

# Care of the Dying: Encouraging conversations about death

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*When your fear touches someone's pain, it becomes pity.  
When your love touches someone's pain, it becomes compassion.<sup>1</sup>*

## **I. A personal conversation about dying. *Introduction*<sup>2</sup>**

I sat and watched as my grandmother coaxed my grandfather, Pop-Pop, to eat another bite of applesauce.

“He’s eating!” she smiled.

His hand twitched in mine and I wondered if it was a sign of life, or a symptom of the six-month old mass of cancer devouring his brain.

Grandma Grace giggled, “The last time I got him to eat, I did it by putting his hand on my chest.” My grandmother was a joyful, rounded, amply endowed woman. “He was so surprised at what I’d done that his mouth fell right open and I put the spoon in!

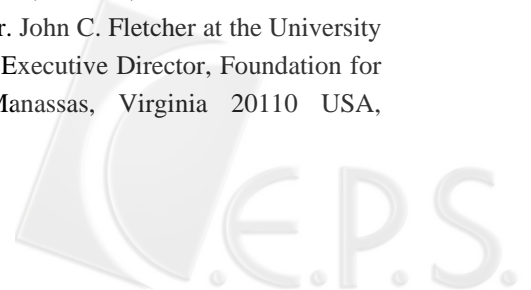
“That was over a week ago. He’s eating for you today.”

She smiled. My heart sank. He lay naked in his bedroom where he had insisted that he wanted to stay. His body, once recently exercise-primed, had in less than six months become a canopy of translucent flesh strung loosely between fragile bones – and still he was strong and he ate for me.

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<sup>1</sup> Steven Levine *quoted in* Taylor, Allegra Acquainted with the Night: A Year on the Frontiers of Death. (London: Fontana, 1989), p. 145, *in* Rinpoche, Sogyal Tibetan Book of Living and Dying (New York: Harper Collins, 1994), p. 200.

<sup>2</sup> This story is paraphrased from my unpublished undergraduate thesis: Williams, Erin D., *Euthanasia: Is it ever Justifiable?* (1991). The paper was reviewed by Dr. James F. Childress and Dr. John C. Fletcher at the University of Virginia in Charlottesville, VA. The text is available from Erin Williams, Executive Director, Foundation for Genetic Medicine, Inc., 10900 University Boulevard, MSN 4E3, Manassas, Virginia 20110 USA, ewilliams@geneticmedicine.org.



That evening Grandma urged me, “If you have anything to say to him, you’d better say it now. You might not get another chance.” Guided by her wisdom, I went into his room and took his hand.

I took a moment to gather my thoughts and began, “I love you Pop-Pop. You were always so strong and dignified.” Swallowing my tears, I continued, “You deserve to do whatever you want to do, live or die, but please don’t do it for me. Don’t eat just for me. I can’t bear the thought of you struggling to stay alive when death might be much less painful. I don’t mean that I want you to die, but I don’t want you to suffer for me.”

Three days later he passed away. I don’t know if he really ate for me. I don’t know if he heard what I said to him that night. I don’t know if my words helped him to cut the final threads that tied him to his life, but I do know that I am affected by his death.

The story above is that of one of the authors, Erin Williams. She wrote it in 1988, approximately one year after the death of her grandfather.

## **II. I don’t want to talk about it. *Difficulties with conversations about dying.***

*No one wishes to be 'rescued' with someone else's beliefs.<sup>3</sup>*

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### *Personalization Exercise:*

Imagine that your father is on a tour of Romania. He has never been there before and he is traveling alone. While he is on the trip, you think about him, you are afraid for him, you fear that he will run into some people who will take advantage of him, or that he will stumble and fall hurt himself, or that he will get sick. You look at the itinerary he gave you and call him one evening in his hotel. “Hi, Dad! How are you?”

“I’m doing fine, honey”

“Dad, I was worried about you – you didn’t call!”

“Well kiddo, this trip is harder on me than I thought it would be. I’m pretty tired.”

“Oh, Dad, today there was some news about some danger where you are headed tomorrow. I am so afraid something will happen to you.”

“Despite my weary bones, this has been a long and fascinating trip. If I die tomorrow I’ll be content.”

Now, change the above scene to the same dialogue, with your father’s trip being his death. Notice the same emotions in a new context. You are fearful that you will lose your father. You can express his fears, which is good, but can you cope with or accept your father’s feelings?

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<sup>3</sup> Rinpoche, Sogyal Tibetan Book of Living and Dying. (New York: Harper Collins, 1994), p. 174.



Discussing the topics of death and dying can be difficult, and can touch on a spectrum of fears. A lack of communication about dying may be one of the factors underlying the “growing body of research suggesting that the dying patients often do not get what they say they want.”<sup>4</sup> We human beings conceal the extent of our emotions, feel confusion about death and dying, fear stigma or embarrassment from initiating conversations about death, and face the weight of cultural prohibitions linked to dying, all of which stop us from raising the topic with loved ones.<sup>5</sup> Talking about death can make us feel vulnerable and defensive.<sup>6</sup> Defensiveness, in turn, impairs our ability to communicate meaningfully about any topic,<sup>7</sup> in particular the inevitable prospect of dying.

In the United States, the health care system adds a layer of factors that can inhibit conversations about the dying process. For instance, end of life conversations have not been incorporated as a routine part of care.<sup>8</sup> This may be due in part to the lexicon used to describe common illnesses. As Susan Sontag noted, war metaphors have long constitutes a large part of the language that we use to describe the progression of certain types of disease. A description of the plague of 1630 reads:

The plague which the Tribunal of Health had feared might enter the Milanese provinces with German troops had in fact entered, as is well known; and it is also well known that it did not stop there, but went on to invade and depopulate a large part of Italy.<sup>9</sup>

A more recent description of AIDS has a similar feel:

The invader is tiny, about one sixteen-thousandth the size of the head of a pin . . . Scouts of the body’s immune system, large cells called macrophages, sense the presence of the diminutive foreigner and promptly alert the immune system. It begins to mobilize an array of cells that, among other things, produce antibodies to deal with the threat. Single mindedly the AIDS virus ignores many of the blood cells in its path, evades the rapidly advancing defenders and homes in on the master coordinator of the immune system, a helper T cell . . .<sup>10</sup>

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<sup>4</sup> Goldstein, Amy. *Dying Patients’ Care Varies Widely by Place Study Says*. The Washington Post, October 18, 1997, pp. A1, A6.

<sup>5</sup> Larson, D, Tobin, D., *End-of-Life Conversations: Evolving Practice and Theory*, JAMA, Sept. 27, 2000, Vol. 284, No. 12, pp. 1573-1578.

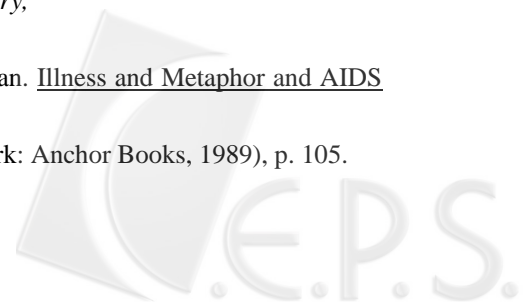
<sup>6</sup> Larson, D, Tobin, D., *End-of-Life Conversations: Evolving Practice and Theory* JAMA, Sept. 27, 2000, Vol. 284, No. 12, pp 1573-1578.

<sup>7</sup> Rogers, Carl, and Farson, Richard, *Active Listening*, in Osland, Joyce, et al., The Organizational Behavior Reader (Seventh Edition). (Upper Saddle River: Prentice-Hall, Inc., 2001) p. 192.

<sup>8</sup> Larson, D, Tobin, D. *End-of-Life Conversations: Evolving Practice and Theory*, JAMA, Sept. 27, 2000, Vol. 284, No. 12, pp 1573-1578.

<sup>9</sup> Manzoni’s account of the plague of 1630 (chapters 31 to 37) in Sontag, Susan. Illness and Metaphor and AIDS and its Metaphors. (New York: Anchor Books, 1989), p. 137.

<sup>10</sup> Sontag, Susan. Illness and Metaphor and AIDS and its Metaphors. (New York: Anchor Books, 1989), p. 105.



The notion of *rallying* the body's *defenses* in order to *fight* an *invading enemy* of disease may feel empowering to some extent. However, when disease is characterized as an enemy to be battled by the weapons of the medical community, then death can only be characterized as defeat. Death is removed from its position as the inevitable, natural conclusion of life, and becomes something to be staved off at all costs. Once death becomes the enemy, discussing the subject raises fears of causing pain and bearing bad news, further deterring health professionals<sup>11</sup> and others from broaching the subject.

The United States' health care system offers no significant compensation for psychosocial conversations<sup>12</sup> that might address the topic of dying, and indeed appears to contain some deterrents. The introduction of managed care in the United States has increased the number of patients that physicians must see daily,<sup>13</sup> decreasing the amount of time available to spend in conversation with any given patient on the topic of dying or any other. Modern health care is frequently provided by multiple physicians in multiple sites, long-term physician-patient relationships are increasingly rare, and relationships between health care workers and physicians are increasingly impersonal.<sup>14</sup> All of these factors inhibit conversations on the topic of dying. Nevertheless, those difficult conversations are prerequisites for many of the modern tools that we have to help guide our health care providers and family members during the final hours of life.

Just as some of us transfer our fear of insects to our children, so might we instead transfer a love and respect for all creatures, and a fascination with their uniqueness. Just as some of us transfer our fear of death to our children, so might we instead transfer a love and respect for all people, and a fascination with each moment of their lives.

### **III. How do you want to die? *Good death. Fun death.***

*Learn to listen, and learn to receive in silence.*<sup>15</sup>

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#### *Personalization Exercise:*

Imagine that you are terminally ill. You feel tired, anxious, fearful, and uncomfortable. An ambulance takes you to an unfamiliar, sterile room, that herds of masked strangers periodically enter. They point to parts of you and speak primarily to each other. The staff feeds you food you have not selected. They keep you cool when you want to be warm. They

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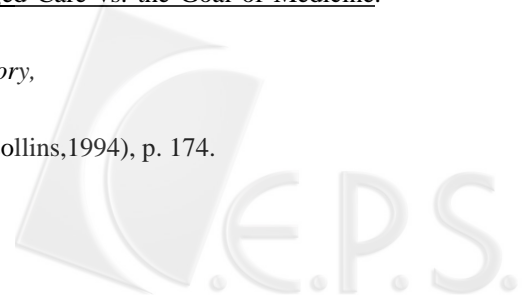
<sup>11</sup> Larson, D, Tobin, D., *End-of-Life Conversations: Evolving Practice and Theory* JAMA, Sept. 27, 2000, Vol. 284, No. 12, pp 1573-1578.

<sup>12</sup> Larson, D, Tobin, D. *End-of-Life Conversations: Evolving Practice and Theory*, JAMA, Sept. 27, 2000, Vol. 284, No. 12, pp 1573-1578.

<sup>13</sup> Williams, Erin, and van der Reis, Leo. Health Care at the Abyss: Managed Care vs. the Goal of Medicine. (Buffalo: William S. Hein & Co., Inc.,1997), p. 171.

<sup>14</sup> Larson, D, Tobin, D. *End-of-Life Conversations: Evolving Practice and Theory*, JAMA, Sept. 27, 2000, Vol. 284, No. 12, pp 1573-1578.

<sup>15</sup> Rinpoche , Sogyal Tibetan Book of Living and Dying (New York: Harper Collins,1994), p. 174.



leave you on your back until the skin on your tailbone aches and dies for lack of circulation. Other strangers take you to the toilet or change your Depends. They come and go according to their own schedules, not when you summon them. A hospital chaplain comes for a visit imposing his view of the hereafter on you in his prayers. And sometimes you are simply and totally alone for long, long hours, and your wonderment begins to turn into fear.

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Past civilizations had notions of what might be characterized as a “good death.” A death was good if the dying person had some warning that death was approaching, and was able to straighten his or her affairs.<sup>16</sup> “If the pathway for communication . . . was functioning properly . . . notions of death and mourning rituals would have evolved with medical advancements.”<sup>17</sup> Instead to the contrary, the concept of a good death has largely evaporated from the United States, despite the fact that advancements in medical technology have significantly increased the duration of pre-death illness.<sup>18</sup>

In search of what constitutes a good death today, researchers recorded the observations of patients, providers and family members. One of the factors, pain and symptom management, addressed patients’ physical needs.<sup>19</sup> All of the other factors, such as preparation for death, affirmation of the whole person, and others, related to nonphysical needs of people who are dying.<sup>20</sup>

Patch Adams, a physician in the United States who is well known for dressing like a clown, introduced the concept of “fun death.” The concept of a “fun death” springs from Dr. Adams’ recognition of the value of laughter and humor for the health care system.

Fun (humor in action) and the accompanying laughter bring great medicine into the hospital room. Studies show that laughter relieves pain, relaxes stress, and stimulates the immune system.<sup>21</sup>

Dr. Adams encourages this approach, particularly when facing frightening, life-threatening illnesses, such as cancer.

Do not presume that if the illness is serious you have to remain solemn. I remember a young man who had cancer that killed him in his twenties. He told

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<sup>16</sup> Martoccio, B. Living While Dying. (Bowie: R.J. Brady Co., Bowie, 1982).

<sup>17</sup> Williams, Erin, and van der Reis, Leo. Health Care at the Abyss: Managed Care vs. the Goal of Medicine. William S. Hein & Co., Inc., Buffalo: New York (1997), p. 166.

<sup>18</sup> The Hastings Center (Steinfels, P. and Veatch, R.M., eds.) Death Inside Out (1<sup>st</sup> ed.). (New York: Harper and Row, 1975).

<sup>19</sup> Steinhauser KE; Clipp EC; McNeilly M; Christakis NA; McIntyre LM; Tulsky JA, *In search of a good death: observations of patients, families, and providers*, Ann. Intern. Med. 2000 May 16;132(10): 825-32.

<sup>20</sup> Steinhauser KE; Clipp EC; McNeilly M; Christakis NA; McIntyre LM; Tulsky JA, *In search of a good death: observations of patients, families, and providers*, Ann. Intern. Med. 2000 May 16;132(10):825-32.

<sup>21</sup> Adams, Patch, MD, House Calls. (San Francisco: Robert D. Reed Publishers, 1998), p. 104.



me how disturbing it was to constantly have people around him treat him as if he were already dead. Friends could not see the cancer in perspective enough to treat him as a regular living person. People are always so much bigger than their illness.<sup>22</sup>

At the Gesundheit! Institute workshop on The Joy of Service in 1998, Dr. Adams shared a story of what these principles of fun in health care might look like in practice. He described the death of a friend of his. Dr. Adams and his buddies stayed with their friend, on both sides of him in bed. They stroked him, prayed with him, and sang with him. They remained fully present to him, addressing his human need for companionship and love right through the final moments of his life. They helped him die as he had lived.

In order to help achieve a good or even fun death, some studies have surveyed the wishes of patients and families. One group of researchers asked patients and families what elements were most important to them in the communications that occur after terminal diagnosis until death. Respondents indicated that honesty and straightforwardness in communications was extremely important, as was a willingness to talk about dying.<sup>23</sup> Other important factors included sensitivity when giving bad news and when patients are ready to talk about death, and listening to and encouraging questions from patients.<sup>24</sup>

The United States' legal system provides some tools for patients to record their wishes relating to their medical treatment and potentially to their dying process. Living wills allow patients to make clear their desire to forego or receive certain types of life-sustaining treatments. A patient can also assign durable power of attorney to a loved one, empowering the loved one to make medical decisions on behalf of the patient if (s)he is unable to do so. These legal tools may serve as a substitute for conversations about one's physical preference while dying. However, they do little to address nonphysical desires for companionship, love, and open communication about the dying process.

#### **IV. I will help you die. *Community conversations about dying.***

*When the dying person is finally communicating his or her most private feelings, do not interrupt, deny, or diminish what the person is saying.*<sup>25</sup>

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#### *Personalization Exercise:*

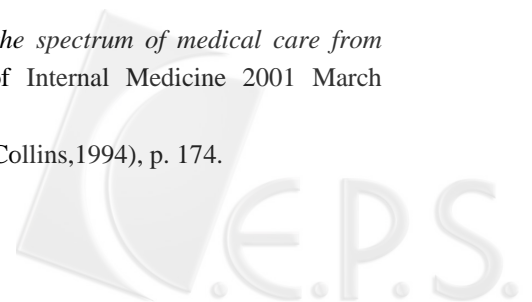
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<sup>22</sup> Adams, Patch, MD, House Calls. (San Francisco: Robert D. Reed Publishers, 1998), p. 104.

<sup>23</sup> Wenrich, Marjorie D. et al., *Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death*. Archives of Internal Medicine, Archives of Internal Medicine 2001 March 26;Vol.161, p. 868.

<sup>24</sup> Wenrich, Marjorie D. et al., *Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death*. Archives of Internal Medicine, Archives of Internal Medicine 2001 March 26;Vol.161, p. 868.

<sup>25</sup> Rinpoche, Sogyal Tibetan Book of Living and Dying. (New York: Harper Collins, 1994), p. 174.





It is a common notion that remaining emotionally stable and taking care of all of your own needs is a virtue. Reaching out to others for emotional support may be seen as a sign of weakness or imperfection. But consider for a moment how good you felt the last time you were able to help a friend or a family member by lending emotional support. That interaction could not have happened without the other person's willingness to share his or her emotional instability, or vulnerability, with you.

Our ability to help each other is one of the most joy inspiring gifts that we can share. Take a moment to think about how you might be able to provide that gift for your loved ones by allowing them help you.

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I, Patricia Williams, was greatly inspired by my mother (who is also Erin's grandmother), Grace. She treated everyone, old and young, sick and well, with love and dignity and delight. At the bedside of my dying grandfather, my mother gave him a reason for living by recording his stories of his childhood for his descendants. My mother's lessons have enriched my life, and even helped to guide me into my current profession.

In 1994, near the end of my mother's life, an octogenarian friend of mine named Dorothy became incapacitated, she had no living family members to help her. She confided, "I can't see very well, I can't hear very well, and I can hardly walk. What good am I! I think society would just put me in the garbage heap."

My friendship with Dorothy and my experience with my mother soon led me to realize that many eight-two year olds need the same love and attention Dorothy craved and my mother gave so generously. It is not fair that our way of life scatters people and leaves them alone and lonely. I needed to do something to change that.

In 1995, in order to help care for our precious seniors I established *Graceful Care, Inc.* in Reston, Virginia. I took my inspiration from the model displayed lovingly for me by my mother, the business' namesake. GraceFul Care's goal is to provide loving assistance and companionship for all our elders and the mission of awakening society to the needs of our elders. As a part of our service, we facilitate personal conversations about the dying process with our clients and their families. We help them to address their fears, and to discover and respect the wishes of the dying

In April 2001, one client who's mother just passed away wrote us the following note. The client's sentiments are representative many of people served by GraceFul Care.

Dear Folks at Graceful Care: I just wanted to again thank you for sending Millie [a caregiver] to us. Millie cared for my mother with gentleness and respect. I trusted Millie completely and always knew my Mom was in good hands when she was with Millie. My family will always be deeply grateful to Millie for her excellent care of our sweet mother.



GraceFul Care, now in its sixth year of service, is not the only organization dedicated to helping to improve the way that we care for our seniors. In 1996, across the United States in Missoula Montana a physician named Ira Byock launched a project to investigate and improve the dying process in his community. As was the case with GraceFul Care, Dr. Byock's contemplation how death is approached in the United States was influenced in part by his experience a parent.

During his medical residency in California, his father, terminally ill with cancer, agreed to die in Byock's Fresno home, attended by his wife and son and daughter-in-law. It was a hard but illuminating experience that Byock thought did honor to them all. And it stayed in his mind for years before his thoughts about how he wanted to change the American way of dying began to jell.<sup>26</sup>

It was many years later that Dr. Byock enlisted the help of friends and colleagues to initiate the Missoula Demonstration Project (MDP). The MDP seeks to initiate conversations about death in Missoula, and to make the dying process better for residents of the town. It has as its mission

*To research the experience of dying and the determinants of quality at life's end.*

*To demonstrate that a community-based approach of excellent physical, psychosocial and spiritual care improves the quality of life for dying persons and their families.<sup>27</sup>*

The Project, now in its fifth year of fifteen, is an effort to demonstrate that a community can give its citizens excellent medical care, psychosocial support and can consistently improve the quality of life among those who are dying and their families.<sup>28</sup> The MDP's rests on the assumption that

prevailing attitudes about the end of life poorly serve patients, families of patients and care providers. Society as a whole suffers from the pervasive denial of death and from the lack of attention to the end of life. For many, attending to the end of life is not even a consideration. . .

As the research progresses, MDP hopes to demonstrate that improved care at the end of life and enhanced personal experience for individuals and families can be achieved through discussion of individual and community goals. MDP fosters

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<sup>26</sup> Atcheson, Richard. *The Missoula Experiment: How a small town learned to make dying a part of life*. Modern Maturity, September – October 2000. Also available electronically at [http://www.aarp.org/mmaturity/sept\\_oct00/missoula.html](http://www.aarp.org/mmaturity/sept_oct00/missoula.html).

<sup>27</sup> Information available electronically from the Missoula Demonstration Project website <http://www.missoulademonstration.org>, April 2001.

<sup>28</sup> Information available electronically from the Missoula Demonstration Project website <http://www.missoulademonstration.org>, April 2001.





that discussion among hundreds of individuals who serve on our local task forces, who agree to be objects of our research and who participate in MDP programs. Our method is to provide pertinent data from the research to the community as a catalyst for discussion and an avenue for change.<sup>29</sup>

The MDP has advanced its work through many task forces. A pain task force worked to make the alleviation of pain a priority of local health agencies.<sup>30</sup> A storytelling task force encourages people to record their life histories.<sup>31</sup> An advanced care planning task force created an advanced-care directive for Missoula County called “My Choices.”<sup>32</sup> A faith communities task force provides a forum to learn about many different religious traditions seek to ease the experience of death, dying, and grief.<sup>33</sup> And a schools task force is gathering information about how local schools are addressing end of life issues.<sup>34</sup> Together, all of the task forces are beginning to help integrate the process of dying onto the lives of people in Missoula.

## V. Final thoughts on finality. *Conclusions.*

*People will die as they have lived, as themselves.*<sup>35</sup>

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### *Personalization Exercise:*

Read this story, and imagine how you might incorporate its lesson into your care for a loved one.

One day when I arrived, she greeted me sadly. “Well, he's out of it now, she said. He doesn't make any sense at all.” I asked why she thought that.

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<sup>29</sup> Information available electronically from the Missoula Demonstration Project website <http://www.missoulademonstration.org>, April 2001.

<sup>30</sup> Atcheson, Richard. *The Missoula Experiment: How a small town learned to make dying a part of life*. Modern Maturity, September – October 2000. Also available electronically at [http://www.aarp.org/mmaturity/sept\\_oct00/missoula.html](http://www.aarp.org/mmaturity/sept_oct00/missoula.html).

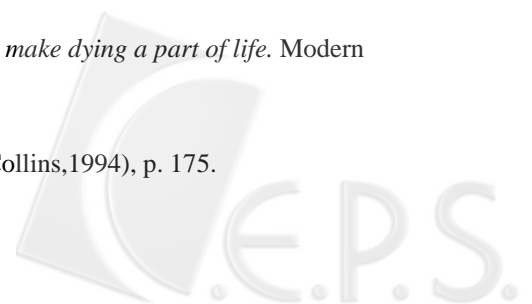
<sup>31</sup> Atcheson, Richard. *The Missoula Experiment: How a small town learned to make dying a part of life*. Modern Maturity, September – October 2000. Also available electronically at [http://www.aarp.org/mmaturity/sept\\_oct00/missoula.html](http://www.aarp.org/mmaturity/sept_oct00/missoula.html).

<sup>32</sup> Atcheson, Richard. *The Missoula Experiment: How a small town learned to make dying a part of life*. Modern Maturity, September – October 2000. Also available electronically at [http://www.aarp.org/mmaturity/sept\\_oct00/missoula.html](http://www.aarp.org/mmaturity/sept_oct00/missoula.html).

<sup>33</sup> Atcheson, Richard. *The Missoula Experiment: How a small town learned to make dying a part of life*. Modern Maturity, September – October 2000. Also available electronically at [http://www.aarp.org/mmaturity/sept\\_oct00/missoula.html](http://www.aarp.org/mmaturity/sept_oct00/missoula.html).

<sup>34</sup> Atcheson, Richard. *The Missoula Experiment: How a small town learned to make dying a part of life*. Modern Maturity, September – October 2000. Also available electronically at [http://www.aarp.org/mmaturity/sept\\_oct00/missoula.html](http://www.aarp.org/mmaturity/sept_oct00/missoula.html).

<sup>35</sup> Rinpoche, Sogyal *Tibetan Book of Living and Dying* (New York: Harper Collins, 1994), p. 175.



“He keeps asking me to get his papers, his passport, and his ticket,” Joan said . . .

I mentioned that talk of travel is often a way that dying people talk of death; I asked if she thought that might be so with George. “No, no,” Joan said. “His mind is wandering, he's thinking about all those trips he's taken over the years.”

When I went into George's room, he seemed anxious . . . “I can't find my passport. Do you know where my ticket is?”

“It sounds like you're planning to go somewhere,” I answered.

George nodded.

“Are you going on a journey? . . . Maybe about leaving here? Maybe about dying?” . . .

He nodded . . .

“If you're talking about that journey, you don't need a passport and tickets,” I said. “Are you wondering what you do need? Are you asking me what it will be like?”

This time he nodded more vigorously. He smiled and said, “Yes, I have to get ready.”

I sat beside him and explained what he'd probably experience. . . He lived ten more days . . . without distress.<sup>36</sup>

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Communities, cultures, and people vary with geography and experience, and our needs and desires related to dying may be as unique as we are. The subtle differences among us may prevent a method that is successful for easing the dying process in one place from being applicable away from its point of origin. What we need depends in part on who we are and what we believe.

Our uniqueness makes the dying process different for each of us, yet it is something that we will all share. As we face the conclusion of our lives, we can find support in one another. Through conversation, we can learn how best to provide care as we die. We can discover how to share the joy of comforting our friends and family members while dying just as we did while living.

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<sup>36</sup> Gallanan, Maggie, and Kelley, Patricia. Final Gifts. (New York: Bantam Books, 1993), pp. 81-2.

