

Rosen Method Bodywork at the End of Life Observations from a Massage Therapist

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Introduction

The focus of this paper is to consider the role and opportunity for Rosen Method Bodywork (RMB) in end of life care (EOL). What follows are my observations, lessons and insights into applications of bodywork among the medically fragile, those on hospice care and others at the end of life who are not on hospice service. I believe that RMB is well-suited for working with this patient population, specifically because of the focused attention to body tension and the breath, while meeting the person in their experience.

Background

I am a massage therapist. I am also an advanced student of Rosen Method bodywork. I worked as a traveling massage therapist with hospice for 3.5 years. I now have a private practice in which I work with cancer and medical patients wherever they are in their journey: treatment, remission or the end of life. Shortly after beginning my work in hospice, I was introduced to RMB. It was an instantaneous merging of what I was already doing and experiencing with patients, but placed in a framework where I could deepen my work with hospice patients by using the dialogue and touch of Rosen Method.

My first end of life training was an in-person three-day course for anyone to deeply consider and befriend their own mortality. During the first morning of the class we were partnered with another classmate, one of whom was 'the patient' while the other was 'the visitor.' The patient was instructed to lie down and get comfortable, as the visitor was guided through a script of how to be with the person in front of them, before ever placing their hands on the "patient." The resounding words were: "there is nothing to do here, there is nothing to fix." Before touching the person, we were asked to look at that individual as they lay in front of us, to wonder about all of their life's experiences, and to approach them with openness. We were then directed to place our hands on their arm, while imagining all of the things that arm had done in their lifetime—such as throwing a ball, hugging someone else, holding hands, chopping vegetables, and so on. The journey around the body continued as we placed our hands on their head and considered all the thoughts, different styles of hair, whispers in their ear, etc., that person had experienced. We continued for 30 minutes, observing and being with this person right where they were, meeting them in their humanness, while imagining that their time on earth was drawing to a close. This experience was profoundly moving to all participants: to be met deeply, while being reminded of the fragility of life.

Defining Hospice

In the United States, the National Hospice and Palliative Care Organization (NHPCO) says this about hospice:

“Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so” (National Hospice and Palliative Care Organization, 2013).

Palliative care, though similar to hospice care, can be distinguished in that it is the management of a chronic diagnosis, not that the diagnosis is life limiting. An individual in cancer treatment may be receiving palliative care and may transition from palliative care to hospice depending on disease advancement; or a person recovering from a severe leg fracture may receive palliative care while recovering from injury, and eventually be discharged from medical care for their broken leg (MedlinePlus Medical Encyclopedia, 2015). In summary all hospice care is palliative care, but not all palliative care is hospice care.

Throughout this article, the term patient is used, as the potential client is a hospice patient admitted into a medical system with a team of medical personnel overseen by a physician in the role of medical director. Care plans are developed for the care of the patient, and supplemental services such as physical, occupational, speech, massage, music therapy and volunteer visits are part of the patient’s chart and care plan. If a Rosen Method Practitioner (RMP) volunteers through hospice, they are viewed as part of the care team. If the RMP is contacted by a family member to work with a person on hospice service, the service is between the patient on hospice, their caregiver and the RMP. This article is written with the intention that the RMP is affiliated with a hospice organization, whether paid or voluntary.

It is also important to note that not all hospices are stand-alone facilities. The hospice I worked for did not have a stand-alone facility. Within a day I could visit between one to five different patients in five different locations. Some patients are in-home, others are in nursing/extended care facilities, and others within a hospital are usually in a room designated for hospice care. This article is written from the standpoint of the practitioner traveling to the patient’s home or care facility. The patient may be able bodied and capable of traveling to the practitioner’s office; however, over time, mobility and stamina may become limited. A person admitted to hospice can be completely able-bodied with no immediate limitations on their daily living activities. A person is admitted to hospice care because it is generally expected that they will not live more than 6 months. Over time, activities will decrease as their disease progresses. A person can also be admitted to hospice while in the stages of actively dying, a term used when the body begins to start shutting down, and death is expected within 72 hours.

Understanding the Role of Bodywork in Hospice

In medical and oncology massage there are modifications for everything with utmost consideration for what is going on both to and inside the client’s body: chemotherapy, radiation, lymphedema, surgical

sites, side-effects to treatment and medication, blood clot risks, the potential for fatigue, neuropathy, nausea, anxiety and pain. The Walton Pressure scale, developed by Tracy Walton, a massage therapist and educator, is used to allow massage therapists a common language when communicating in charts and with other therapists. The scale ranges from 1- 5, with 1 being the lightest touch, and 5 being deep pressure (Tracy Walton & Associates, 2012). A pressure of 1 is described as “light lotioning with skin movement only.” The tendency is to go too lightly at this level which can result in incomplete hand contact, connecting with the fingertips, instead of with full hand contact. This is typically caused by the therapist working quickly over an area rather than slowly and mindfully. A pressure of 2 is movement of superficial adipose tissue and muscle, similar to the amount of pressure used to rub in sunscreen or lotion. Pressure levels 3, 4 and 5 engage muscles and deeper layers of fascia. Pressure levels 1 and 2 are most commonly used in the hospice setting, since these levels typically do not pose a challenge to the body.

Holding Space

In end of life work, and in working with medically fragile clients there is the concept of ‘holding,’ without using lotion, or movement with the hands, instead meeting the perceived ‘tight’ areas of the client’s body with the practitioner’s hands. Movement can be too stimulating. As the pressure and movement of the practitioner’s hands decreases, there is the opportunity to venture into something deeper. In this holding is where I believe the dialogue and touch of RMB can meet a hospice patient.

The idea of holding space means “that we are willing to walk alongside another person in whatever journey they’re on without judging them, making them feel inadequate, trying to fix them, or trying to impact the outcome. When we hold space for other people, we open our hearts, offer unconditional support, and let go of judgement and control” (Plett, H., 2016). This definition resonates with RMB, and is why I believe RMB is a perfect fit for working with hospice patients. As quoted by Marion Rosen, the founder of Rosen Method, “change comes about not as a result of the RMP doing something to the client in an intrusive way but by providing a supporting and caring environment for something new to happen through verbal and physical contact with the holding (muscular)” (Mayland & Rosen, 2005).

The Power of Touch

The title of Sandra Wooten’s book “Touching the Body, Reaching the Soul” (Wooten, 1995) is a summation of the potential of what can happen during a session with a hospice patient, or non-hospice patient. In RMB the focused attention and gentle touch creates the potential for ease to enter the body and breath. One thing that becomes strikingly obvious when working with hospice patients is the opportunity to venture into a deeper, more keenly aware state of the ‘unknown.’ What is known is that the patient was placed on hospice care because of a life expectancy of less than six months: what is not known is how or when death will arrive. The practitioner comes face-to-face with mortality, both their own, and that of their patient. If there is one lesson that working with hospice patients can teach, it is the fragility of life. I carried a quote from a D.H. Lawrence poem as a reminder of the sacredness of the work I was called to share: “Now here was I, newly-awakened, with my hand stretching out and touching the unknown, the real unknown, the unknown unknown” (Lawrence, de Sola Pinto, & Roberts, 1977).

I have found that it is important for the ego, and any form of an agenda to be left at the door. What remains is one human being with another human in their human experience, while holding them and holding space. “Rosen Method practitioners can feel, see and trace the movement of the client’s breath into

formerly held areas. No value or importance is placed by the RMP on the trauma in one's life that made it necessary at the time to create a barrier or chronic muscle tension. A barrier is a barrier. The practitioner contacts the barrier, not the experience itself. But the client may become aware of the emotion attached to the barrier and thereby gain access to a new way of being in the world" (Mayland & Rosen, 2005b). As Salibian addresses in her trauma article, "no one can truly facilitate the healing of clients caught in trauma symptoms by going through a set protocol one has memorized. One has to really be there in each unfolding moment" (Salibian, 2016). As humans, we all have unconscious trauma, whether on hospice or not, it is necessary to hold space and to be with what is, in that moment. A set agenda or protocol in working with the unconscious does not fit together, nor does the assumption that being on hospice is traumatic.

In an article titled "The Gift of Presence, The Perils of Advice" the author states:

"The human soul doesn't want to be advised or fixed or saved. It simply wants to be witnessed — to be seen, heard and companioned exactly as it is. When we make that kind of deep bow to the soul of a suffering person, our respect reinforces the soul's healing resources, the only resources that can help the sufferer make it through. Many professionals in helping roles are as much or more concerned with being seen as good helpers as we are with serving the soul-deep needs of the person who needs help. Witnessing and companioning take time and patience, which we often lack — especially when we're in the presence of suffering so painful we can barely stand to be there, as if we were in danger of catching a contagious disease. We want to apply our "fix," then cut and run, figuring we've done the best we can to "save" the other person" (Palmer, 2016).

As excerpted from the Rosen Institute's Ethical Principles, Scope of Practice and Code of Professional Conduct:

"Rosen Method Bodywork is an experiential body-centered somatic modality that uses a combination of gentle, respectful touch and verbal communication related to the client's experience and what is felt in the client's body by the practitioner. The intention within a RMB session is to invite relaxation, self-awareness, and the experience of self-connection. RMB also can bring awareness of chronic, habitual muscle tension that can cause discomfort or pain, limit free movement, and restrict the rhythm of the breath."

Further, in working with hospice populations:

"In assessing the appropriateness of Rosen Method for individuals, it is important to keep in mind that there are times when a person needs containment and protection rather than an opening to explore more sensitive areas. This must be carefully assessed on an individual basis, taking into consideration the support system of the person, and his/her fragility and ability to self-regulate" (Rosen Institute, 2016).

The beauty of RMB is the work with the diaphragm and breath, in its natural state, while holding all of it in a safe container of the patient/client's and RMPs experience. "By influencing the movement of the diaphragm muscle through many different routes, RMPs facilitate the release of the diaphragm and the freeing of the natural breath" (Green, 2012). Throughout a patient's journey on hospice, their breath

will change and eventually end. Each person's end of life journey is uniquely their own, whether it's 24 hours on hospice service or one year. A RMP can meet the patient where they are, and also be present while the patient grapples with their end of life realities whether physically, mentally or spiritually. Rosen assumes that the conscious and unconscious processes meet at the diaphragm. "The way our breath moves through our bodies is as individual as our signatures, and as revealing of our personalities. RMB students and practitioners do not rely on formulas that tell them the meaning of what they observe; rather, they strive to be open to the unique experience of the client in the present moment" (Green, 2012). The hospice patient's experience could be directly correlated to the patient preparing for and leaving their physical body through death. "When the diaphragm swings freely, the boundaries of the personal ego relax and expand, bringing the experience of a loving connection with something greater than the individual self - God, universal intelligence, universal love" (Green, 2012b). And as Marion Rosen stated: "When you touch clients in a way that frees them, that makes them feel acknowledged, there is a wave that goes through the body. Sometimes all that is necessary is for them to be listened to, to be looked at and touched..." (Mayland & Rosen, 2005c).

Green's article, "The Role of the Diaphragm in Self-Awareness and Transformation" provides a thorough examination of how the diaphragm works and its involvement with the nervous system and modulation of the flight/fright or freeze response and the body's attempt at homeostasis. And as Hrossowyc addresses in her article "Resonance, Regulation and Revision," touch has the potential to engage oxytocin and the 'human connection system' (Hrossowyc, 2009). The combination of understanding the role of the diaphragm, the breath and the power of touch forms a profound symbiotic relationship, especially when working with hospice patients.

Modifications and Adaptability

The first 'rule' is, "Do no harm" (Walton, T., 2016). Before a session begins the biggest considerations are modifications and adaptability. A session may occur on a massage table, however it is very likely the hospice patient will not be on a massage table for a session. Mobility and level of comfort must be considered when preparing for a session. The question to ask is: "How can this patient receive the most benefit from the session without taxing their body in any way, both before, during and after a session?" If they are in a wheelchair, transferring to a bed is an option, however such a transfer could be too energy draining and increase heart rate and respiration. Is it possible to work with the client while they are in their wheelchair? Or, if the patient is comfortable in their oversized recliner with their feet elevated, can you work there?

Positioning of Patient: Positioning a patient is vital to establish comfort and a sense of support. If their body is not comfortable, nothing further can be achieved, as they will just be tolerating the session. A bodywork session is perhaps one of the few times a patient can 'just be' and not have to do anything. Supplementing the body with rolled towels, pillows and blankets can help tremendously. A change in position can help decrease tender points and bring ease back to the body. Exposing the skin may cause the patient to feel cold, so working through clothes or a sheet is a possibility. Perhaps the session can be done entirely with the patient lying on his/her side, or supine in a hospital bed with the head elevated. Comfort of the patient is of highest priority.

Medical Equipment: It is important to understand and work with and around medical devices including hospital beds, high back reclining wheelchairs (oftentimes referred to by their brand name BRODA

chairs) (BRODA, 2014), oxygen lines, pain medication patches, port sites, catheter and colostomy bags, a tracheostomy or feeding tube, and/or compression socks. Other medical equipment may also be in the room including a wheelchair and portable commode limiting space the practitioner has to work in.

Body mechanics of the practitioner: The practitioner needs to ensure their own body is supported and not being twisted into unnatural or painful positions to accommodate the patient. I carried a small three-legged backpacking chair with me, which could easily be sanitized between patients, fit neatly into my bag, and was the perfect height to work alongside floor level hospital beds and recliners. Also, if the patient chooses to be in their regular bed, take care when reaching across the bed to touch the patient, as it's an incredible strain on the lower back. If they are able, and not a fall risk, have the patient slide closer to the side of the bed.

Length of a session: The practitioner should take cues from the patient and the patient's body response, as well as the practitioner's own inner knowing. Sessions might be much shorter than expected.

Acknowledging a patient's NO: One of the most empowering things for a hospice patient, is to have their 'no' recognized and honored. There is the potential for a lot of people to be in and out of the patient's space on a daily or weekly basis, over which the patient often has little to no control. The chaplain visits, the nurse, the certified nursing assistant (CNA), the social worker, a neighbor, a friend, a relative. The RMP is one more person in the mix.

It is wise to place a call in the morning to inquire if a patient would like a session, realizing that circumstances can change. The practitioner may arrive at the patient's home to be told they no longer want a session. There may be issues such as nausea, pain, constipation, sudden decline or change in mental status. Building rapport with the patient is valuable and may allow a suggestion for a short session of five minutes with a re-assessment and check-in. I have found that repositioning and bolstering can be valuable tools when helping the patient get more comfortable. Keeping an open dialogue with the patient and caregivers is important, especially when a caregiver may feel protective and not understand the benefits of the work. Accept and honor what the patient wants after a bit of inquiry. The practitioner may be the only person the patient can say "no" to, and this needs to be honored.

Others Schedules: It is often necessary to work around other hospice staff schedules: RN, CNA, other therapists, realizing that they may have been delayed somewhere else and may be present when the practitioner arrives. Also a relative or friend may have just arrived as the practitioner is about to start their session. Flexibility is paramount.

Other people in the room: A room may be filled with not only the patient but with other visitors, some of whom may want to stay and watch the session. Arrival of the practitioner may also be the signal for visitors to take a break.

Talking to the patient: The patient may be alert and orientated and completely aware of what's going on in their surroundings. They may also be able-bodied and up and about doing activities. I once had my initial visit with a hospice patient while we weeded their garden. The patient may also be bedridden, non-cognizant and surrounded by a room full of people not talking to the patient or interacting with them. This again is why I believe RMB is a perfect fit for a hospice patient, because a practitioner has the opportunity to touch and listen with their hands to the patient, to assure them that they are not alone, and to perhaps encourage the family to do the same.

Case Reports

Working with hospice is a dynamic experience—one that stretches through emotions, rawness, and meeting another human who may soon die. The depth of Rosen is to stay with what is present in the moment. What follows are three case reports from my experiences with hospice. I introduced myself as a massage therapist. Large parts of my sessions; however, were mainly Rosen Method techniques: meeting tension with my hands, watching and feeling for the breath and dialoguing with the patient.

All names in the following case studies were changed to maintain patient confidentiality.

Case Report 1

Carol was 76 years old and recently widowed. She was a patient on service for chronic obstructive pulmonary disease (COPD). She had never received a massage before and had recently been admitted to a nursing home to assist with her daily care. She used nasal canula oxygen with a compressor located in her private room. She was alert and orientated, yet was not able to lie completely prone or supine because of her difficulties breathing. She was open to trying bodywork to see if it could help her.

Because of COPD, her breathing was labored. She breathed through pursed lips and leaned over her hospital tray for added support. The first goal was to position her comfortably to allow her to rest after the session, and then to ensure that I could maintain proper body mechanics. She was in a hospital bed which both raised and lowered, and also had a head tilt. I was able to position her lying on her right side, and bolstered her with pillows to ensure proper joint alignment and maximum comfort. She was able to roll her shirt up to her neck which provided full access to her back and side ribs. Removing the shirt would have been too labor intensive for her. I then covered her with a sheet.

I felt her body through the sheet, as a way to warm up my hands, and to introduce my hands to Carol's back. The first thing she noticed was the warmth of my hands on her back and their softness. After five minutes of getting to know Carol's body from her head to her feet, I rolled the sheet down to her hip. I was drawn to work with her ribs and intercostal muscles, because of her breathing limitations. Within minutes her breathing became less labored as her diaphragm relaxed, and then her breathing became longer, deeper and fuller. I continued to look for still places on her back, and to meet them with my hands and words. Carol would talk about the sadness she felt, the anxiety of not knowing what her death would be like and the feeling of letting her family down. She also cried, because she felt 'safe.' Her words were, "I don't have to pretend around you and there's something about your hands, they just know'.

I visited Carol weekly for four months. A family member was always with her, but would leave when I arrived. My arrival was a bit of respite for them, and perhaps for her. When I walked into the room, she would smile and roll onto the side that allowed her to breathe most easily that day. Over time her breathing became more labored, and speaking became more challenging, many times limited to a short phrase or word. I reassured her that she didn't need to talk or entertain me, and the session time was for her.

During my last session with Carol, she was experiencing Cheyne-Stokes breathing, which is also referred to as the 'death-rattle' — 'an abnormal pattern of breathing characterized by progressively deeper and sometimes faster breathing, followed by a gradual decrease that results in a temporary stop in breathing' (Wikipedia, 2012). She was supine in her bed with her head elevated. The family was not sure

if I could offer any assistance, yet I felt drawn to be with Carol, to be with her in her experience. The family was welcomed to stay in the room, to observe, and to perhaps be reassured that Carol was beginning her journey of dying. This time I placed one hand on the side of her ribs, and my other hand on her forearm, and met her with the words, "we are here." Her body softened, and her breathing relaxed, evidenced by a long, slow deep breath related to the reassurance that she was not alone. Her upper back and head also relaxed onto the pillow, her breath expanding into her chest, and the gasping diminishing. Next I placed both of my hands, one on each lateral side of her rib cage near the diaphragm, wrapping my hands around her back. Again, her body settled and softened, her face also looked less strained, more peaceful. The family members saw it too, the evidence of relaxation. I then stepped away, and encouraged her family to touch her just as I had done, along her arm, to reassure her they were with her, to trust their instincts in being with their mother.

Case Report 2

Peter was a 62 year old recent retiree and former farmer. He had spent two weeks in a nursing home during medical tests, and after his diagnosis of an aggressive bile duct cancer, at his request, was moved back to his home. He was on in-home hospice service with his wife, Barb, and his son, as primary caregivers. He was in a hospital bed in the sunroom overlooking farm fields covered in snow. Peter and his family were religious. He was struggling with break-through pain and nausea.

During my first introduction to Peter he was propped up in his hospital bed, listening to music, sipping on soup. His demeanor was light and humorous and everything was fine. His wife was in the room and she struggled with wondering if it was okay to leave. She was overwhelmed with Peter's recent diagnosis and her caregiving responsibilities. Peter reassured her it was okay for her to go somewhere else, and that I would get her if anything was needed.

With his wife no longer in the room, I reintroduced myself, and placed my hand on his upper forearm, as a way to say hello to Peter's body. Peter started crying, and rather than trying to fix or sooth with words, I met Peter right where he was in his hospital bed, with my hand on his forearm to assure him of my presence with him. I could feel the emotion being held in his chest, and the tightness in his shoulders and jaw. I said the words, "it's okay to cry Peter" and he did. Slowly the tears ran down his cheeks, and eventually there were sobs. I was there with him, with one hand on his upper back and the other on his forearm. There was nothing I could fix, yet I could be with him and provide a safe container for him to experience all that was swirling around in his world. And then the calm came, the deep, uninhibited relaxing breaths. Peter relaxed onto his bed, with a look of absolute calm and ease across his face and body. We made eye contact, and it was two souls looking at one another. He simply smiled, said "thank you," and wanted to rest.

After our first session, I visited Peter in his home twice a week for five weeks. Our sessions became shorter as his tolerance for any type of touch decreased. His abdomen was swollen with ascites and his skin jaundiced from the decline of his liver function. His neck ached from being propped in a hospital bed. Most of the time he was lying on his back with his head elevated. Instinctively I placed one hand under his neck/upper back, and my other hand under his lower back to offer a sense of support, and encouraged him to feel my hands. Softening. A sense of relief. Deep abdominal breathing extended to the upper chest. All of it was without any words, but instead I kept moving my hands to where the tension was.

In working with Peter, I also had a chance to offer a session to his wife, to provide a moment for her to be met and to be away from the sudden demands placed on her. In observing her, the breath was shallow

and located in her upper chest. I encouraged her to sit on a chair. I placed my hands on her shoulders, and encouraged her to feel my hands touching her. Her shoulders were hypertonic, and felt as though they were holding down much emotion. Slowly she began softening. From deep within I felt her emotions surfacing. I stayed with her as the first sob emerged, followed by more, as waves of grief, sadness and frustration showed up. We were in the middle of her kitchen as she allowed herself the space to grieve while being held. Afterwards her demeanor was softer, and according to Barb, she felt freer without having words to describe it.

Case Study 3

Gladys was an 82 year old non-verbal female with Alzheimer's dementia. She lived in a locked memory care unit and alternated between a high backed BRODA wheelchair and her bed. It was common that she was holding her baby doll and singing songs to it, or it was clutched lovingly to her chest. Baby doll was the gateway to working with Gladys. If affection was shown to baby doll, Gladys was open and receptive to visitors.

I visited Gladys twice a month in the afternoon, the best time for her. She loved having someone hold her hand and be with her; she also had unexpected emotional, violent outbursts. If she was in her wheelchair, I would sit next to her and place my hand on her arm, meeting her in that moment, saying, "Gladys I'm here to spend time with you," and she would look at my face and make eye contact. She responded deeply to focused touch. Koenig-Coste reports that: "People with Alzheimer's, in trying to compensate for their cognitive and sensory losses, pay more attention to nonverbal communication and become quite adept at understanding it" (Koenig-Coste, 2003).

During one visit Gladys was in bed. The staff reported that the last 24 hours she had been fidgety and rather anxious. I went to sit with her and placed my hand on the lateral side of her shoulder, allowing both of us to settle in. Five minutes into the session I felt drawn to place my hand on her sternum as her breathing was quite shallow. I could feel the essence of Gladys under my hand. Gladys looked at me, and as a tear started rolling down her cheek, she stated, "I'm scared, I'm so scared." I held Gladys, not only with my hands, but with my presence and eye contact.

A CNA was in the room with me and asked who made the comment. I told her it was Gladys, who hadn't spoken in months. Gladys' breathing also changed; it became more relaxed, wider and deeper. Her body softened into the bed, a felt sense of peace came over her. I placed one of my hands along the side of her face, meeting her where she was in that moment, in resonance with the divine. As I left her room, I made sure baby doll was tucked next to her. Early the next morning Gladys passed away.

Conclusion

Working with hospice patients is not for everyone. Hospice is sacred work. Rosen Method Bodywork is also sacred. RMB within hospice could potentially alter a person's end of life experience in being acknowledged and witnessed in the space of a Rosen Method session by providing space for items in the unconscious to be expressed. I've worked with people younger than myself who had small children in their home. I've worked with hospice patients my age. I've worked with people who seemed robust and died before my next visit. I've worked with wards of the state. I've held people as they breathed their last breath. To work with hospice is to come face to face with death and dying, and the reality of our own mortality. Life

does not end like a Hallmark movie. The patients and their families I worked with will always hold a place in my heart, as they let me into their lives during difficult circumstances and trusted me to be with their loved ones.

Additional Resources

- Opening to the Mystery: Presence in Caregiving at the End of Life, (<http://www.lighthold.org>)
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