive and mobility impairments. He was confused, could not stand on his own or walk, and he had left neglect - meaning his brain no longer recognized that there was a left side to his body. His neurosurgeon, and the physical therapist and occupational therapist treating him post-op said he needed follow-up treatment in an acute rehabilitation and skilled nursing care center to regain some of the functions he had lost. We were given the names of three such highly specialized centers in our area and we applied to all three. Of the three, Gaylord Hospital for Specialty Care in Wallingford had a bed and accepted him as a patient. Gaylord has an outstanding reputation and we were pleased that he would be receiving their services.

Enter the Medicare Advantage " barriers accessing necessary care and treatment" your committee is asking about. We were told to expect his transfer to Gaylord on Wednesday, June 8. No approval from our Medicare Care Advantage provider had been received so the transfer was delayed. Finally, on a Friday afternoon, June 10, I received a call from our case manager at the hospital. United HealthCare, via something called naviHealth had just denied the request for acute rehab services claiming that Gary did not meet Medicare guidelines because he "wouldn't be able to withstand the intense therapy schedule." His surgeon and post-op physical therapist actually treating him, prescribed acute rehabilitation services, but someone, somewhere, in naviHealth, after reading his chart, decided he wouldn't be able to handle the therapy.

I asked if we could appeal the denial and was told the doctors had already appealed and lost. The next step was for our family to review local short term rehab and skilled nursing facilities in the area and submit three names to our case manager who would apply for services. Then the approval process would begin again. Never having had his treatments denied before I accepted this and spent the week-end in search of another facility.

Around June 13th his admission to Seabury Health Services in Bloomfield CT was approved by United Health Care/naviHealth for three days and he was transferred on June 14th. Shortly after his admission there we were told he would be assessed by physical therapy, occupational therapy and speech therapy. On June 27 I went to a plan of care meeting with Seabury staff to get the results of his assessments. Prior to this meeting I had already received a phone call from a naviHealth representative who was going to "help" me through the process. Before the Seabury assessments were even complete, she told me United HealthCare planned to discharge my husband on July 4th and that it was now my job to secure the safest possible housing situation for him to go to on discharge, based on the worst case scenario- that he would be a permanent wheelchair user. She strongly suggested I arrange for self-pay long term care and, failing that, since our home was not wheelchair accessible I should move - by July 4.

I was still processing that my spouse, holding a doctorate in physics could no longer tell time, didn't know the date, couldn't remember we had visited him each day and felt abandoned, might never regain mobility — I had neither the emotional nor financial wherewith all to pick myself up, dust myself off and in two weeks, create a new home for us all.

It was at the June 27 Seabury meeting that I learned all of us were going to have to fight - Gary by working hard at his therapies to regain functions and my daughter and me by withstanding the assault on services and coverage that naviHealth was going to launch. My telling the Seabury staff that I had been contacted by naviHealth filled the room with groans. They then outlined exactly what was coming our way in terms of attempts by naviHealth to deny payment by Medicare as soon as they possibly could. It unfolded exactly as they said it would, based on their past experience with other patients covered by Managed Medicare controlled by companies like United Health Care.

July 4th passed with no discharge demand. I heard from the naviHealth representative on a regular basis, usually to tell me of a coming discharge date - July 10th, July 15th, in two days. All of these calls filled me with anxiety. Meanwhile she called Seabury and reviewed Gary's health records regularly. Gary was receiving therapies six days a week and sooner than we thought might be possible he was able to transfer from bed to wheelchair, wheelchair to walker, walker to toilet with the support of two people. He was a fighter!

Our first notice of nonpayment of medicare coverage arrived on July 23 with a discharge date of July 25. The denial process goes like this: a Notice Of Medicare Non Coverage (NOMNC) is received by the facility providing services to the patient. The facility is responsible for notifying the patient or their agent of the NOMNC. The patient or agent then has 24 hours to appeal the denial to Kepro - the Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO). Kepro, according to Kepro "helps people who are on Medicare - and their families and caregivers - to file quality of care complaints and hospital discharge and skilled service termination appeals." A Kepro reviewer examines the reason for termination of services and the patient records and then deems the termination to be appropriate or inappropriate. Once the appeal is filed the discharge is on hold and coverage continues until the review is complete.

Seabury was ready for the July 23 denial, notified us promptly of the NOMNC and I filed an appeal with Kepro. On July 24 we were notified the reviewing physician for Kepro found the denial to be inappropriate, noting "You require minimal to maximum assistance with transfers. You appear to be making progress with skilled therapies. It is safe and appropriate to continue the present level of therapies and services. Based on this documentation, the independent physician has decided that you require skilled services."

We had won our first appeal. Gary's care continued, he and his therapists continued to work hard and he was able to move to one person assisted transfers and he was able to take some steps in the hallway using a walker. He wore a gait belt, got significant support from a therapist, and was followed by someone with a wheelchair so that when he needed to take a break he could. Those breaks came frequently, but he was up walking.

August 2 we received our second NOMNC - late on a Friday afternoon. Again, Seabury was ready, we were notified promptly and able to file our appeal in time. Again the reviewer for Kepro found the denial inappropriate; "With therapies, you require moderate assistance for bed, mobility, and toilet transfers. You require supervision for sit -to -stand and can walk 60 feet with a walker and contact guard assistance. You are dependent for stops. You require maximum assistance for upper body activities of daily living …. Given your functional status as well as discharge plans for home you would be at high risk for decline. It is safe and appropriate to continue present level of services. The independent physician has decided you require skilled services."

We had won another appeal and Gary's care continued. Therapists continued to work on use of the walker and, because we had made the decision to bring him home on discharge, the care plan now included instructing our daughter in assist techniques and assessing Gary's ability to transfer from wheelchair into our car. The plan was for him to return to oncology and immunotherapy to hold off further melanoma spread when he had regained some strength and he could safely transfer chair to car, car to chair.

While we were supporting him with frequent visits to Seabury we were also looking for wheelchair accessible three bedroom apartments, because we would have to combine two households into one to provide the 2 to 1 care provider to patient ratio we were told we would have to meet to care for him at home and receive at home support.

We had been told that once a patient had won a couple of appeals, the naviHealth pattern was to speed up the denials - the more appeals the patient won, the faster the denials would begin to come afterward. True to pattern, we won appeal 2 on August 3 and the next denial came four days later. That appeal we lost. Four days after concluding he would be at risk of decline if denied services and with no remarkable changes in his status that I observed, the Kepro reviewer said, "Based upon a complete review of the medical record, the beneficiary may benefit from additional skilled services: however, continued daily skilled nursing and therapy services in a skilled nursing facility (SNF) are no longer reasonable and necessary. Additionally, continued stay in a SNF is not required to maintain the beneficiary's current condition or to prevent or slow a further decline."

He was discharged on August 7th. On discharge I was told Medicare Advantage would provide a hospital bed rental and I would be contacted in a few days by the approved rental company. Unfortunately I needed a bed for him the next day, so we had to rent at our expense. When I asked about a wheelchair I was told Medicare Advantage considered him mobile, so no chair.

The denial of coverage beginning August 5th meant our daughter did not receive the training in helping him transfer that we had been promised by staff. Nor did we get to learn how to facilitate his transfer from wheelchair to car. I asked that he come home via ambulance. We would have to make do in an inaccessible apartment until we could move into the accessible apartment we had found in Hartford.

Gary arrived home from Seabury at 7 pm. The EMT who brought him noted that Gary seemed very warm, was probably running a fever and had complained about headaches and neck pain whenever they crossed a bump in the road. Gary was unable to do any of the transferring he had done in Seabury and seemed to be disconnected and out of touch with us. He was running a low grade fever; we gave him Tylenol and monitored him through the night. We struggled to assist him with transfers from wheelchair into the hospital bed we had rented. Early the next morning his fever was elevated and it was very difficult to rouse him. When we did rouse him he did not know who he was, where he was or who we were. He was immobile. We called 911, EMTs arrived, told us they thought he had an infection, and they transferred him to the UCONN Health Center emergency room. August 8th, after being home 11 hours, he was admitted to the hospital, underwent many tests and was ultimately diagnosed with meningitis. He had been discharged from the skilled nursing facility the aforementioned Medicare Advantage Plan determined he no longer needed with bacterial meningitis. He remained at Dempsey Hospital on IV antibiotics until early September.

He was discharged home to our care, still on IV antibiotics in early September because he had developed COVID while in the hospital. The hospital wanted to send him to one of three short term care centers in the state that took covid positive patients. After reading the reviews of the facilities we opted, Covid or not, to bring him home with us.

We cared for him 24/7 with support from Masonicare. While fighting meningitis he lost all of the abilities he had regained at Seabury. He received physical therapy and occupational therapy through Masonicare and was on his way to recovering some of those lost- yet- again skills - pulling himself into a standing position using a walker, beginning to take small steps with support and the walker in preparation for regaining the ability to transfer. He continued to plan via telehealth with his oncologist for a return to immunotherapy. In December, while fighting a urinary tract infection and the side effect of extreme fatigue caused by the antibiotic he was taking, Masonicare physical therapy was terminated because he was no longer making progress. The infection and fatigue, we were told, could not be considered in his recertification of services. He wasn't making progress. He seemed to lose hope when the therapists stopped coming. In mid January with the discovery of nodules in both lungs, his primary care physician told him it was time to move into home hospice care and Accent Hospice Care became our supporters. He died at home on March 3rd, 2023.

The last ten months of his life were devastating for all of us - physically and mentally exhausting, always overshadowed by the fear of what service would be denied next. With the reappearance of melanoma in May of 2022, a rug was pulled out from under us all, then came the added trauma of having to fight for the care he needed and was entitled to. This should not be happening to patients and their families. It is cruel.

Our family has come through this experience struggling with this question: Why are people who are looking at patients only on paper making decisions that override or deny the services that are judged necessary by health care providers who know their patients, are interacting with them in person and in some cases have been working with them for months or for years? We hope that the result of this hearing will be real change in the ways decisions are made about the services managed medicare patients receive, that providers will drive the decisions and that the primary goal will always be to provide the best possible care for the patient. We want no other family to have the heartbreaking experience we did.

Gloria S. Bent