MOVING THROUGH DISEASE

THE INTERTWINED CHALLENGES AND SURPRISING JOYS OF PATIENTS, CAREGIVERS AND HEALTH PRACTITIONERS

by

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Abstract

According to a mental health professional I met fifteen years ago, people like me—those who prefer to be in control—are most susceptible to developing anxiety when people close to them are ill. A committed health advocate, I strive to help family who are ill quickly recover. I started this master's program from my mother's hospital room. Although her hip replacement surgery was successful, she received a surprising diagnosis of amyotrophic lateral sclerosis (ALS) five weeks later. This thesis reflects the medical topics I investigated during my mother's debilitating health journey. I followed Professor Zvirzdin's advice to "compartmentalize" as I proceeded with coursework in tandem with caregiving. The act of questioning quelled my anxiety and drew me closer to answers. The process of researching, reporting and writing these stories has been empowering.

Thesis Advisor:

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Introduction

As a teen I was encouraged by my high school guidance counselor to serve as a community volunteer. I briefly contemplated a career in healthcare one summer when I worked in the geriatrics ward as a candy striper—a young female volunteer who cheerfully helped refill pitchers of water, handed out magazines, and changed the bedsheets for elderly patients at the neighborhood hospital. Despite my fear of hospitals and phobias about death and dying (a topic forbidden at the dinner table of my youth), I fulfilled my volunteer duties. But witnessing a patient not survive a code blue emergency was enough to stunt my future involvement with healthcare.

My aversion to caregiving dramatically shifted when I became a spouse and parent. My husband suffered from ulcerative colitis, a chronic and inflammatory auto-immune disease. My son needed surgery at twelve days old and then again at six years old due to intestinal malrotation, a rare anatomical condition that affects one in five hundred live births. As an infant, my daughter was diagnosed with food allergies to milk, wheat, soy, egg, and tree nuts. This barrage of health challenges in my family was enough to pull me back into the world of healthcare. It was not enough for me to receive information from their doctors. I needed to understand how and why this could happen to my loved ones and what I could do to help them manage life despite their conditions. I panicked because there were many things, despite my best efforts, that I could not control. I could not control the illness hurting a loved one. I could not control how a loved one would respond to a medicine, a procedure or a therapy. But as I asked questions and searched for answers, I discovered that my inner strength grew.

This thesis includes a collection of personal essays, articles, and an opinion piece. The stories were inspired by questions I investigated on behalf of those ill in my family.

Much of the writing explores my experiences as a caregiver and health advocate during my mother's sporadic and aggressive onset of amyotrophic lateral sclerosis which coincided with the start of my Master of Arts program in science writing. My research helped me to process her mysterious illness and ultimately, her death, one year from the date of her surgery. The theme of movement weaves through the stories: the literal challenges of a movement disorder, the figurative movement through the illness, and the healthcare system supporting it. The stories provide the perspective of the patient, caregivers, health advocates and health providers. While they appear in memoir-like sequence, these stand-alone pieces may have some overlap of facts and reflections. My hope is to capture not only the complexities of ALS—a relentless, degenerative condition—but also to highlight the triumphs of the patient and their family when they receive adequate caregiver support.

I am grateful for the constructive guidance from all my Johns Hopkins professors, especially Jamie Zvirzdin, Tim Wendel, David Taylor, Sue Eisenfeld, and Kim O'Connell, whose generous feedback and support nurtured my growth during an emotional time. Many thanks to my thesis advisor Melissa Hendricks Joyce, who helped me to improve the focus and flow of each story. Thank you to my classmates for their thoughtful critique and camaraderie. Special thanks to my husband Jonathan, my children Nathaniel and Amanda, my Mom and Dad, and family, who have been my cheerleaders.

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Lola Moving

A few weeks after my mother had hip-joint replacement surgery, a nurse assistant at her rehab center noticed the pair of sneakers parked under the armchair opposite her electric bed. The designer shoes were pink suede, with a white, ribbed rim at the base.

“Are those your fancy shoes, Alita?” asked the assistant. “They are so cute.”

My mother’s name, Alita, sounded as beautiful as its definition: full of joy, a phrase that accurately depicted her cheerful character. But our entire family and some of our closest friends called her Lola, which meant “grandmother” in her native Filipino language. My father, who we called Lolo (“grandfather” in Filipino), observed her constant interest in other people. Lola easily made conversation with any stranger. She was the same way with the nursing home staff. She awkwardly grasped a pen with her osteoarthritic right hand and scribbled each of their names in shaky ink on the back of her menu.

I had reached for the trendy pink sneakers on the clearance rack of DSW Shoe Warehouse simply because of their three Velcro fasteners. Function, not fashion, determined my choice. I’d presented them to my eighty-seven-year-old mother just in time for her next physical therapy session at Greentree Manor, the rehab center where she spent many weeks recovering from her surgery. From her blank reaction, I couldn’t tell if she disapproved of the color or the look of the three-strapped shoes. Lola preferred to coordinate the color of her shoes with her clothes and purse, so black was her go-to color. She probably wondered how useful it would be to have pink sneakers in her limited wardrobe. But she said nothing, only smiled and accepted them as she did her recent health circumstances—graciously.

These shoes could help provide the traction she needed when standing in tandem with her physical therapist. According to Denise, the director of physical therapy, it was time for my mother to forego shoelaces since she could no longer don her own shoes. The Velcro made it easier for staff to pop her shoes on and off before her therapy sessions.

Due to severe cramps and stiffness which were now also creeping into her left hand, it had become impossible for Lola to maneuver zippered pants, button-down shirts or jackets, bra hook-and-eye closures, or jewelry fasteners. She missed not only the ability to do simple things like this for herself, but also being in her own space. After many weeks of being away from home, she missed her indoor plants, the framed photos of her grandchildren, the knickknacks in her glass cabinet, her recipe books, and ninety percent of her wardrobe. Most of all, she longed to be in the apartment she shared with her husband who had happily taken over all the cooking, cleaning, and laundering during the past year. Injuries from her last two falls had exacerbated her disabilities.

She had survived the surgery; that was what mattered.

Post-hip surgery patients were expected to stand by day two, with assistance from physical therapists. On day fourteen, Lola still could not stand. But no one on her health care team seemed to worry; she was well into her eighties, so the delay in healing was understandable.

For many weeks, the soles of those fancy shoes remained unscuffed by any surface. It became clearer each day that walking would remain elusive. Instead of launching Lola forward, the shoes warmed her stationary feet on the footrests of her wheelchair, like baby shoes that simply completed a look.

Lola missed her physically active self, always doing and moving. Although only four feet and nine inches tall and ninety pounds, she defied people's expectations of her physical form. My father recalled the time when they were childhood neighbors in the Philippines. He caught a glimpse of her beautiful teenage figure as she pounded the rooftop of her family's nipa hut home. It was no surprise that Lola, the fiercest among her all-female household consisting of her mother and two older sisters, had taken the initiative to do the repair on her own.

At sixty years old, Lola swung at arc-pitched softballs in a batting cage. She bowled a strike at the age of eighty-two years old. Just three years ago, she had the endurance to stand at the kitchen counter for many hours over several weeks, to roll five hundred lumpia eggrolls, her trademark family appetizer dish and granddaughter's favorite Filipino delight, on the granddaughter's bat mitzvah.

After five weeks at Greentree, Lola was determined to reclaim her active life. She no longer waited all day for a PT session that would either get bumped or forgotten. She insisted that her aides dress her completely, including her pink sneakers, and move her to the wheelchair so she was ready to go. Weeks of practice rolling the wheels of her wheelchair up and down the hallway outside her room primed her arms with the strength to launch herself down two corridors; she arrived at the rehab exercise room, ready to work.

After much coaching by her physical therapist and thanks to her tremendous upper arm strength, she had managed to stand momentarily. But something was not right.

Lola's left hip bore the brunt of her weight as her right leg caved inward and her right foot remained limp.

"The foot drop is worrisome," said Denise. "Something is going on with that leg."

For some reason, we could not understand why Lola was unable to lift the front part of her right foot. She had fractured that same foot in three places a few months ago, but it had healed in time for the hip replacement surgery. She also could not raise her right knee at all. Both motions were critical to taking a step. It was Denise, a physical therapist, not the medical director, who was instrumental in helping to steer us toward some potential answers. She brought up the issue of Lola's unresponsive right leg and foot drop.

"She needs an EMG, a nerve conduction study," Denise said to me. "It's very important that we find out what is going on with that leg." She handed me a set of ankle-foot orthotics (AFO). "She can keep these. I had them especially made for her."

The soles of the AFO slipped into the shoes as the neck of the brace cradled Lola's flaccid calf muscles. Thick Velcro straps wrapped around her calves to keep them in place. The AFO's job was to act as a support for the ankle join, to help keep Lola's foot at a ninety-degree angle with the leg.

But as we soon learned, the nerve conduction study would not provide answers anytime soon. Soon after the electromyography (EMG) appointment was scheduled, Lola's health insurance company abruptly ended her rehab center coverage because she was no longer showing progress after five weeks.

"Good luck to you," said Denise, who squatted on the floor beside Lola. She gave Lola's motionless right foot a gentle pat. "Remember to do the heel slides whenever you're in bed. And don't put pillows under your knees. You need to engage those quad muscles."

Lola and Lolo enjoyed two days of each other's company in their apartment. They went back to their routine; he served her breakfast in bed, a bowl of fresh fruit and a smoothie. At night, he saved her the trip to the bathroom and managed her bedpan.

Then, at three o'clock in the morning on the third day, my cell phone rang, startling me from sleep.

"Your mother fell," said Lolo. "We need your help."

"Is she okay? What happened?" I fired back. I was now wide awake.

When I arrived, my father and their neighbor Sheila were hovering over Lola. She was sitting on the bathroom floor with her legs extended toward the foot of the toilet bowl. Apparently, the wheelchair had been unlocked when Lolo attempted to help her transfer to the handicap accessible toilet. As the wheelchair gradually rolled away from her, she had slowly descended to the floor.

"I'm okay," she said. "Just my butt and back are sore from waiting."

Sheila insisted on calling an ambulance for a lift assist. She assured us that it would not cost a cent. After the ambulance arrived, the crew put Lola back on the toilet bowl so she could finish her business, and they wished us all a good day.

The next morning, Lola moaned with back pain. She had hurt herself from the semi-fall the previous day. We reluctantly called the ambulance again; this time they took her to the emergency room.

The ER doctor reported that the X-ray images did not show any fractures.

"She likely just has a couple of internal contusions in her back," he said, and prescribed anti-inflammatory pain medication. He said nothing about discharge and walked away.

The hospital kept her for eleven days, running all sorts of blood tests, X-rays, and CAT scans, which showed more detail. Hospitalists explored why her legs still could not support her weight several weeks after the hip surgery.

"We can't explain the severe weakness in her legs. Her brain and central nervous system are fine," said Dr. Neer Zeevi, a neurologist who reviewed Lola's case.

"Our current diagnosis is multifocal motor neuropathy," he continued. The rare condition involves the immune system attacking its own motor neurons in the limbs. It is characterized by an uneven weakness in the legs, lower arms or hands, muscle wasting, and foot drop or wrist drop.

She could feel her right leg and foot. But she could not move them much.

"Our first course of action is to treat her for five days with an intravenous immunoglobulin," said one of her hospitalists. "And then we'll see. It will take about four weeks for the treatment to reach its full effect."

Assuming that it was such an auto-immune disorder, the doctors hoped that after the immunoglobulin therapy, Lola would regain her strength over time.

During this period, it was distressing to see my mom lose even more independence. Aides required her to use the bedpan instead of the commode because Lola was considered "an assist of two." They often set it up and walked away; sometimes they didn't return for another thirty minutes. This was humiliating for Lola. She was used to being the caretaker; she preferred being helpful, not helpless.

Back to Bayview Healthcare Lola went, another rehab facility, where she would remain for three additional months. But because her leg weakness and muscle atrophy progressed and there was no improvement in her ability to stand independently let alone walk, multifocal motor neuropathy was eventually ruled out.

Another few weeks later, at Yale New Haven Hospital's Neuromuscular Center, Lola's long-awaited examination with a neuromuscular specialist finally arrived. Could she stand? Could she lift her feet and legs from a seated position? How well could her arms and hands resist opposing force? How strong was her grip? Was she often short of breath? How well could she move her eyes and her tongue? And yes, she did have a history of falls: three years ago, she fell and sprained her right foot; last year, she tripped while strolling at the park; and five months ago, she fractured her foot.

The answers to this series of questions, along with the results of her nerve conduction study and her fading strength finally revealed some answers. Lola's neuromuscular specialist suspected ALS, or amyotrophic lateral sclerosis (also known as Lou Gehrig's disease), a condition in which the neurons that send signals from the brain to move muscles in the body will dwindle in numbers; it gradually prevents movement of the legs, arms, and neck; and eventually, it will freeze the muscles that control breathing, eating, and excreting. The results of another follow-up EMG would later be compared to confirm the diagnosis.

Most of the science went over my mother's head. I scribbled feverishly into my notebook, so I could remember what the doctor said about the worsening of her disabilities and later communicate it to my father and the rest of the family. Her treatment options would only slow the progression of the motor neuron disease. There was no cure for ALS, but we could buy another nine months to ensure that Lola's life was supported and made as comfortable as possible.

Lolo and I protected Lola from the harsh truth. We treated the appointment like any other doctor's visit. We told her what medicine she needed to take and when she would need to return for a follow-up. The rest of the family did not know what to make of the diagnosis. They received the news like it was a conspiracy theory. How could this be the case just six months after a routine procedure? Her doctors didn't know for sure yet, right?

"At least you're not in pain anymore," I said to Lola, as we folded scrapbook paper in monochromatic colors to make a star-like wreathe. She had missed out on her granddaughter's high school performances because she either had no energy or was battling long periods of groin pain, leg stiffness and muscle cramps. Now, even after the ALS diagnosis, Lola could enjoy activities like making arts and crafts with me. It was usually a colorful distraction, like origami, watercolor painting, coloring an adult coloring book with crayons or molding play dough into temporary sculptures, that helped her escape the boredom and depressing thoughts about her health's descent.

It troubled me to see her sitting in the dark side of the room, away from the window view, which her roommate kept blocked by drawn shades during her daily afternoon nap. That was my cue to take Mom to one of the social rooms to work on a puzzle or to sit with her in the outdoor courtyard for some fresh air.

Lola's point of view grew darker. She recalled moving relatively well with her walker just a few months ago. Why had she bothered with the hip surgery? What if she had instead taken anti-inflammatory medication to deal with the hip pain? To my mother, her loss of freedom seemed to point back to that fateful decision.

Her theory was not too far-fetched. A 2013 scientific study published in the *Journal of Neurology, Neurosurgery and Psychiatry* investigated the impact of surgery on patients who had undiagnosed ALS. Within three months of surgery, a significant number of the study patients showed a rapid progression of ALS symptoms.

Lola's Bayview care team scheduled a meeting to strategize safe discharge plans for her. We all agreed that Lola's care was now beyond what Lolo could handle. The nursing home insisted that her health would only become more tragic and unsafe if we were to take care home. They promised to help secure a wheelchair and a Hoyer lift for her to use at home. Our job was to secure a safety ramp for the house and an electric hospital bed. We wanted better quality of life for her as well as meaningful time with her.

Time passed and Bayview made more excuses for why they had not yet secured the needed equipment to release her home to us. During this time, my mom had started becoming short of breath whenever she lay flat or exerted energy. Health care staff gave her breathing treatments using a nebulizer mask, along with a nose cannula, to deliver supplemental oxygen to the lungs. The cause of the problem was unclear: Was it ALS weakening the muscles in her diaphragm and making breathing a challenged when she was reclined?

Then, I received a distressing call on a Saturday afternoon.

"She is having difficulty breathing again. We called the paramedics. They are taking your mom to Lawrence & Memorial," said the morning nurse on duty.

Congestive heart failure was the reason Mom’s lungs had filled with fluid. Because of weakened function, her heart was unable to adequately pump blood received from the lungs out to the rest of the body. This caused pressure to build up in the heart, forcing fluid to pool in her lungs and interfering with her ability to breathe. Lola was prescribed a diuretic called Lasix, to help her eliminate the retained fluids.

“She’s not going back there,” insisted Lolo about Bayview. I agreed.

Lola hated the overcooked vegetables and canned fruit they served. The PT and OT had stopped visiting her, especially after her ALS diagnosis; they assumed that she needed more rest due to her shortness of breath.

Lolo and I plotted Lola’s escape. At the hospital, we pressured Lola’s case manager and hospitalist to discharge her to home rather than back to rehab. We insisted that they help to secure a Hoyer lift and a proper wheelchair to ensure a safe discharge. On our own, we acquired a safety ramp, hospital bed, bedpan, and other useful healthcare supplies like a pulse oximeter, which is placed on a finger to measure oxygen level and pulse rate. We could provide the care she needed. We wanted to maximize her time with the family before her symptoms became worse.

Within a couple of days, my husband and I had converted a sunroom into a bedroom for my mother. We furnished it with all the necessary trimmings of a private hospital room, plus the added warmth of family being in the same space. We were thrilled to welcome her home as the ambulance EMTs transported her from the stretcher to her new wheelchair. She could share meals with us at the dinner table and use decorative comforters and accent pillows.

Once at home, Lola began receiving physical therapy from Nurse Pauline Wyatt, through the Visiting Nurse Association. On the first visit with my mom, Pauline shook her head in disapproval when I explained how PT and OT had given up on her at Bayview. “I don’t understand,” Pauline said. “She has three limbs that are still functional.”

“We’re going to get you back your independence. Do whatever you can do to contribute. Move anything at all that you can still use, okay?” Pauline said to Lola, encouraging her to scoot herself to the edge of the bed. She only supported Lola’s weak leg. “I’m going to make you work. I’m a toughie. We will remind your body how to move again.”

Three weeks later, Lola’s lungs were clear and her blood pressure, pulse rate and oxygen levels were all normal. The aides and I took turns helping her in and out of bed, without the use of the Hoyer lift. Using a gait belt and a pivot disc, we supported her weight as she fought to engage her leg muscles, to stand, and to sit.

Meanwhile, all her muscles were used, even the weaker ones. Lola felt useful folding clean laundry in the family room or stirring a bowl of muffin batter in the kitchen. She did word search puzzles, played cards, and ate her breakfast on the outdoor deck. Despite the grim prognosis of her health, we were determined to create more happy memories with her and to help her keep moving.

Those pink Velcro shoes recorded significant distances: from the foot of her bed to her wheelchair, to her commode, to the dining room, to the recliner, to the primary care physician, to her cardiologist, to the ALS specialist, to the dentist, and to a fabulous handicap accessible beach resort for a family reunion. Wherever the tips of her shoes pointed, her view shifted every few hours. Instead of the ceiling or a small television hung high on a clinical wall, she faced the sky, the trees, the view of the road ahead, and the smiling company of family and friends.

Senior Lifelines

I grip the cap, press downward, and turn counterclockwise. I tap the rim once on the edge of my left hand. The tiny and round yellow pill bounces out; this pill thins the blood, which can help prevent a stroke, important for people who suffer from the irregular heart rhythm caused by atrial fibrillation. I let it slide gently into the Monday evening compartment of the deluxe pill organizer that features separate fourteen different pockets, one for each morning and each evening of the week. Next, I subject a small, round white one to a pharmaceutical guillotine so that my eighty-seven-year-old mother can take half a dose of it twice per day. Its job is to relax the high pressure flowing through her blood vessels and slow the heart rate, to prevent a heart attack.

My mother takes eight other medications, including a four hundred milligram pastel-yellow, almond-shaped pill, a nasty drug called amiodarone hydrochloride, whose job is to make sure that her heart rhythm does not get too high. The problem is that this medication can cause the heart rhythm to become too slow. A symptom like low pulse rate needs to be constantly monitored. The cardiologist must adjust the dosage level to hit her pulse sweet spot.

Managing medications is just one thread of a sturdy lifeline that I granted Mom as her family health advocate. The U.S. healthcare system offers some professional health advocates as helpful patient resources; for example, visiting nurses, hospital social workers, and nursing home case managers as helpful patient resources. But as seniors age, they need more assistance with interpretation of healthcare terminology and the flow of accurate information with their physicians.

I accompany my mom to doctor appointments and give physicians a detailed history of her recent medical issues and hospitalizations. I am there to make sure the exchange between doctor and patient is productive and well understood on both ends. I facilitate scheduling of her appointments with the primary care physician, cardiologist, and all her other health practitioners, from nurses to physical therapists to occupational therapists to hospitalists, the attending hospital doctors who treat her while she is confined at the hospital. I am the one who secures safe wheelchair van transportation to her appointments. I have also spoken to health insurance coverage representatives and social work case managers at the hospital and at the skilled nursing facility.

My background is not in healthcare. I care deeply about my mother's life not being taken too soon, and to prevent negligence and complications. I ask many questions and take copious notes.

Eight months earlier, when Mom fell and fractured three bones in her right foot, I watched her visiting nurse reorganize my mom’s pill box. My mother’s health insurance company had sent the nurse to do a follow-up after her foot injury. She was there to check her vitals, but she also asked about my mother’s medications. She matched the name of each drug and their corresponding dosage against the list in her computer, then handed expired prescription bottles to me.

“You're using it wrong,” the nurse said to my mother. “Drop one of each of your prescription drugs in each day of the week.”

Simply keeping medications organized could be a life saver.

According to an April 2019 article published in *StatPearls Journal*, seven to nine thousand people die each year due to medication errors in the United States. The article also states that hundreds of thousands of people have an adverse reaction to medication but fail to report it. Another study published in the June 2015 issue of *Expert Opinion on Drug Safety* says that nineteen percent to fifty-nine percent of patient medication errors occur at home. Among the top reasons were “incorrect dosage," "forgetting," and "mixing up medications."

It’s good that my mother’s health plan sent the nurse to follow-up on her recovery, but the nurse came once per week a few times and that was it. Once the visits concluded, when I realized my mother could no longer manage her own medications, I immediately appointed myself as my mom's family health advocate.

My father often came along to her appointments out of routine, but he gladly waited in reception because his impaired hearing kept him from being of more help. I made it my business to keep track of my mother’s health status and represent her needs to all her health practitioners. There was a time when she could manage this on her own, but ALS was a neurodegenerative condition that multiplied her progressive disabilities, and it would eventually also affect her cognitive abilities.

After her broken foot healed, my mother underwent an elective hip surgery to alleviate tremendous hip pain caused by osteoarthritis, a condition where the cartilage between joints is completely worn. Unfortunately, that surgery resulted in complications. She later suffered from atrial fibrillation, congestive heart failure, and several symptoms associated with amyotrophic lateral sclerosis (ALS), a neurological condition affecting nerve cells in the brain that control muscle movement. As the incurable ALS disease progressed, her legs continued to weaken, making her reliant on a wheelchair for the rest of her life. It became medically necessary for her to have help with managing many day-to-day tasks such as transferring from bed to chair to commode, bathing, cooking, cleaning, and so on. My mother spent six months in and out of two different skilled nursing facilities and became hospitalized five times in seven months. As someone with significant disabilities who was on a fixed social security income, she soon needed to apply for Medicaid benefits to help pay for costly home healthcare support.

At this point, my mother found additional sources of support: the hospital case manager and the rehab facility social worker.

Hospitals offer the services of a case manager after a hospital stay that either involves an extended recovery period or requires ongoing professional monitoring. Most families are unable to provide the kind of skilled assistance that a rehab facility offers. People with ALS are unable to safely stand, walk or do basic things such as bathing and toileting for themselves. The hospital case manager made sure that my mother could be cared for at a nursing home. She took care of securing a bed for my mother at the facility and her safe discharge. While at the nursing home, my mother could receive physical therapy and occupational therapy as well as dining service and the assistance of health aides.

At the nursing home, we had help from another professional health advocate, a social worker from a rehab facility. The social worker advised us how to fill out Title 19 paperwork or Medicaid assistance through state resources. There was so much to learn, to manage my mother's care. All that paperwork would have been dizzying for my parents without my questions on her behalf and the input of the experienced social worker. Although I didn’t realize it at the time, I was learning the role of health advocate.

I wondered how many people with elderly parents could spend this amount of time helping with such logistics. I was a graduate student who only worked part-time, so my schedule was flexible. But what about other people in the same boat? How could they help their aging parents manage?

For those who can afford it, there is a new category of professional health advocate available: the private health advocate. Seniors may also reach out to private health advocates like Art Mulligan of Senior Advocate Services.

Mulligan’s agency is based in Southbury, Connecticut, a state which he said is among those with a larger retirement population. The 2018 Census Bureau report indicates that Connecticut has 615 thousand people aged sixty-five and over, about 17.2 percent of the state population. According to the agency's website, Mulligan and his associates “can assist with Senior Citizens and their children in understanding and navigating the Medical Event Challenges that may occur as Mom and Dad age.” Prior to founding this new venture, Mulligan spent thirty years advocating for employees with their group insurance and serving as president of the board of directors for a home care agency. He has extensive knowledge about Medicare, Medicaid, and hospice and is passionate about helping adults who are facing two sets of caregiving responsibilities: kids in college as well as elderly parents.

“They are worried about their parents,” said Mulligan. “They don't have the time to help Mom and Dad with their decisions about home healthcare.”

Many of Mulligan's clients want to be educated on the multitude of home care agencies around. Which are reputable? What should they be looking for? Which of the home care agencies are any good and will treat their parents with dignity? He helps his clients' aging parents find the right healthcare support based on their medical needs and their financial resources. He also helps them with taking necessary legal action such as filing power-of-attorney paperwork, addressing healthcare staff turnover, and filling out the complicated long-term health care application.

“I want the children to feel good about what they're doing," said Mulligan. "We're working together as a team.”

Since March 2018, people considering a professional career as a patient advocate may earn credentials through the Patient Advocate Certification Board (PACB), an organization that developed standards for the field. PACB's board includes a diverse group of patient advocacy practitioners, educators, and professionals in medical disciplines such as nursing, public health, social work, health communication, and law. The test includes questions regarding ethical standards, competencies, best practices, and definitions.

Based on membership, the Alliance of Professional Health Advocates (APHA) estimates that there are over 500 practicing professional advocates in the nation. The field of professional patient advocates will surely expand as demographic shifts indicate a rise in senior population. According to the U.S. Census Bureau, the number of U.S. residents 65 years and older increased by 34 percent, from 40.3 million in the 2010 Census to more than 54 million on July 1, 2019.

According to Salary.com, the average salary of a professional patient advocate is $63,422 and the average hourly rate is about $30 per hour as of February 26,2021, but it depends on education, certifications, and the number of years in the field. In fact, private patient advocates who are members of APHA are advised not to publish an hourly rate because each case varies in terms of need and each patient advocate's background varies in terms of experience. My family considered hiring a professional health advocate, then ruled out the option because of cost. I realized I could serve this role. I could take the time to do the research and ask questions. It would just take longer than tapping someone already with the knowledge and expertise.

My family eventually decided to maximize our time with Mom and to improve her quality of life by moving her into my home. She was very unhappy at rehab. While most certified nurse aides were kind to her, the center was understaffed, and many times aides could not get to her very quickly for toileting. The staff relegated her to bedpan use and Hoyer lifting—using a type of people crane to move her back and forth from the bed to the chair—she was becoming weaker each day. We felt she was also being robbed of her dignity. Caring for her had become a twenty-four hour and seven days per week job—one that my eighty-eight-year-old Dad would not be able to manage by himself at home. It was too risky for Mom to have only him as the caregiver.

Thankfully, she was approved for home healthcare benefits through Medicaid. However, this only secured the help she needed eight hours per day. Once the health aides checked out for the day, I accepted the dual role of health advocate and back-up caregiver overnight.

I knew that my decision to serve as health advocate and caregiver would be time-consuming and difficult at times, but it was for the short term. Seeing my mother thrive emotionally in my home with her compassionate and goal-driven home healthcare practitioners made it worthwhile for me. We developed a new rhythm that included regular visits from her nurse, OT, PT, and health aides who became an extension of our family, and her medications remained in tip-top order.

Patient Advocate with Truckside Manners

Small clouds of white billowed in front of Dr. Michael Betten as he sat in a red Ford F-150 pickup truck. Puffing a robust vitola was a ritual he performed before picking up a patient. He reserved an extra unopened cigar in his navy-blue fleece jacket pocket.

Although his bald head and eyeglasses might give away his age, Betten, age 80, has not slowed down since retiring from ophthalmology 30 years ago. He has volunteered as a patient advocate for six friends and neighbors. He accompanied them on their appointments to the eye doctor, cardiologist, podiatrist, oncologist, and other health visits. On a cold winter day, I hopped into his truck at the park and ride lot just off Interstate 395 so I could shadow him for the morning.

As someone who spent three decades working with his own patients, Betten understood and could explain medical terminology in simpler terms. "They say, 'I don't understand what they're telling me,'" recalled Betten. He usually takes neighbors for a cup of coffee or a beer after their medical appointment.

Betten was careful never to give any medical advice of his own, even if he was an ophthalmologist taking a patient to the eye doctor. He was simply there to clarify anything confusing for patients and to relay their healthcare options. "I tell them it's their decision," said Betten.

Although Betten had the ideal background to be a professional patient advocate, he was not certified. People don’t need a physician’s training and don’t need to be certified to do the job if they are volunteers. The Patient Advocate Certification Board, an organization that certifies and sets standards for those who want to practice as a certified professional, provides a standard examination process that “advances a universally recognized credential for patient/health advocates.” To become eligible to take the patient advocate certification test, people must have a bachelor’s degree or higher or equivalent paid or volunteer experience, two letters of recommendation and they need to complete a self-assessment tool. The PACB Handbook states that "Patient advocates will avoid making any decision for, or on behalf of, a client." Patient advocates are also prohibited from diagnosing or prescribing any treatment for clients, even if the advocate has the appropriate license or training. Based on membership, the Alliance of Professional Health Advocates (APHA) estimates that there are over 500 practicing professional advocates in the nation.

After driving a few miles through the streets of Norwichtown, Betten parked the pickup truck at Dr. Kay Taylor’s home. Taylor is an eighty-three-year-old retired dermatologist. Betten had agreed to take him to an ophthalmology appointment. The two men had been friends for over forty years.

As the men walked from Taylor’s front door to the pickup, their gaits were in stark contrast. Betten sauntered with long strides and a tall posture. Taylor's head hung forward, his arms drawn inward with closed fists, while he shuffled with short, quick steps, taking five paces for every one of Betten’s. He suffered from dystonia, a movement disorder that causes involuntary muscle spasms, and Parkinson's disease, a progressive nervous system disorder that causes tremors, stiffness, and slowing of movement. He had difficulty moving his neck and head; he also experienced slurred speech.

"Is Dawn doing alright? Kids, everybody, doing alright?" Betten asked, as he steered the truck out of the driveway. Taylor's mumbled reply was unintelligible to me. I could barely understand the former Arkansan's nasal drawl from the backseat as his lips didn't seem to make contact.

On the way to the ophthalmology appointment, Taylor and Betten discussed highlights from a recent UCONN men's basketball game. Betten had told me earlier that he enjoyed talking about sports or the outdoors with his male patients. He and Taylor used to play tennis together many years ago. Taylor was a New England Patriots football season pass holder.

When we arrived at Southeast Eye Care's office, I sat across from Taylor in the waiting room. Once I faced him as he spoke, I could better read his body gestures and comprehend his speech. “You name it, he does it,” Taylor said to me, as he reflected on Betten’s willingness to help him and others. “The neighbors all call him.”

In addition to serving as patient advocate, Betten was known to show up to a neighbor’s home with his truck and a chainsaw, ready to help clear a fallen tree and grind the stump. After plowing the snow from his own one-mile-long driveway, he always proceeded to plow seven more driveways in the neighborhood.

“You’re helping fellow man,” said Betten. “That’s why we’re on Earth. If I can do it, I do it. It’s important to be active mentally and physically.”

When Taylor’s name was called, he proceeded to Dr. Kevin Cranmer's examination room with an ophthalmic technician. Betten followed, clutching Taylor's coat, then stood at attention next to the door. Taylor was given a visual acuity screening and then a standard vision test.

Finally, it was time for Taylor's general ophthalmologist, Dr. Kevin Cranmer, to check his eye pressure using a device called a tonometer. Taylor had seen a retina specialist, who was concerned about his increased eye pressure. Cranmer had to rule out glaucoma. When pressure inside the eye (intraocular pressure or IOP) increased above normal levels, it could damage the optic nerve and potentially lead to vision loss.

For Cranmer to conduct the exam, Taylor had to lift his chin and lean it on the tonometer’s chin rest. But he was having difficulty positioning his head. His neck bones had been surgically fused to settle thirty years of spasms caused by dystonia. "I'm sorry I can't," said Taylor.

"I'll push you forward," said Betten. He gently tilted Taylor’s head slightly back and helped hold it steady. "Let's get your chin up there."

Taylor's eyelids started to droop. "Keep them open, Kay," encouraged Betten,

"Yes, both eyes, wide open," said Cranmer. The technician used a cotton swab to hold Taylor's eyelid in position as Cranmer gently touched the front surface of each eye with a circular instrument that glowed with a blue light; he applied a small amount of pressure to the eyes.

Betten explained to Cranmer that the other eye doctor was concerned about a drainage problem possibly causing Taylor’s eye pressure. Normal eye pressure was between one and twenty-one millimeters of mercury (mm Hg) but not greater than twenty-two mm Hg. Taylor’s seemed to have steadily increased. Four months ago, his eye pressure was twenty-one mm Hg in one eye and twenty-three mm Hg in the other. Now it was thirty-one and thirty-two. When the drainage system narrowed, the eye's cornea pushed up against the iris, increasing eye pressure.

Cranmer explained that laser therapy could help. A lens to focus a laser light into Taylor’s eyes will create a drainage channel. It will feel like a brief zap to the eye. "There tends to be small risk, maybe slight bleeding. Eye pressure can rise. But I can put you on some drops to lower it," said Cranmer.

Taylor agreed to have the procedure. While Cranmer left the room to get a health consent form for him to sign, he turned to Betten with more questions. He seemed uneasy about the treatment and turned to Betten for reassurance.

"There shouldn't be any pain," Betten reassured him. "The treatment is just a little hole he will put in your iris to drain the extra fluid. If the pressure is not low enough, he will put you on anti-inflammatory eye drops to lower it. Your vision is still really good. You can drive legally without glasses. And, you can still have scotch and a cigar!"

"That's the important thing!" Taylor said, his concern relaxing into a chuckle.

Betten explained that cataracts form as people age, making the typically clear lens of the eye much cloudier and causing blurry vision; it can also cause increased fluid pressure in the eyes. He recalled much more involved surgeries in the operating room when he was still practicing ophthalmology. It was typical for him to perform seventeen cataract surgeries back-to-back in one day. These days, thanks to laser technology, outpatient procedures may last less than ten minutes.

Fortunately, Cranmer accommodated the procedure that same afternoon. After waiting about thirty minutes while Cranmer met with other scheduled patients, Taylor received the ten-minute treatment in both eyes. After the procedure, Taylor worried that his eye pressure had increased instead of decreased.

"Does that mean the procedure didn't work?" he said to Betten.

"That doesn't mean anything. He's going to give you some steroid drops to keep the pressure down. Call me if Dawn can't do the drops for you," replied Betten.

Before leaving, Betten arranged for Taylor to return to the office for a checkup before his trip to Chicago. Betten also clarified the prescription instructions for the eye drops while Cranmer typed exam notes on the computer.

Once we had returned to Taylor's driveway, Betten helped him out of the truck. "I'll give you a call tonight to check in on you. Make sure everything's okay. Did you write down the appointment for next Wednesday?" said Betten.

Taylor nodded. Betten reached into his pocket and handed him two prescriptions from Cranmer and his scribbled notes with eye drop instructions and the next appointment. "Remember, don't put the drops on top of each other. Wait fifteen minutes," emphasized Betten.

"Okay," said Taylor.

"Good. Here's a cigar for you," said Betten, handing him the extra one tucked in his pocket. "Give Dawn a kiss from me."

Home May Be Best for Hip Surgery Recovery

Before my mother, Alita Sevilla, had hip replacement surgery, she and I attended a pre-operational education class offered by Westerly Hospital. We sat in a conference room with other caregivers, patients, a registered nurse, and physical therapists, following along with the presentations by flipping through an informational binder provided to us. The presenter walked us through surgery preparation expectations, the actual procedure, post-surgery care, and physical therapy exercises.

My head spun as I took note of all the don’ts for my mother’s post hip surgery recovery: don’t bend at the hip, don’t pivot, don’t knee-cross, and don’t stop moving. We learned that she should use a bedside commode rather than the toilet as it had safety arm rests to help with standing. Special gadgets such as a reacher and a sock aid would also be helpful—these could be found in a hip kit, a collection of products to improve independence and reach after hip surgery. Physical therapy would begin on day one after the surgery.

Choosing my mother’s venue for healing would be a critical decision. At the time, the best decision for my family seemed to be to leave everything to the health professionals. We were not aware that statistics proved otherwise.

According to a research study published in the September 2017 issue of *Journal of Arthroplasty*, more than three-quarters of over 54 thousand patients went home after their hospital stay for hip surgery. The remaining one-quarter went to an inpatient rehabilitation or skilled nursing facility, and those patients were more likely to have a septic, urinary, wound, and respiratory complications, and more likely to be readmitted to the hospital. Researchers controlled for predischarge patient factors such as older age, body mass index, and functional non dependence.

My mother's primary physician and cardiologist had cleared her for a hip joint replacement procedure despite her intermittent atrial fibrillation condition, an irregular heart rhythm that puts patients at a much greater risk of stroke. They said the pros outweighed the cons. At age eighty-seven, she had lived with chronic pain from osteoarthritis in her right hip for a few years. But she reached the point at which she could no longer avoid the decision to finally undergo surgery. She had become too sedentary. Because of her heart issues, a lack of physical activity put her at risk of stroke. Repairing the hip meant that she could return to being physically active and improve her blood circulation.

Visions of walking daily at a beachside foot bridge, cooking, as well as standing, kneeling, and sitting at church, filled my mom's head. Although fearful of potential surgery complications, she looked forward to walking again after inactivity for the past couple of years. She had become weak and reliant on a wheelchair by choice—due to being in pain and being a fall risk.

According to the Centers for Disease Control and Prevention (CDC), one out of four older people falls each year, and falling once doubles the chances of falling again. A fall might cause only bumps and bruises, but each year, a sizable number of people die from a fall. Alarmingly, the CDC reports that fall death rates in the United States have increased thirty percent from 2009 to 2018. An aging population is likely one factor—the population aged eighty-five years and older is the fastest growing age segment in the U.S. *The Journal of Safety Research* points to another possible factor for the increase in deaths from falls: “longer survival after the onset of common diseases such as heart disease, cancer, and stroke.” The CDC also projects that if fall rates continue to climb, we can expect seven fall deaths every hour by the year 2030.

My mother had fallen several times, but thankfully, none of the falls had resulted in serious injury. Mom only sprained her right foot one time and then later fractured the same foot in three places. Another time she fell, she only suffered contusions on her back. Still, the next fall could be much worse.

Mom's surgery went smoothly, although the surgeon did mention that her heart went into atrial fibrillation as the surgery began. Before the procedure, her blood thinner intake was halted so her body could heal properly. Afterward, she went back on blood thinners, which made her more vulnerable to bruising or the dangerous inability to develop blood clots or heal from a serious fall. Immediately, her hospital doorway was labeled with a yellow caution sign featuring a “high fall risk” stick figure. On the white board, her nurse wrote the phrase “assist-of-two” which meant that two people were needed to help transfer her safely from her bed to an armchair, or to a commode.

My mother chose to recover at a rehab program in a skilled nursing facility. She felt that her care would be too much for my eighty-eight-year-old father in their home. He certainly had the energy to ensure clear pathways, to put all items at waist level, and to continue to provide warm, home-cooked meals for her. But she would need the constant help of trained health aides to safely move her, to prevent hip dislocation and potential blood clot issues. It seemed wise to leave Mom's recovery process in the hands of health professionals.

Given the choice, my mom opted for a single room for privacy rather than sharing a double with another patient. This was a mistake. After her experience, I've concluded that patients are better off sharing a double in the short-term wing, which is a busier and more inspiring environment recovery. Patients see their roommates or their neighbors leaving their rooms often to go for physical therapy or to socialize in the dining hall or arts and crafts room. The long-term wing is where dementia and very feeble patients tend to live out their remaining days. Rather than being inspired to move by fellow short-term rehab patients who would soon go home, my mom only saw full-time residents parked outside their rooms, with little stimulation.

Staying in the long-term wing rather than the short-term wing was like being at a lovely romantic table for two in the remote corner of a restaurant; the staff might get to you much later when out of sight. Mom received less attention from physical therapists (PTs) and occupational therapists (OTs) making their rounds. In contrast, the short-term wing is a fast-paced recovery area where rehab patients help motivate each other. The average stay for rehab patients is twenty days, with some being discharged as soon as seven to fourteen days, depending on their recovery progress.

After five weeks, Mom was not showing enough progress because of a significantly weaker right leg and foot drop after surgery. This made it difficult for her to take a single step. We learned that her health insurance would only cover the cost of a skilled nursing facility when the patient demonstrated increasing rehabilitation progress. Mom was not showing such progress. So instead of a skilled nursing facility, she was sent home. Before her discharge, the helpful PTs and OTs kindly showed us exercises to do with Mom twice per day, not just twice per week. We had a plan.

Sadly, after two days at home, Mom fell and suffered contusions on her back, and was sent back to the hospital. The hospital staff was concerned about her very weak right leg and foot drop. Why was she not walking yet after what was considered a successful hip replacement surgery? The surgical site had healed nicely. She was no longer in pain. She was beyond the risk period for hip dislocation. After many diagnostic tests, they attempted immunoglobulin intravenous therapy. One possibility was that my mom's leg weakness was due to an autoimmune disease; if so, the therapy might help increase her strength. Because it would take four weeks for the therapy to take effect, the hospital decided to send her to rehab once again.

Mom had another choice to make. Should she go to the hospital's inpatient rehab facility or did she want to go back to a skilled nursing facility?

An inpatient rehab at the hospital offers the convenience of nursing, health aides, PTs, OTs, along with access to medical doctors who follow each patient's progress, on-site diagnostics, as well as any needed specialists such as neurologists, all under the same roof. The downside of the inpatient rehab is the very clinical hospital environment; the patient basically stays in their own room for meals and there is no access to any social activities. A skilled nursing facility provides nursing, health aides, PTs, OTs, social activities for the patients, and the supervision of one medical director shared with all patients in the entire facility. The downside of skilled nursing facilities is that any patients experiencing serious complications or requiring immediate medical attention are transported back to the acute care services of hospitals.

Based on my mother's experience and reading the research literature, I now believe that we should have taken advantage of the high-rated inpatient rehab department at the hospital. A 2014 study by the Center for Medicare Advocacy that investigated patient clinical outcomes over a two-year period found that patients from inpatient rehab facilities recover twice as fast as those who go to skilled nursing facilities (12.4 days versus 26.4 days average length of stay for post-acute care). The very selective rehab program at the hospital was designed to be an intensive and focused rehab environment for those who were likely to successfully reach their rehab goals. Although this is a confounding or unmeasured variable in the study, and skilled nursing patients may tend to be healthier, this was not the issue for my mother. The neurologists on my mother's case believed she was an excellent candidate for the inpatient program, but we thought the nursing home environment would offer a less clinical and more comfortable environment, and we chose this option.

We came to regret this decision. The second nursing home rehab department immediately labeled Mom as a bedpan-and-people crane-patient from day one. They used a Hoyer lift to hoist her to and from the wheelchair and bed during her entire stay, even though they had the staff to accommodate her need for two health aides. An aide with whom I spoke guessed that their staff was too stretched with the number of rehab patients and that repeated lift-assists might present potential safety liabilities. Of course, the physical and occupational therapy sessions thereafter showed diminishing progress as my mother was robbed of any leg strength she had left.

Mom fell into a dark period over the next four weeks while at the nursing home rehab. She was hospitalized three times for shortness of breath due to congestive heart failure and atrial fibrillation. It was during one of those hospitalizations when mom underwent a test that would clear up a mystery underlying her condition, but also present extremely sobering news. A neuromuscular specialist administered a nerve conduction test to see why her right leg and foot movement was fading rather than improving with all the physical and occupational therapy she was receiving. It revealed that she had spontaneously contracted amyotrophic lateral sclerosis (ALS), a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. She likely already had ALS before her hip replacement surgery, and the procedure probably accelerated her condition.

At this point, it made the most sense for us to consider home healthcare rather than to have Mom live out her days with this degenerative condition in a facility with strangers. We wanted to increase her quality of life. The average stay of patients in a nursing home for acute rehabilitation was twenty-three days. At this point, Mom had spent one hundred twelve days—more than four times longer than the average stay of nursing home rehab patients— in a skilled nursing facility, only to become weaker in her legs, her heart, her lungs, and her mind. Enough was enough. Plus, her Medicare health insurance benefits maxed out at coverage for one hundred days at a nursing home. My mother applied for and was approved for Medicaid benefits through Title 19, a federal health insurance program available to people with low income and few resources, to pay for nursing home healthcare.

At the hospital, the goal had been to keep my mom away from imminent death's door. Otherwise, she received bare minimum interaction there. At the nursing home rehabs, the focus had been getting my mom moving and released as quickly as possible; otherwise, she was marked for permanent residence. But once we brought my mom home, my family and the home healthcare team could set more realistic goals and see measured progress.

Looking back, I now know home was a better place for my mom. The statistics from the *Journal of Arthroplasty* had correctly predicted my mother's respiratory issues and hospitalization—several times—perhaps because she had not been sent home to recover from the hip surgery. Everything on the list of don'ts was followed, but a critical "do"— move—was significantly limited during her time at the nursing home. Every single hour that she sat in a chair waiting to be transferred or lay in bed waiting for health aides to strap her into a Hoyer lift, motor neurons in her feet, legs and eventually those controlling the movement of her diaphragm and heart became fewer and fewer in numbers.

The most compelling reason to bring a senior home after elective hip surgery was to keep them moving. Our wider team of support—extended family members, other caregivers, nurses, PTs, and OTs—all worked together to make sure that she was moving every muscle while she still could, at least twice per day rather than twice per week. She transferred with our help from her bed to a wheelchair and to a commode all day long. With each transfer, her leg muscles continued to serve a purpose.

Had we been better informed of some pitfalls in day-to-day nursing home rehab life, or about the advantages of assembling a powerful and motivating team of home healthcare practitioners and caregivers, perhaps my mother would have suffered fewer indignities. Home healthcare is about managing symptoms and maximizing life potential through nutrition, support team services, with the goal of keeping the patient as independent as possible while maintaining dignity.

Music Therapy is Real: The Healing Promise of Improv Circles

My six-year-old son looked defeated as he sat in a junior-size hospital bed. His shoulders slumped forward. His stared blankly downward, blocking all who attempted to speak to him. Nathaniel had undergone surgery one day earlier to untwist a congenital condition that caused his mal-rotated small intestines. The surgery was successful, but when Nathaniel finally opened his disoriented bloodshot eyes, he was clearly uncomfortable and anxious. His instinct was to tug at his sources of discomfort, from the I.V. in his arm, to the long vertical tape holding his mid-section together, and the long plastic tube that ran from his nose down through the esophagus and stomach.

Nathaniel had suffered acute abdominal pain for 12 hours leading up to the procedure. He was shocked to learn what had happened inside his body and that he was to remain attached to these tubes for many more hours. Now, after hearing that he would not be allowed to eat or drink for the next three days, he declared a communication strike, refusing to talk or acknowledge anyone.

The next morning, a cheerful woman wearing an acoustic guitar and carrying a tote bag filled with hand instruments entered the room. Recreational therapy, the use of music or arts and crafts activities to help pediatric patients deal with being hospitalized, was a standard free-of-charge service provided by Yale New Haven Children's Hospital. She enticed Nathaniel with a triangle and striker percussion instrument. He snuck a glance at it, but lay motionless, a resigned heap of deep sadness, just as he had the day before, in between long bouts of naps. This did not discourage our smiling visitor. She handed a tambourine to my husband and a pair of maracas to me, gesturing that we follow her lead.

The woman, who led our family's bedside session fifteen years ago, was a board-certified music therapist employed by the Arts for Healing program at the hospital. Her goal, she explained, was for Nathaniel to create music with her, as a way for him to cope with his pain, anxiety, and isolation.

The key was not just listening to music. Music therapy was more effective when patients actively participated in the music making.

The day after the music therapist orchestrated our family musical intervention at the children's hospital, our circle of three improvised another song. This time, Nathaniel joined in, striking the triangle on every fourth beat. The next day, he visited with other children on his floor. They held a music and arts festival in the social room. Parents observed as the music and art therapists worked with their children; they made stick puppets, sang along with the song leader, and later narrated an improvised shadow puppet play from behind a white screen on which light was projected. Nathaniel stood together with the other children for their curtain call. Still connected to his I.V. on wheels, he beamed at us.

At the time, I was not aware that music improvisation was deliberately being used as medicine. I thought the musician was just a volunteer generously lending her talent to rescue my son from his temporary misery. I have since learned that music therapists are board-certified professionals who work in tandem with other health practitioners to treat patients with physical, psychological, cognitive and/or social disorders.

Music therapy is a growing field that is being more widely used as another therapeutic tool. Recalling music therapy’s positive outcome for my son, I became curious about its use for more chronic mental health conditions and other illnesses.

My search led me to Courtney Biddle, a board-certified music therapist and founder of Progressions Music Therapy in Old Mystic, Connecticut. We arranged to meet at her office, which is located in a former mill on a peaceful waterfront site beside the Mystic River. The building had an industrial-chic architectural appeal with its open plan, brick walls, high wooden ceilings, and large windows. Biddle’s music therapy studio was a modest but open space that was half meeting room, half performance space. We sat at a table, a few feet from Biddle’s collection of music instruments lining the wall next to an open rug area. I recognized a ukulele, mandolin, and a host of drums. Biddle explained that a goblet-shaped drum was a West African djembe and a straight cylinder-like one was a tubano drum.

Prior to opening her own music therapy practice, Biddle had trained to be a musical virtuoso of sorts. But a member of the faculty noticed something that confirmed her personal interest in psychology issues.

“You’re really good at relating to people,” her orchestra director said to her. “You should look into music therapy as a profession.”

So, Biddle followed the director’s advice. She studied music education as an undergraduate and completed a master’s degree in music therapy. She took courses in music theory, music history, different types of music classes, psychology, sociology, and music education.

As a music therapist, Biddle is proficient at guitar, piano, voice, and percussion instruments. She also plays every major orchestra instrument, including the violin, viola, trumpet, and trombone. Biddle is well versed in all music styles, from heavy metal to rap to opera music. During a music therapy session, Biddle might play music covers and lay down the twelve-bar blues. Her client plays one part, as she plays a different part. "I might be working with a teenager and have his parents come in and I help them make music together. This facilitates lots of different feelings within a family," said Biddle.

Sometimes the patient chooses a song meaningful to him or her and they will do lyric analysis to figure out what the song means to her client. How did the songwriter deal with conflict and how can they deal with their own issues? Is this healthy or not healthy? Sometimes Biddle encourages clients to try songwriting. They might "fill in the blanks" or write their own lyrics and then together, they set it to music.

"It's really empowering for them to hear and sing their own words," said Biddle.

Biddle has seen firsthand, how music therapy has helped her patients suffering from depression.

Music therapy may be an option for families with younger children and adolescents who need depression treatment, but don't want to rely on medications that might have a scary black box label—that boldfaced print from the Food and Drug Administration, warning that antidepressant usage among adolescents may increase their risk of suicide.

In a scientific study published in the May 2017 issue of Journal of Child Psychology and Psychiatry, researchers concluded that music therapy is a promising alternative or supplement to psychotherapy and other conventional treatment for depression. The randomized and controlled clinical trial included 251 children and adolescents between the ages of eight to sixteen who had social, emotional, behavioral, and developmental difficulties. The control group received psychiatric counseling and/or medication. Patients assigned to the experimental group participated in improvisation with a music therapist, “to create music and sound freely through voice, instrument or movement, while receiving support and encouragement tailored to suit their needs as assessed by their therapist,” according to the study.

At week thirteen, depression scores were significantly lower in the experimental group that received counseling and/or medication plus music therapy, when compared to the control group that only received counseling and/or medication. While researchers saw much potential for music therapy to promote mental health in young people, they believed more research was needed to determine which patients, which health conditions and what kind of music therapy treatment was effective.

Biddle also works with patients who have autism, attention-deficit/hyperactivity disorder (ADHD), physical handicaps, or those recovering from stroke or dealing with chronic disease or cancer. She does not believe that music therapy is a replacement for other treatments. She believes in collaborating with other health practitioners as her practice allows her to work on motor, education, psychological and sociological conditions.

“Someone who is a speech and language pathologist is trained in that,” said Biddle, reflecting on her role relative to counterparts who also treat her patients from another angle. “How can I work on that in a musical way?”

According to a meta-analysis (or study of studies) published in the January 2011 Harvard Review of Psychiatry, growing evidence from over twenty years of neuroscientific and clinical studies indicates that music can have positive physiological effects related to mood.

One study found that serotonin levels in blood samples from non-depressed study participants were much higher after they listened to music for three to five minutes. Serotonin is a hormone and neurotransmitter in the brain that plays a role in regulating mood. Low levels of serotonin have been associated with depression. In another study, rats exposed to new age music every day for six hours during twenty-one consecutive days, experienced an increase in brain-derived neurotrophic factor (BDNF). This molecule controls emotional recall and regulation.

Low levels of expression of the BDNF gene appears to make people susceptible to developing depression.

“As music therapists, we work in a bio-psycho-social model,” said Biddle. “When we are working with patients with mental health issues, making music is even better. When we are making music, our body responds in ways similar to the way they do to some pharmaceuticals.”

Music therapy appears to be a growing field. A statistical profile of the 2015 American Music Therapy Association (AMTA) membership estimated that 1.5 million people in thirty countries received music therapy services in 2014. Career Explorer, a career advancement and assessment service, estimates that there are 19,200 music therapists in the United States and expects the music therapist job market to grow by 6.8% between 2016 and 2026.

Session times vary depending on the patient’s condition and goals. Biddle might work with a detox or hospice patient one time, but her patients with mental health issues might need music therapy in conjunction with their psychiatric counseling sessions on a weekly basis until they get to a safe place.

Individual music therapy sessions cost sixty-five dollars per hour on average, according to the 2015 ATMA survey. Most health insurance plans do not yet cover music therapist services, according to Biddle, so most of her patients pay out-of-pocket. The report also said that only twenty-nine percent of the survey respondents received some form of reimbursement from health insurance companies and that twenty-six percent were private music therapy business owners.

Biddle is passionate about her work and excited about the future of her profession.

“I try to tell my client in my improvisational circles that no one will ever do that song the same way again,” said Biddle. “How incredible is that?”

Nathaniel could attest to this. Although he did not have the benefit of music therapy as a formal treatment when he later experienced symptoms of anxiety and depression as a teen, he did recall the positive impact of music improv on his mood as a young child after his surgery. He discovered organically that when he wrote music compositions and jammed on the bass guitar or piano with a jazz improv band, he felt better and lighter.

Music therapy is real, after all.

A Hops Quest for Challenge, Peace, and Preservation

Tom Smith squints under the limited shade provided by his boonie hat as he squats on the ground, scouting for enemies in the ninety-three-degree heat. For many years after serving as a U.S. Marine, he loved wearing his government-issued wide-brim hat. The original hat has worn out, so now he wears a similar run-of-the-mill head cover. He hunches over the base of a teepee-shaped trellis at his two-year-old hops farm in Southeastern Connecticut, inspecting the leaves of hops plant shoots for evidence of pest attacks.

“I like the challenge. So much could go wrong,” says Smith, explaining why he decided to start the hops farm in retirement. We’re standing at the base of his farm, where I arrived after a thirty-minute drive from my suburban home in Waterford.

“Gary, the dairy farmer at the end of the road, he’s milking. But when he dies, there is no question his son will sell that land,” says Smith.

Seven dairy farms used to neighbor the hops farm on Miller Road; only one remains. One by one, these pieces of property have been sold for residential development. Smith took classes from Dr. Heather Darby, an agronomic and soils specialist at the University of Vermont Extension, to learn about hops as an alternative cash crop so that land may continue to be used for farming in the region. The hops plant, scientifically known as *Humulus lupulus* (related to cannabis), produces cone-shaped flowers that are used in beermaking. The flowers contain essential oils and alpha and beta acids, which give beer a slightly bitter tangy flavor and help keep the beer fresh longer through their antimicrobial properties.

Today, the Pacific Northwest (Washington, Oregon and Idaho) represents ninety-nine percent of the U.S. hops crop. Yet in the past seven years, new hopyards have been emerging all over Connecticut, primarily due to an increased interest in home brewing and microbreweries, and to revive many abandoned farms.

“I have a real affinity for maintaining land in Eastern Connecticut. I am interested in keeping the agrarian culture here,” says Smith.

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On my way to meet with Smith, I travelled north on Interstate 95 and drove east on route 2A. As I passed over the northernmost portion of the Thames River, I saw on my left Mohegan Sun Casino’s Sky Tower and Earth Tower, whose two angular glass peaks jut vertically on the water’s edge. This Mohegan Tribe reservation property reached toward the clouds but never quite scraped the underside of low hanging ones. The riverside metropolis offered busloads of tourists and locals a mecca of restaurants, live music entertainment, conventions, upscale shopping, and gambling as an escape. Its energy was the flipside to the valleys of green across the river, where the hopyard was nestled among rural farmland, new suburban home constructions and hilly woods.

Preston featured a string of roadside bed and breakfast inns that welcomed guests for over two hundred and fifty years, a gothic church building and an abandoned printing mill. The town’s prevailing character was more evident on Miller Road, which I reached after making yet another left, a hairpin turn that led up a windy and hilly road that zigzagged past a scatter of original and new farmland and residential constructions. Now two hundred sixty-four feet above sea level, I passed a cow farm, a vineyard, an egg farm (for vaccine production), and even a view of Mohegan Sun in the distance, before finally turning left into a long driveway that led to Tom Smith’s hopyard.

After four years of aviation training, he had finished number one in his class and served as an aircraft mechanic at the Marine Corps. He later spent over thirty years as an engineer for Electric Boat, a company that built U.S. submarines. Smith believed his time training for Vietnam prepared him well for hops farming. He noted that both required a similar mindset: perseverance, adaptability and troubleshooting skills.

Initially, Smith wanted to support local brewer friends with hard-to-find hop varieties. He went on a mission to find “a scruffy piece of land” and to learn as much as he could about setting up a farm and growing hops. During a hike with a friend one day, he mentioned that he had been attending a hops conference at the University of Vermont Extension. This friend, who had thirty acres of land on Miller Road, was inspired by Smith’s mission to keep the area’s farming culture alive; he, too, enjoyed spending time in the great outdoors. He invited Smith to develop plans for them to cultivate two acres of his Miller Road property into farmland for hops. It had been primarily used for recreation, a place for friends to commune with nature, and gather for casual paintball tournaments, outdoor barbecues, and camping.

Together, their team of hired demolition, excavation and site preparation specialists, family members, and friends, cleared the land, removed boulders, lay richer soil, constructed hops teepee trellises and dug out a large pond to support the farm’s irrigation system. Smith, who had zero experience as a farmer, followed his engineering instincts, learning by trial and error, and applying acquired knowledge from Darby’s hops farming references.

For the past eleven years, Darby’s annual hops meeting had attracted homebrewers, local hops farmers, and microbrewers. Smith attended presentations on topics such as hop pest management, redefining and refining hop production in the northeast, scaling a hop presentation, hop harvest timing, sensory analysis, and considerations of hop quality for both the grower and brewer.

Farming in New England had been a challenge historically, due to the rocky soil and short growing season, not to mention the area’s wet and humid climate, which made crops susceptible to mold, bacteria and pests that could cause the crops to fail. New England’s moist weather was ideal for growing hops, but hops farmers from Vermont moved west to states like California for the dryer climate where maintaining hops was more optimal.

“Settlers brought beer with them. It was an important part of colonial life,” said Darby when I contacted her about the genesis of her Northwest Crops and Soils Program at University of Vermont Extension. “It was a way to keep people from getting sick.”

Hops’ antibacterial properties ensured that the beer was safer to drink. Hedgerows of hops plants were found all over New England in U.S. history until Prohibition.

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When I arrive at the hops farm, I drive down a steep gravel road in the woods that veers sharply to the left and then opens to a panoramic view of sky and the two-acre farm below. From my vantage point, the overlook reveals a congregation of hops teepee trellises like a small village just a few feet beyond some fruit trees.

Each teepee trellis consists of a thirteen-foot post; at the apex of the post are twelve latch hooks through which twenty-three-feet of string or wire guide the growth of plant stems called bines or hops stems. The hops plants climb up the strings toward the top of the teepee trellis by winding their bines using rough spines to cling upward. Once they reach the top they will continue downward until the plant’s full maturity length of twenty-three feet. Commercial trellises could be up to twenty feet tall, but Smith’s shorter posts only require climbing a five-foot ladder when it’s time to harvest the hops flowers, which is safer.

Some of the new shoots accidentally wrap themselves around two strings. Smith shows me how to unwrap three shoots to get to the one shoot that decides to cling to the end of the neighboring line. Because of the nubs on the bines, untangling them from other shoots requires patience. I don’t want any of the fragile new growths to snap. The newer one-foot bines feels wiry, like al dente angel hair pasta. In contrast, some of the first shoots, some of which have already climbed six feet up, are more like thicker Japanese udon noodles. The leaves on these shoots grow in pairs at ninety degrees angles.

Each of these trellises have a total of twelve hops plants and each rope or cable trains at least three bines, for a total of thirty-six bines per trellis. As this is year two of production, these hops plants will produce an estimated yield of five hundred forty bines and approximately seven hundred and seventy-four pounds of hops flowers. Once dried, they could be ground and pressed into pellets for sale to local breweries. But Smith’s plan is to do this in year three, after the crown and root system are well established, when one hundred percent of production can be expected.

Smith has succeeded in identifying a force of destructive intruders on the farm. The hops plant leaves that were riddled with holes were due to Japanese beetles. Because he prefers to keep his defense ammunitions organic, he wears a mask and sprays the leaves with a solution of water and diatomaceous earth, a non-pesticide white powder made of silica, a natural substance found in dead single-celled algae called diatoms. It neutralizes the attack of Japanese beetles by shattering their outer shells, leaving them to dehydrate in the sun.

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Later, I have a chance for a closer inspection of a dehydrated hop from Smith's first ever harvest. I gently grasp this seed cone or flower of the *Humulus lupulus* plant. This hop flower is part of the meager introductory yield; few cones are produced in the first year—about ten percent of production potential.

I place it in the center of my left palm to admire its anatomy. The dried bloom, about the size of a mission fig the length of my thumb, hangs from its stem like an upside-down miniature spruce tree. Its spade-shaped petals point toward the tip of its tear drop figure. The view from the center of the tip reminds me of a rose's concentric arrangement of petals, only spikier.

Even in its dried and rustling state, it springs back to shape after I squeeze it. I pry open the papery bloom to reveal the secrets of the seed cone. The main stem, known as the strig, is connected to the bine or stem of the plant, which contains the polyphenols that some believe contain medicinal properties. Inside the bracteoles or pockets formed at the base of the hops flower's petals, lives the pungent yellow clusters of waxy grains. These lipulin glands hold the essential oils, alpha acids and beta acids, that are responsible for the bitter aroma and flavors in beer production.

Aside from preserving beer with its antibacterial properties, the chemicals in hops are used in some home remedies such as hops tinctures or tea-like infusions to promote anti-anxiety health benefits. They are used orally in herbal medicines by holistic medicine practitioners to help conditions such as insomnia and attention deficit hyperactive disorder (ADHD) and to relieve menopause symptoms; however, there is little scientific evidence to support this, just centuries of herbal remedies that have been passed through the generations.

Smith and his partners will supply hops to craft beer brewers—and their product might potentially help preserve the minds of people who choose to drink beer with higher concentrations of hops. Recent science research indicates encouraging positive effects for middle-aged adults in need of a brain boost. A recent randomized, double-blind placebo-controlled clinical trial published in the January 2020 issue of *Biomolecules* found a connection between hops' bitter acids and enhanced cognitive function through vagus nerve stimulation (a major nerve system that connects the digestive system with the brain) which may help prevent cognitive decline. In the study, sixty healthy adults aged forty-five to sixty-four years old who self-reported cognitive decline were given matured hops bitter acids (MHBAs), a liquid form of oxidized bitter acids obtained from a water extract of stored hops, or placebo, for twelve weeks. Researchers measured their cognitive levels at baseline, six weeks, and twelve weeks.

Results suggested that MHBA increased study patients' levels of dopamine, norepinephrine, and acetylcholine, which suggested that it may be effective in "improving cognitive function" in people. A secondary outcome of the study was that MHBA also "improved memory and mood state." The MHBAs attach themselves to hormone producing cells in the lining of the intestinal tract, which triggers the release of messenger cells up the vagus nerve, a superhighway of the parasympathetic nervous system that controls many bodily functions, including brain activity. The increase of dopamine neurotransmitters promotes motor function, mood and decision making. A boost in norepinephrine levels allows people to better pay attention, focus and react with greater speed. Acetylcholine levels affect long-term and working memory.

“These compounds may contribute to the dementia prevention effects of alcoholic beverages including beer, and it is expected that certain types of beer brewed with a large amount of hops might be more beneficial. Daily intake of hop-derived bitter acids may, thus, be beneficial for the maintenance of cognitive function,” wrote Tatsuhiro Ayabe, Ph.D. and his fellow study researchers. As this was the first report to investigate the MHBA connection with the vagus nerve, this research needs to be further studied.

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Back at Smith’s farm, hired hands are in the midst of the next major phase: building a formation of hedgerows. Seven new rows will each consist of three consecutively aligned thirteen-foot posts, a long horizontal configuration of hops trellises at the base of the property. Cables connect the tops of the first, second and third posts. Next, more cables will be hung vertically from the horizontal lines. After this year’s harvest, hop rhizomes or small roots will be cut from the main root system of the mature female hop plants of the teepee trellises to multiply the harvest next season.

As Smith proceeds with the daily challenges of engineering the best hops ingredients he can supply to home brewer friends and local brewing companies, he will need to be constantly vigilant against unwanted pestilence. The farm also faces current market conditions. In the past year during the COVID-19 pandemic, many brewers were forced to purchase hops based on price, not locally, according to the Connecticut Hop

Growers Association. Hops farmers are being advised to diversify and grow other crops to supplement their source of sales. Smith is experimenting a bit with patches of blueberry, strawberry, zucchini, potatoes, among other potential harvests that will be sharing water and sunlight with the hops. Despite these many gambles, he admits that working the land has been “euphoric”—a source of tranquility.

“It cleanses my mind and calms me,” says Smith. “I like being in God’s good country and moving dirt around.”

Diagnosing ALS: Trained Rehab Eyes Spot Clues

The parallel bars were set just wide enough for the child-sized wheelchair to roll through. The physical therapist, a tall woman with broad shoulders and booming voice, hovered over my mother's four-foot-eleven-inch frame.

"The only thing we're doing is standing. Just. Stand," said the PT, as she secured the chair's wheels into the locked position. My mom, Alita Sevilla, smiled as she grunted on her way up, her entire upper body shaking as she relied significantly on her arms to support her weight.

"I want you to work on equal pressure through your two feet," said the PT, who tapped each of her feet and lightly pushed against her right knee, which kept buckling forward.

Judging by the PT's tone, my mother was falling short of rehab milestone expectations at Greentree Manor Nursing and Rehabilitation Center in Waterford, Connecticut. Typical hip surgery patients would have been walking within a matter of days, if not hours. My mother still could not even stand on her own, two weeks after elective hip joint replacement surgery.

Before the surgery, Alita could pull herself up from a car passenger seat and take slow steps with the help of a walker. She had finally decided, after years of osteoarthritic hip pain due to worn out cartilage, that it was time for surgery. Just a few weeks after the surgery, her inability to stand perplexed doctors, nurses, and rehab specialists. One particular PT took notice, spotting potential signs of ALS, an especially difficult disease to diagnose because its symptoms were often mistaken for aging.

“We just did not understand. She wasn’t recovering at all in that leg,” said Denise LePage-Martino, another PT who worked with Alita. A nineteen-year veteran as a physical therapy assistant with patients in outpatient, hospital, nursing homes and home health, LePage-Martino served as the physical therapy supervisor at Greentree Manor Rehabilitation Center in Waterford, Connecticut.

Non-neurologists such as LePage-Martino may be able to play a more significant role in helping to diagnose patients. Because it is difficult for the elderly to remember every symptom and some patients tend not to complain when visiting a doctor, health practitioners such as physical therapists and occupational therapists, might notice that something is amiss. They work intimately with patients to strengthen muscles or rebuild their coordination after an injury or surgery; they often spot a symptom that a primary care physician might overlook.

A physical therapist’s role is to apply treatment that will help improve a patient’s ability to move or alleviate pain. But in my mother’s case, LePage-Martino ventured into diagnostic thinking, seeking answers to persistent questions that had puzzled her entire rehab staff about Alita’s condition. Or maybe she had treated enough cases to suspect that this was entirely another beast.

Alita, she said, “presented like somebody who had a stroke.” However, it was not quite paralysis; my mother’s right leg was just persistently weak and her foot drooped. Despite being able to feel her toes when they were touched, she could barely move them.

LePage-Martino used what she referred to as the “Russian stim machine,” a device that provided neuromuscular electric stimulation. The machine sent electric pulses through wires that were adhered to specific spots by sticky patches. The pulses stimulated Alita’s leg and foot muscles to contract. LePage-Martino had hoped that the treatment would “retrain or wake up the muscles and fire the brain-to-body connection.”

Alita’s physical condition clinically “plateaued” after six weeks, so the health insurance company instructed Greentree to release her back to home.

“They don’t want to pay for this environment if somebody is not making enough progress,” said LePage-Martino.

LePage-Martino granted Alita two gifts before she left rehab. The first was a custom-fitted ankle-foot orthosis (AFO), a plastic brace inserted under her foot into the shoe and wrapped around her calf muscle; it provided her with extra support when standing. Otherwise, when attempting to stand, my mother’s floppy right foot tended to slide away. The second gift was her professional recommendation for Greentree’s medical doctor to schedule an Electromyography (EMG) or testing that would measure muscle response to electric stimulation.

Alita was devastated to be unable to walk and to have developed a mysterious new condition after hip surgery. At least someone on her healthcare team was motivated to investigate the root cause of her disability.

Three days after being released from Greentree, Alita was back in the hospital with a spinal hematoma, or bruised back, after sliding down from her wheelchair to the floor of her apartment. When an elderly person falls, hospitals must run all sorts of diagnostics to determine the trigger for the fall. Was it due to an event in her heart or her brain?

Doctors wanted to know why her leg muscles were so weak and why they appeared to be thinning or wasting away. Why had she fallen three times in the past two years?

After eleven days of testing and ruling out several possible conditions, the hospitalists at Lawrence and Memorial Hospital in New London narrowed it down to two possibilities: an auto-immune disorder that attacks the peripheral nervous system, causing nerve inflammation and muscle weakness, or amyotrophic lateral sclerosis (ALS), a neurodegenerative disease in which the motor neurons or nerves controlling the movement of muscles throughout the body gradually die off. Ultimately, the results of Alita's EMG study and a follow-up examination by a neuromuscular specialist pointed to ALS.

LePage-Martino had been on the right track when she questioned Alita's inability to move her toes, bear weight evenly on both feet to stand unassisted, or take one step. According to the National Institute of Neurological Disorders and Stroke, ALS is a notoriously difficult disease to diagnose because many of its early symptoms mimic other conditions in the elderly population. Early ALS symptoms include muscle stiffness and weakness.

ALS occurs annually in 30,000 people in the United States but up to ninety percent of cases are sporadic or randomly contracted and the number of cases is on the rise. The estimated number is expected to increase globally by sixty-nine percent by the year 2040. There is no known cure for the progressively debilitating disease. Because the average age for patients to receive an ALS diagnosis is sixty years old, it is rarely suspected in the elderly population.

“A lot of times in our setting we’ll question symptoms we see,” said Annaliza Lewerk, an occupational therapy assistant at Pendleton Health and Rehabilitation in Mystic CT. “We might suggest a neurological consult. In a nursing home, patients are already under the care of nurses. For elderly at home, it would be kind of hard to notice ALS symptoms.”

Lewerk is trained to notice that when a patient begins dropping things that there might be a cognitive reason. She is concerned about the lack of continuity in care for patients. Doctor visits are usually focused on specific complaints. Her point of view is that doctors are not able to spend enough time with patients to connect the dots between related symptoms in complicated neurodegenerative diseases like ALS.

Amy Mooradian, an experienced physical therapist in the home health setting through the Visiting Nurse Association of Southeastern Connecticut, believes physical therapists can help rule in or rule out certain patient diagnoses based on patterns. For example, she can look at specific movements where pain is traveling or not traveling.

“We spend a lot more time with patients than doctors do,” said Mooradian. “Doctors only get to see patients for fifteen to thirty minutes. We work with patients for thirty to sixty minutes two to three times per week over a period of time.” Her trained eye can tell the difference between the slightest movement of muscles controlled by either the dermatomes, a group of nerves controlling gross motor skills such as movement of the head and limbs, or myotomes, a group of nerves responsible for slight movements such as shrugging or extending the fingers and toes. Mooradian understands how spinal nerve stimulation can treat upper or lower motor neuron dysfunction.

Mooradian explained that her profession is poised to make even greater contributions due to more stringent requirements for recent graduates. As of 2020, those applying for physical therapy school are required to complete a doctoral level program.

“I have missed ALS many times myself, actually probably more that I don't know about,” said Dr. Claire Warren, who just retired from her family medicine practice after forty years. “Fortunately, I had only had two cases in my practice, but it took a lot of missed clues in those two cases.”

A recent study published in the *Journal of the Neurological Sciences* on July 23, 2020 found that the average ALS diagnosis period is between ten and sixteen months from the onset of symptoms, according to studies analyzed over the past thirty years. Only sixty percent of cases are referred to neurologists whereas forty percent are referred to non-neurologists. Up to sixty-eight percent of patients received a misdiagnosis.

According to Dr. Mario Moro-de-Casillas, a neurologist in New London, Connecticut, a PT’s input has become extremely valuable when diagnosing diseases like ALS.

“Sometimes mild symptoms of movement disorders that haven’t yet been diagnosed are attributed to aging,” continued Moro-de-Casillas. She explained that it takes acute events such as pneumonia or surprising outcomes of surgery for a more complex neurological diagnosis process to begin.

In someone with early symptoms of ALS, the messengers tasked with sending signals from the brain to move muscles in the extremities such as the leg, feet, and hands, begin ceasing to exist. Eventually, as the disease progresses, this will also happen with muscles controlling the body’s core: the digestive system, the mouth and eventually the heart and lungs.

“We are moving more toward a multi-disciplinary approach in the movement disorder world,” she said, highlighting the recent trend over the past five years. “A lot of times for many neurodegenerative disorders, we only see the tip of the iceberg.”

Pasquale Folino: Lifeline in the Shadows

I sense a hovering presence in my peripheral vision. He is a motionless blur, just a long black overcoat observing us from the shadows of my foyer. My mother is breathless on her hospital bed in the space between the kitchen and family room, surrounded by us. My sister and I each clasp one of her cooling hands. The hospice nurse notes the time on my clicking wall clock and scribbles on her clipboard. Our father stands at the foot of the bed, bewildered by the rush of strangers into our very private anguish.

On January 21, 2020, by the time the hospice nurse arrives, there is no need for the comfort kit containing morphine liquid and atropine drops. Her role is simply to pronounce the time of death at 3:09 p.m. and immediate cause of death: respiratory failure due to Amyotrophic Lateral Sclerosis (ALS), an incurable neuromuscular disease that strips the afflicted of their ability to move, to eat, and eventually to breathe. Next, the nurse bathes and prepares the body for transport to the funeral home.

“Can we please have some more time with her?” I plead, as the nurse changes Mom’s clothes into one of her favorite outfits, a pastel pink New York Yankees tee shirt and maroon velvet hooded sweatsuit.

“Of course, take as much time as you need,” says the man standing in the corner of the foyer, just three steps from the front door. His downward gaze is on his hands, palm over fist, as he awaits the handoff cue from the nurse. We sneak a few more moments to embrace Mom, cheek-to-cheek, and whisper our weepy farewells into her vacant ears.

“You’ll see her again in a few days,” says Pasquale Folino, handing me his business card. He tells us to contact him at Neilan Funeral Home when we feel ready for funeral planning.

“Our deepest sympathy for your loss,” he says, closing his eyes and offering a slight bow. His dark hair is trimmed tightly at the sides but atop his head perky waves point upward. He shifts to a professional tone. “You may want to leave the room for about fifteen minutes. Some people find the transport procedure to be traumatic.”

Spotting the black hearse in our driveway on my way upstairs, I feel my heart flutter. Our beloved mother will be a temporary resident in the funeral home Folino manages until she is laid to rest. His role will soon morph from a mysterious figure in the background to a trusted guide as our muddled minds are suddenly hit with a barrage of questions. We need him to shed light on each next step.

The following day, Folino greets us at the funeral home. This time, he is not wearing the long black overcoat, but is sporting a tailored blue suit paired with stylish brown shoes. The décor features tasteful floral accents; it oddly feels like a familiar home. We give him the details needed for Mom’s death certificate application. Part mortician, part consultant, and part counselor, Folino hands us a folder filled with reference booklets and checklists. Coffin element selection is a surprise-free and no-haggling process. Details speak for themselves as all options on display are clearly labeled. We later meet him at a couple of cemeteries, to evaluate the location and environment for Mom’s final resting place. He helps us arrive at every decision we need to make in a handful of days.

Members of our family divvy up the task list and coordinate with Folino for delivery; the newspaper obituary, two photographs of Mom to be enlarged, personal items for the wake display, clothes and perhaps jewelry for her to wear, photos for the video tribute and photo board collages, and anything we want buried with her. Folino refers us to the church bereavement committee for funeral ceremony plans and the eulogy; he advises us about flowers and the reception.

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Ideally between four to twelve hours after death, the body of the deceased is typically embalmed, a temporary preservation and restoration process done to prepare the body for a viewing at calling hours days, weeks or even a few months later. The embalmer makes an incision about three to four inches in the carotid artery in the neck or the femoral artery in the leg. An artery is raised to the surface of the skin, then a small incision is made to the blood vessel so that formaldehyde can be injected. Once the embalming fluid is flowing through the artery, chemicals react to the proteins in the tissue and then preserve it so that the color of the deceased's skin returns to a true-to-life appearance. The blood vessels are connected to a tube's hose leading to a machine, so that the fluid from the body's veinous system can be drained. The entire process usually takes one to two hours.

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During the intense and foggy time of loss, my family and I set aside all responsibilities so we could focus on the sacred task of properly honoring my mother's life. Folino was our tether to the real world. We could barely eat between hysterical episodes of despair.

Several months after Folino helped us through the obligatory but significant traditions of burial, I could finally reflect and wonder about his chosen profession. How could his vocation be in such a sad industry?

I met with him once the snow had thawed, to discuss the design and inscription for my mother’s headstone. He graciously agreed to be interviewed about his road to becoming a funeral director.

“The natural progression of children who grew up in a funeral home was to follow in the footsteps of the family business,” said Folino.

This was not the case for him. His father died when Folino was eleven, and he remembered how the “kind and compassionate” funeral director had helped his mother through the grief process. Inspired by his interactions with those in grief, he became immersed in the funeral world five years later, working after school for the funeral home as a landscaper and later working part-time to help with other tasks. Shortly after, he decided to officially pursue mortuary science as a profession.

Folino has been a funeral director and embalmer since 1988 after he graduated with a degree from the Cincinnati College of Mortuary Science. His education included coursework in anatomy, chemistry, psychology, grief, business, legal requirements, and cosmetology. Training nuances vary by state in the U.S., but most require at least an associate degree (states like Ohio require a bachelor’s degree), passing the state and national boards practical exam, and one year of apprenticeship in which the embalmer is supervised by officials. Folino joined Neilan Funeral Homes as a funeral director thirty years ago and became a partner of the firm in 2002. He currently serves as president of the Connecticut Funeral Directors Association, representing over 220 funeral homes and funeral directors statewide.

According to Folino, one of the most rewarding aspects of the mortuary science profession was his ability to help restore the appearance of someone whose body is deteriorating so that the last image mourners have of their loved-one is positive.

“Someone who couldn’t dress for months—dad is in a suit or mom is in a dress with earrings—this brings you back to happier times, if you will. It’s how they would want to be remembered,” said Folino.

When Folino was in mortuary school, he predicted that sixty percent of his classmates would be out of the profession within five years. It was time consuming (on call 24/7) and emotionally demanding. But he found emotional rewards on the job and appreciated the evolution of funeral services over the past decades. He recalled a time in the past when funerals were all the same—"more formulaic with no talking and just wailing.” He found recent funeral gatherings to be more enjoyable now that funeral directors can introduce ways for families to make each one different and more meaningful. For example, calling hours and funeral services could now incorporate memory tables, picture boards, slideshows, video tributes and online remembrances.

“What we do is allow the community to come together, embrace each other and interact with one another to show that the person who died mattered,” said Folino. “Why else would you go and look at a dead person in a casket? We're there for the living, not the dead."

Many standard funeral practices were halted temporarily during the current global COVID-19 health crisis. According to the National Funeral Directors Association, the Centers for Disease Control and Prevention (CDC) required that no more than a total of ten people, including funeral home staff, clergy, and cemetery staff, could be present for a funeral. Social distancing and personal protective equipment were expected for staff and attendees at scheduled funeral services. In many cases, funeral directors steered mourners toward teleconference or videoconference meetings during service planning and suggested that they postpone a funeral service or memorial.

Whether or not the deceased was a COVID-19 case, social distancing guidelines significantly impacted how people around the world mourned. What deeply saddened Folino was mourners' inability to interact and physically console each other during this time. He was not a fan of virtual funerals, which he considered to be "a bit removed."

Mom's wake and funeral service was a beautiful whirlwind of emotions, bittersweet remembrances, and embraces. Folino and his team of funeral and visitation attendants gave us impeccable support. They ushered visitors, the pallbearers, Mom, and my family into position throughout the proceedings. They parted traffic to maintain our car procession behind the hearse all the way to the burial site. They transported flowers, photo collage boards and the memory book from the wake to the reception.

A couple of weeks later, Folino sent me a DVD and special USB flash drive etched with Mom's photo; they contained the video tribute he produced for her wake. He fetched five more certified copies of Mom’s death certificate and coordinated the design and construction of her headstone.

“We don’t understand fully the grief they are feeling,” Folino said, as he reflected on his role in mourners’ lives. “But [we] can lighten the load a little.”

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Fu M, Samuel A, Sculco P, MacLean C, Padgett D, McLawhorn A. Discharge to Inpatient Facilities After Total Hip Arthroplasty Is Associated With Increased Postdischarge Morbidity. *Journal of Arthoplasty*. Vol. 32, No. 9, September 2017 Supplement, pp S144-S149, doi:10.1016/j.arth.2017.03.044

5. Music Therapy is Real: The Healing Promise of Improv Circles

www.ynhh.org (click on “Services” link on home page, then “Children’s (Pediatrics),” then “Support Services,” then “Child Life,” then “Arts for Healing.” (Website maintained by Yale New Haven Health)

www.musictherapy.org (search in upper right corner for “mental health,” then click on “Music Therapy & Mental Health” (Website maintained by American Music Therapy Association, Inc.)

Courtney R. Biddle MMT, MT-BC, Founder of Progressions Music Therapy Services, personal interview, 2/19/19. 860-389-1356. Old Mystic Mill, 11 Main Street, Suite 1A, Old Mystic, CT 06372. Courtney@progressionsmusictherapy.com

Porter, S. et al. (2017) ‘Music therapy for children and adolescents with behavioural and emotional problems: A randomised controlled trial’, *Journal of Child Psychology and Psychiatry*, 58(5), pp. 586–594. doi: 10.1111/jcpp.12656.

Lin, S.-T. et al. (2011) ‘Mental Health Implications of Music: Insight from Neuroscientific and Clinical Studies’, *Harvard Review of Psychiatry* (Taylor & Francis Ltd), 19(1), pp. 34–46. doi: 10.3109/10673229.2011.549769.

7. Challenge and Healing in a Budding Hops Garden

Ayabe T, Fukuda T, Ano Y. Improving Effects of Hop-Derived Bitter Acids in Beer on Cognitive Functions: A New Strategy for Vagus Nerve Stimulation. *Biomolecules*. 2020;10(1):131. Published 2020 Jan 13. doi:10.3390/biom10010131

WWW.uvm.edu/extension/nwcrops/2020-hop-conference, 2020 Hops Conference presentations, (Web site maintained by University of Vermont Extension)

Tom Smith, observation and personal interview at hops farm on 6/15/2020 at 30 Miller Road, Preston, Connecticut and phone interview on 6/30/2020, (860) 625-8086.

Dr. Heather Darby, phone interview on 7/17/2020, (802) 782-6054. Office location: 278 S. Main Street, St. Albans, VT, heather.darby@uvm.edu

8. Diagnosing ALS: Trained Eyes Spot Clues

Denise LePage-Martino, physical therapy supervisor, observation on 3/8/19 (video footage) and personal interview on 9/10/2020 via Zoom link, Greentree Manor Nursing & Rehabilitation Center, 4 Greentree Drive, Waterford, CT 06385.

Dr. Maria Moro-de-Casillas, neurologist, Northeast Medical Group, 194 Howard St, New London, CT, 06320, phone interview on 9/17/2020, (860) 444-3366.

Annaliza Lewerk, occupational therapy assistant, Pendleton Health & Rehabilitation, 194 Howard St, New London, CT, 06320, phone interview on 9/17/2020, (860) 334-5495.

Amy Mooradian, physical therapist, Visiting Nurse Association of Southeastern Connecticut, phone interview on 9/17/2020, (860) 271-1737.

Dr. Claire Warren, retired family medicine doctor, Plainfield Walk-In and Medical Center, LLC, 558 Norwich Rd, Plainfield, CT, 06374, phone interview on 9/24/2020, (860) 608-1660.

WWW.ninds.nih.gov (click on "Disorders" on home page, then click on "Patient & Caregiver Education," then click on "Fact Sheets," then click on "Amyotrophic Lateral Sclerosis." (Web site maintained by National Institute of Neurological Disorders and Stroke.)

WWW.als.org (click on “Understanding ALS” on home page, then click on “Symptoms and Diagnosis.” (Web site maintained by The ALS Association.)

Richards, D, Morren, J, Pioro, E. Time to diagnosis and factors affecting diagnostic delay in amyotrophic lateral sclerosis. *Journal of the Neurological Sciences*. Published 2020 Jul 23. doi:10.1016/j.jns.2020.117054

9. Pasquale Folino: Lifeline in the Shadows

Pasquale Folino, funeral director/owner, personal interview, 4/1/2020. 860-861-5563. Neilan Funeral Home, 12 Ocean Avenue, New London, CT 06320. pasquale@neilanfuneralhome.com

Jody Smith, personal interview, 4/8/2020. 860-575-2606. 10 East Street, Waterford, CT 06385. summerbluedolphin7@sbcglobal.net

Email interview with Robin Cunningham, managing director, Cunninghams Funeral Directors. 4/3/2020. robin@cunninghamsfunerals.com

WWW.rememberingalife.com (hover over “Covid-19” tab on top of home page, then scroll to “Planning a funeral during the Covid-19 pandemic,” and then on click on “Funeral options during the pandemic” (Web site maintained by National Funeral Directors Association.)

WWW.neilanfuneralhome.com (click on “A death has occurred or is imminent” link on home page, then scroll to “Frequently asked questions,” (Web site maintained by Thomas L. Neilan & Sons Funeral Homes.)

WWW.cunninghamsfunerals.com (click on “News” link on lower right area of home page, then click on “A Guide for the Bereaved during the Covid-19 Pandemic” (Web site maintained by Cunninghams Funeral Directors Meath, Kildare and Dublin.)

WWW.textbooks.opensuny.org (click on “Browse by subject” link on home page, then “Nursing care,” then choose “Nursing Care at the End of Life: What Every Clinician Should Know,” then “Table of contents,” then “Care at the Time of Death” (Web site maintained by Milne Library Publishing at SUNY Geneseo.) Textbook author: Dr. Susan E. Lowey.

Author’s Biographical Sketch

Armi S. Rowe was born in Manila, Philippines, and became a naturalized United States citizen as a teenager. Her fast-paced upbringing in New York City was followed by a nature-inspired environment during the past eighteen years in Waterford, a quiet shoreline community in Southeastern Connecticut. She earned a Bachelor of Arts degree in Literature and Rhetoric from Binghamton University. She has a background in media planning and market research analysis. She was a feature and profile reporter for a community newspaper and a science communicator for a pharmaceutical research and development division. Armi has owned and operated a small business creating personal documentaries for clients. This MA in Science Writing program is deeply meaningful to her growth as a writer. In this next phase of her writing life and as a health advocate, Armi looks forward to investigating and writing about the latest research in science, medicine, technology, and environmental science to help patients navigate their health challenges.