



National Hospice and Palliative Care Organization
Palliative Care Resource Series

**FINDING MEANING AND HOPE WHILE
"MY BODY ENTOMBS ME": MUSIC
THERAPY FOR PATIENTS WITH ALS**

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"I don't believe in bad luck. This disease, it's my punishment. I'm paying my dues for all the bad I did in my life." Mr. H was in his late 60s when I met him seated in his wheelchair at home. Amyotrophic Lateral Sclerosis (also known as Lou Gehrig's disease) had been diagnosed several years beforehand, with Mr. H frequently living between his home and the hospital. Palliative Care services had been initiated when he verbalized to his team at the V.A. that "awaiting my body to entomb me between hospitalizations is no way to live." He wanted nothing more than to live out his days for and with his wife.

The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (2013). The MD who referred Mr. H to music therapy referenced the terms *quality of life*, *pain*, and *suffering* when he approached me initially.

MR. H: FINDING MEANING

"I don't believe in bad luck. This disease, it's my punishment. I'm paying my dues for all the bad I did in my life." Upon hearing the statement, Mr. H's wife became tearful, verbalizing "but you did so much good too." We watched Mr. H respond with disbelief, slowly building a wall between himself and us. Using lyrics from some of the pieces he favored, I was able to take reign of the discussion: "we've all done something bad in our lives...what's important now is what we do moving forward." There was a long period of silence, followed by his gentle nod for me to start playing.

He was a doo-wop guy, self-proclaimed, who had been "in love with my wife before I could convince her to court me." I chose the music carefully, focusing almost exclusively on their relationship. *You Belong to Me* lent itself well to reinforcing their love within a safe context. He tapped his left foot lightly (it was one of the few movements that were still available to him) and began singing along with me. When he paused in the middle of the song and made eye contact, I chose to continue the musical accompaniment on my guitar but did not proceed to the next verse..." then my task now is to take care of my dear, sweet C. That is how I will absolve myself." In that brief moment, Mr. H had found his meaning and purpose out of the darkness of his illness.

In the coming years as I worked with him, reinforcing that meaning became the core of our sessions together. Instead of focusing within the music that had simply framed his life-review, together we built a legacy of recordings that framed his hopes and future goals. Hopes "reflect what is important to the patient, what they are wishing for, and how they understand their illness" (Block, 2006) and we learned to find new meaning at every turn. As his body "continued to fail" him in its physiologic deterioration, he found new ways to be successful in the music-making. When the tapping became a greater challenge, decreasing the volume he could generate, I'd offer a tambourine rimmed with mini cymbals by his left foot to elicit a greater sound. Before he could no longer tap his foot, we taught his wife C to find her own rhythm, she became part of our ensemble and on days when Mr. H's pain increased, she would place it on the ground near her

own foot to distract him through humor. When his index finger could no longer strum my guitar, I brought an iPad with a guitar application so that we could place his hand upon it and with each accidental and intermittent purposeful movement, it would play along and he would remain actively engaged and successful within the limitations of his disease progression.

As a music therapist, however, I recognized that his early statements around penance and needing to atone were never far from the surface. And in fact, in those early sessions I questioned whether he simply appeased us (mainly C) with his response. Awaiting for days when C was at appointments, leaving Mr. H and I alone in the session, I would prompt – musically at first and later with directed verbal interventions. The music remained that safe context but he'd always catch me, calling me out on making him "dive deeply." Because our therapeutic alliance was strong and because he trusted me, I never wavered and eventually learned that his retribution was due to his time in the service – active duty on the front lines in Vietnam. Our one-on-one sessions became like a confessional, confidential in a protected place to engage in life-review. We sang what he called "dark pieces" in these sessions. Sometimes we improvised together and he would create dissonances (initially on the guitar app, later with just the voice, and prior to his death by means of a signal for me to initiate a dissent in the music), becoming tearful and often wailing vocally.

Entrainment became the intervention in which I matched him, grounded his need for expression of these veiled emotions, and sat presently in that solemnity. He disclosed to me that his illness was like a tomb to his body, the way his memories of the war were a tomb to his soul. He found himself often confused in the juxtaposition of his emotions – the way he felt towards himself, the way he felt towards C, the way C loved him, and the kindness of "the strangers who feel more like my closest friends." We explored this together, we lived in it together, and we sought meaning together.

Throughout the music therapy sessions, I continued to find moments to create legacy, to record portions of the music-making, to record us singing his favorite pieces and C's favorite songs. It became a ritualistic part of the sessions, providing tangible ways to engage in purpose and meaning-making. When we neared their 25th Wedding Anniversary, I asked if Mr. H would journey with me to create something beautiful for her. We took old photographs, each one leading to reminiscence of that time between them, and listened to our recordings in chronological order. It was a clinical decision I had made and became pivotal because Mr. H didn't notice his somatic decline in the recordings, what he heard was his progress, his way towards some forgiveness of self. We created a beautiful slideshow with him recording a final voiceover, the last before breathy whispers was all he could expel, that thanked his wife for giving him the "chance to live, love, and find joy." He presented it with pride, asking me to decorate his now-motorized wheelchair with her favorite colors and even adding humor by having me place bows all over him and the room in which he now spent the majority of his time. That was his meaning, that was his legacy.

C still plays the slideshow and listens to his voice every day. "He was my hero..." and in many ways, mine as well.

J: REAFFIRMING LIFE

For J, his diagnosis sent him spiraling. The impact to his sense of self as a 56-year old, who had just accomplished his goal of early retirement, was devastating. His disease progression was rapid, with the Palliative Care team believing that a sense of hopelessness had set in. Like Mr. H, J had lost a sense of meaning and presented with what Kissane would have referred to as *Demoralization Syndrome* (2001). He was belligerent towards staff, his family, and withdrawn from his children. His marriage failed following his diagnosis, and when he left his wife, he isolated himself completely. The existential distress was palpable, the suffering clear, and his ALS “had won.” In an early visit with the Social Worker, J had noted that his greatest concerns were about being a burden and becoming dependent on others for his care. Detaching from his relationships and refusal to form new bonds was the symptomatic presentation of this. In those early days on the unit, J spent a tremendous amount of time reading and educating himself about the disease and its trajectory, which pulled him further and further away from others.

In the first month of his care, only the Social Worker and MD were permitted in his room, most visits short and ending with J throwing a light object towards the wall in anger and frustration. His “entombment” was rapid, far more so than Mr. H, and within the first month he went from ambulating unassisted to with a cane, by month two he reported difficulty dressing himself, and towards the end of that month, he was having difficulty holding anything in his hands and started using his motorized wheelchair with greater frequency. As the holidays approached, J lost his ability to dress himself and experienced increasing periods of dyspnea at rest. It was fast, uncomfortably so, and with it came a worsening (though explicable) temper and often disproportionate symptoms of anxiety and sadness to the issue at hand. His coping increasingly impaired, this began making caregiving by the nurses and aides nearly impossible.

Though his family had originally honored his desire for privacy and time to “reflect on and struggle with” the diagnosis, they began visiting the unit more often around this time, openly welcoming support from the team because J would rarely let them visit with him. In his sessions with the Social Worker, he had communicated his pride for his family – he had raised two adult sons who he put through college, a daughter about to graduate, and had just welcomed his first grandchild. They understood the diagnosis and prognosis, and continually reiterated a desire to spend “daddy’s last Christmas with him.” The team immediately asked for music therapy to be initiated.

In those first few attempted sessions, I was met with complete disregard, my presence was a burden. But I knew that J had been a professional musician alongside his other career for much of his life, and that music and his faith had once played a central role in all that he did. I persisted, recognizing the importance of helping him define some form of meaning and identity to his new self, if not for him, for his family. One day as I was being *kicked out* of his room, I *accidentally* left behind a recording of his favorite song, playing quietly on a loop. I returned approximately 20 minutes later to find J, listening silently, with tears streaming down his face. “Did you know I used to sing this song to my daughter each night when she was little?” I nodded *no* and seated myself silently next to him. For nearly an hour he just spoke, sharing his story, quiet and strained but oblivious to both. I remained present, actively listening to him reminisce about “what was no more.”

At one point, I moved my hand and placed it upon his arm, continuing with non-verbal cues of support. As he became increasingly fatigued, he shared one last narrative with me. His early retirement was planned so that he could take his sons on a motorbike journey across the U.S., they had talked about it "since the boys were little...and now we'll never make that memory." He told me he was tired but asked me to leave the song playing. I thanked him and didn't ask for permission to return, I knew that was my opening.

In meeting the team following and utilizing this visit as an early assessment for music therapy, his plan of care was born. In the more immediate and physiologic needs, music therapy interventions focused upon enhancing relaxed breath patterns through progressive relaxation and guided imagery, which could facilitate opportunities for comfort and thereby decrease his anxiety. Other goals would focus upon the existential and psychological needs, resolving inner conflicts in relation to accepting (or even tolerating) this new self and finding a new means for expression that maximized the strengths and abilities still present, which we believed would help J cope in a healthier manner with the chronic loss of self and deterioration. And the ultimate purpose of the sessions, would draw on the social and emotional domains, and would be to utilize music therapy legacy initiatives to fulfill his personal dream and reconnect to his family.

A few days later I had entered his room and found him asking me to pick my preferred chair when I visited. I had brought something for him on this day, a large map of the U.S. that I asked for permission to hang on the wall he faced the most. His curiosity was evident and he agreed. I seated myself next to him, looking up at this map, and placed several pins in his line of sight. The staff and I had drawn miniature motorcycles on them and I shared with him that I wanted to take that journey he had told me about the other day, that I wanted to partner with him, but that we would do something completely new to both of us so that the experience of learning together would necessitate building on one another's support. I proposed that we took the route he had planned out for him and his boys, and would learn a piece of music of his choosing, as we rode through the various states. In essence, I proposed a virtual motorcycle ride around the U.S. utilizing music. He smiled slightly, made eye contact, and stated that we had to start in his home of Puerto Rico so that I could learn his favorite song.

For the next months of J's life, we did just that, we learned and recorded music together. He even came to a point where he would ask me to press the record button so that we could capture all the variances in our learning "including the crap," which brought humor to his days. As we rode together, I began to initiate songwriting and parody into the music therapy interventions, in which we would first learn the piece as written, record it, and then go back and rewrite the lyrics for one of his children or close friends, completing a secondary recording for them.

J's presentation changed, his children visited often and for hours at a time. The staff were slowly welcomed into the journey, and J would commonly ask for them to sing a portion of a song with us and be recorded. He reconciled with his wife by forming a strong friendship together, and allowed her to provide some of the intimate caregiving because she voiced needing to care for him. He formed realistic future goals – to attend his daughter's graduation and to leave messages behind for his granddaughter.

We never finished the journey together, J died surrounded by family, friends, and staff singing his favorite song to him when we reached Wisconsin on the map. In homage to him, the team completed the project over the course of the next year and sent the family the package (the map, flags, lyrics, and recordings) on the first anniversary of his death. Somewhere in his journey, we had found meaning and hope.

Music is a wonderful vehicle to explore emotions, create ritual, and find ways to memorialize through legacy. It is this term – legacy – that has been central to my music therapy practice with patients diagnosed with ALS. Though it is not the sole intervention, what makes a legacy initiative complementary is that both create opportunities to provide joy in a time of sorrow, pain, and fear. Both can encourage humor, laughter, and pleasure for those with a life-limiting condition, where most cannot see past the confines of illness.

Dedicated to Mr. H, Mr. J and their families – with gratitude for gifting us the privilege of their wisdom, light, and love.

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