

# Twilight and Me: A Soliloquy

SPECIAL ARTICLE

By Daniel Alejandro Drubach, MD, FAAN

## ABSTRACT

Dementia with Lewy bodies (DLB) is the third most frequent type of dementia. The range of symptoms it causes is quite broad and includes parkinsonism, autonomic dysfunction, cognitive deficits, visual and auditory hallucinations, dream disturbances, and other unusual manifestations such as “sense of presence,” Capgras syndrome, and fluctuations in neurologic status. The author, an experienced behavioral neurologist and previous *Continuum* author, has been diagnosed with DLB and assumes the dual role of physician and patient. Each role provides a unique perspective. He discusses the importance of hope and fear in coping with the illness.

## INTRODUCTION

My mother had a saying that she would recite when something bad had occurred. It consisted of five words, *de lo malo, lo bueno*, which translates from Spanish as “from the bad, the good.” It means extracting the drop of good from anything that is bad; it also assumes that the bad always contains some particle of good.

Despite my mother’s precious and desperately necessary optimism, it is hard to find some good in being diagnosed with dementia with Lewy bodies (DLB). It is the third most frequent cause of dementia, following Alzheimer disease and vascular dementia and ahead of frontotemporal dementia. It most frequently affects individuals around the age of 75 and is more common in men than in women. It is a degenerative disorder that courses with relentless progression and for which there is no treatment or cure.

I diagnosed myself with DLB at approximately age 60. Almost immediately after I accepted the news, I decided to give my disease a unique name. I learned early on that the manifestations of the disorder were unique in every individual, and thus I wanted to communicate with my disease in a personal fashion. So I named it Twilight, perhaps because I realized that I am reaching the twilight of my life.

While finding some good in being diagnosed with DLB is difficult, the symptoms of this disorder are quite unique and artistic. Entering the land of DLB with a certain degree of curiosity and an open mind results in the discovery of unique visions and sensations, strange emotions, unusual forms of dreaming, and even a bit of magic. It is like entering an alternate reality that the healthy are not privy to, with things in a steady state of flux. At times I feel I am riding in a gondola in an amusement park. I ride from room to room, each one revealing a different experience, but I cannot tell what the next room will contain.

## CITE AS:

CONTINUUM (MINNEAP MINN) 2021;27(6, BEHAVIORAL NEUROLOGY AND PSYCHIATRY):1809-1817.

Address correspondence to Dr Daniel A. Drubach, Department of Neurology, Mayo Clinic and College of Medicine and Science, 200 First St SW, Rochester, MN, 55905, drubach.daniel@mayo.edu.

## RELATIONSHIP DISCLOSURE:

Dr Drubach reports no disclosure.

## UNLABELED USE OF PRODUCTS/INVESTIGATIONAL USE DISCLOSURE:

Dr Drubach reports no disclosure.

© 2021 American Academy of Neurology.

Twilight has resulted in two distinct, simultaneous, and unique roles in my life. The first is that of a neurologist with decades of experience with DLB and a large practice of patients with the disorder. The second is that of a patient with DLB. They are two very different experiences. An analogy would be to look at a hurricane from far away versus looking at it from within. The inner and outer visions result in very different perspectives.

As treating physicians, we sometimes respond to patients with statements such as, “I know how you feel,” or “I know what you are experiencing,” but are we being entirely truthful?

We need to rely on our patients to express their symptoms, and so we only hear them secondhand. Being a patient and a treating physician at the same time presents some challenges and many advantages. Among the latter is the increased ability to understand what patients tell me about their symptoms because I feel those symptoms firsthand.

I diagnosed myself with DLB long before consulting with another neurologist, who confirmed the diagnosis. My reaction to the diagnosis was mixed. I told myself that there was no reason to consider myself so special as to be spared from a relatively common disease. And, of course, I thought of death. One could argue that there is no shortage of causes for our deaths, and the only prerequisite for dying is being alive.

### HOPE AND FEAR

Shortly after my diagnosis, I dealt with two prevailing cognitive states: hope and fear. And at times, I sink into despair. I seek consolation from my God. He listens closely to my concerns, fears, and sadness. I sensed once that He was crying. He embraced me warmly and quoted a phrase from the Talmud Berachot 10. It states that even when a sharp sword is resting on the neck of a person, they should never give up. It is debatable as to what “giving up” refers to. Presumably, it refers to not giving up asking for mercy. After all, it would seem that a person with a sharp sword on their neck does not have much wiggle room. And yet the sages also clarify it does not mean solely to continue praying to the end. Rather, it refers to an attitude or state of mind, a spirit for fighting, a taking of one’s circumstances in one’s own hands as much as possible. And more than anything else, it refers to not giving up on the fairest and most precious of gifts: hope. No definition of hope does it justice, and words cannot encompass its monumental magnificence. It is an “experiential perception” that can only be understood by cognitively recalling prior experience with it.

Apart from hope’s fundamental role in healing, giving hope is one of the most beautiful acts of kindness. True, there is always the danger that the hope given may be unrealistic. But just as a bit of light dissipates a lot of darkness, so can a bit of hope ameliorate a lot of despair. Thus, the risk of being unrealistic is outweighed in many cases by the potential benefits of hope.

As a physician, I am frequently called upon to give bad news while attempting to instill hope. The fragile tidbits of hope given to patients and family members include allusions to upcoming research, stories of patients who survived much longer than usual, and the vague assertion that a good quality of life is still possible. But where to find hope?

A few years ago, I visited a market in La Paz, Bolivia, consisting of many stalls selling a variety of products. Popular were fetuses of llamas to be buried in the foundation of a house to provide luck. In one stall, hundreds of small colored

bottles contained many potions with different names and purposes. One potion caught my eye. It was in a small blue bottle with whitish crystals floating in a thick fluid. I reached for it to get a closer look, but the saleswoman stopped me with a strong grip of my wrist. She was an older woman with almost no teeth and a face so wrinkled it looked like parched earth. She told me that the potion contained in that small bottle was the most valuable item in the entire market. In broken Spanish (her native language was Aymara), she said that the potion's name was *pura esperanza*, or pure hope, uncontaminated by any other emotion. She explained that just one drop could restore hope in someone who had lost it. I offered to buy it, but she told me that it was not for sale. It was too precious to assign a monetary price. Instead, it was given at no cost to those who desperately needed it. But because the amount remaining in the bottle was so small and the potion so infinitely difficult to make, she dispensed it only with supreme care. And then she looked into my eyes and quietly said, "If there comes a day in your life that you truly need it, please find me." And as she smiled widely, exposing her toothless mouth, I thought that it was the most beautiful and compassionate smile I had ever seen. Now I suspect that she knew more about my future than I did. Her beautiful smile has been stored in my book of precious memories, a catalog, or diary, where I write down precious events, people, and all other instances of beauty so that they can be recalled when no longer remembered.

But at that time in my life, I was not devoid of hope. Thinking of myself as invincible, I sailed with full wind through all circumstances. I had only small things to hope for—a new car, a relationship, a pay raise. But after being stricken with Twilight, I developed bigger, more important, and urgent hopes: that I could play guitar again, that my hallucinations would not scare me, that I would be able to attend important family events, and so much more.

But now, in my current state, nearly devoid of hope, I so wish that I had access to the *pura esperanza* potion. I have thought of going to Bolivia to seek out that woman, but I am afraid of disillusionment. If I did not find her, or if the potion's powers were false, then I would lose all hope.

One of hope's magical powers is to ameliorate the most painful of emotions, fear. As with hope, fear is an experiential perception. Its definition cannot be encompassed by words but rather by recalling what one felt. Clearly, fear has an important role in survival, but I envision great fear as a horrifying growling and monstrous canine.

Then there are the fearless. They march into every situation as knights in shining armor, tall and proud. I wish I were like that. Instead, I have succumbed to fear: of a quick worsening of my illness, of leaving my family, and so much more. In essence, I am afraid (at times terrified) of where Twilight will take me.

The philosopher Martin Buber stated, "All journeys have secret destinations of which the traveler is unaware." I suppose that if this is true, Twilight is my secret destination. Before my association with Twilight, I had a path set out. I built safety net over safety net to assure that all would go as planned. But now I realize that the power of the safety nets was not great. The path that I had planned so carefully has disintegrated.

I ask myself: Is it possible for a person who has been stricken by a relentless disease with no treatment or cure to continue to live fully?

## THE PRESENCE

The first symptom that I experienced was what I learned to consider a sense of presence, the strange sensation that somebody was close to me or walking by my

side, at times leaning against me. I named the sensation The Presence because it seemed that it existed as a soul separate from mine. It was not a visual hallucination (I never saw anybody). Instead, it was a sensation. The Presence walked on my left side and became so prominent that I found myself constantly looking toward my left and, of course, seeing nothing. While on a few occasions I felt the presence of a person well known to me, such as a friend, The Presence was most often a stranger. I learned to appreciate The Presence, and when it was not by my side, I searched for it. Sometimes at night, I sensed The Presence next to me in bed. The Presence became an integral part of this strange world that I was entering. On a few occasions, The Presence pushed me onto the sidewalk when I walked on a busy street. On one occasion, I believe it saved my life.

At times, when The Presence had left my side, I tried to imagine what it looked like by constructing a picture from a feeling. I imagined it to be an older man, unkempt but clean, with gray hair down to his broad shoulders. When walking, he held his hands behind his back. He never spoke or looked at me. When I went to a coffee shop, my faithful and silent companion sat in the chair next to me. Never once did he order a drink. And in my days of delirium, when I was lost in absolute and chaotic loneliness, I also thought that The Presence was God.

I cannot be sure of the role of The Presence. Is it acting as a bodyguard, trying to protect me from the rest of the world, or is it attempting to protect the rest of the world from me? Could it be protecting me from myself? Or could it be (as an older patient once whispered in my ear), an angel from God sent to alleviate my fear? Otherwise, is it possible that his role was to ameliorate my eternal loneliness? One day I asked The Presence this question. He did not respond, but I felt him look into my eyes with what I thought was pity or sadness.

In addition to having The Presence walking by my side, I also developed the sensation that somebody was missing in my house. While there are three of us in my family, I felt that there should be four. I do not know who the fourth person represented.

It is my way to look for parallels between literature and reality; they are two faces (or perspectives) of the same coin, and much can be learned from looking at both. In an amazing story, “How Love Came to Professor Guildea,” by the English writer Robert S. Hichens, an unlikely relationship and close friendship forms between a kind and compassionate priest (the Father) and a highly accomplished, skeptical, and unfeeling scientist. The scientist confesses to the friend that he has a sensation (not a hallucination) that an unseen presence is in his house. He also feels “something” accompanying him and nestling up against him. However, the scientist sees nothing, hears nothing, and only on a few occasions feels a gentle but determined push against him. Hichens’ story is an excellent description of sense of presence.

The genre of Hichens’ story is horror or fantasy literature, and readers often refer to it as frightening. I found that the scientist’s description of his experiences was surprisingly similar to mine. In the story, the sensations suffered by the scientist become more disturbing with time, as did mine. It is also interesting that the intruder is felt by the scientist to be human. I agree with Hichens that human touch is something unique, distinct from being touched by a leaf or even an animal.

## VISUAL PHENOMENA

I do experience visual sensations. A friend with DLB told me that contained within what we see or hear is another layer of reality that can be accessed with

some effort. On my daily walk in a beautiful park, I practice accessing it frequently. I see a tree in all of its majesty. If I concentrate on that vision, I can see a prophetlike figure holding his arms up as if reaching to the sky. If I focus on the prophet, I see a flamenco dancer with her hands moving to the wind. And so on, I presume, to eternity. Antoine de Saint-Exupéry, the author of the masterpiece *The Little Prince* states, “A rock pile ceases to be a rock pile the moment a single man contemplates it, bearing within him the image of a cathedral.”

I have also become adept at shadow sculpting, which consists of morphing shadows into inanimate or animate objects. For instance, I will see the shadow of a coat rack and that of a lampshade and they will morph into the shape of a dinosaur. Especially in the darkness, shadow sculptures can be quite frightening.

Then there are the hallucinations. The first I remember having was while I was discussing a patient with a colleague. Suddenly, I saw a ballerina dancing in the middle of the room. The vision was very clear. My colleague, deeply enthralled in looking at a computer screen, did not notice my surprise. Over the following months, this was followed by hordes of furry little animals invading my bedroom. The content of my hallucinations and those of my patients is quite varied and curious. I keep an informal list that includes an armadillo walking majestically from one end of the room to the other; a tall man wearing a turban and a long gray cape; a baby who playfully crawled under the bed, forcing me to go after him again and again; and white butterflies who caressed my face when I went to sleep. Seemingly friendly faces looking in from outside the window have also been common in my case and with others. A patient reported seeing a curious cow in the bathroom. Yet another saw a pig in a dog collar and sunglasses run alongside his convertible, looking at him as if he were challenging him to a race.

Interestingly, I heard from a nurse who worked in a nursing home about a couple in their late nineties who simultaneously had the same hallucination; it must be the strongest of loves when everything is shared, including hallucinations. To lace tragedy with humor, a few weeks ago, I saw a car whose license plate read “Don’t tailgate; I brake for hallucinations.” Unfortunately, that can occur in patients with DLB.

At first, I blew off the hallucinations as a product of the imagination; as I told my patients, they were not at all threatening. But months later, the hallucinations underwent a prominent change. It became difficult to tell whether their content was real or not. With time, more of them appeared to be real and therefore more frightful. The gigantic rat that ran across my line of vision was terrifying. So was the previously innocuous armadillo; now it would charge at me showing its teeth, and I had to climb onto the bed to escape from it. Now the faces looking through the window had threatening and horrifying looks. Medications have failed to completely eradicate the visions and ameliorate the agitation associated with them.

We exist in a universe that we call reality. The opposite of that world is (for lack of a better term) nonreality. I believe that Twilight has given me the skill of jumping between those two universes, a strangely beautiful experience. When I see a dark furry object running across the kitchen floor, I need to decide whether it is real or not. The brain contains a process that Sigmund Freud coined “reality testing” that discerns whether an experience is real or unreal. However, hallucinations and delusions such as those of Capgras syndrome, a fascinating manifestation seen in DLB in which a patient believes that a person they know



well is actually an impostor, are outside the realm of reality. In these cases, the reality testing process seems to malfunction.

Twilight also has allowed me to see fascinating sights. For example, on clear nights, I sometimes walk on a path in the forest surrounding my neighborhood. On several nights, I saw a small group of moonlight artists sitting at the edge of a trail. Moonlight artists are whitish, slow-moving, ghostlike creatures that mix paint and moonlight in their palettes to create magnificent colors that they use for their art. However, if for any reason the moonlight abates, such as when clouds move in, the moonlight artists silently pick up their materials and fade into the trees. I have not been able to see any of their paintings. Twilight has also affected my sleep, as increased need for sleep and vivid dreams are among the main symptoms of DLB.

### DREAMS

I have always been fascinated by dreams, and DLB allows me to simultaneously be a participant in and observer of my dreams. For instance, if I dream about a physical altercation between two individuals, I tend to be one of them, physically acting out the fighter's role.

During an internship rotation in northern Argentina, I once met a renowned dream molder. It was told that he could enter a dreamer's dream as an actor enters the stage of a play in progress and assist the dreamer in overcoming troubling recurring dreams. I have often wondered whether I could hire a dream molder to eradicate the horrifying dreams that I frequently act out. One wonders who writes the script for the dreams of patients with DLB and why are they often so violent? In my REM sleep behavior disorder (RBD) dreams, I fight, kick, get chased, and, at times, holler. We do not fully understand whether the content of dreams in RBD is similar to those of people who do not have RBD. But if it is, then the popular maxim to go after your dreams is not the best advice.

Twilight has also blessed me with lucid dreaming. It is said that some individuals can learn how to lucid dream, but in my case, it comes on without any effort or warning. For those who are not privy to the experience, it is a difficult concept to understand. In normal dreaming, we are not aware that we are dreaming but can recall the dreams after waking. In lucid dreaming, the subject is aware that they are in a dream scene and not in the real world; in that dissociated state, they can learn to modify the course of the dream action and even communicate to the real waking world by eye movements.

### AUDITORY HALLUCINATIONS

Then there are the auditory hallucinations and sensations, initially not at all unpleasant. The sound of the washing machine in the basement sounds like a rock band playing. The sound of a chainsaw in the distance seems like the woeful lament of someone who has given up after a long and arduous struggle. It brings to mind a memory from the past: When hiking in Valle de la Luna, a beautiful site in northern Chile, I saw a guitar hanging from the top of a well, although nobody was around. Back in town I inquired about the significance. I was told that when a person is in dire search of peace, they hang a guitar over that well, listening for the music that emerges from the wind stroking the strings. After a few hours, the music soothes the aching soul. In my nights of unrelenting insomnia, I hear that music.

But like all else with DLB, the character of the auditory hallucinations has changed with time. I often hear my name called out; at times it is the voice of a young woman, a beautiful and soothing call. But at other times it is that of a man with a strong Spanish accent, a harsh threatening voice. I run away as fast as I can, but there is no escaping. The sounds of many voices, like a Gregorian chant, also seem to follow me, getting louder and more distorted as I try to get away.

One particular hallucination I initially loved and eventually came to dislike: In the Jewish Hasidic tradition, wordless tunes, called *nigunim*, are sung over and over by a gathering of religious men. It is said that some *nigunim* have the power to heal matters of the heart, as I believe is the case with the one I hallucinate. Unfortunately, the tune at times goes on for hours, which can get quite uncomfortable.

## LOST IN MIRRORS

One of the strangest features I have encountered with Twilight and that has also been described by a few patients is an unusual relationship with mirrors. I remember the first time that I experienced this. I was in a restaurant that had mirrored walls. I left the table for a few minutes, but when I tried making my way back, I felt trapped within the mirror. I could not get out, and I despaired. Fortunately, a friend of mine sitting at the table came to me, grabbed my hand, and took me to my seat. I was quite embarrassed, and as I sat down I caught a glance of the elderly and beaten-down gentleman looking at me from within the mirror. He looked quite familiar, and I then realized that it was me. In the brief moment that we looked at each other, I realized how much I had changed. My face was tense, emotionless; I looked aloof, distant. I am reminded of the literary masterpiece *The Metamorphosis*, written by the German-speaking Czech writer Franz Kafka, who died at age 40 from tuberculosis. In the story, a man wakes up one day transformed into an insect (frequently translated as a cockroach). One of the literally thousands of interpretations of his writings suggests that the insect is a metaphor for a person who becomes sick and is changed both physically and mentally by that illness. I believe that I am undergoing a metamorphosis. The changes are subtle but significant. People who know me well tell me that I look different but are not able to describe what is different about me. The innumerable features that make me a unique individual, including physical features and personality, have been changed by Twilight to such a degree that I am not the same.

## LOSSES

Twilight has taken much from me. Initially, writing and typing became difficult. Since I presume myself to be a writer, this was a sad situation. But especially painful was developing difficulty in playing guitar. My fingers did not seem to respond to what I asked them to do to play a tune. If there is one thing that helps define me, it is playing guitar. I am not particularly good or accomplished, but I enjoy playing in bars, restaurants, and coffee shops. Being pretty much the only guitarist in my town, I can safely claim to be the best, and the guitar has been the best of friends throughout my lifetime. She is my perpetual listener, and what more precious act of kindness is there than to just listen with all the mind and heart? When she realized that I was having difficulties, she did all she could to make up for the distorted sounds caused by my unresponsive fingers. Being unsuccessful and understanding my pain, I could hear her at night crying with a mournful cry.

Then there is the loss of words. This is not universally present in patients with DLB, but it has happened to me. Few things in the universe are more magnificent and precious than words. Conversely, few experiences are as devastating as the loss of words. We humans rely heavily on words not only to communicate with others but also to communicate with ourselves, since thought is, to a large degree, made up of words.

Fluctuations are one of the most fascinating and poorly understood neurologic symptoms of DLB. My neurologic status, including difficulty with cognition, degree of hallucinations, and ability to write and even play guitar, can fluctuate from week to week, hour to hour, and even minute to minute. At times, I even feel normal and reach a point of ecstasy. I feel the lightness of an eagle and fly higher and higher, only to miserably fall to the ground. What a cruel tease.

There is also the issue of speed. Almost everything in the universe moves or flows at a certain speed. This includes physical matter, such as our walking or a leaf falling to the ground. These movements also include metaphysical or metacognitive activity such as thought and affect. These highly harmonious movements are affected by Twilight. My world has become slower. I walk, talk, and even think slower than I used to. It seems that I am out of sync with the rest of the world. Maybe that's not necessarily bad. My mother said that the faster one goes in life, the faster one will get to their own funeral.

And then there is the issue of memory. Since life is contained within our memories, when we lose them, a bit of ourselves is lost. And I have lost much. There is a perfect harmony between remembering and forgetting. I imagine a scale; one arm holds forgotten things, the other those remembered. How much and to what side the scale tilts is determined by what is remembered and what is forgotten.

Unfortunately, it's not in our power to tilt the scale. We cannot choose what to remember and, just as important, what to forget. It would be such a special blessing to have the ability to choose what to forget. The plea for selective forgetting is nowhere as eloquently expressed as by William Shakespeare in his masterpiece *Macbeth*. Discussing with a doctor an ailment affecting his wife, Macbeth asks, "Canst thou not minister to a mind diseased, pluck from the memory a rooted sorrow, raze out the written troubles of the brain, and with some sweet oblivious antidote cleanse the stuff'd bosom of that perilous stuff which weighs upon the heart?"

### TWILIGHT'S JOURNEY

A few weeks ago, I had a lengthy conversation with Twilight. On the agenda were many issues, but the topic of healing took top importance. We discussed a statement from the Talmud that speaks about a book of cures that contained a cure for all maladies and was hidden by King Hezekiah, a king of Judah who ruled approximately 700 to 600 BCE and was considered a righteous ruler. Hezekiah's reasons for hiding the seemingly important book are somewhat unclear, but sages have proposed that it was because the book eliminated the need for people to pray for health and healing. In my nights of insomnia, I search for that book.

I am reaching the end of my journey, the secret destination proposed by Martin Buber. And thus, I am reminded of the words of Pablo Neruda: "Someday, somewhere-anywhere, unfailingly, you'll find yourself, and that, and only that, can be the happiest or bitterest hour of your life."



A person should approach every moment of their life with a certain degree of curiosity and wondering, considering every event encountered as an opportunity for self-discovery. And so it is with me and Twilight. Without him, I would have missed many opportunities to discover facets of my being.

Throughout our lifetimes, we find ourselves in an infinite number of circumstances, each of them the clay with which we create and reinvent ourselves. We need to choose each brick of clay carefully. Some bricks create unimaginable beauty; others are used to break windows by those who invent hate. The clay given to me is Twilight, a relentless progressive neurodegenerative disease for which there is no treatment and no cure. Loaded with a heavy toolbox, I build the road that will take me to the end of my path. I have also been placed in a unique situation: I am both a patient and a healer. Because of my experience treating patients, I have some knowledge of what awaits me. While I do not hold pity for myself, I do acknowledge a certain degree of compassion.

And how to end this soliloquy? Perhaps with a thought by a Hasidic master of the late 18th century, Nachman of Breslov. He stated, “A person walks in life on a very narrow bridge. The most important thing is not to be afraid.”