Caring for patients near the end-of-life at Mayo Clinic: A narrative

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Article abstract
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CARING FOR PATIENTS NEAR THE END-OF-LIFE AT MAYO CLINIC: A NARRATIVE

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ABSTRACT

I'm a palliative care and hospice doctor focusing my clinical care on families near the end of life. It has been a great privilege to be welcomed to the bedside of so many seriously ill and dying patients to care for them and their families. Pursuing geriatrics and palliative care were not always met with welcome sentiments from my peers. “You’re going to take care of sick and dying patients.” “It is so depressing.” My experience is that geriatrics and palliative care are a little like peeking through the old skeletal keyhole into a living room. You have to get up real close to peek inside and if you dare to go through and enter in, a whole new world opens. It is often a sacred space. A space for a team of professionals caring together.

KEYWORDS: Hospice; Palliative Care; End of life; Communication in health care; Geriatrics

Last year, while still sipping my coffee and preparing for hospital rounds, I received a page from a concerned intern Courtney. Not even having completed her second week of internship, she found herself managing the care of a young 42-year-old father of 3 in the intensive care unit at Mayo Clinic. Remembering my intern year, I could relate to what I had experienced as having more responsibility than experience or knowledge. A native of a rural state from birth through medical school, Courtney shared, she had worked with palliative care in Medical School and consulted them often. Perhaps, she was telling me that to telegram that she was comfortable handling this situation without palliative medicine input or that...
she was excited to partner with us. I wasn’t certain. One thing was for certain, Courtney knew her patient and knew how to present the case succinctly.

Anyway about it, on morning ICU rounds her attending ICU consultant had requested she place a palliative medicine consult. The text page read: Please call ICU, Urgent, Courtney 3-XXXX.

“This is Dr. Ingram, consultant on the palliative medicine service. Thanks for calling. How may I be helpful?”, I said. Courtney was thoughtful, kind, and got to the point of her call.

Courtney said, “My ICU consultant, Dr. Rogers, asked me to call you because you may be helpful for us and our patient.” Once again, I wasn’t certain if this was a vote of confidence or a questioning of the need for our input. Courtney went on, “You see, we have a 42-year-old gentleman Mr. Marten, Mike, in the ICU with end stage lung cancer metastatic to his liver, lung, and brain. He exhausted all treatment options and they recently declined hospice care at home in a neighboring state.” I affirmed understanding, “OK.” Courtney continued, “now he is here, full code, with liver failure, dehydrated, possible pneumonia, barely responsive, and his wife Kate and several family members are crowded in his room praying for a miracle.” Courtney paused briefly and in an almost slow motion like cadence said, “They want a miracle.”

Once again affirming understanding, “OK.” “We think he is dying and the only response they give our team when we talk about how to care for him is that they are hoping for a miracle,” Courtney said. Once again affirming understanding, “OK.” “It’s really challenging because Kate and Mike have 3 young children who are being kept from seeing him until he gets a miracle,” Courtney sighed sounding respectful and overwhelmed. She continued, “We’re just not certain what to do and our ICU nursing staff is concerned about “Coding” him when he dies.” Having reviewed scans, labs, and notes while Courtney was talking, I said, “Sounds like a difficult situation. How about I come up and we can meet with the family.” “Yes please,” Courtney replied. “See you in a few minutes,” I said.

Intern Courtney was caring for Kate and Mike, and Mike lacked capacity and his wife represented his care and goals of care as summarized in the grand statement, “Hoping for a miracle.” I imagine that many of you may have experienced this before. Not an uncommon experience. Being a weekend, I was alone and without my trusted team. I would have to do my best all by myself. I’ll take you to the bedside in a moment, but first let me tell you what is already on the agenda for the rest of the morning.

Later that morning, I was scheduled to hold a care conference that had been planned for Saturday morning at 11 a.m. to accommodate the patient’s adult children’s work schedule. I was to meet with Fred and Julia. Married now for more than 6 decades, unkind and uncharacteristic behaviors now punctuated Julia’s ongoing steady cognitive and functional decline. Reviewing the chart led me to believe Fred must have
aged years in these last weeks and decades in these last years. Julia was living with Alzheimer’s dementia and Fred and their adult children were at the crossroads of more difficult decisions.

Julia was now aspirating on her own secretions and any food or water that she was hand fed. She spent her days in bed, unable to speak, unable to walk and having ongoing restless behaviors. Julia was approaching the end of her life and her family was struggling to recognize this and create a care plan that honored this time near life’s end. This stage and time of life called dying.

Another patient that we will be seeing this morning is Judy who I met yesterday. Last night, had found me visiting Judy in the ICU. If there were five visitors in her room, there were 40; there was standing room only. Ranging in ages from yet to be born and just born to grieving generations encircling the bed as nurse Emily tended to Judy’s needs. Judy has end stage emphysema and heart failure. John, the senior resident in the ICU that I have watched grow during residency said, “Dr. Ingram, thanks for coming up to see Judy and her family. She wants to stop the non-invasive ventilatory support, BiPAP, soon.” John said. I asked, “John, would it be ok if she came off your service and on to our general inpatient hospice service?” “Certainly,” John replied as I approached the glass wall, and slid a portion open just enough to enter. Working my way through the crowd and there lay Judy, BiPAP mask on, struggling to breath. Judy was at the nadir of the last of several dips in her function rendering her functionally debilitated and too weak to press on. “I just want to be comfortable,” was all Judy could and needed to say. More about Judy and her family in a moment.

Before heading up to the ICU to meet Courtney and go see Mike and visit with Kate, my pager started to beep and vibrate again: “Neuro-ICU, please call 8-XXXX.” I thought, “OK, they must be calling about the new consult I saw come through on the consult list.” I continued to review images, labs and notes as I dialed the neuro-ICU from the speaker phone on my workroom desk. Not knowing the fellow, Catherine, who answered, I said, “This is Dr. Ingram, consultant in palliative medicine, glad you called, how can I be helpful?”

“We have an elderly gentleman living in assisted living, who, when preparing for his grandson’s graduation this morning, developed a severe headache, right sided weakness and now he is becoming less responsive. Upon arrival here at Mayo his testing shows he has had a large left-sided intra cranial hemorrhage with midline shift and likely aspiration. Neurosurgery says there are no viable surgical interventions and according to his advanced directive his daughter Stephanie is serving as his decision maker and is honoring her father’s pre-stated wishes to have his care directed towards comfort.”

“Just reviewing his chart as you are reviewing his care, this is Dale Williams?” I clarified. Catherine continued, “Yes, and the family is coping well as Dale seemingly shared his wishes for end-of-life care in
the event something like this happened. The one issue that I am calling about is that I offered to the family that we could turn off Dale’s pacemaker. That seems to be one question they weren’t prepared for and are considering what they may want to do. His daughter Stephanie responded a bit shocked when I offered that." Frankly, I was too, but I didn’t say that to Catherine.

So, let’s go round together. We’ll head to the Mary Brigh 6 to see Kate and Mike with Courtney, then head to Domitila 4 to check on Judy before heading to Domitila 2 for a Family Meeting with Fred and Julia at 11am. From there we’ll go check on Mr. Williams in the neuro ICU on Mary Brigh 8.

We were met in the ICU by our intern, Courtney, who said, “Kate, Mike’s wife, requests that we wait 20 minutes before coming to talk with them.” “OK.” I said. “Seems she is collecting her thoughts. She says she wants to know when Mike will be well enough to go home. She wants to know what their options are.” she continued. “OK.” I said.

Glancing in the direction of Mike’s room, the curtains behind the glass wall were pulled closed. Like many of our ICU rooms there is a closet sized countertop workstation room adjoining by a door to the patient room and then a door knobbed door leading to the main ICU space. It is a passageway we use during moments of infectious isolation. It is just a small pass-through area.

It was in this confined space that 20 minutes later we would meet. Standing. Shaking hands. Looking eye to eye. I could see Mike in the bed through the adjoining doorway. His nurse, Aubrey, who had spent the last 20 minutes reviewing his care with us stood to the left of my line of sight to Kate. Courtney stood to the right with one foot in the general ICU space and one foot in the closet. Over my left shoulder, nurse practitioner Megan. Megan had come along out of interest to perhaps witness how we may thoughtfully approach a family requesting a miracle. She was also there to provide support to ICU staff and the patient and family depending on how this conversation would unfold.

Immediately following introductions, while thumb scrolling a Facebook page Kate said, “What you need to know Dr. Ingram is that there are thousands of people across this country and world praying for Mike and for us and we are awaiting a miracle to heal Mike so we can take him home.” If you would have been there you would have perhaps felt my uncertainty, my uneasiness, and my vulnerability.

I was listening to understand Kate and at the same time, thinking of a way I could respectfully pause the conversation, examine Mike, and then return to the conversation without the conversation continuing in my absence. “Can I ask us all to pause for a minute so I may examine Mike? And upon my return in a minute, we’ll pick up right where we left off Kate. Would that be ok with everyone?” Kate nodded. I moved forward, past Kate entering the sacred space that was being created in Mike’s room.
Mike’s room was filled with young adults. The ambiance felt like family and friends were dressed for a summer afternoon English high tea, smiling, laughing, eating cake, drinking coffee and tea, and praying. My first emotional response was that they were aloof to what was unfolding here, however, perhaps they were simply celebrating Mike. I felt Mike’s right wrist, no pulse. Cold. Pale yellow facial color, the white of his eyes now yellow. Hair combed perfectly. Unresponsive. Gentle forward repetitive protrusion of the lower jaw. Breathing fast, heart racing, fluid causing abdominal distension, peripheral swelling, jaundice, no pulses. “Mike, we’ll keep checking on you,” I said while letting go of his hand and turning away from Mike’s bedside.

I returned to the closet size countertop workstation space where, to the best of my understanding and medical judgement, a soon to be widowed lady was requesting a miracle for Mike. “What did you find?” Kate said. Hesitant to answer Kate’s question, I kept my promise to return to the conversation where we had left off. “I’ll share my findings with you in a moment, Kate. I certainly will. However, I first want to honor and understand what you mean about hoping for a miracle,” I said. “Well, like I said, we’re hoping for a miracle. We’ve had several setbacks since Mike’s diagnosis in 2015, and we also have had positive things happen that the doctors never thought could happen. We’ve already experienced several miracles during his illness.” Kate shared.

“That was helpful to hear, Kate. I have a better sense of how you and Mike have experienced miracles. Sincerely and with all due respect Kate for your experience with miracles and your wish for a miracle, I must share my professional medical opinion with you too. In fact, you requested my opinion just a few moments ago. My opinion, Kate, may differ from what you are wishing for and may be difficult to hear, so would it be OK if I were to share it with you,” I asked permission. “Yes”, Kate softly and cautiously murmured. Continuing, “One thing you said Kate, that I think is important to highlight, is that the doctors had no control over the miracles that you and Mike have received?” “I guess not?” she endorsed.

“What I need to share with you is what I think will happen and why. I also understand that there are three children who are awaiting to see their father when he returns home healed and well,” I set the context for the information. Kate, gazing downward, nodded, “Yes, that’s right they’ll see him when he returns home.” “So, Kate, with all that being said, I think I should offer my professional opinion. “Is that OK?” I reiterated at the risk of upsetting her? Wanting to provide a last warning shot for the news. “With all respect for your faith and for a miracle for Mike, I believe Mike is showing signs that he may only have about 12 hours to spend with you and your children before he dies.”

Leaving Kate’s room, Courtney, Megan, Aubrey, and I debriefed in the ICU conference space before I headed to Domitila 4 to check on Judy who we titrated off a calming medication called Precedex™, replacing it with morphine and Ativan for her vicious shortness of breath/anxiety cycle, transitioning her off
of BIPAP to a simple and more comfortable nasal cannula. Last night, I had encouraged the family to share what most people value sharing before they are forced to say goodbye: Please forgive me, I forgive you, thank you, and I love you. Judy’s family had this under control.

Turning the corner to the corridor where Judy’s room was located, Ben, her nurse, met me at the door to her room. Ben was a newly graduated nurse who shared her heart rate increased to 110, her PCO2 was 87 and I thought to myself, “Who ordered labs?” I was happy to hear how her heart rate increased off the Precedex™ that can sometimes lower the heart rate.

“She is ordering scrambled eggs and chocolate milk for breakfast.” Ben announced. “Must be feeling better,” I said. Animal prints were still the theme of the day as I joked with husband Richard and their two older sons dressed in camo and wildlife prints. They were smiling now. Judy was comfortable, able to talk, and ordering her breakfast.

“You weren’t much for talking yesterday,” I quipped with Judy. With a smile that filled the room, she replied, “Thanks for letting me feel better and enjoy this time.” “I understand this is the way you want to ride this out,” I stated as I leaned in to take her hand. “It is,” she affirmed squeezing my hand as I sat at her bedside. “Nothing left unsaid or undone?” I asked. “Oh, probably, isn’t there always?” she said. “Yep, but what I am hearing is that it wouldn’t be anything critical to those you love,” I clarified. “All is well,” Judy affirmed. “We’ll keep checking on you, Judy. Enjoy the eggs and chocolate milk”, I offered as I stood and turned for the door. Thank you and you are welcome was exchanged around the room.

Taking the stairs two flights down to Domitila 2, I went to the Family Medicine workroom to talk with the Family Medicine team in preparation for what we anticipated would be a challenging, emotional, and difficult family meeting with Fred, Julia, and their family.

Dr. Wilson, a 2nd year Family Medicine resident, walked us all through the series of events of the admission and even the weeks prior to admission. Dr. Wilson started, “Fred and Julia have been married for more than 60 years and Fred was caring for Julia in their home on the farm north of Cannon Falls up until 18 days ago when he brought her to the ER because “he couldn’t handle her, at home, any longer.” It seems Julia had wandered off the property more than once in recent months. Most recently, she had fallen while walking in the yard and fractured many bones. She had lost 17 pounds and her memory was worse and behaviors less redirectable. Around the time of admission, it was thought that she had aspirated food into her lungs, and she continued to fail swallowing evaluations during her hospitalization. She continued to aspirate. Her behaviors also became challenging. She experienced violent outbursts towards staff and family. Behavior that she had never had before. The family couldn’t understand her violent behaviors in
light of her typically upbeat personality. Throughout her hospitalization it seemed like one step forward and 2 or 3 back.

She hadn't walked now in over a week and her medicines had seen many changes as recommended by many consulting teams: neurology, psychiatry, and palliative medicine. She had had mood stabilizers, pain medications, antipsychotics, and anxiety medicines in various shapes and sizes. Her clinical changes were attributed solely to the medications by the family and her behaviors and clinical condition immediately worsened without the medications. Everyone was suffering. Her case reminded me of the saying that death doesn't cause suffering but rather resistance to death causes suffering. All that being said, it now appeared that Julia was in a state of irreversible decline that had been foreshadowed by her falls, weight loss, and worsening cognition in the weeks prior to her admission.

Despite everyone's best efforts, Julia continued to decline, aspirate, hallucinate, say unkind and uncharacteristic things to staff and family. Fred had loved Julia for more than 60 years and now felt as though he had let her down. From his vantage point he shared, "I should have never brought her to the hospital. She was fine when we were at home." Of course, that wasn't the case. He had contacted several care facilities in the area even prior to her most recent hospitalization and was declining in health himself from caregiver fatigue. Fred directed his frustration and grief towards the medical teams.

When Dr. Wilson had finished summarizing the clinical particulars and Fred’s specific sentiments, the Family Medicine attending consultant, Dr. Langstraat stated, “The only approach that seems to match what is happening here is a comfort focused approach. Fred just wants Julia back the way she used to be”, said Dr. Wilson. Therein lies the focus of our family meeting.

Just then the clock struck 11 a.m. and we approached their room, collected Fred and the adult children, and departed for a reserved consultation room. Leaving Julia in good hands with her nursing assistant Sharita.

As a medical team, we had agreed to avoid, what is all too common in family meetings, a recounting of the medical sequence of events that punctuated the hospitalization. We hoped to avoid a medical conversation of between artificially created opposing sides of life versus death or death versus rehabilitation when the truth of the situation was that Julia was irreversibly nearing the end of life. She was dying. With this in mind, I had been asked to lead the family meeting.

Following introductions and appreciations for gathering on behalf of Julia, I entered a three-step process for delivering Julia from anonymity. The three steps are providing context, stating the obvious, and asking a question of invitation. ‘Prior to meeting with you today and in the days prior our medical teams have had
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a good chance to review Julia’s medical chart, her tests, her images, and her overall medical condition. However, we haven’t had an opportunity like we have today to meet all of you and learn about her as a person. I was wondering if, for the next three minutes or so, we could hear about what your mother is best known for or what you might consider her claim to fame. Our teams don’t even know where exactly she raised all of you. Would one of you like to start us off to, in a way, include Julia in the conversation today by learning more about her as a person,” I asked. Following a few minutes of sharing we learned about Julia as a quilter, baker, mother, and important member of the church. Julia was now a person with us in the meeting that we were all honoring and talking about. It only took a few minutes.

It felt like tensions had dropped and everyone had spoken, laughed and some had cried tears of fondness and sadness. Delivering a person from anonymity has a way of bringing everyone from varying points of view and understanding together to honor the person at the center of the conversation when they are unable to be present due to relative states of incapacity.

The second large and last question of this family meeting would follow the same three steps. I started, “I know I speak for all of us when I say that it is really lovely to learn more about Julia. It sounds like she is the cornerstone of this family and brings so much joy to each of you. Thank you for sharing, what I am certain, were snapshots into her life. What I know we are interested in talking about today is Julia’s medical condition and medical care. In taking the next step in the conversation, it is important for us to learn a bit more from you as a family. As I previously mentioned, our medical teams have reviewed Julia’s medical condition and we have a good sense of what is happening with her condition and we can review that with you, however, we first need to gain an understanding of her medical condition from all of you. This helps us to know how to tailor our conversation to meet your needs and Julia’s needs. So, with this in mind, I am not requesting that you give us a play-by-play account of what has happened with your mother and wife, rather, I am wondering if you wouldn’t mind sharing with us, in the next few minutes, how conversations amongst yourselves unfold when someone outside the family asks how your mother is doing. What do you say to them in your own words?”

The family shared in unison, as hard as it was, that they were observing Julia nearing the end of her life. They were most focused on how to practically care for her near the end of life. A lovely conversation unfolded that honored Julia’s life and prepared the family and Julia for the practical hospice plan of care that would be created in the days ahead.

Now 12:30 p.m. I thought I best get to the neuro ICU to see Mr. Dale Williams. He was our elderly gentleman nearing the end of his life from an intracerebral hemorrhage with midline shift and aspiration now on comfort measures only. As I walk to Mary Brigh 8, I consider all the anticipation and expectations that this day had started with for this family; a grandson to graduate and a patriarch now unexpectedly dying.
I met the neuro-ICU fellow, Dr. Catherine Johnson, in the neuro-ICU workroom. We invited Dale’s nurse, Josh, to join us in reviewing the irreversibility of his terminal situation. Josh shared that the family was largely at peace and their biggest concern was turning off his pacemaker. That’s when the fellow spoke up, “I think I may have offered something that I shouldn’t have.” “It’s OK”, I said. “They’ll be OK, he’ll be OK, and we’ll all be OK”, I offered.

I seem to be “OK” with a lot of stuff going on about the hospital. It is true, the less I say the more others share. The more they share the more I understand. The more I understand the more I can help by dosing my comments as carefully and minimally as possible.

“May I simply suggest to them that there are no decisions to be made at this time?” I asked. Continuing, “Good intentions, your good intentions Catherine, raised an important question that in this particular situation isn’t an issue. Turning off pacemakers is something we rarely, if ever, do and not in this acute situation.” “Did I say something wrong?” Catherine asked. “Not wrong, just not now and not in this acute situation. It is pretty uncommon.” I offered. I continued, “How about all three of us go and talk with them briefly. Would you be ok with that Catherine and Josh?” “Certainly”, they said.

It was a typical neuro-ICU room. Large, bed in the center, window at the headend of the bed but room enough to parade around the bed and all the equipment. Many visitors lined the exterior wall leaving space at Dale’s bedside for his three adult children, each holding a hand and one caressing his brow. I approached his daughter, Stephanie, that Josh had identified through the fishbowl style wall concealing the sliding glass door through which we had entered.

“Stephanie,” I said kneeling beside her, “I’m Dr. Ingram from the palliative care team, Cory. You already met Dr. Johnson and you know Josh well. I’ve reviewed your father’s situation. I’m sorry for all that has happened today.” I said. Kneeling near Stephanie allowed me in their sacred space and communicated that I was there but also not staying long. Just long enough to address a concern and return the sacred space undisturbed. I steadied myself with my left hand on the bed rail. Being close and low to Stephanie’s gaze towards her father allowed me to briefly intercept her gaze and speak softly. Stephanie reached out with her right hand placing it on my left hand on the bed rail. “We could talk for a while Stephanie; however, time appears short and meant for family. I understand you have been considering a question posed to you earlier”, I posited. Before Stephanie might reply, I intentionally pressed on to say, “I only have two things to say and one suggestion. Would it be OK if I offered that?” “Yes”, she said.

“There are no more decisions that need to be made, Stephanie. I don’t recommend we change anything about your father’s pacemaker. My one suggestion is that you continue to celebrate your father as you were when we entered the room.” She repositioned her hand from my hand to my shoulder and gave me a hug,
and said, “Thank you.” “Is there anything else we can do to make this day a little better”, I asked. “Not at this time, everyone has been wonderful to Dad and all of us”, Stephanie said. Thank you echoed in the room as I released Dale's hand and left with Dr. Johnson leaving Josh to care for them.

In my short career, there have been many changes in end-of-life care. Similar to the hospice nurses that served to train me during my residency and fellowships, these patients were likewise served by hospice. The difference now was the use of hospice in the hospital.

That afternoon, Mike enrolled in General Inpatient Hospice. The children, all three, visited and the hospice team made handprints with them and Mike. I heard that they were well. Mike died shortly after 10 p.m. surrounded by his family in the ICU room. Just 12 hours after our meeting. Not that we were right, but that our assessments and attention to detail matters. Reluctantly, Courtney had gone home at 7 p.m. knowing Mike was well cared for on hospice. I have crossed paths with Courtney since in the medical wards where she rotated following her rotation in the ICU. The growth curve of an intern is steep. She consults palliative care regularly.

Following her scrambled eggs and chocolate milk, Judy enjoyed watching TV with her family. Towards early evening Ben's shift was ending and Judy was becoming sleepier. Her CO2 was likely increasing, and she was peaceful. No labs needed. Judy was well within herself and died shortly after 11 p.m. with her sons at her bedside.

Fred, supported by his adult children, made plans for Julia to transition to hospice on Monday. Fred visited daily until Julia died several days later. We considered him high risk for complicated bereavement and follow him closely.

Mr. Dale Williams drifted off deeper in coma. His grandson graduated. His family celebrated and their patriarch died early Monday morning on general inpatient hospice care.

I'm a palliative care and hospice doctor focusing my clinical care on families near the end of life; and there is nothing I would rather be. It has been a great privilege to be welcomed to the bedside of so many seriously ill and dying patients to care for them and their families. Pursuing geriatrics and palliative care were not always met with welcome sentiments from my peers. “You’re going to take care of sick and dying patients.” “It is so depressing.” My experience is that geriatrics and palliative care are a little like peeking through the old skeletal keyhole into a living room. You must get up real close to peek inside and if you dare to go through and enter in, a whole new world opens. It is often a sacred space. A space for a team of professionals caring together. A space for medical, social, emotional, spiritual management of complex issues and competing interests with medication interactions, pressing clinical scenarios requiring titration.
of medicines, and a freedom to apply clinical judgement or wisdom outside of any printed guidelines. This
work often invites a challenge for quick relationship building and forming a trusting relationship in a
moment’s notice. A space to work on stage, under scrutiny from colleagues, family, and staff. I sometimes
find myself saying the darndest things with an audience I don’t even know. Total strangers. I must be
intentional about my every word. There is also often a space to care for our medical teams and staff, not
only the patients and families.

All these spaces and invitations are susceptible to becoming routine for those of us in this work, however,
for patients and families, this moment of life is challenged with expectations of achieving legacy worthy
memories through re-storying of a life well lived with an embellishment of the good times and a
minimalization of the bad. Not all stories end well. There is real sadness. There are life stories that end and
are sometimes complete and sometimes incomplete with things remaining left undone or unsaid. For all of
these, I am grateful to accompany them.

For many there is a re-storying with the intention to create a legacy that transcends this life providing
meaning and comfort for those that live on. A re-storying as a lesson and an example for something that
awaits us all. A re-storying to move away from suffering towards healing. Towards a reintegration of self,
other, and family. A space to ask seemingly unanswerable questions about how we’ll move forward now.
How will our family function? What do we believe? What do we know to be true? Did we do this right? What
did this all mean? What was the purpose? What was my purpose? And across generations, lifetimes of
stories and many other answerable and unanswerable questions, beckoning from beyond a new horizon of
life just now faintly coming into view.

It has been a pleasure.

I have become concerned about increasing efforts to distinguish palliative care from hospice with the
overarching mantra that palliative care isn’t hospice and hospice is for dying patients. Which has truth to it,
however considering the number of articles and emphasis placed on messaging by national organizations
coupled with continued public confusion, I think the perceived need for these efforts and the persistent
public confusion is because the difference is so very small. I am concerned the effort to contrast palliative
care and hospice is hampering the field and confusing the public even more. Hospice and palliative care
teams are identical, they both provide excellent care for dying patients and their families, and palliative care
teams affiliated with a hospice or not will provide excellent palliative care for seriously ill patients in the last
years of their lives or in some cases patients who are curable. We should call our field what it is, hospice
and palliative care. We should also see our services across a landscape from diagnosis through the end of
life and into grief support. At a time when it seems efforts are being made to change our name or divide our
field, I think we need to proudly stand together and do our work to serve our patients and families. Ultimately, the care we provide will be our best messaging for our communities and culture.

The clinical scenarios depict aspects from typical rounds for a hospice and palliative care clinician and are anonymized through changes in illness, names, gender, age, geography, and family composition. These scenarios identify common themes in caring for patients near the end of life and those themes are easily recognized by many clinicians, patients and families who have experienced these situations.