# Experiences of the Dying: Evidence of Survival of Human Consciousness

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#### 1. OVERVIEW

When I became a hospice doctor 23 years ago, neither my medical training nor my doctoral degree in neurobiology could have prepared me for what I would witness at bedside of patients nearing death. I used to believe that my job was caring for life pre-death. Instead, I came to realize that there is more to dying than death.

My observations at bedside have led me to the counterintuitive claim that the survival of human consciousness after death may be nowhere more evident than in what happens to the dying *before* death. These are moments of transition when the mind's elevation transcends the body and brain's deterioration. Put another way, we can't look into the continuity of consciousness past death by having an exclusive focus on the after. Doing so would assume a before/after division that the dying experience itself renders irrelevant. The dying process is a continuum within which our patients experience a heightening of consciousness and an acute awareness of their past and present existence. This experience includes a consciousness that is most often shared with others who died before them and but who are now fully present to them. The dying process reveals a connectivity between and across lives, both living and dead. This continuity of connectivity persists regardless of time or bodily existence and supports the hypothesis that consciousness survives beyond bodily death.

I used to believe that end of life includes processes that understandably draw us inward towards introspection and reflection, processes that distill life into what truly counts and in so doing, validate having lived and mattered. That the dying process would alter the patient's perception made sense. What was unexpected if not jarring was that the process entails so much more than just a changed outlook in patients. Shortly before death, the dying have dreams and visions of their predeceased loved ones, scenes of vivid and meaningful reunions that testify to an inexplicably rich and transformative inner life. The phenomenon includes a lived, felt, often lucid experiential reality whereby those loved and "lost" return to the dying in ways that cannot be explained by memory alone. Children and parents sometimes lost decades earlier come back to put patients back together and help them transition peacefully. At the precise moment we associate with darkness, loss, physical decline, and sadness, their presence helps the dying achieve peace, comfort, and forgiveness, which suggests an existence beyond our bodily form. A

failing brain does not imply a failing mind, and biological decline does not diminish the soul. In fact, in our final days, our physical form does not follow function: patients are spiritually and perceptually alive and vibrant despite a failing body. This is the paradox of dying.

A remarkable body of work on Near-Death Experiences (NDE) has been cited as evidence that consciousness is more than a byproduct of our brain and survives our mortal form (1-5). Skeptics offer physiologic explanations and argue that the memories or sensations of NDE-like experiences are actually triggered by the brain as it shuts down or reboots; they attribute the phenomena to causes including oxygen shortage, anesthesia, neurochemical responses to trauma and "post-resuscitation syndrome" (6-8). Critics of NDE study protocols also suggest that this research does not "exclude that the reported memories were based on retrospective imaginative (re)constructions built up from memories, prior knowledge, and/or expectations about the world" (9). Others explain NDEs based on spiritual or psychological interpretations, ranging from the theories of Expectancy to Dissociation (6, 9, 10).

Proving consciousness beyond death must not only account for neurobiological changes associated with "clinical death" but also address factors that define and inform consciousness, such as changes in awareness, wakefulness, and connectedness. At Hospice, we routinely care for dying patients who are not only neurologically intact but fully aware and awake. Whereas physical death is a circumscribed event, dying for most is a prolonged process that inherently alters consciousness. The dying processes we witness are anticipated, non-acute and physically irreversible. Yet, instead of exhibiting a waning consciousness, many of our patients display a heightened acuity and a rich inner life which includes changes in perception as well as an awareness of both their internal and external existence. Not surprisingly, such experiences of consciousness are qualitatively distinct from those events described in traumatic or acute death, alterations in brain function from anesthesia or recovery from recusation. The studies conducted at Hospice Buffalo for over a decade further corroborate that the dying are paradoxically often emotionally and spiritually alive, even enlightened, despite their terminal physical decline, not just in the minutes or hours before physical death, but in the days and weeks. In other words, these extraordinary inner experiences that has been attributed to a failing brain with NDEs occur

during the dying process on a continuum that goes from intact cognition to the fluctuating states of consciousness and failing organs that define the immediate hours before death.

We hypothesize that only those who are actively dying have the vantage point and the language to define their changing and enlightened existence, the keyhole through which to see what's beyond. Our work focuses not only on the dying process but specifically, on the experiencing of it, the subjective or conscious dimensions of dying. The tragic physical process of dying often obscures the experiential, inner or subjective dimensions of dying which represent a heightened form of consciousness, an awakening of feelings, wonderous perceptual experiences, insights into one's present and future existence as well as a feeling of connectivity, wholeness and belonging. Our patients exhibit changes in awareness of thought, memories, feelings, sensations, and environments. Not only are such experiences near universal, but they are remarkably similar. This is why to find evidence of the survival of human consciousness after death, we need to look at what happens *before* death, in these moments of transition when the before and after merge to the point of irrelevance and the enlightened mind transcends the body and brain's deterioration.

The following is a video of our patient Florence, six days before death. She is free of neurologic disease and has not taken any psychoactive medication. Although dying, Florence is physically unburdened and cognitively intact while describing the closing of her life. To her, dying is a conscious experience that is vibrant as well as self-fulfilling. Her consciousness is lucid: she is fully awake, aware and connected. Through this keyhole, Florence doesn't dream, analyze or simply remember, but instead feels the familiar and comforting presence of those she has loved and lost. Unlike the epiphanies or revelations often associated with NDEs, there are no great insights or messages. In fact, language is near absent and not needed. Florence is instead at her family's kitchen table in the company of her deceased husband and daughter; she has been put back together and is truly home. Her awareness is acute, complete and secured in the certainty of what has always defined who she is: her relationships. She is now restored in a promise of what lays ahead. Florence doesn't have any feeling of being out of her body or any perception that she is dead: her existence, as defined by love, is understood and sustained. These experiences are not only validating but remove any fear of physical death. Florence is already on her journey, her consciousness continuing where her body can no longer go (Link to: Florence Interview Video).

These moments of life-affirming enlightenment at the time of death have been acknowledged across cultures and throughout history. Indeed, while modern medicine has been resolutely silent on the topic of dying, often reducing it to mere "medical failure", the humanities, the realm of culture and religion, have long testified to its significance to humanity. From writers, poets and philosophers as far back as ancient Greece, from Buddhist and Islamic texts to accounts from China, Siberia, Bolivia, Argentina, India and Finland, from the religious and sacred traditions of Native Americans and other indigenous peoples around the world, meaningful pre-death dreams and visions have been widely recognized and celebrated. They are mentioned in the Bible, Plato's *Republic*, and in medieval writings such as the 14<sup>th</sup> century mystic Julian of Norwich's *The Revelations of Divine Love*. They show up in Renaissance paintings and in Shakespeare's King Lear. They appear in 19th-century American and British novels, in T.S. Eliot's poetry, and last but not least, in the Dalai Lama's meditations on death. If anything, the medicalization of death has obscured a language that has always been available to make sense of our finitude and that has been integral to humanity's need to maintain connection with the departed. This awareness that we remain intertwined beyond death is central to the story of our shared humanity.

Starting in the twentieth century, reports on pre-death experiences began to be collected systematically through eyewitness accounts (11-16). More recently, a research team at Hospice Buffalo, has conducted studies on over 1,500 patients and families. The process of dying is a reality that only the dying could tell us about, from a vantage point that the living do not share. It was the testimonies of these patients as well as our subsequent systematic studies of their inner experiences that helped us reframe dying and our notion of a before and an after death and of consciousness itself. The data confirmed that the vast majority of dying patients, shortly before death, have these comforting dreams and visions that most commonly summon predeceased loved ones. After witnessing how these bonds of love re-emerge as unbreakable at life's end, the question we were left pondering was "are the deceased ever really gone?" Indeed, those who returned were not just random appearances; they were most commonly, as with Florence, people who best loved and secured the dying in life and were reuniting at a depth that suggests they were never gone. One ninety-five-year-old gentleman claimed to smell his mother's perfume as

she whispered "I love you" in his ear. His mother had passed ninety years earlier when he was five years old, yet his vision of her was as crisp as if she had just left him. Such experiences return at life's end in ways that transcend mere recollection and are instead tangible, material, and lived. With full lucidity, these patients claim such experiences are "more real than real" and rich in detail not previously recalled but now vividly summoned.

"Transcendence" is typically the concept used to denote an existence or experience beyond the normal or physical level. The word literally means "going beyond." It is also a state that is associated with the afterlife and that best represents the work that pre-death experiences do in helping patients transition to death. In fact, the power of the spiritual transformation and "transcendence" they occasion in patients' lives cannot be overstated. Near death, the boundaries between the experiential and the spiritual, body and mind, present and past, conscious and unconscious impulses dissolve to provide comfort through a process of connectivity across the living, the dying, and the dead. The process brings about a form of spiritual and emotional solace that is rooted in lived experience rather than just dreams or memories. Recognizing people's experience of dying as the gateway to continued consciousness beyond life and death is crucial if we are to become more literate on what constitutes our mortality.

#### 2. STUDY SUMMARIES

#### A. BACKGROUND & SIGNIFICANCE

Our research began in 2010 and has so far resulted in 9 peer-reviewed publications (17-25). However, it did not originally seek to demonstrate the continued existence of consciousness after death. In fact, our intention was quite different. Our work grew out of frustration in trying to teach young doctors that dying is more than failing organs but should instead be regarded as a closing of a life in which the patients live and die in totality, not in parts. Our objective was to honor and validate the patient experience rather than fulfill the expectations, prophecies or the beliefs of the observer. We were consistent and intentional in our commitment to translate the words and experiences of dying patients without extrapolating or editorializing about the afterlife, the paranormal or the religious. But when we paused and listened to our patients, they told a story we had neither sought nor anticipated. The results of one study spurred on the next such that when taken together, an overarching yet unanticipated theme emerged which indeed

suggests that consciousness extends beyond physical death and connects us to one another, whether living or dead.

The common notion that nothing valuable can come from patients in the final days and weeks of life reflects a limited insight into the meaning of the patient's dying experience which includes pre-death experiences. Too often, the medical students or fellows with whom I worked at Hospice would dismiss the patient's inner experiences as the manifestations of psychogenic drivers or the neuronal workings of a dying brain. Their reaction inevitably failed to account for the spiritual and psychological benefits of the occurrences. The more I taught the more I heard young doctors retort that there was "no evidence," which meant measurable evidence, in language *they* considered valid. To help them rethink their approach, we needed science-based evidence; that meant studies that were objective, systematic, and rigorous, that met the standards of scientific scrutiny and could be published in peer-reviewed medical journals.

To achieve this, it was essential to add authenticity and hear from the patients and families in their own voice. To further corroborate and better represent the patient's perspective, as well as refute the notion that end-of-life experiences are merely manifestations of a cognitively impaired or confused mind, the decision was made to videotape many of our patients. We all have biases or assumptions about the dying process, and such misconceptions are best addressed by hearing from the patients themselves. We wanted to show that dying patients are not just what they are too often imagined to be--faded, lethargic and often time-ravaged people in a hospital gown, too frail to function, think or express themselves. Rather, they represent the full diversity of the living; they may be alert, contemplative, thoughtful or intuitive, young or old, able-bodied or disabled. They may each be unique in their own way, but they all represent the universality of the phenomenon we set out to examine. Perhaps, most importantly, these patients wanted their voices heard.

Clinicians unfamiliar with pre-death experiences often discount them as hallucinations caused by medications, fever, or confusional states, thus insinuating that these experiences hold little intrinsic or clinical value (26). Although it is common for dying patients to exhibit delirium when transitioning from life to death (27, 28), the state is marked by disorganized thinking,

altered sensorium, agitation, anxiety, or fearfulness (29, 30). Patients frequently experience predeath phenomena as well as fluctuating states of delirium, particularly before death, but predeath experiences, even in the context of episodic delirium, typically involve clear consciousness, heightened acuity, and awareness of one's surroundings; they are memorable and recalled with clarity; they contain subjective meaning, provide a source of personal solace, and are mostly characterized as comforting or extremely comforting in contrast to delirium (13, 32, 33, 34). Pre-death experiences differ most from hallucinations or delirium by the responses they evoke, including inner peace, acceptance, and the sense of impending death (34, 35, 36). These distinctions are critical, because medicating pre-death experiences mistakenly perceived as delirium may remove the dying patient from comforting experiences inherent to the dying process. This further causes isolation, suffering, and impairment in the dying person's ability to experience and communicate meaning at end of life (14, 34).

Our understanding of the experiences at life's end is complicated by inconsistent nomenclature or terminology that is not fully applicable to the occurrence and may even be misleading. End-of-Life Experiences is a broad term that is commonly used to describe a wide range of phenomena that people may experience near the time of death (11, 12, 37, 38). End-of-Life Dreams and Visions (ELDVs) are a form of End-of-Life Experiences and our preferred nomenclature in our research.

For reference purposes, the word dreaming is often used to describe pre-death experiences, simply because this is the closest description or reference point we have. Yet, it's important to note that patients frequently insist that their subjective experiences are more dissimilar than like previously experienced dreams. In fact, they often refer to these episodes as "visions" to convey the distinct realism. What is more, half of the patients in one study reported that these events occurred while they were awake (18).

Although the topic of End-of-Life Dreams and Visions has been well-documented over time, our research approach is unique in several ways. With the exception of some case reports, the majority of previous studies rely on surveys or interviews with families of the deceased or with clinicians who work with the dying (13, 26, 33, 35, 39). By contrast, our studies adopt an

objective approach to the reports taken directly from patients themselves rather than their observers. What is more, previous researchers had collected their data during singular or sporadic moments very near death, thus failing to capture dying as a process that changes over days to months. By contrast, we interviewed patients longitudinally and, in some cases, near daily until death. Our approach included both quantitative and qualitative studies as well as hundreds of hours of video footage. Finally, all study patients were screened for any evidence of confusion or delirium and were excluded if any cognitive impairment was detected. We also documented the experiences of children as well as adults.

The next section is a review of most of our published studies, some in more detail when relevant. The presentation of our results is organized according to three conceptual groupings: 1/ studies that focus on the subjective experience of dying, 2/ studies that center on the experience of the bereaved and 3/ a study that redefines dying as an active process of growth and adaptation.

#### B. PUBLISHED DATA

# **<u>I.</u>** Studies from the Perspective of the Dying

# i. Adult patients

Although there was growing cultural recognition that ELDVs are psychologically and existentially significant, they had rarely been explained in a clinical context or presented as medically relevant. There was also a scarcity of data addressing the prevalence, content, and significance of ELDVs. Nor had studies directly addressed the issue of delirium or confusional states that may confound our interpretation of ELDs.

The first study (18) was therefore designed to 1) document ELDV experiences using a longitudinal survey and semi-structured interview format in hospice patients nearing the end of life; 2) examine the content and subjective significance of ELDVs; 3) relate the prevalence, content, and significance of ELEs over time until death and 4) clearly address the issue of altered cognition or confusion by excluding those who met diagnostic criteria for either dementia or delirium.

For this study, Hospice patients who had been admitted to a Hospice Inpatient Unit were screened for eligibility. Inclusion criteria were age 18 or older, capacity to provide informed consent, and a Palliative Performance Scale (PPS16) score of 40 or greater. Exclusion criteria were diagnosis of a psychotic disorder as per the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV) and a barrier of language or communication. 59 patients agreed to participate in the study and were interviewed daily by a study investigator using a standard framework of questions.

The study included close-ended questions related to the presence or absence of dreams/visions, whether these experiences occurred during sleep or wakefulness, dream/vision content and frequency, degree of realism, and comfort versus discomfort. For questions regarding dream content, investigators checked boxes from a list of eight items (deceased friends/relatives, living friends/relatives, other people, deceased pets/animals, living pets/animals, religious figures, past meaningful experiences, other). Patients reported dream frequency by choosing a range of once a day, 2 to 4 times/day, or > 4 times a day. Comfort provided by the dream/vision was rated on a 5-point semantic differential scale with 1 = Extremely Distressing and 5 = Extremely Comforting.

Investigators also recorded key clinical indicators: overall clinical status (Palliative Performance Score), oral intake, presence/absence of fever, alertness level, as well as medication changes. With respect to data analysis, multiple approaches were used and included descriptive statistics, graphic analyses, and inferential analyses. Multilevel models were chosen to account for the varying patterns of reports by individual patients, including variation in number of days included, missing days due to patient condition, and the possibility of multiple event reports per day.

The results of this initial study were based on 59 patients and a total of 453 interviews with a mean of 7.68 interviews per person. Range of days before death for interviews was 0 to 87 days, with a mean of 21.58 and a median of 15 days. Of the 59 patients who were interviewed, 52 (88.1%) reported experiencing at least one dream or vision. Almost half of the dreams/visions (45.3%) occurred while asleep, 15.7% occurred while awake, and 39.1% occurred while both

asleep and awake. Degree of realism was recorded on a 10-point Likert scale and nearly all ELDV events (267/269, 99%) were reported by patients to seem or "feel more real than real." Most daily reports included a single ELDV event (179, 81.4%) with two (13.2%), three (4.1%), and four events (1.4%) on other days.

Patients were also asked to describe what they had dreamt about. The interviewer coded responses on a checklist with eight categories, noting all that were included. Many patients reported end-of-life experiences that included reunions with deceased friends or relatives (72 %) living friends or relatives (17%), other people (10%), and deceased pets or animals, living pets or animals, religious figures, past meaningful experiences, and other content not listed (singly and in combination, 35%). Note that the total percentage is greater than 100% because multiple responses could be recorded for each event (e.g., deceased friend/relative and living friend/ relative in the same dream). In addition, 38.9% of all dreams included a theme of going or preparing to go somewhere.

Patients also rated the degree of comfort/distress associated with their ELDVs on a 5-point scale ranging from Extremely Comforting (5) to Extremely Distressing (1). The mean comfort rating for all dreams and visions was 3.59 (SD= 1.21, 95% confidence interval [CI] = 3.44–3.73) with 60.3% rated as comforting or extremely comforting, 18.8% distressing or extremely distressing and 20.7% neither comforting nor distressing. The highest average comfort rating was associated with dreams/visions about the deceased (mean = 4.08, SD= 1.05), followed by deceased and living (mean = 3.61, SD= 0.78), living (mean = 3.22, SD= 1.15), and finally other people and experiences (mean = 2.86, SD= 1.19).

One other clear pattern was evident: the frequency of end-of-life experiences not only increased as death neared, but the most prevalent ELDV content involved reunions with the deceased which were also rated as the most comforting theme. In other words, as patient drew closer to the physical end of life, they were progressively more soothed by the comforting presence of those they loved and who had died. ELDVs may also be prognostically significant based on changes in content and increased frequency as death nears. This pattern of ELDVs bringing greater level of

comfort with approaching death challenges the notion the dying involves increasing psychogenic distress.

There seems to be a distinction between the dying process we imagine, and often fear, versus the death experienced. In the following video is of an interview of a dying woman named Jeanne, as well as input from her daughter Julie (Link to: <u>Jeanne and Julie Interview Video</u>). Clearly, Jeanne isn't confused and describes the experiences as vivid, rich in detail (including tactile sensations) and interprets these experiences as having "actually happened".

In summary, our original study demonstrated that ELDVs were common, as 87% of study patients reported such dreams/visions. Regardless of whether the experience occurred during waking (19%) or sleep states (46%) or both (35%), the dreams/visions conveyed a sense of realism. In fact, many patients reported that these in fact were not dreams but actual occurrences, and many were adamant that they don't usually dream or recall their dreams. The descriptions of ELDVs provided by participants were typically vivid with great detail and personal meaning. There were several important and unforeseen observations made by the investigators while conducting the study. For example, patients' pre-death dreams were frequently so intense that the dream carried into wakefulness and the dying often experienced them as waking reality. The realism of pre-death dreams/visions is consistent with prior research suggesting that during stages of transition or crisis, dreams become more vivid, intense, and memorable. In addition, despite very little spoken dialogue within the dreams/visions, the circumstances and significance of the experiences were still conveyed. The predominant quality of pre-death dreams/visions was a sense of personal meaning, which frequently carried emotional significance for the patient. This was also true of ELDVs that were not comforting.

After documenting the prevalence and characteristics of ELDVs, we wanted to better understand their content, and what they meant to the dying. In the second study (19), we conducted multiple interviews with 63 Hospice patients. We began the study with patients in our Hospice Inpatient Unit, which included a survey and a structured interview. We visited participating individuals daily to complete the survey and interviewed them for as long as they were able. The study utilized quantitative data as well as open-ended questions and

interviews, which allowed each participant to describe their experiences in detail. The data was analyzed using a mixed-method design called concurrent triangulation that is used to confirm or corroborate the findings of 2 different methods; both quantitative and qualitative data were collected at the same time.

### The results revealed 6 categories of ELDVs:

- 1. Comforting Presence: Dreams and visions that featured the presence of dead friends and relatives were well represented throughout the data. Some also included living friends and relatives as well as dead pets or other animals. These dreams and visions were overwhelmingly described as comforting to the patient. For example, one patient reported that she had frequent dreams of her dead sister sitting beside her bed. She described these dreams as extremely comforting because "I am not going alone [my sister] will be with me." Another patient reported dreaming of her dead mother talking to her in a beautiful garden, saying "everything will be okay." This was very comforting to the patient and she told her family that she wanted to go back to sleep because her mother would be coming back. Another patient who dreamed of both dead and living friends and relatives also reported that they were all "telling me I will be OK." Yet another patient reported dreaming of his mother who had died when he was a child. The dream was so vivid that he reported smelling her perfume as well as hearing her soothing, comforting voice, say, "I love you". The following video of Alice, who describes an intense vision of deceased loved ones and is left with a feeling of "enormous love" as well as a sense of "joy and peace that was hard to describe" (Link to: Alice Interview Video).
- 2. Preparing to Go: Some participants reported that in their dreams they seemed to be preparing to go somewhere. One patient described seeing his parents, grandparents, and old friends in his dreams. He observed, "I know we are going somewhere, but don't know where." Another patient dreamed that he was driving around [town] and had to go somewhere, but again, he did not know where. A third patient dreamed of boarding a plane with her son and although she could not describe where they were going, she reported feeling comforted. In a subsequent interview, she said that she and her son "were on the edge" of leaving. Although there were a few reports of distress because dreamers felt "hurried," the participants primarily found this experience of preparing

- to go somewhere to be comforting.
- 3. Watching or Engaging With the Dead: Participants in this category described the presence of others in their dreams/visions as simply being there or watching but not engaging with the patient. For example, one patient reported that she had dreamed of her two aunts standing over and watching her while she was lying on the couch. She found this to be very comforting. There were also reports, however, where patients described themselves as engaging with people in their dreams. One patient reported that her husband and her dead sister had joined her for breakfast; she also dreamed of playing cards with her dead friends. Another patient dreamed that her father and two brothers, all dead, were silently hugging her and playing games; then she described how "they were welcoming [her] to the dead." Yet another patient described a dream where he was able to play with and pet his dead dog. Again, these experiences were largely reported as comforting.
- 4. Loved Ones Waiting: Some patients in the study described dead friends and relatives in their dreams as "waiting for them." One woman reported that she had both waking and sleeping dreams of six dead family members in her room. She added that they were "waiting for me" and that it was good to see them. Three days before another woman died, she reported experiencing both waking visions and dreams of being at the top of a staircase with her dead husband "waiting" for her at the bottom of the staircase. Once again, the presence of these dead friends and family members was primarily experienced as comforting. There were, however, some patients who expressed that they were not ready to die. These patients experienced some distress at the fact that the dead were "waiting" for them.
- 5. Distressing Experiences: Not all dreams/visions experienced by the patients in the study were perceived as comforting. There were also reports of distressing dreams, some of which replayed traumatic life experiences. One patient, for example, reported dreaming of his previous war experience. A second patient reported dreaming of her son's serious injury that occurred on a naval ship. Several patients had dreams about abusive childhood experiences. Other distressing dreams were reminiscent of the difficult situations or relationships the patients had had. For example, a male patient reported having distressing dreams of his brother being very critical of him and also reported distressing,

anxiety-provoking dreams about his work, both of which were based on actual past experiences. Some of the dreams in this category were described as reminiscent of negative past experiences with friends or family members that had previously been distressing. It is notable, however, that many distressing dreams also included elements that brought resolution or meaning. For example, one veteran who dreamed of war also relived the day he received his discharge papers as well as a comforting reunion with fellow soldiers who had died.

6. Unfinished Business- Participants also reported dreams that centered on their fears of no longer being able to do the things they felt they needed to accomplish in life. One young mother, for example, had distressing dreams of her daily responsibilities with her children. The dreams involved getting her children ready for school, getting them to practice, and other parental responsibilities. A second young mother experienced distressing dreams related to real-life worries about her bills and her children. The continuity within the dying experience of the preoccupations and experiences that had defined living is itself significant. This too speaks to the continuity of consciousness across living, dying, and death.

## ii. Pediatric Patients

The study of end-of-life dreams and visions typically focuses on adults; however, children with terminal diagnoses also have these experiences, further demonstrating that this is an occurrence related to the transition to death and not to age or physical decline.

Our third publication was a pediatric case series (22). Although children and adolescents process the experience of illness and impending death in ways that are distinct from adults, they still contend with existential and spiritual concerns no matter how difficult these may be for them to express. When facing serious illness, children are often confronted with an unimaginable reality for which both context and language are limited. As they struggle with illness, they also must cope with fears around death, including existential questions that are challenging to communicate and equally difficult for clinicians to answer. We have been fortunate to be able to film several of these children.

In several pediatric cases, the children's ELDVs didn't deny their impending death but informed and transcended the inevitable. In all cases recorded, their ELDVs provided comfort and meaning. For example, Ginny was a 15-year-old girl whose dreams and visions heavily impacted her dying process and her mother Michele's bereavement experience (Link to: Ginny and Michelle Interview Video). With exceptional detail, Ginny recounts a dream in which she is playing dolls and singing songs with her deceased aunt. She describes being in a beautiful castle filled with warmth and light. Adorning one of the walls is a stained-glass window depicting "a baby and you can see the sun through it." In her own words, Ginny describes the castle as a "safe place" and emphasizes that she is "not alone." In addition to her aunt, the castle is also populated with numerous pre-deceased family pets that now appear alive, healthy, and playful. Upon waking from sleep, Ginny found immediate meaning in her ELDV experience, telling her mother, "I'm going to be okay, I'm not alone." Four days before her death, on what had been a quiet afternoon, Michele heard an animated conversation through a baby monitor that was kept beside Ginny's bed. When Michele asked Ginny whom she was talking to, Ginny responded, "I was talking to God." She added "He's old, but he's kinda cute." She said to her mother, "I'm not going to be sick; you know, where I'm going. You know, to the castle." Ginny's conversation with God also addressed her concern as to whether her family would be able to join her when their time came.

# **II.** Studies from the Perspective of the Bereaved

In our next series of 3 studies, we focused on the bereaved. In the first two studies (21,25), we assessed the effect of our patients' ELDVs on the bereaved, specifically, how ELDVs affect grief and bereavement for those who lost a loved one. These studies, which combined included roughly 750 bereaved loved ones, demonstrate that participants felt the dreams helped with their overall grief (58.2%), accepting their loss (49.3%), working through the pain of grief (46.1%), adjusting to their new world without the deceased (39%), and continuing the bond with their loved one (45.9%). In general, the more comfort they felt an ELDV brought to their dying loved one, the more comforted caregivers were during bereavement. The impact of ELDV's impact on grief processing was also quantified and shown to be statistically significant when measured using validated instruments such as the Core Bereavement Items. The following video of a widower named Norb is one such example (Link to: Norb Interview Video).

In addition to the above studies which focused on the impact of the dying patients' experiences on the bereaved, we also published a study which focuses on the dreams of the bereaved, specifically dreams that focus on loved ones who have passed (17). The distinction is important: these individuals were not actively dying yet they too often reported a continuous connection to loved ones who had passed. In this study, 58% of 278 bereaved respondents reported dreaming of the deceased. Prevalent dream themes include pleasant memories or experiences, the deceased free of illness, memories of the deceased's illness or time of death, the deceased in the afterlife appearing comfortable and at peace, and the deceased communicating a message. The following video is of a woman named Patricia who is recalling dreams of her deceased husband, Chuck, who had passed 13 years earlier. In these dreams, Patricia gets to reexperience a daily ritual that they shared during their long marriage (Link to: <u>Patricia Interview Video</u>).

Those who dreamed about a loved one did so with varying frequency: daily (7.5%, n = 12), weekly (23.6%, n = 38), monthly (15.5%, n = 25), less than monthly (26.7%, n = 43), and other (25.5%, n = 41). Most respondents reported that their dreams were pleasant (n = 89), specifically dreams that featured pleasant past memories or experiences (n = 105). Other prominent categories included the deceased free of illness (n = 65), memories of the deceased's illness or time of death (n = 56), the deceased in the afterlife appearing comfortable and at peace (n = 43), and the deceased communicating a message (n = 41). Many respondents described the content of their dreams in vivid detail. Most respondents who dreamed of the deceased also felt that this experience impacted the emotions related to their bereavement process (60.2%, n = 97). Some reported that their dreams helped them accept the death of a loved one. Others described how their dreams helped them retain a connection with the deceased: "I feel closer to mom than at the time of her death. At the time I felt cut off. Now feel as if I was reconnected in at least a small way." The deceased continued to live in the consciousness of those left behind, in a way that represented both the bereaved's vantage point and that of the deceased. Again, these experiences are less "dream-like" than experiential.

Taken together, the above studies strongly suggest that both the dying and the bereaved experience meaningful inner processes that strengthen connectivity amongst those they love and

were loved by, whether physically present or not. Such connectivity exists beyond our physical forms and supports the existence of a consciousness that extends beyond our dichotomized understanding of life and death.

# **III.** Studies on the Dying Process

After several years of studying the subjective experiences of the dying, we began to question the common perception of dying as a passive process leading to emptiness and finality. We were now intrigued by the notion that dying was not about a "fading of the light" but may instead represent a period of remarkable growth for the patient. We conducted a study that asked if experiencing ELDVs affected patients' post-traumatic growth, or the positive psychological changes that can occur during or after trauma (23). Here, the trauma for patients is forgoing curative treatment and entering hospice, as accepting one's impending death is undoubtedly a traumatic event. Could ELDVs change the amount of post-traumatic growth felt by a dying individual? In this study, patients experiencing ELDVs generally scored higher in every category of post-traumatic growth than patients who were not having ELDVs. The most significant differences were in personal strength, spiritual change, and overall post-traumatic growth. This means that patients with ELDVs showed greater strength and resilience, forged a deeper spiritual and existential connection, and generally exhibited greater positive change. In other words, patients do not stop living because they are dying. This definition of "living" defies physical form and instead occurs when eyes are closed, and brains are fading. The inner world of the dying patients, defined more by mind than brain function, appears to thrive in dimensions unseen.

# 3. CLINICAL CASES

Having reviewed the data above, this section will provide a series of case examples drawn from our formal studies. The facts and numbers presented from our studies cannot fully capture what is a deeply human experience, as unique as each individual experiencing the ELDV. Ultimately, the specific meaning and experience of ELDVs need to be understood on an individual basis and within the context of the life that was led. These cases studies are not only significant in number but share remarkably similar qualities. At end of life, consciousness heightens and reveals an

existence that is ultimately not defined by a before or an after death but instead connects us to those who have died and continue to exist through, with as well as within us.

The sample cases below will move from more to less representative examples, to reveal the extent to which the continued presence of consciousness after death can be observed irrespective of the patient's background, age, or variations in cognition.

#### A. More Real Than Real: ELDVs

Of the over 1500 patient/families interviewed, few could be more representative than Bridget, an 81-year-old devoted Lutheran grandmother who suffered from chronic obstructive lung disease.

Bridget was so uneasy about the implications of her ELDVs that she grew increasingly, and uncharacteristically, quiet. When her dreams became so vivid that they seemed to blend into her awake state, she repeatedly asked, "why am I seeing this? Am I going crazy?" Bridget's daughter, herself uncertain, did not know what to say. Bridget shared her recurring dream of two deceased aunts who were standing and watching over her. These experiences were followed by visions of her mother, dressed in a long, luminous white dress and sitting at the dining room table, crocheting. Although without voice, this motherly figure was a powerfully felt presence. Bridget could not come to terms with what she herself described as her "visions." They created somewhat of a crisis of faith since at life's end, she could not reconcile what she saw with the precepts of her religion. She had expected to see angels, not dead people. Like so many, the deceased return to the dying in a way that feels as though they were never gone but waiting to reunite at the appointed hour. As with most patients, such reunions feel not only needed but right. Bridget's consciousness was not only vibrant, defined by love but was now shared with those she loved most. These were the relationships that had defined her in life. The reunion of the deceased with the dying suggests that consciousness, beyond our physical existence, may be shared or unifying. As Fenwick postulates, in this way consciousness appears to act as a filter, one that arises and opens up towards the end of life (40).

The weight of the world was lifted off of Bridget's shoulders when we explained to her how common these end-of-life dreams and visions were, that what was happening to her was no

anecdotal oddity but a recognized and studied phenomenon. It helped to cite the results of our study: that the vast majority of our patients, nearly 90% in fact, had reported at least one end-of-life experience during their enrollment in our research. From that point on, Bridget became so comfortable discussing her end-of-life experiences that she delighted in telling us that spirits like to follow the living, especially disbelieving people.

When patients have their pre-death dreams and visions validated, life's end can become a journey toward a transformed state, often of wholeness regained. Our study confirmed that ELDVs help patients connect and reconnect to who they were, those they loved and who loved them back. They become a way of preserving or resurrecting the integrity of the self. Within the words of our dying patients were illuminating stories of deeper meaning, an inner journey through which selves were honored, wounds were healed, and bonds restored. For many, this meant reuniting with those who loved them best and whom they needed most.

Like Bridget, Ryan, a fifty-one-year-old Protestant with metastatic colorectal cancer, initially worried "am I losing my mind? I haven't seen some of these people in years." But when his dreams and visions ceased in correlation with clinical improvement, he sighed: "I am back... I miss the other stuff."

Ryan had never married, and never moved out of the neighborhood in which he had been raised. By any measure, he had experienced limited success in his career but found tremendous joy in life's simple pleasures and dependable affections. He had a loyal group of friends, most of whom he knew from childhood. He loved the 1970's, the music and culture that had shaped his youth, and he had shown no inclination to move beyond that decade. His point of reference had remained safely anchored in a past of rock and roll--a virtual time capsule. Now dying, he dreamed of deceased friends with whom he was going to concerts; he revisited the weekly garage sales through which they had casually roamed, mostly looking for old record albums; they went fishing in the local river. At other times, he "traveled with relatives", although he never knew where they were going. In these moments, he felt alive, unburdened by the limitations of his illness. The physical complications that came with dying had been an affront to Ryan because they had compromised his socially active lifestyle. It took re-experiencing

freedom in his end-of-life dreams for him to reach acceptance. Now, despite his physical decline, he again felt the warmth of familiarity and cheerful living that had defined his social life, one rich with friends, music, and small adventures. This was Ryan's consciousness awakened, his awareness and perceptions heightened through the connectivity he was re-experiencing. Now his acuity was sharpened and centered on what had defined his existence in health, his relationships. This was no memory or nostalgia for times gone by, but rather a satisfying, lived experience he could not wait to rejoin, again and again.

Another patient Frank had been admitted to the Hospice Inpatient Unit with severe congestive heart failure. At 95, he was still completely aware of his surroundings and loved a good conversation. He had collected encyclopedic bits of baseball lore the way others do treasured objects and could talk the game like no one else. Yet, despite his recall and engagement, when Frank closed his eyes to rest, his room became crowded with dead relatives. One of them was Uncle Harry who had been dead for 46 years and who "wouldn't shut up." This was a recurring phenomenon I now knew better than to mistake for the manifestation of a broken mind.

Like for so many of our dying patients, time was now inconsequential and what was before was now in the present while realities, whether current or past, living or dead, merged. His body was shutting down, but his mind had not lost its foothold in consciousness. In truth, he had a foot in two worlds, only one of which we shared.

Over time, Frank's inner-world experiences returned him to what he treasured most in life, his wife's love. The more he dreamt of her, the more he felt her presence and the more peaceful he became. He finally requested that we discontinue treatment. His decision to decline care was medically appropriate. As is so often the case, patients recognize medical futility before their physician and, in a sense, release the doctor from an obligation that can no longer be honored. Frank wanted to join "Ruthie in heaven". We helped him reach comfort for this much-awaited reunion, and he died with the beauty and grace he had lived and created. As his organs failed, his senses, perceptions and awareness did not. In fact, they were telling Frank that his soul was in fact very much alive. In contrast to the notion of "raging against the dying of the light", Frank, like most of our patients, was fighting towards not against. The "towards' he was drawn to

resided within his ELDV, a renewed consciousness warmed in familiar love. This was where he was now experiencing "life", beyond his physical boundaries.

Paul's ELDV experiences capture many of the common features of ELDVs reported in our studies. This video was taken 3 weeks before his death and includes commentary from his daughter Dianne (Link to: Paul Interview Video). Paul's ELDVs were rich in detail and easily recalled. In Pauls' ELDV, his most recurring dream was that of Joyce waving at him in her favorite light blue dress. He described how she'd given him 'the little beauty pageant wave" to let him know that she was fine, and that he'd be fine, too. Very little was said between Paul and his wife, yet he felt her presence, her smile, and her beauty. Paul also had ELDVs that involved packing. The theme of traveling or preparing to go is evident in over 39% of our dying patients. We have also noted in our studies that patients often relive past traumatic events such as war. Paul was a veteran whose ELDV also included returning to his Basic Training days from which he awoke to comment "I don't want to do this again".

Paul enjoyed sharing his experiences, while his daughter Diane, a nurse, was in turn heartened to see him talk about his end-of-life dreams and "get a lot out of it... He chose to remember the positive dreams that he had so we all enjoyed always hearing about dad's dreams... I could always take my cues from dad. If dad was comforted by those dreams, that is what I was looking for... My father's last few days on earth were the last gift that he gave us as a father. Because of circumstances from the past, as soon as dad had a stroke four and a half days before he died, everybody raced to be there. Two of my brothers were not able to be with us when my mother had died and it was important to all [seven] of us to be there. We spent four days in our childhood home, cooking for each other, taking care of dad, visiting with dad, priests came and went, family members, friends and neighbors came and went, and we were given the greatest gift to know that we were all going to be together, that dad might not be there but he brought us all together one more time and we took that with us, that was a tremendous gift he gave us... He couldn't speak but he could smile and the light was in his eyes... he was there with us until the last couple of hours before he died." Where do their minds and hearts drift when we can no longer speak and have closed our eyes? Paul's pre-death experiences helped answer these questions and fears: he was returned to love.

Sometimes a patient's consciousness may be intact without including the kind of obvious awareness of one's surroundings the definition of the term implies. Sometimes, a patient's consciousness is not visible to others. This was true in the case of Sierra, a vibrant young lady who was only 28 years old when she was transferred from our local cancer hospital to our Hospice Inpatient Unit (Link to: Sierra Interview Video). Upon transfer, it was clear that Sierra had only days to live yet seemed in denial about the severity of her condition; there had been so little time for Sierra to process the implications of her being transferred from hospitalized treatment to Hospice. Despite unrelenting pain and a rapidly deteriorating condition, she insistently told her puzzled Hospice nurses and doctors that "I am going to beat this."

We prioritized symptom management, but it was also urgent to help her and her family understand that her time was limited, so they could find some level of acceptance and the words to be reconciled with the reality of physical death. We were particularly concerned for her young son. We had come to understand that end-of-life dreams and visions help patients come to terms with death, but in Sierra's case, we naturally assumed that her denial meant the absence of such experiences.

Sierra was struggling to reconcile the different realities that were clashing around her. She needed clarity about her condition so that she could acknowledge the inevitable. This was something that the science of medicine alone could not bring forth. It was also one which, unbeknownst to her caretakers, Sierra's end-of-life experiences had already initiated. They were preparing her for the reality which her loved ones were so hesitant to put into words, and they were doing it by bypassing language altogether.

Her care team became aware of Sierra's inner processes only after her physician, Dr. Megan Farrell, asked Sierra if she had had any dreams. Fully lucid, Sierra replied "Yes, strange dreams and they don't always make sense. Sometimes, I don't remember them very well" Dr. Farrell continued, "Sierra is there anyone you have been dreaming about or someone in particular who comes to you in your dreams?" A long pause ensued. With eyes half-opened, Sierra looked over her doctor's shoulder, smiled and whispered, "Hi Grandpa!"

Sierra had been dreaming of her deceased grandpa Howard, an army veteran and a man who had loved and nurtured her. But now, in the stillness of her Hospice room, surrounded by loved ones, what Sierra's vision represented was so much more than just a recurring dream. It was a state of being that brought clarity and made words like "dying" and "terminal illness" irrelevant. When her mother Tammy asked: "Sierra, what is grandpa saying?" Sierra answered "He says he is proud of the young woman and mother I have become... He does not want me to suffer." We had entered the room thinking Sierra may need an intervention but were instead subjected to one, a reminder that the best lessons are often witnessed, not given.

Sierra's experiences at the end of her life provided her with a sense of unconditional love and guidance at the threshold of death. And for her mother Tammy, that awareness helped usher the sorrow she had not given herself permission to feel. ELDVs often pull together multiple losses and consciousnesses, those that occur across generations and wide swathes of time, across the living and the dead, for the dying as well as their loved ones. As can be seen in the video, Sierra's care team were left in awe of an unseen but powerful exchange between the living and the dead. Sierra's grandfather reached Sierra in a way the clinical team could not.

There are times when ELDVs transcend the boundary that separate the living from the dead to meet spiritual and emotional needs, those that tie couples and that restore bonds. Sometimes, ELDVs do not interrupt the reality of the bereaved so much as replace it. This often happens with elderly couples who, following a lifetime of togetherness, cannot shift to living without their other half. And so, they don't. Instead, they maintain their unbreakable bond through and in end-of-life dreams and visions. Attention wholly switches to this other world where they go on coexisting with their deceased partner and can feel whole again. That is when bereavement does not involve a before and an after, only a different, a more so, and a with.

After Sonny's death, Joan kept her husband alive through recurring pre-death visions that occurred in her dreams as well as when awake. Her health began to deteriorate rapidly, but her end-of-life experiences and visions helped her, as well as her family, cope with the deep wound left by Sonny's loss. When Joan returned to her daughters' home from the Hospice Inpatient Unit, her dreams kept Sonny alive. During many nights, Lisa and her family could hear Joan

calling out to her husband: "Come get me. I miss you! Sonny, come and get me!". The strength of these dreams would soon carry from sleep to wakefulness and Joan, fully lucid, would often claim to see Sonny in the room.

Joan and Sonny's story exemplifies the uniqueness and the intensity with which end-of-life dreams and visions are experienced as a site of togetherness. Joan lived for two months beyond Sonny's death but never without him. She would call out to him every night and have visions of him every day. After Joan's death, Lisa and her family sat down for a filmed interview (Link to: Sonny & Joan Family Interview Video).

As seen in the film, Joan's ELDVs not only kept Sonny present as her husband but was also shared with Lisa, their daughter and caregiver. As a result, it was only when Joan passed that her daughter finally took stock of her loss, a now double one. Lisa felt that her parents both died but only when Joan did because their consciousness was shared, whether physically present or not. She only realized the full impact of her mother's ELDVs when her mother's visions no longer embodied her father's felt presence. Joan's own consciousness had been heightened to the point that Sonny was present, not just for her but for Lisa too; this awareness was shared.

And when the time came for Joan and Sonny to be reunited and for Lisa to take stock of the reality of her double loss, the knowledge that their remarkable love story had survived death helped their daughter come to terms with her own grief and sorrow. Her bereavement process was aided by the recognition that her parents' bond had remained unbroken thanks, in large part, to her mother's ELDVs.

# B. We Die as We Live: Distressing ELDVs

End-of-life experiences do not always occur in a context of love, togetherness and seeming purity of mind or intent however. In fact, they occur irrespective of the life led or rather as an extension of it. While devoid of judgment, the capstone they provide is in keeping with the type of existence each individual lived: people die the same way they lived. In Dwayne's case, a 48-year-old patient who was dying of throat cancer after a lifetime of substance abuse, the end-of-life experiences that would bring him to consciousness were as violent as the life he had led.

The Dwayne we admitted to the Hospice inpatient unit was a puzzle: he was charming, funny, sociable, warm, and completely unfazed by the life of delinquency and crime from which his disease provided a reprieve. He had lived "ripping and running" as he put it, but his demeanor was that of a person with a clear conscience. He was not known as a violent man, even though he had killed two men in self-defense. And although the courts acquitted him on both counts, it was hard to reconcile his past deeds with the casual nonchalance that was now his trademark. He acted as if his actions did not define who he was.

Despite his weakened bodily condition, he jigged and jogged when he shuffled across the hallway floors, even as he had to lean on his medical walker for support. He would say things like "everything is gonna be ok man, God loves you" or "We are on a roll man, we can go to the mountain". And with his inimitable cheerful and beaming smile, he would add "but I may need another cold one". It did not take long for me to understand that his casual manner was actually a survival mechanism. If Dwayne was carefree and seemed to float on clouds made of jokes and funny asides, it was not because he didn't care. He did not have the luxury to do so. He had spent a lifetime living on the street and relying on hard drugs to counter the stress, fear and pain that came hand in hand with it. His life had been about substance abuse since he was 16 years old. The only thing that mattered was scoring the next hit and avoiding the dull and numb feelings that overtook him when the effects wore off.

For Dwayne, the drug detoxification that came from being physically confined with terminal illness did not change his outlook on life. His survival instincts remained in high gear, all the more so since he was terrified at the prospect of being sent back to "the street," a place overrun with malevolent and violent people, constant threats, injustice, crime, fear, and pure terror. The Dwayne who arrived at Hospice could not look back. Resurrecting the past was too risky an endeavor for a man who had finally reached a place of safety and physical comfort. It would have meant processing the irreconcilable, the abandonment, hunger, injustice and murder.

In avoiding his demons, Dwayne was experiencing end of life much as he had lived, by guarding himself from the shame and guilt that overcame him were he to glance back at his failures and

crimes. It was ultimately his distressing ELDVs that would bring him the awakening and awareness he needed, albeit just under the wire. In his most troubled dreams, Dwayne was grabbed and stabbed at the site of his cancer: "It was like I was fighting somebody. I probably done something wrong to somebody on the street in the past, and now they caught up with me, and now they know my symptoms. It was like they were jigging the knife, trying to cut off my neck where the cancer was at. That is how I was feeling. It stopped but I still couldn't let my shoulders down, I was in pain". Dwayne experienced this violent dream as an avenging attempt on his life.

When he told the attending nurse about his stabbing nightmare, she reassured him that this was probably nothing, since "a lot of people talk in their sleep". But Dwayne would not have any of it. "No, this was real," he insisted. The nurse inquired if he needed some medication, and he nodded "because this nightmare I just had was hurting my neck anyway". Hearing him describe the real-life effects of a wound that was inflicted in an ELDV was one of the most heartrending illustrations of the concept of "total pain" described by Hospice pioneer Dr. Cicely Saunders. It dawned on me that the dying patient's pain was even more multidimensional than originally conceived: it includes not just psychological or emotional turmoil but also physical pain. And ELDVs strike such a cord in the patient near death that the very line between bodily reality and the spiritual world comes undone in the process.

Dwayne's recurring dreams and visions led to a radical shift in his demeanor and attitude at life's end. This became clearer when Dwayne was filmed for the documentary on end-of-life experiences (Link to: <a href="Dwayne Interview Video">Dwayne Interview Video</a>). He was on camera and was just about to tell us about his recurring dream when the man whose sashaying and quipping was legendary at Hospice, started sobbing uncontrollably. Nothing used to faze the Dwayne we knew, everything was cause for laughter, and here he was, an unrecognizably vulnerable soul who was crying, trembling, and shaking, while talking in an unbroken stream of tears and words we could neither interrupt nor bear to hear. It was the distress with which Dwayne was sharing his end-of-life experience that was overwhelming. Dwayne was finally allowing himself to confront rather than evade. He was now a soul in search of redemption, talking about his cancer as karma and regretting his life of 'ripping and running': "One thing I do know is I hurt a lot of people and I

feel bad about doing it, you know, very bad and I just hope and pray that they do forgive me because they see what influence I was under at the time when I was trying to scheme and scam and be sick with them.... I am not gonna lie to you, I have used drugs in my past, that is not a good thing man, ... I don't want to go back to that lifestyle. It is not good for you, it is not good for me.... And I just pray to my higher power that he keeps me away from it with the help of my peers, hospice, you know, I am not really gonna say friends in the street. I had no friends because 95-98% of my friends were doing the same thing I was doing."

Dwayne was facing his day of reckoning. He went on to have variations of this recurring dream, recounting that "the guy was pouring acid down my neck, burning a hole in my neck.... It is because my past is coming back at me from doing wrong. Because I am not gonna say I am a perfect guy when out there because I was ripping and running the street doing wrong to individuals, I should not have...". There was no doubt in Dwayne's mind that his subjective experiences were making him pay for his past mistakes and misdeeds, and pay he was willing to do, provided he could make amends to the person he cared most about, his daughter Brittany.

Bereaved family members also benefit from the effects of their dying relative's end-of-life experiences, sometimes years down the line. After being estranged from his daughter Brittany, Dwayne went through a transformation at the threshold of death that carried over into his daughter's life. Indeed, their deathbed reunion and the forgiveness that flowed from their love is what would eventually help his daughter forge a commitment to turn her own life around. The incidence of drug abuse among children of drug addicts is disproportionately high, and his oldest daughter had not escaped the trend. In honor of the father who had changed the course of his life at the eleventh hour, she set out to do the same. Her dad's love was restored to her through the coming together of consciousnesses that were once embroiled in hostility but that were now enacting a much-needed reckoning. She herself credited her father's ELDVs for the transformation in both of their lives, and this awareness led her to a regained sense of self.

Despite a lifetime of denying certain realities of his life, Dwyane's consciousness not only returned but did so with a vengeance. His ELDVs were more than just memories, they were well thought-out and organized processes that were not just retold but relived, and whose material and

ripple effects were felt across lives and beyond his and others' death. He was not only lucid as he experienced them but described feeling the sensation of being stabbed. The lives Dwayne had taken and tried to forget could not be forgotten. They continued to exist as part of Dwayne's existence, within a consciousness that was shared between and across lives.

Sometimes, ELDVs uncover aspects of a patient's past that they had long hidden from view. This was the case for John Stinson, the 87-year-old man who had fought his whole life to suppress his experience of war. John had never told his family about the horrors he had witnessed during his rescue mission on the shores of Normandy. He suffered silently until his final days, when distant memories fought to surface.

It was through John's end-of-life experiences that his family got to meet the man they had never known of, the 20-year-old soldier who would one day become their father. "I learned more about my dad in the last 2 weeks than I did during his lifetime", John's son explained while reminiscing about his father's end-of-life reckoning. His sister corroborated the sentiment: "My brother (as well as the rest of us) knew very little about my father's war experience. He rarely spoke of that time in his life. Some of what we learned in those last few weeks of his life we had never heard before. He just never really talked to us about it!" They may have been in the dark about the details of the past their father was finally revisiting, but not about the positive outcome of what transpired on his deathbed. Several years after their dad's passing, the account of their father's peaceful transition still brought tears of gratitude.

John was only 20 when he enrolled as a gunner on the SS James L. Ackerson which entered Normandy beside the USS Texas. He was and would always remain a proud Texan who took his duty as a soldier to heart and believed in the ideals of his country. On June 7, 1944, he was part of the Infantry Division that was sent ashore to Omaha, the bloodiest of the D-Day beaches. Their assignment was to retrieve the soldiers who had been isolated from the rest of the forces ashore. The mission was successful, and the landing craft came back with the wounded Rangers they had been sent to rescue. Still, John could never wipe away the vision of the bloodied beach strewn with the mutilated bodies and floating limbs he saw upon landing. This was the

experience in the war that, unbeknownst to his family, was going to haunt him for the rest of his life.

As he lay dying at Hospice, John was assailed by nightmares about the fallen American soldiers he could not save: "There is nothing but death, dead soldiers all around me." I had witnessed people in a state of fear before, but John was not just frightened. He was terrified. His terror was palpable. I had never been able to adjust to the idea of a young man facing the horrors of war, the possibility of death at life's beginning, but watching John return to that site of terror a second time as an old man defied words. He described his nightmares as so intensely real that they felt embodied. He could not overcome his pain, and his dreams reflected it.

This is why the complete transformation he underwent a few days later was all the more remarkable. I went to see him, and he was visibly comfortable, even at peace; he could sleep, he said smiling. He credited two of his more recent dreams for this welcome development. In a first joyful dream, he had relived the day he had finally gotten his discharge papers from the military. His second dream sounded more like a nightmare, but to him it was anything but. He dreamt he was approached by a soldier who had been killed on Omaha Beach and had come back to tell him: "Soon, they are going to come and get you." John instinctively knew that "they" referred to his fellow soldiers, and that the dream was about reuniting with his comrades, not judgment. He finally had closure. He could close his eyes and rest.

Far from denying his reality, or his war, John's ELDV's recast these in such as to grant him his hard-earned peace. The soul of that courageous 20-year-old boy that had fought the ghosts of war for 67 years was finally released from his sense enormous obligation and from its injustice. John's story exemplifies the process through which even the most difficult dreams can provide substantial psychological or spiritual benefits to the dying patient. For him, the tortured memory of the deadliest of the D-Day assaults morphed into the site of the very military camaraderie he thought he had betrayed. He needed to be released from the obligation he had been unable to fulfill and from the overwhelming shame he could not escape. Most importantly, he needed to forgive himself for his inability to save his brothers in arms. Thankfully, their consciousness returned allowed him to do just that.

Those who were loved and lost and come back through end-of-life dreams and visions help fulfil each patient's unique needs, whether it is the need to be forgiven, to be loved, or to be granted peace. For many, their longing is so overwhelming that it affects not just ELDV content but also their external reality. We often hear of dying patients who wait for a particular anniversary, birthday or visitor before taking their last breath. Prior to working at Hospice, I assumed this phenomenon to be part of the lore that was passed around hospitals and whose origin may have been as nebulous as the evidence evoked to support it. Then I met Maisy, a 98-year-old matriarch, who simply refused to pass before her son Ronnie made it to the hospital.

Maisy had not seen her son in 8 years. This may have been due to an interpersonal conflict or just time's swift passage. I was not about to inquire. She had stopped eating several days earlier and was no longer verbal, so we knew her to be teetering at the threshold of death. Her relatives had gathered around and were talking freely, not with her, who had seemingly lost consciousness, but certainly about her, the woman who had taken in over 100 foster kids in her lifetime. They didn't know that she could hear them. Someone mentioned that they had had the police track down her biological son Ronnie in Oregon, and that he had booked a flight to Buffalo. They were now worried he would not make it in time to see her. The next day Maisy opened her eyes, sat up in bed, and cried out her husband's name: "Amos! My Amos!" she said, followed by "I can't come to you now. My son's coming." Ronnie arrived on the same day, and 24 hours later, Maisy closed her eyes for the last time.

As a scientist, I could give a protracted explanation for what happened to allow Maisy to stall a process over which she seemingly had no control. It would have to do with sleep patterns and their relation to the dying process. I could explain that dying is progressive sleep, and that to sleep deeply one must be able to relax and let go. I could go on providing evidence about the biological processes involved in not yet dying, but that would not do justice to what I and others commonly witness. It would not even come close. Maisy's mind was unable to find peace until Ronnie arrived. In the final analysis, dying, like living, is about love and consciousnesses that endure no matter what, and that finds a way to persist within and beyond the confines of our existence.

#### C. Pediatric Patients

The power the resurrected consciousnesses in ELDVs have in facilitating the dying process as well as the grief of those left behind is at no time more resonant than in the case of the passing of young children, whose innocence defies understanding. Children have an intuitive ability to understand when death is imminent, including when the reality of it is kept from them. It is often in the show-not-tell of their dreams and visions that they get informed and inform us.

I remember meeting thirteen-year-old Jessica. As I walked into her room, trying to be the doctor I thought she would want me to be, I quickly realized that no level of experience would match her innocence, or the innocent wisdom reflected in her ELDVs. Her consciousness was not clouded by any of the considerations that often darken an adult one. She dreamed in distinct tones and textures, which not only created awareness of her impending death but also secured her in love. The knowledge of death that adults first experience as grief and sadness was to Jessica an intuition reframed by her ELDVs into sensory images of joy, color, warmth, and security; what we perceive as separation, she experienced as a loving reunion. Whereas we obsess about the border that separate the living from the dying, Jessica did not so much as see a distinction between her immediate world and the imaginary one of her dreams and vision. (Link to: Jessica Interview Video.)

Where I was bracing myself for an excruciating conversation, I instead encountered a brighteyed little girl who was eager to chat about her day, her mom, her pets, and her dreams. Jessica did not pause to mourn the life she would not get to live, or to talk about the career or kids she would not have.; she had no regrets to mull over, or could-have-beens, or missed opportunities to work through. She was too busy living in the now, and her ELDVs were part of that present, an extension of the life she was living and where the dead roamed as freely as if they were visible to all.

Children's end-of-life experiences, like those of other patients, feature 'loved ones' who come back to them. The difference is in the lack of questioning and of the boundaries with which we preoccupy ourselves. Recurring dreams are lived as certainties, as if they are actual visions,

visible in this world as well as in theirs, because the two worlds are one. It is not that they cannot tell which is which but that they know they are inseparable, an extension of one another. It is not a matter of failed perception but of a transcended one.

Jessica went on to dream about Mary, her mother's best friend who'd died at 35, when Jessica was only 8: "Mary is one of my mom's best friends who passed away from leukemia. I think I was pretty close to her, and she was very close to my mom. I liked her. She was very nice. I'd seen her in my mom's room. Coming up the stairs, I was going into my room and stopped when I saw from the corner of my eye something playing with my mom's curtains. She had her favorite shirt on, my mom told me that it was. Because I told my mom it was a grey and blue, checkered flannel shirt." Jessica was the only child of a single mother, which left one last uncertainty once her concern about dying had been resolved: 'What will I do without my mom?' The vision of this mother surrogate, her mother's best friend, in her mother's room, brought tremendous peace to her. She felt "relief and happiness". She continued, "Mary was a very strong person, and I know that I am strong, and my mom tells me all the time that I was, am like her." Kristin, who never left her daughter's side, reminded her that "You told me all the time that: 'Mom I saw an angel,' and then you were able to go to sleep." "Yes," Jessica nodded, "I was able to go to sleep... it was really comforting, and I was not afraid of it at all." Again, ELDV's typically address our individual needs or the wounds that need tending.

Until Jessica, I could not imagine that children would have access to their own set of tools during the dying process. I assumed that a young mind was not fit to handle a conversation about life's end, and I failed to appreciate the sophisticated ways in which they may already have had one. Jessica had an understanding of death that exceeded anything I could have imagined; she created connections we could not have given her, in details she should not have remembered.

A child's innocence goes infinitely deeper than ignorance. Unbeknownst to her, Jessica's ELDVs were teaching her, as well as her caretakers, how to cope with the inconceivable. Most importantly, for her mother, they helped initiate the process she could not consciously accept, that of letting go. But it was not of her daughter that Kristin had to let go—she could never do that--it was of denial.

Mother and daughter shared an unspoken language and a spiritual bond that have carried over to this day. Six years after her daughter's death, Kristin still feels Jessica's presence. She still decorates her house to fit the themes of each coming holiday because "Jess would not have it any other way". She still cares for her little girl's spoiled and overweight orange cat Lulu, who continues to wear the silly ornament Jess once attached to its collar. She still smiles at the memories and the presence she continues to feel alongside her.

No words can adequately describe the relief on the face of a parent who watches their dying child go from fear of the unknown to acceptance. For Michelle, it was her daughter Ginny's last dream that made her realize that, while the end was near, it would be a peaceful one. Indeed, it was following her pre-death dream about God that Ginny stopped calling out to Michele every five minutes and started sleeping soundly. It was also in its wake that Michele herself felt inexplicably calm and settled, so much so that she finally found the strength to inquire about funeral arrangements that would honor her daughter's legacy.

Ginny told me about the shadows she'd sometimes see flitting around her when she woke up at night. They used to frighten her, but after one particular dream experience, she started finding them comforting. The shift occurred during an MRI when Ginny fell asleep inside the pulsing machine and had a vision of her beloved Aunt Mimi, who had recently died. Like Jessica, Ginny did not have or need a complex vocabulary for dying, so she imagined a new reality based on the language and imagery she had at hand. In her dream, she saw her aunt in a castle "with a baby in the window, and you can see the sun through it." Ginny described her castle as 'a safe place' for Aunt Mimi as well as for Grandma Rose, who had also died not long ago. Ginny could feel Mimi hugging her and whispering in her ear, 'You've got to go back down there and fight.' When she woke up after the MRI, she was almost euphoric and proclaimed to her mother: "I'm going to be okay, I'm not alone."

Both Ginny and Jess were met with loved ones who provided them with what their actual world could not – the opportunity to be made whole again. They knew that they would be leaving the reality of the living but only insofar as the living fail to recognize the connectivity that imposes

itself as real through ELDVs. In their alternative world, the one that encompasses both the living and the dead, the knowledge of impending death is seamlessly integrated within the certainty of love, and continued life.

Children may lack language for death or a full understanding of mortality, yet they innately have deep inner processes at life's end that not only inform and guide them but enlighten and expand their sense of existence, both present and beyond. All this suggests that consciousness is not only inherent but vibrant regardless of age and years of physical existence prior to physical death. The cases illustrate that the consciousness of children is rich in sense, perception, resonance, memory and emotion; like that of adults, it can accommodate the departed and give them voice and countenance, sometimes in ways we don't expect, all the while ensuring that the dying child is still living vibrantly even as her body fails.

# D. Cognitive Impairment

The sample cases we have so far discussed show that, regardless of the types or length of lives led or experiences had, humanity's final moments do not merely consist of a passive disintegration of the flesh. Instead, the course of dying is transformed by resurrected consciousnesses that inhabit the inexplicably heightened awareness and cognition of the dying. But what about people whose minds function differently? Those with cognitive or perceptual impairments, those categorized or labeled as mentally ill, demented, disabled or "neuro atypical," and whose voices and stories are often hidden and marginalized in life? Do the labels and preconceptions that so often limit them in life, also do so at the end to prevent them from partaking of the complex spiritual transformation we have identified in others? Our research shows that dying people with cognitive and developmental conditions have rich and vibrant inner processes that include their loved ones returning to usher them peacefully into death.

Many patients whose cognitive impairment is severe, arrive at the end of life without the kind of alignment of inner and outer self that others achieve. Instead, these patients are estranged from their core self. The loss of cognitive functioning, often referred to as Alzheimer's dementia, is an extreme example of that condition. The disease separates us from ourselves or from what Oliver Sacks refers to as the "inner state" in profound and irremediable ways. Unlike other afflictions,

Alzheimer's dementia creates a world where cognition unravels, yet emotions and senses remain the same.

People with dementia are typically excluded from formal research studies that depend on informed consent and therefore intact cognition. Yet, they should be considered if we are to do justice to the full range of human experiences at life's end. And of course, disentangling the world of those suffering from dementia also entails considering the caregiver on whom they depend to navigate an unrecognizable world.

The descent into dementia typically leads to a disproportionate clinical focus on the patient's challenging behaviors and their management to the detriment of the person's buried psychological states of being. The clinical world may also inadvertently obscure the subjective world of those with dementia by only considering the loss of measurable cognitive abilities. The clinician may be continually drawn to observable behaviors and evidence of defectiveness. This clinical nomenclature becomes the currency through which we discuss patients, as we become overly reliant on assessing people's inability to repeat numbers or recall the names of past presidents. In so doing, we ignore the view from inside, the richness within the subjective states of dementia. We fail to consider the lived experiences of people with dementia because we let our awareness of their condition obscure their personhood and consciousness.

Although it is true that the details and facts of much of their earlier lives may be lost, the defining emotional richness of having lived often persists in the inner world of those with brain disorders. It is not uncommon for an Alzheimer's patient to remember the color of the gown they wore to their high school prom and not recall what they ate for breakfast. That is because dementia impairs the ability to form new memories. The disease is unusually cruel for people like my colleague and friend Dr. John Tangeman, whose mother suffered a traumatic early life and was therefore cursed to relive a painful past rather than her more hopeful and forgiving present.

Gerd Vaagen was born in 1925 in Aalesund Norway to a Sea Captain and a housewife. She had an idyllic childhood, which included Alpine skiing on magnificent mountain ranges in winter,

and aquatic sports and sailing in the fjords during the summer. Gerd was a freshman in high school when the Nazis invaded Norway on April 9th, 1940. The 5-year occupation by the Wehrmacht led to German-imposed food shortages, the wide censorship of the press, and a blatantly improbable Nazi propaganda that tried, for instance, to rebrand the well-known "heil" salute as an ancient Norwegian tradition dating back to the Vikings. Gerd witnessed horrors that would haunt her for the rest of her life. She saw her school principal being summarily executed when he was caught with a radio transmitter. She lost numerous friends who had become involved in the Resistance. Her family suffered from what bordered on famine.

Tragically, Gerd's life was marked by continued trauma and loss after the war. She married her high school sweetheart Rolph only to lose him, shortly after their marriage, to a sailing accident. In 1954, in an effort to leave the past behind, Gerd left her family and friends to travel to the United States, where she eventually remarried and settled in Buffalo where she had two sons, the younger of whom, Thomas, died of leukemia at age 3. When she turned 52, Gerd's second husband died unexpectedly, and the family that was once four was now two.

Gerd's second son, my colleague John, remembers to this day his mother's lifelong grief as well as her anger and bitterness toward the war and those who waged it. Family gatherings used to begin with pleas to limit the reliving of Nazi atrocities. The trauma of the war consumed much of her identity and only worsened with the loss of her husband, John's father. Early on in the course of her dementia, Gerd became ever more obsessed with memories of the war, so much so that she believed Hitler himself was directly to blame for any frustration that occurred during the day, from a meal served cold to a lost TV remote.

Dementia is particularly challenging for close family members who progressively lose the person they once held dear and no longer recognize. They watch powerlessly as their relative gradually becomes a shell of their former self. John could not help but feel a sense of abandonment in his mother's absence. He felt robbed of his relationship with her, so much so that he began grieving his parent's loss long before her death. As the years past and death neared, an unusual transformation took place that gradually erased the bitterness and anger that had so dominated Gerd's life. Hitler's ill-doings were forgotten, and the terrors of the war gave way to an

extraordinary sense of composure. Gerd also became uncharacteristically pleasant and demonstrably affectionate with those providing care. Instead of living within the confines of past anguish, she now spent hours staring lovingly at the portrait of her deceased son Thomas. John would often find his mother blowing kisses to his late brother's picture, recalling the good years, and professing her undying love. Gerd was reclaiming long-departed son.

As her dementia progressed, the burden of her life's memories were lifted and she seemed to be the person she was before her lifetime of trauma. Her transformation was so complete that she would become frightened at her own image in the mirror, which she referred to as the "Crazy Lady". John would eventually have to cover the mirror with a cloth. She was now so anchored to a distant past that she could no longer recognize her own 85-year-old self's reflection, or maybe she rejected what she saw as a representation of her damaged soul.

Several weeks later, Gerd died, peacefully, within a distorted notion of reality, but returned to the one memory that had released her from anguish and brought her closer to a less damaged sense of self. Parts of GERD's story is captured in episode five of the Netflix docu-series *Surviving Death*.

For patients suffering from Alzheimer's and other dementias, the line between the ELDVs in sleep versus wakefulness is even more blurred than the reality they cannot share. And because people with dementia exist within an unshared world, their dream experiences ultimately remain their secret. Yet these patients also frequently undergo inner changes as part of the dying process. It may be that they heal old wounds, reveal what's lost or reclaim distant love. We may not be able to collect evidence to prove it, at any rate not of the kind that would withstand scientific scrutiny, but I have seen the process unravel again and again. I have witnessed patients with severe cognitive loss paradoxically experience a vibrant and rejuvenating end of life. Again, we see that regardless of age or cognitive status, one's sense of self and one's existence expand as the body and even the brain, fails.

Physicians such as Oliver Sacks have noted that those with dementia have an emotional intelligence that can be unlocked with the right key, such as music for instance. This underscores

the error commonly made in evaluating patients and consciousness based on a capacity to reason rather than feel. Their minds may be lost to us, but they still resonate within themselves. Nor can they be separated from their heart and its capacity for love.

Autism too is one of the conditions that often lead to misconceptions about how affected people process the larger meanings of death and dying. Assumptions are made about how they may or may not respond to a terminal diagnosis and what information should be shared. I don't presume to have answers to these questions, but I have witnessed in such patients a remarkable resilience; an ability to cultivate peace as well as find meaning within their illness.

End-of-life experiences in particular have the potential to help the dying reach emotions that may not otherwise be accessible. This was the case for a patient named Andre, a man with autism, who provided yet another powerful reminder that conclusions and conjectures surrounding end of life can only be accurate if they draw on patient testimony.

Andre was a high-functioning autistic man who had worked as a bag boy at a local grocery store for most of his life. After his parents died, he was cared for by his cousin Lisa's parents, and years later, when she became a mother of three, he was integrated into her family. Andre would live with Lisa's family for the next thirteen years until his death at 75, and his purity of heart and joyfulness grounded his strong and easy identification with their children. Lisa's son Hazen was 3 years old when Andre moved in, and the two connected instantly. They became inseparable, the best of friends, playing nerf guns around the house, communicating with walkie-talkies from different rooms, dressing up for Halloween, carving pumpkins, and hiding under piles of leaves in the yard. Andre loved family trips and Easter egg hunts. His family described him as "childlike' but also respected his strong sense of independence. He could put together breakfast, make his own lunch for work, buy things in the store with little to no help.

In May 2017, Andre, then 74, was diagnosed with congestive heart failure and bladder cancer. The doctors estimated that it would be his heart not the cancer that would eventually cause his death. None of this was shared with Andre, who went on to live happily and unencumbered until his stroke on December 1<sup>st</sup>, 2017. Lisa and her husband Merle focused on helping Andre each

day to the fullest. At this time, he was using a walker, and had a catheter bag 24/7, but he always smiled and met each day with a sense of wonder. He lived without a full awareness of his terminality. This is why it was so moving to Lisa when a month before he died, he started seeing what she later identified as deceased relatives. It was always during the daytime hours, and she could tell when it occurred because he would stare at the window with big, open eyes. In these moments, Merle noted that Andre seemed to "perk up" with an "excitable curiosity" that he immediately wanted to share.

The first time, it was a man with a hat. Andre didn't recognize who that was, but it was a friendly presence who waived at him. The next time, it was a man and woman. Lisa would go through old photos with Andre, and he thought the woman he had seen looked vaguely familiar... maybe like a grandmother. His description, however, fit those of her long-lost relatives to a T. The "visits" happened almost daily. He once saw another man taking pictures, which also happened to be his favorite hobby. On another occasion, it was Lisa's deceased mom who was in the room and whom he pointed to while talking to his second cousin. She was sitting on his suitcase, Andre exclaimed with a laugh. Like over two thirds of our patients, his ELDVs included themes of "preparing to go", either through travel or packing.

To Lisa, Andre's most moving vision was the one he had of her nephew Lucas as a boy. Lucas had died at almost 6 years old from an aggressive form of leukemia. He was the same age as Lisa's daughter Gabrielle with whom he had grown up. The two kids were inseparable, and their favorite thing in the world was to catch butterflies. It was fitting Andre's inner experiences would reflect his fondness for children.

Andre's vision included a child chasing butterflies. But it meant so much more than a snapchat of a past attachment. It also carried a message which he matter-of-factly relayed to Lisa in the following words: "He told me that he had died". This was how his end-of-life experiences most effectively familiarized him with the imminence of a death he had not been told about, by making mortality as conceivable and harmless as chasing butterflies.

Andre lived these pre-death experiences as if they were natural extensions of his everyday life. He never paused to wonder whether he was dreaming. He didn't ask who these people were. He was not worried about what this could possibly mean. He just knew at an intuitive level that these were real and positive experiences that made him feel good. He felt secure, surrounded, loved. And he giggled.

For Lisa and Merle, being able to share Andre's end-of-life experiences, sometimes through the photo albums and pictures in which he recognized a face, was an unforgettable time of togetherness. Their daughter Gabrielle was similarly moved; they allowed her to revisit her preteen years with her beloved cousin Lucas without reliving his unexpected and tragic loss. The whole family found comfort in knowing that Andre was blessed with end-of-life experiences that helped him transition with what he cherished most, his sense of belonging. Lisa commented that while "so many are on drugs for pain at the end, Andre was not".

Andre's last inner experiences were not only comforting to him but, in Lisa's words, also "welcoming". He was "fully awake" up until two days before death.

Whereas most of us exist with clear definitional boundaries between what we perceive as reality and what our inner life and unconscious tell us, Andre moved seamlessly between the two, through the consciousness of relatives who came back to soothe him in his ELDVs. For him, predeath dreams were less about a new, emerging consciousness that had to be reconciled with his surroundings than an extension of the love and supportive people that had always defined his life and relationships. Andre's inner experiences represented a continued reflection of who he was through consciousnesses that merged with his. His persona never varied with circumstance and his disposition remained as beautiful as it was true. His was a journey through grace.

That patients with cognitive impairment have as lucid and meaningful ELDVs as neurotypicals not only speaks to our inherent humanity, but it also suggests that consciousness exists regardless of the cognitive differences that surround it.

#### E. The Bereaved

The human grief experience is multidimensional, flexible, and personal. Bereaved family members and caregivers learn to adjust to a world without the deceased in myriad ways. What remains a constant, however, is 1/ the higher level of acceptance achieved by the dying and the bereaved alike when they get to witness the life-affirming, material, and transformative effects of end-of-life experiences 2/ the triggering of their own richer emotional and spiritual inner experiences. In our studies, the bereaved describe deriving peace and reassurance from the knowledge that their family member felt at ease and loved in their last moments. For example, the elderly sister of one of our patients shared that "when he told me that he saw his favorite sister (deceased) hold out her hands to him, it made me feel comforted because I knew it comforted him." Caregivers repeatedly and explicitly use words that denote contentment rather than mourning: "He did find comfort talking to and seeing people who passed before him. He was not afraid or scared – he had told me."

Many bereaved family members make sense of their dying relative's end-of-life dreams and visions by drawing on their belief in the afterlife, God, angels, or heaven. That is what the rather agnostic Michele did after her daughter Ginny's last conversation with God. But how each family caregiver chooses to make sense of their loved one's end-of-life dreams and visions matters little. What is remarkable is how the meaning making sometimes develops independently of one's interpretive framework, since Michele was originally agnostic and was swayed by her daughter's ELDVs. These experiences help the dying and their loved ones alike work through the pain of loss by creating continuity and presence across time and death.

The therapeutic quality of end-of-life experiences extends to the bereaved in ways that can never be fully accounted for if we merely approach them as representations or memories. It embodies, for caregivers as much as for the dying, the possibility of being reunited, and it allows them to adjust to life without their loved one while maintaining a continuing bond. The desire and need for connectivity remain a constant across dying and grieving, death and bereavement.

Michele and Kristin both responded to their child's death with the same paradoxical disregard for the separation death supposedly entails. They both still talk about and to their respective daughters on a daily basis. They dream about them. They both continue decorating their homes for the holidays for their little girls' sake. They do it because "Ginny expects it" and "Jess would be upset with me if I ever skipped a year".

Like Michele, it is in her daughter's last end-of-life experience that Kristin finds the comfort she needs. In particular, Jess's vision of her mother's deceased friend Mary, whom she identified as "an angel", is what provides Kristin with the reassurance that her little girl's transition transcended the emotional and physical toll of death.

Michele worked through the pain of grief in ways that echo Kristin's emotional trajectory. She too was awed and comforted by her daughter's rich inner world and by the extraordinarily soothing quality of her end-of-life experiences. "She is always teaching me something", Michele said two days before Ginny's passing when her daughter was no longer responsive. This too was an extension of the remarkable effects of Ginny's end-of-life experiences. Michele was left to question her own belief system. "Who knows?" she concluded, throwing up her hands in surrender, "Maybe there is a castle. I no longer know what not to believe."

Like Kristin, Michele is now moved by mementos, pictures, and toy animals that recall her daughter's presence. A rainbow appears and makes her smile. Heart shapes in clouds, rocks, and water drops are evidence of Ginny's presence. She often takes refuge in Ginny's room which she has left untouched. Bereavement has become a steady and gentle companion, a process and extension of the continuity that Ginny's end-of-life experiences represented.

In the midst of immense tragedy, Michele has found solace and meaning in the same love and evidence of consciousness that permeated her daughter's end-of-life experiences and whose cascading influence will sustain her until the day, she says, she too finds her way to Ginny's "castle."

As our study on the dreams of the bereaved suggests, patients' end-of-life experiences seem to find a reflective counterpart in their loved ones' dreams. Our quantitative study conducted at Hospice shows that many recently bereaved individuals experience vivid and deeply meaningful dreams themselves that feature the presence of the deceased. Prevalent dream themes included

pleasant past experiences, the deceased free of illness or at the time of death, in the afterlife appearing comfortable and at peace, and the deceased communicating a message. These themes overlap significantly with previous models of bereavement dream content. As with ELDVs, the specific effects of these dreams on bereavement processes include increased acceptance of the loved one's death, comfort, spirituality, sadness, and quality of life, among others. These results support the theory that dreams of the deceased are highly prevalent among and often deeply meaningful for the bereaved who have them. Again, as with ELDVs, a positive growth or transformation in the person have them hinges on the continued presence of predeceased loved ones.

While this study does not assess whether or how the dreams of the bereaved are related to or different from ELDVs, the coincidence in content and effect is remarkable and noteworthy. For example, one participant wrote "[the dream] put my mind at peace about my brother's death. I miss him very much, but I know he is in God's hands and happy." Others described how their dreams helped them to retain a connection with the deceased: "I feel closer to mom than at the time of her death. At the time I felt cut off. Now feel as if I was reconnected in at least a small way." Some explained how their dreams intensified their feelings of grief ("My sister and I cared for our mother around the clock. The dreams just make me sadder and I miss her when I wake up") or support ("My mother speaks to me while I dream. She tells me things about situations in my life and how to handle them. I get to hold my mother in my dreams and get to feel her warmth and love"). Another participant had a dream of her [deceased] mother walking on the beach and holding the hand of a small boy named Eric. Her parents had previously lost a baby and named him Eric "who had died before Jane was born. Eric was to be our last of three children, but when he died, we had Jane."

Like ELDVs, the dreams of the bereaved bring back the departed in moments of transcendence where the consciousness of the recently departed is summoned to bring peace, sometimes resolution, and always love.

### 4. CONCLUSION

ELDVs testify to our greatest needs--to love and be loved, to be nurtured and feel connected, to be remembered and forgiven. They are centered on self-understanding, concrete relationships,

personal histories and singular events. They are made of images and vignettes that emanate from each person's life experiences rather than from abstract preoccupations with the great beyond: a walk in the woods relived alongside a loving parent, car rides or fishing trips taken with close family members. Long-lost loved ones come back to reassure; past wounds are healed; loose ends are tied; lifelong conflicts are revisited; forgiveness is achieved. And based on the content of these dreams, it's obvious that the forgiveness and love that count the most come from family. For thirteen-year-old Jessica, who was nearing death, her greatest fear was being alone in an afterlife without her mother, that is until Jessica's ELDV conjured up her mother's best friend Mary who predeceased her. In her own words, Jessica knew with certainty that she was "not going to be alone" after death, and that she would be "loved." Jessica's profound and enduring feelings of being loved and secured didn't emerge from a distant dream. Jessica was clear: she observed Mary in wakefulness. Jessica also had dreams of her deceased dog Shadow who reaffirmed that she was "ok," secured in love.

Although ELDVs, like Near Death Experiences (NDEs), entail the same paradox of a vibrant mind in a declining body, there are critical qualitative differences between NDEs and ELDVs. Characteristics of NDEs include impressions of being outside one's physical body, awareness of being dead, a "tunnel" experience, movement toward and/or being immersed in "light", life review and entering another realm of existence. These characteristics are not typically described in patients experiencing ELDVs. ELDVs are reported with much less abstraction or complexity. NDEs are commonly associated with a dramatic and lasting change in personality and outlook on life, whereas ELDVs leave the dying restored rather than changed.

ELDVs are felt and aligned with the life led – personal and core to self and one's relationship to others. Unlike the person experiencing NDEs who is often motivated to analyze and share their experiences, the patient experiencing ELDV is not. A critical distinction between NDEs and ELDVs are that NDEs are often explained or dismissed in terms of changes in physiological function as part and parcel of the biological changes occurring as a result of "clinical" or nearing dying. The same criticism cannot be used to dismiss or refute ELDVs. Patients in our studies were not just interviewed in the last minutes and hours before death but longitudinally, in the days and weeks before death. All our study patients were screened for confusion, and many were

high functioning and living independently when their ELDVs began. In other words, the experience of NDE occurs within clinical death whereas the ELDV experience occurs irrespective of how strong or tenuous the link between body and mind is or has become.

The results of our studies clearly reveal ELDVs as a state of consciousness that is different from other states of mind we may experience in health. For example, we have shown that ELDVs are distinct from dreams in several ways. Regular dreams are often defined as projections of latent psychodynamic processes and are rich in symbolism. By contrast, pre-death dreams and visions rarely contain the abstraction, behind-the-scene or metaphorical meanings we have come to expect from typical dreams. We have yet to have a patient emerge from an ELDV and ask for interpretation, analysis, or input. The time for introspection and therapy has passed. In fact, this is what patients tell us loud and clear: these dreams are different and unlike other dreams, because they are lived, virtual, experienced, and "more real than real." They are a form of communication and connectivity that exit on a different plane which might be called transcendental and in which there is no distance between the dreamer and their dream experience. They often offer blueprints for a peaceful, visionary, and certainly revisionary end of life, and the meaning transcends the relation to the self to emanate from and in our relationship with loved ones. The following video is of a dying patient named Horace. In the video you will notice how Horace struggles to find language to describe what he is experiencing when his eyes are closed. He is overwhelmed just trying to describe his feelings of "happiness", comfort, reunion, and love. He describes his deceased wife as even more beautiful than he remembered and felt "everywhere was "happiness" (Link to: Horace Interview Video).

ELDVs are also most commonly defined by unique communication between the dying patient and those individuals featured within the ELDV. They entail reframing the communication they stage as something that transcends language: participants typically report very little verbal exchange with those who pre-deceased them. The smile of the long-deceased child or the wave of a departed wife doesn't require language or explanation. The exchange resides in a dimension of consciousness that is simply felt, understood and shared.

As the data revealed, End-of-Life Dreams and Visions also challenge the parameters of typical recollection or memory. Recollecting implies retrieving a prior time from the vantage point of the present, and ELDVs go beyond what we consider re-accessed or rekindled memories. The dying do not remember a person as in a picture, but rather, they are themselves immersed in a larger experience that is lived, rich and sense filled rather than simply conjured from memory. There is a qualitative change in perception or state of awareness, of something within oneself. Simply put, patients are not looking back; they are ensconced within the experience, sometimes communicating with someone whose recent death they had not been informed of, or resurrecting smells, sounds, and details that go well beyond our usual cognitive interpretations. The following video is of Jennifer who is describing the inner experiences of her dying partner Patrick. In it, Patrick relives eating his family's "secret" spaghetti sauce with his deceased grandmother. His consciousness is immersed and responding to unseen surroundings that exist in a shared mental space, and Patrick now relays an awareness of feelings, perceptions and senses that may not be shared with the living but is shared with the dead, including the sensation of being full after having shared a meal. Patrick's ELDVs even include new "memories": just before death, Patrick now remembers the long-forgotten and missing ingredient in the secret sauce (Link to: Jennifer Interview Video).

ELDVs are inherent to our human existence and are evident in dying patients regardless of age or cognitive ability. As noted in our case study, ELDVs challenge our limited understanding of cognition and mental ability: patients who experience ELDVs aren't confused but rather display heightened acuity, insight and consciousness, and such experiences occur in patients who are cognitively different such as those with dementia or Downs Syndrome. Past events that may not have previously been recalled with such vividness and detail prior to their terminal decline now return to resurrect a life rich in emotional tones, meaning and history. More than recalled, these experiences are relived and felt with a renewed sense of existence. Such patients often reexperience the best parts of having lived beyond even their conscious control. Based on their compromised cognitive status, such patients were not included in our formal studies, but we did document, and even videotape, family reports of their loved ones' end-of-life experiences. An elderly woman named Irene, who suffered with advanced dementia, kept re-experiencing the presence and love of her long-departed husband Gary. The following video is of Irene's

daughter, Sue, describing her mother's experiences at life's end. Irene was joyful and complete in her final days. Days before death, Irene attempted to leave the nursing home: she was reexperiencing the best day of her life, her wedding day, and needed to get to the service (Link to: Sue Interview Video).

It has been noted--by our research team and others--that patients rarely report religious content in their end-of-life experiences (15, 41). Still, while this may be surprising, it is also not the point. While there are relatively few references to the symbols of faith, the tenets of faith, love and forgiveness, are common themes within pre-death dreams and visions. This is an insight that is beautifully expressed in the writings of Kerry Egan, a hospice chaplain in Massachusetts (42). In her short but powerful piece "My Faith: What people talk about before they die," Ms. Egan explains that she is routinely called to the bedside of dying patients who want to talk, not about God but about their families and "the love they felt, and the love they gave .... people talk to the chaplain about their families because that is how we talk about God". To Ms. Egan, not mentioning God directly does not create conflict with her own religious faith or role as chaplain because it is in the love felt by family members for each other that she recognizes God and the teachings of her religion: "If God is love, and we believe that to be true, then we learn about God when we learn about love. The first, and usually the last classroom of love is the family... We don't have to use words of theology to talk about God; people who are close to death almost never do. We should learn from those who are dying that the best way to teach our children about God is by loving each other wholly and forgiving each other fully - just as each of us longs to be loved and forgiven by our mothers and fathers, sons and daughters." At the hour of our death, spiritual transformation is no longer external to the self. It happens in the innermost recesses of our being. As we progress toward acceptance, illness and death place us on a spiritual path that that reunites us with consciousnesses that were never gone and ultimately re-affirm who we are through their returned love.

We have lost our way with dying and with death. It has become easier to live longer, but harder to die well. I had been trained to view dying as medical failure when I began working at Hospice in 1999. Sadly, the acceleration of the science of medicine has obscured its art, and medicine, less comfortable with the subjective, has been more concerned with disproving the unseen than

revering its meaning. Amid the current madness of medical excess, there is a need for spiritual and cultural renewal that medicine alone cannot address. It is when medicine can no longer defy death that nature assumes its rightful role, and the process of dying becomes what it has always been: a human experience with physical and spiritual dimensions, seen and unseen. From this vantage point, the dying process, which includes transformative subjective or inner experiences such as end-of-life dreams and visions, becomes less about finality than about life's resilience.

As Hospice work demonstrates again and again, when the patient is kept comfortable and otherwise left to follow the natural course of things, death becomes more enlightening than a simple pulling down of the shades. This enlightenment is one that encompasses altered forms of consciousnesses, a double consciousness as it were, those of the departed as well as the patients. Whereas traditionally, consciousness is defined as an awareness of self and of the world around, ELDVs include alternative forms and beings that include not just dreams and visions of them but the lucid consciousness of others as constitutive of the self. The departed loved one's consciousness exists as an extension of one's own and their surroundings become indistinguishable from the patient's as inner and outer worlds collide and become one. What observers may view as a sudden change in perception is lived, in other words, as an expanded consciousness rather than as a change by the patient. It is not that an alternate reality supplants theirs, but rather that their reality grows to include what is an "other world" only to outsiders. To the patient, the distinction does not exist, and their loved one's world is merely an expansion of their immediate surroundings. As such, the tragedy of human existence is not the fact of death or suffering or the inability to defeat these but our inability to think dying as anything other than the "diming of the light." By exploring the nonphysical and subjective experiences of dying in an objective fashion, through both research and film, we have worked to reframe and humanize dying from an irredeemably grim reality to an experience that contains richness and continuity of meaning and relationships for patients and loved ones alike.

At life's end, dying patients summon up comforting processes at life's end are beset by symptoms of a failing body over which they have limited control. They are at their most frail and vulnerable, existing within suffering states of aching bones and air hunger. Catheters, IV's and pills may now be part of their everyday, sometimes literally functioning as extensions of their

bodies under the daily medical management that is their new and irreversible lot. They may experience various degrees of cognitive, psychological and spiritual dissonance. Yet even as the inexorable march of time is taking its toll on their bodies and minds, many also display remarkable awareness and mental sharpness in the context of their inner experience, an awareness that resides in their consciousness, a consciousness that transcends death and its limitations.

### 5. ADDENDUM

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# **CURRICULUM VITAE**

PROFESSIONAL EXPERIENCE	
Chief Executive Officer, The Center for Hospice & Palliative Care, Buffalo,	2016-present
NY	
Chief Medical Officer, The Center for Hospice & Palliative Care, Buffalo,	2011-present
NY	
Interim Chief Executive Officer, The Center for Hospice & Palliative Care,	2013 - 2014
Buffalo, NY	
Palliative Care Medical Director, Great Lakes Health System, Buffalo, NY	2011- present
Chief Executive Officer, Supportive Medical Partners PLLC, Amherst, NY	2011-present
Core Faculty, Division of Palliative Medicine, University at Buffalo, SUNY	2007-present
Clinical Assistant Professor, Department of Medicine, University at Buffalo,	2003-present
Buffalo, NY	
Medical Director, The Center for Hospice & Palliative Care, Buffalo, NY	2007 - 2011
Associate Medical Director, The Center for Hospice & Palliative Care	1999 - 2007
Postdoctoral Research Fellow/Research Associate, Department of	1998 - 2000
Cardiology, University at Buffalo, SUNY	
Internal Medicine Resident, Department of Internal Medicine, University of	1995 - 1998
Rochester, NY	
Graduate Teaching and Research Associate, Department of Cell Biology,	1987 - 1992
Neurobiology and Anatomy, The Ohio State University, Columbus, OH	
EDUCATION	
Medical Resident, Internal Medicine, University of Rochester, NY	1995 -1998
Medical Doctor (M.D.), Medical College of Ohio, Toledo, OH	1995
Ph.D., Neurobiology, Ohio State University, Columbus, OH	1991
B.A., Psychology, Kent State University, Kent, OH	1987

### **AWARDS AND HONORS**

Joseph Castiglia Award, Sisters of Charity Hospital Foundation	2020
<b>Buffalo Business First's Excellence in Health Care Award Physician of</b>	2019
the Year Award, Western NY Perinatal Bereavement Network	
Hope, Care and Dignity Award, The Center for Hospice & Palliative Care,	2011
Buffalo, NY	
Circle of Life Award, Recipient on behalf of The Center for Hospice &	2011
Palliative Care, American Hospital Association, San Diego, CA	
Siegel Award: Distinguished Clinical Teacher Award, University at	2000
Buffalo, SUNY	
John C Sable Memorial Heart Fund Award, Winner, University at Buffalo,	1999
Department of Cardiology, Buffalo, NY	
Lawrence E. Young Awards for Outstanding Resident, Winner, University	1987
of Rochester, Internal Medicine Program, Rochester, NY	
National Kaplan Medical Student Research Content, Winner, University	1993
of Cincinnati, Cincinnati, OH	
Henry Hartman Award in Clinical Psychiatry, Winner, Medical College of	1993
Ohio, Toledo, OH	
National Chairman's Award for Outstanding Doctoral Dissertation, Third	1992
place, American Association of Anatomist	
Presidential Fellowship Award, Ohio State University, Columbus, OH	1991
National Academic Honors Society, Phi Kappa Phi: G.P.A.>3.8, Ohio State	1991
University, Columbus, OH	

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### **BOOKS**

Kerr CW, with Mardorossian C. *Death is But a Dream: Finding Hope and Meaning at Life's End* (2020). Penguin Random House. <u>Link to Book</u>

#### OTHER COVERAGE

- Research has been featured nationally and internationally through media coverage including the
  - New York Times
  - Washington Post
  - Huffington Post
  - o The Atlantic
  - $\circ$  BBC
  - o Scientific American Mind
  - o Discover Magazine
  - Psychology Today
- Research was featured in a Netflix docuseries "Surviving Death" (2021, S1 E05)
- Research was also featured in a full-length documentary on the PBS WORLD Channel released in the spring of 2021. It will continue to air over the next three years through various PBS affiliates across the country. The documentary is also set for distribution through Good Docs. <u>Link to Documentary</u>
- 2015 TEDx Buffalo Talk with 3.8 million views. Link to TEDx Buffalo Talk

**NOTE:** Please see attached link for a list of media coverage, podcasts, radio, and lectures.

Link to Publicity Events

The organizations that cover our work range from the medical to relevant organizations including among others, the *Afterlife Conference*, *Spiritual Awakenings International* and *IANDS*. Our research attracts attention from a diversity of disciplines interested in the topic of dying and/or the afterlife. Examples include interest from those in the fields of technology (*Wired Magazine*) to interpretations of Operatic themes (*Aria Code Podcast*).