

VOLUME 19  
ISSUE 1  
SPRING  
2009

*Published by the  
National  
Association of  
Professional  
Geriatric Care  
Managers*

3275 West Ina Road  
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Tucson, Arizona  
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# Journal of Geriatric Care Management

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# Guest Editor's Message

By *Gwen Harris*

Treatment for advanced illness is complicated and stressful and, with even the best planning, very difficult to maneuver challenges while one is grieving. Communication and information are key tools in managing end-of-life care. Whether our clients are looking to pursue aggressive treatment options or are seeking to forego cures and choose quality of life and comfort, geriatric care managers are able to coordinate care for everyone—client and the family.

This issue of the Geriatric Care Management Journal examines managing end-of-life care questions. My client's illness is chronic right now; when is the right time to shift to end-of-life care? What is palliative care, and how can geriatric care managers (GCMs) start to incorporate it into their existing service? How can I, as a GCM, best prepare my client as illness progresses? How can

I give my clients comfort if they come from different backgrounds? What tools can I use to help my clients "let go" and find comfort as they move towards the end of their lives? The articles in this issue will examine the different care options available to our clients facing serious and life-threatening illness.

The first article "Slow Medicine: When Less is More" by Debra lyn Johnson discusses the current challenges the United States faces in providing care to seniors with chronic illness. It also examines the benefits of "slowing down" the automatic decision-making process of medical treatments and looking at the quality vs. quantity of life.

The second article "Honoring Cultural Differences at the End of Life" by Pat Forman examines techniques geriatric care managers can use in order to become culturally

sensitive to the end-of-life needs of our clients. Ms. Forman describes what culture is and how it may differ based on our clients' experiences. She also describes an ABCDE model of cultural inquiry as a guide to help geriatric care managers enhance their cultural understanding.

The third article "Palliative Care and Geriatric Care Managing" explains what palliative care is and the major role that geriatric care managers may play in providing excellent end-of-life care for our clients with chronic and serious illness.

Finally, Pat McNees explores life story and legacy activities in her article "The Beneficial Effects of Life Story and Legacy Activities." With deep compassion and insight, Pat shares case stories of end-of-life clients who benefited from telling their stories and finding resolutions before their passing.



# Journal of Geriatric Care Management

Published by the:

**National Association of Professional Geriatric Care Managers**

3275 West Ina Road, Suite 130, Tucson, Arizona 85741 • [www.caremanager.org](http://www.caremanager.org)

Published two times a year for members of NAPGCM

Non-member subscriptions: \$95.00 per year

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The *Journal of Geriatric Care Management* is published as a membership benefit to members of the National Association of Professional Geriatric Care Managers. Non-members may subscribe to *Journal of Geriatric Care Management* for \$95.00 per year. Send a check for your one-year subscription to: Subscription Department, NAPGCM, 3275 West Ina Road, Suite 130, Tucson, Arizona 85741.

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# Slow Medicine: When Less is More

By Debra lyn Johnson, MA, CMC

***“I received life because the time had come.  
I will lose it because the order of things passes on.”***

—Chuang Tzu

The U.S. faces the challenge of providing appropriate and accessible care for aging people with chronic conditions. We must, as a society, begin to question the morality and ethical consequences of the direction that society is taking as aging has become increasingly medicalized. A societal shift is called for that abandons the current myth that surrounds eternal longevity. There is an urgent need for a wider frame of reference in the study of aging that allows for the full exploration of the question of meaning in old age. The biological model alone is not adequate to explore and create new dimensions for understanding the meaning of growing and being old.

The goal of prolonging life without comprehensive evaluation and consideration for the quality of life is where Slow Medicine parts from mainstream medical practice in the treatment of the elderly patient. The term Slow Medicine was coined by Dr. Dennis McCullough, a Dartmouth geriatrician and medical director at Kendal’s Continuing Care Retirement Community in Hanover, New Hampshire. He is the author of “My Mother, Your Mother: Embracing Slow Medicine, the Compassionate Approach to Caring for your Aging Loved One.”

Slow Medicine invites an acceptance of growing old and letting go of earlier stages in life when the dominant focus was on cure, prevention, and the lengthening of life. McCullough describes Slow Medicine as an exercise in evaluation and reflection, attentive observation, and listening. This includes questions regarding medical problems as well as how someone spends their time, what is their emotional state, how engaged are they in their community, and who are their friends and family. Most importantly, Slow Medicine requires the caring hands of many. Effective results are not determined by the doctor alone. It requires the commitment and intimate involvement of all who are in a client’s circle of concern, including doctors, nurses, social workers, family, friends, geriatric care managers, other health professionals, and neighbors.

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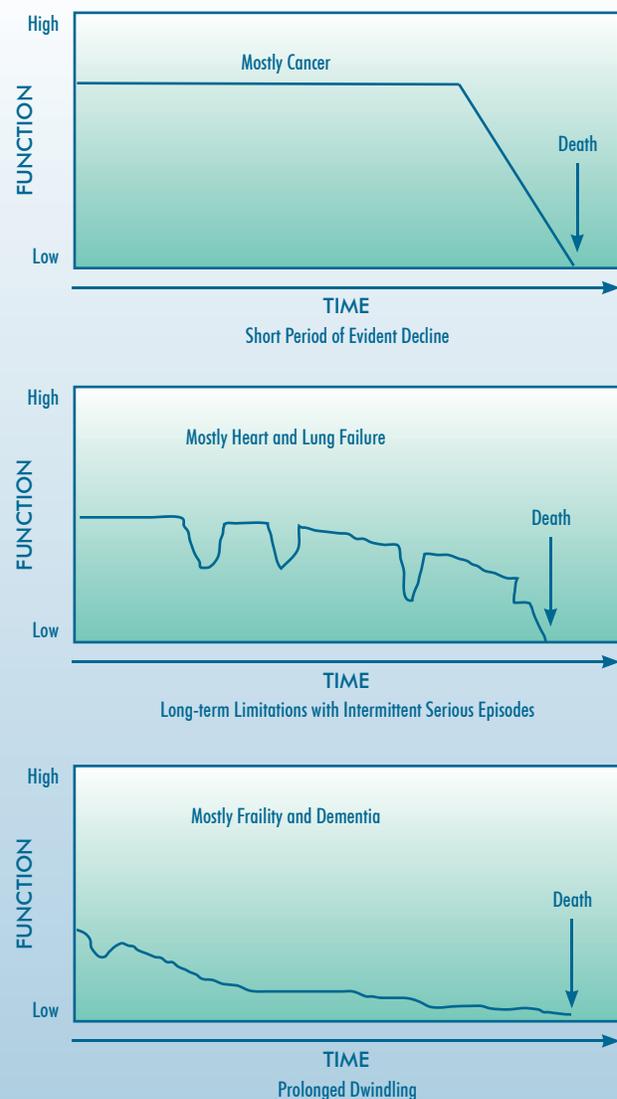


FIGURE 1: The Trajectory of Decline in the Elderly Over Time  
Based on the Disease Type (The Rand Corporation, 2006, p.2).

## Slow Medicine: When Less is More

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A geriatrician who practices Slow Medicine takes the whole person into account. Qualities such as kindness and understanding are the bedrock of this approach. Dr. McCullough describes the slow medicine physician-patient relationship as a “covenantal relationship”—a two-way personal and professional relationship of mutual trust providing a strong foundation for the kind of care elders need along the road to late life. The physician in this model of care might look to make sure the arthritis pain is controlled, that medications are appropriately updated and revised, that toenails have been trimmed and the skin integrity is maintained, that meals are well taken, and that the hearing aid is working sufficiently. They look for signs of isolation, depression, and work with a care manager or social worker to make sure the patient’s home is safe, and that he or she is cared for. The goal is to maintain normal function for as long as possible and to postpone the development of disability. This requires an emphasis on preventive strategies tailored to the realities of aging.

### Medicalization of Old Age: Longevity vs. Quality of Life

More people are living longer than their ancestors imagined possible, but their deaths are preceded by years of chronic disease. Living longer often means suffering numerous chronic but not deadly conditions such as dementia, blindness, deafness, osteoporosis, and arthritis. Chronic conditions are the major cause of illness, disability, and death in the United States and limit independence. Almost 100 million Americans have chronic conditions, and millions more will develop them as America

ages (Nadkarni, 2004). By 2030, 26 percent of the U.S. population will be aged 65 or older, compared with 17 percent today, according to government projections (Bostrom, 2005). As baby boomers age and as people live longer, the continued growth in the number of elderly will cause an increase in people who are most vulnerable to and most affected by chronic conditions. Despite the enormous gains in longevity through medical and technological progress, there is increasing confusion over the meaning and purpose of human life. Aggressive and invasive treatments for the elderly patient can have a small effect or produce an effect of no benefit to the patient except in reducing their quality of life.

It appears that longevity for the sake of living longer is contributing to a far greater problem: Profound spiritual malaise, a sense of emptiness and meaninglessness in the lives of our elders.

Striving to find meaning in life is a primary motivational force throughout the life-cycle and is a universal human motive. Ross Synder

*It appears that longevity for the sake of living longer is contributing to a far greater problem: Profound spiritual malaise, a sense of emptiness and meaninglessness in the lives of our elders.*

states that meaning formation is a central activity of the species “Human Being.” The vitality and graciousness of a person’s life depends upon their supply of meanings, particularly in the second half of life. What are the distinct developmental tasks in the last lap of life’s journey? Rabbi Zalman Schachter-Shalomi, in his book *Aging to Saging*, says that the late years are the time for spiritual eldering; a time to come to terms with one’s own mortality. Life Review is

an example of a developmental task that facilitates the next stage, which includes death. Reclaiming memory through a review of one’s life enables elders to confirm who they are, who they were, and to shape and interpret their life in new ways. It is more than a sentimental journey back through time; it is a psychological, therapeutic process that helps that person identify meanings in his or her life.

When we, as professional geriatric care managers, have a chance to encourage the geriatric Slow Medicine approach to health care for the frail older client over the strictly bio-medical model of care, we have, at least, taken one step back from a system that has gone too far, and one step forward towards creating a new paradigm of care for the oldest of the population.

### Benefits of Slow Medicine

Good prevention, and avoidance of over- and under-treatment are cornerstones in Slow Medicine that keep care focused on an elder’s remaining years to protect, as much

as possible, the quality of life in the face of frailty and old age. Avoidance of over-treatment involves critical evaluation and slower decision making when considering options of treatment. Some questions to ask physicians and/or suggest to the family members for discussion

and consideration before going forward with certain procedures or interventions might include: What is the nature of any potential treatment? Will it impose immediate burdens on the patient, and are they burdens he is equipped to endure physically and mentally? What is the likelihood of success and the nature of recovery? Will there be potential side effects that will adversely affect patient welfare even if the

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treatment is successful? How might the prescribed treatment threaten the client's baseline of health? For example, what is the long-term effect of their life energy and the likelihood that they will bounce back to their previous levels of health?

Cancer chemotherapy trials for elders may offer a small chance of success, but can double the burden on the elder when side effects of chemotherapy exact their toll (McCullough). "Elders have the highest likelihood of benefiting from care that is more measured and reflective, and that stands back from rushed, in-hospital interventions and slows down to balance thoughtfully the separate, multiple, and complex issues of late life (McCullough)." Good prevention means screening for conditions that are relevant to quality of life for the older adult: hearing loss, blood pressure monitoring, balance and fall risk, cognitive and psychological health. The goal, states McCullough, is to postpone as long as possible any decline of function that might require "institutionalization" in a nursing home or that puts an elder at greater risk of losing quality of life. Mr. Fritof illustrates case in point: a 95-year old man had been a patient of Dr. Reuben, geriatrician at UCLA, for decades. Dr. Reuben had to convince a specialist to do a cochlear implant procedure for Mr. Fritof who was going deaf. Then he pushed to have it covered by insurance. Expensive hearing devices like that aren't usually recommended for someone Mr. Fritof's age. Yet, if Mr. Fritof had been dismissed, he would no longer be able to communicate to his wife or family, which would severely have impacted his quality of life (Carrol, 2008). Dr. Reuben says overseeing an elderly patient's complicated medical care is just part of his job. He refers to it as quarterbacking, but it's more than that. It's more like being a head coach. It's coordinating, it's communicating, it's getting everyone

on board. It's working play-by-play to inch one's way down to the finish line.

The rewards of Slow Medicine, geriatricians say, come from caring for vulnerable, often misunderstood patients and the strong relationships geriatricians develop with their families. "Yes, they do die in the end. We all do," Philadelphia geriatrician, Judith Black says. "But the effort is to bring dignity to those later stages of their lives" (Kim, 2008).

## Medical Intervention for Persons with Dementia

Prolongation of the human lifespan is increasing the number of individuals suffering from Alzheimer's disease and other progressive dementia worldwide. Because there is no curative treatment for these diseases, most individuals with dementia survive to an advanced stage of dementia at which time many of them require institutional care.

Older people, when asked, say that if they developed Alzheimer's disease they would not want invasive and painful medical care intended to prolong their lives. Invasive treatments and interventions performed on people with dementia can further advance their condition. Yet, for many, their long-term care plan and healthcare proxy have not been developed by the time they lose the ability to make decisions for themselves. In these cases individuals with dementia are subject to more medical treatment that most of them prefer. Geriatric Care Managers need to be diligent in their follow up with clients and discuss their preferences for care and document them in a Health Care Directive, or a Physician's Order for Life Sustaining Treatment

(POLST) form. It is necessary to ask them, well before signs of serious cognitive impairment, to think about the approach to medical care they would favor. This is where a care manager can be of great benefit by helping the client and family members understand the realities of what is likely to occur if there is no health care instructive.

Most treatment modalities incur some degree of discomfort that a cognitively intact person may understand and tolerate. A person with dementia is sometimes unable to cope with such treatments and, given the outcome of the treatment, may not ultimately benefit from it. One New York hospital reported that among a group of elderly patients with

advanced dementia or cancer, 47% received invasive non-palliative treatments during their stay at the hospital, and 51% of patients with dementia received enteral tube feeding, (Ahronheim, 1996). It is the responsibility of the treatment team to clearly educate and inform the family, or other responsible party, about these risks and outcomes. The discussion of risk versus benefit for the dementia patient may be

*Older people, when asked, say that if they developed Alzheimer's disease they would not want invasive and painful medical care intended to prolong their lives.*

significantly different than that for a patient who is not cognitively impaired. The discussion process is key in the Slow Medicine approach. And, in fact, if things seem to be moving too quickly, it may be time to speak up, step in, and help apply the brakes.

The Professional Geriatric Care Manager needs to be aware of courses of action suggested to a client with dementia. We have a responsibility

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to make sure that a discussion about quality of life and risks vs. benefits is initiated to advocate for the client with their family and physician to ensure best care practices with regard to quality of life. At the same time, it is our ethical and moral imperative to respect our client's wishes and those of the family. There are times when a family wants everything to be done at all costs to keep their loved one alive; to repair him or her once more, no matter how old or how frail. We have become accustomed to the commonality of medical miracles over an extended lifespan, and not knowing when to stop asking for them can be a tragedy when it comes to late life health care decisions. Chief medical officer at UCLA, Dr. Rosenthal, says although aggressive treatment for the elderly at acute care hospitals can be "inhumane," once a patient and family are drawn into the system, "it's really hard to pull back from it" (Gross, 2008). Slow Medicine encourages physicians to apply the brakes more often when considering procedures and interventions that may carry greater risks than benefits.

In an article by Jeanne Wright entitled *Gray Matters* (2007), she writes:

"...Geriatricians may argue that their role in caring for older adults is profound and continues to shape the way society treats its elderly. Dr. Small points out that doctors who have not been trained specifically to treat the elderly may incorrectly diagnose older patients or are at risk for not recognizing certain diseases or drug interactions that might affect the elderly. The National Center for Health Statistics estimates that medication problems may be involved in up to 17 percent of all hospitalizations of older persons. "If doctors are out of touch with caring for older patients, they could end up treating an 85-year-old the same way they would care for a 50-year-old," Dr. Small notes. "The healthcare

system tends to limit the time doctors spend with patients, and they can miss critical mental and physical problems if they are unfamiliar with symptoms that are expressed in the aged."

Professional care managers can encourage deeper discussion with their clients and family members to educate them about risks, quality of life, and explore their willingness to apply the Slow Medicine model for the greatest good of their loved one. With the severe geriatrician shortage, the more that our profession understands the medical crises and risks elders face, the more we can be effective team players in mitigating crisis, acute, and chronic care situations.

Family members sometimes have great difficulty in talking about the intimate details of their loved one's condition and can deny what may be the last stages of decline. We must, in turn, face our own fears and denials of aging and mortality in order to better serve our clients. By not facing our own fears, we cannot see and do not address the fears in others.

## Conclusion

Decline increases with each long-lived year; death will come. How those last years are navigated is a choice. We must begin to question, and to some degree reverse the full-scale medicalization of old age, both in our outlook and in our institutions. Slow Medicine offers renewed hope. In its approach to treating the most frail of society with kindness, understanding, empathy, compassion, and medical care as appropriate to the particularities of each patient, Slow Medicine can restore grace and dignity to the human experience of aging and dying.

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# Honoring Cultural Differences at the End of Life

*By Pat Forman, MPH, MA*

Other than birth, there is no more profound time in human life than its ending. Working with people in this last phase of their lives, we are privileged to be part of a process both uniquely individual and utterly universal. All of us will die; all of us will die differently. Every time we have the privilege of serving an older or dying patient and his or her loved ones, we are touching their most fundamental and deepest humanity. As health professionals, our role is to find a way to support each individual through this time in a manner that honors who they are culturally, spiritually, and individually.

Our role is to honor them by supporting their unique experience, rather than helping them to have our experience. To effectively assist people through this difficult and meaningful process, we must recognize and honor the cultural differences that impact on their attitudes, values, beliefs, concerns and wishes. And, we must also acknowledge our own attitudes, values, beliefs, and fears that we bring to this work.

Culturally sensitive end-of-life care requires that we develop an understanding of what culture is, how it shapes us, that it shapes us as caregivers and care managers, and how we can best understand and honor the cultural beliefs of our clients. After defining culture as it will be used in this context, and the multicultural nature of our

relationships, we will explore ways to better understand our own beliefs, as well as those of our clients. While no two clients are the same, there are some common cultural issues that surface in working with others at this time in their lives. We will explore some approaches to becoming more culturally sensitive, as well as some tools/skills to use when working with clients and their loved ones.

*Other than birth, there is no more profound time in human life than its ending. Working with people in this last phase of their lives, we are privileged to be part of a process both uniquely individual and utterly universal.*

While our cultures shape us throughout our lives, cultural (as well as spiritual and religious) beliefs may become even more important as we look to find a way to understand and cope with the pain, the fear, and the mystery of death and dying.

## What is culture?

Culture, which influences the way we each see life and death, is a complex term that means different things to different individuals, and in different contexts. One common definition sees culture as a set of beliefs, attitudes, values, and behaviors, shared by a group, and transmitted from one generation to the next. Culture can also be

defined as the shared experiences or other commonalities that groups of individuals – based on race, ethnicity, sexual orientation, class, disability status, religion, age, language, immigration or axes of identification – have developed in relation to changing social and political contexts (Warrier, 2000).

Culture is multi-faceted, often changing, and sometimes containing contradictory elements. Culture influences the way we view the world, and ourselves within that world. It is often transmitted unconsciously and as a result, we are often unaware of our own culture (finding it easier to recognize that those who behave or look differently from us have a culture). For example, those who are part of the majority or dominant culture sometimes fail to realize that they have a culture, while seeing the minority as evidencing cultural attitudes or behaviors.

In fact, each of us is shaped by a myriad of cultures: the culture of our generation or age group, our sexual orientation, immigration experience, education or socioeconomic status. Some confuse culture with ethnicity. While there are shared attitudes and beliefs within ethnic groups, there are often wider variations within an ethnic group than between groups. Knowing someone's ethnicity or obvious cultural background, only tells part of the story. This

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knowledge only becomes meaningful when interpreted in the context of the patient's unique history, family constellation, and socioeconomic status (Koenig, BA and Gates-Williams J; *Western Journal of Medicine*, 9/95). Thus assuming that "African-Americans believe" or "Chinese-Americans believe," rather than recognizing that "some African-Americans believe," can prevent us from seeing the uniqueness of each individual's end-of-life path and lead to stereotyping. As caregivers, it is important for us to recognize, learn about, and appreciate the differences and similarities among our clients.

To work effectively with clients at the end of life, we need to become aware of our own cultural biases and behaviors and to understand that ALL our interactions, ALL of our relationships, are multicultural or cross-cultural. When we relate to clients and their families, we are interacting with their culture, our own culture as well as the culture of the healthcare system. Within each are numerous factors that make the individual's views and experiences unique. Our own view of the dying process, or death itself, is but one way of viewing it. An honest inquiry into one's own cultural beliefs, values and attitudes can provide one with a foundation for understanding and appreciating the beliefs, values, and attitudes of others.

### Self-awareness: examining our own views about death and dying

Taking the time to reflect on your own views and values around

death and dying offers a starting point for understanding and relating compassionately to others. Ours is a "death-denying" society, and for many of us it is very difficult to think about or talk about issues related to the end of life. As hard as it is for you/us to reflect on these issues while healthy, it is harder to do when one is terminally ill or diagnosed with a terminal illness.

Alone, or with colleagues, friends or family, take some time to ask yourself some of the following

your immediate family or close friends?

- How comfortable are people from your cultural background with talking about intimate, sensitive issues (like dying) with someone outside your family or culture?
- What does death mean to you?
- What about your death concerns you most?
- What about the process of dying concerns you most?

• If you were told you had a limited time to live, how would you want to spend your time until you died?

• How comfortable would you be (or were you) in talking about your wishes for the last part of your life, with your loved ones?

- Some people want everything done to delay their death; others do not want to prolong their dying. Where do you stand?

If you have not yet completed an Advance Directive for yourself or someone close to you, doing so offers another opportunity to reflect on your own wishes, beliefs, and attitudes about the end of your life. Sharing these thoughts with those closest to you can not only help clarify your own beliefs, but help you to better understand the difficulty your clients may feel when they need to talk with you about these issues. Sharing your reflections with someone from a different cultural background may offer you another window into how your client may feel discussing her wishes or concerns with you.

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questions (These are also questions that you can use with your clients):

- How do you identify yourself racially, ethnically, culturally?
- When were you first aware of your own culture?
- What is your understanding of how your culture views death and dying? How do your views differ?
- What factors besides your culture have influenced your views on death and dying?
- What was your first personal experience with someone dying?
- How did your family respond to this death?
- How, if in any way, are your views on death and dying different from those of

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### **Cultural differences around death and dying:**

In working with clients from different cultural backgrounds, health care providers may encounter difficulties in communication, interpretations, in values and in decision-making styles. The following examples represent some of the types of cultural issues you might face when working with clients around issues related to chronic or terminal illness, pain, death and dying.

### **Different cultures have different understandings of the meaning of illness and death.**

Professional Geriatric Care Managers (PGCMs) can sensitively probe for these differences. The anthropologist Arthur Kleinman talks about “explanatory models,” which are the notions that clients, families and practitioners have about a specific illness episode.” They represent the patient’s “story” about their illness and its meaning (Kleinman, 1978). Take the time to ask your clients about their story. What is your understanding of your illness and what is happening to you? What do you call the problem? What does death mean to you? I remember offering my sympathies to a Franciscan client whose sister had just died. Her response was surprise. “Nothing to be sad about. This is a joyous event. She will be with God.”

### **Role of the patient vs. the family in decision-making:**

Patient autonomy is important in some cultures, not others. In many western cultures such as that of the U.S., the right of a patient to receive full disclosure, to fully understand options, risks and benefits, and to make her own decisions is the accepted approach. However, in other cultures, it is the family, or a specific family member who is

the recognized decision-maker. In some Asian-American cultures, it is believed that the patient should be protected from difficult choices about their medical care. Some Filipino-Americans believe that decisions should be made by the family, sometimes with the help of a priest, rather than the patient.

If you are unsure about a patient’s chosen approach, it can be helpful to ask clients the following questions: If we needed to discuss a serious medical issue relating to your condition, or if your health status changes, how would you and your family like to handle that? Or, how would you want to handle decision-making related to your health? Do you want to make the decisions about your care, or would you prefer that decisions be made by someone else (others) in the family? For patients wanting to formalize a decision-making process, appointing the person or persons they would like to make medical decisions for them as their Health Care Agent(s) may be a useful approach.

Another cultural difference to be aware of is that some cultures believe that a dying or terminally ill patient should not be told about their situation. Some African-Americans believe that discussing death may bring it closer. Some Chinese-Americans and some Filipino-Americans believe that talking about death is a bad omen. In some Latino cultures there are those who believe that talking about death can make it happen or that the person talking about it wants it to happen; thus it is

felt that a dying patient should not be told his/her prognosis. Asking clients what they want to be told or who they want to be told about their situation can help you support their personal choices.

As palliative care becomes more readily available, cultural issues around pain and pain management will surface. Some cultures view pain and suffering as a test of faith. Buddhists believe that suffering is a means of spiritual growth and may not disclose that they are in pain.

The practice of palliative or comfort care is still not well understood in some cultures and socioeconomic groups. Some still believe that offering palliative care means that there is nothing more to be done. Others may not understand the side effects of pain medication. Stoicism and failure to report pain may stem from a cultural belief that pain and suffering are a test of

faith. Others don’t report it because their role as caregivers is more important to them than their role as care receivers. It’s important to try to understand each patient’s beliefs about pain and to be sure that they understand the risks and benefits of pain management (e.g. sleepiness).

Individual beliefs about the dying process, about death, afterlife, and the rites or rituals following death are often influenced by cultural, religious, and spiritual beliefs. Where one chooses to die (at home, in hospice, in a hospital), how the body is handled; cremation or burial; funeral arrangements and mourning

*Another cultural difference to be aware of is that some cultures believe that a dying or terminally ill patient should not be told about their situation. Some African-Americans believe that discussing death may bring it closer.*

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rituals are different in different situations. In some Asian families, for example, people do not want to die at home because of the belief that the death will affect the future of the house. In some populations, assisted suicide is considered compassionate; in others, it is taboo. As caregivers, we need to be conscious of how we would respond if a client's belief differed markedly from our own.

So, how do we begin to deal with these cultural concepts? How do we become "culturally sensitive" when we work around death and dying?

One model, The ABCDE of Cultural Inquiry at the End of Life, offers a guide to the areas of inquiry that should be pursued to enhance your understanding. The five areas are:

- **Attitudes of clients and families:** What are the attitudes of the group in general and the specific attitudes of the family/patient in particular about truth telling regarding diagnosis and prognosis, and to discussions about death and dying. How reflective are their practices of traditional practices and beliefs? What is unique to their viewpoint?
- **Beliefs:** What are the religious and spiritual beliefs that are especially important as they relate to death and dying, e.g. meaning of death, of after-life? Do they believe in the possibility of miracles? What are their religious or spiritual beliefs? How important is their faith to them?
- **Context:** What has been the historical and political context within which they have lived?

Some issues to consider include: the place of birth, immigration or refugee status, economic situation, experience with discrimination or lack of access to healthcare, languages spoken and understood, length of time in the U.S., and their degree of integration into their community.

- **Decision-making style:** Who is the decision-maker and how do they want decisions to be made? Assess the style both of the group in general, and the patient/family in particular. Is the patient the decision-maker or are decisions to be family-

understand a culture with which you are not familiar? Are there translators available? (Kagawa-Singer, M and Blackhall, 2001).

One note here about translators or interpreters. Just as caregivers and clients bring their cultural attitudes and beliefs to the table when dealing with end-of-life issues, translators may also bring their views. It is important to try to determine how comfortable the translator is with issues related to death and dying. Will s/he be able to deliver difficult news? (This is particularly salient if the translator is a child or other family member.) It's also important to understand how the translator

sees her role: is she speaking on behalf of the patient? On your behalf, as a clinical partner? Is she a cultural "broker"? Is she interpreting or filtering information to protect the patient? Is she expressing her views or translating yours and/or the client's?

*It takes openness and courage to face the end of our lives. Bringing unconditional positive regard, respect, and empathic understanding to your clients is a true gift.*

centered? Is there one particular family member(s) responsible? Autonomy or reliance on family? When family members indicate answers to these questions, it is important to honor them as much as possible. It is also important to be certain that the patient is in agreement with the proposed process.

- **Environment:** What resources are available to you to help interpret the cultural dimensions of a particular case? For example, is there a quiet, safe place where you can talk with the family? Is there the time to develop a trusting relationship? Can you bring together all who need to be present (family, spiritual leader, trusted friend)? What resources are available to you to help you better

To effectively use this model of inquiry, as well as Kleinman's explanatory model to try to understand the cultural context of each patient with whom you are working, PGCMs are being asked to use their empathic, non-judgmental listening skills. The following suggestions may be helpful in building cross-cultural understanding:

- Approach each patient and family as individuals as well as members of a cultural group. Try to develop a sound knowledge base about clients from different cultures – their cultural values, beliefs, and health behaviors – but, remember that there are many different "cultural" influences which shape end-of-life beliefs: age, generation, geography, education, place of birth, etc.

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## Honoring Cultural Differences at the End of Life

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You don't have to have all the answers, you just need to be open to the other's views, stay present, and try to understand their perspective.

- Take the time to build a relationship with your client and family; take the time to build trust. Conversation is key. Remember that cultural differences often become less of a barrier as relationships develop. With time and exposure we more accurately perceive both emotions and attitudes in the other. The more you can understand someone's beliefs and values, the more likely it is that you will be trusted.
- Maintain a nonjudgmental attitude toward unfamiliar beliefs and practices and be willing to negotiate and compromise when world views conflict. Be conscious of any of your own views or behaviors that may consciously or unconsciously affect how you respond.
- Ask open-ended questions and check back frequently with clients to be sure you both

understand what the other is saying. Pay attention to nonverbal communication, such as head nodding, as that gesture has different meanings in different cultures; or eye contact which may be considered inappropriate, too intimate, in others.

Most importantly, be authentic—don't pretend to be an expert on a person's culture, religion, or illness, and listen from the heart, treating each person with respect and dignity.

### Conclusions

Supporting someone through the dying process may be one of the most challenging and rewarding experiences you will ever have. It takes openness and courage to face the end of our lives. Bringing unconditional positive regard, respect, and empathic understanding to your clients is a true gift.

As a PGCM you may be called upon to support a variety of people from many different cultures. Your willingness and ability to learn about and honor, without judgment, each of their cultural attitudes and beliefs about the end of their lives, can be a great gift to each of them. Cultural understanding is essential to providing compassionate quality care to ethnically diverse clients at the end of life.

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# Palliative Care and Geriatric Care Managing

By Gwen Harris

***“An awareness of death enables us to live each day—each moment—with appreciation for the unique opportunity we have to create something of our time on earth. I believe that in order to enjoy true happiness, we should live each moment as if it were our last. Today will never return... confronting the reality of death actually enables us to bring unlimited creativity, courage and joy into each instance of our lives. The impermanence of life is an inescapable fact.”***

—Daisaku Ikeda

Buddhism has been an important part of my life since my early teens, and the reality of death became part of my life at eight years old. My understanding of death has evolved much over the years. I now believe death has the same effect on life as salt on food. Death makes every day alive so much better.

Both my parents died in hospice care, my father after 12 years of battling Alzheimer's, and my mother after decades of battling chronic illness. The medical, emotional, and physical care our family received in hospice was the best care since the onset of their illnesses. The biggest questions I had after their deaths were: Why couldn't we have received this type of care during the last stage of their lives? Why did we have to wait until the last few weeks of their lives to receive this supportive care? Becoming a geriatric care manager

who works with palliative and end-of-life clients has become my mission.

Palliative Care is the answer to my questions. It is a system of care that improves the quality of the life of patients and their families facing chronic and life-threatening illnesses. This is accomplished through the prevention and relief of suffering. Early identification, impeccable

assessment and treatment of pain and physical, psycho-social and spiritual problems are addressed. Palliative care can be useful at any stage of a serious illness (unlike the hospice model of six months or less) and works as a bridge between traditional disease-model medical treatments (curative medicine) and hospice (comfort care). Palliative Care is a philosophy of care and a highly structured system of treatment.

Palliative Care traditionally takes place in a hospital setting, but is finding its way into the home care system. It is a team-type of approach. The team is comprised of:

- Client
- Family
- Medical--Doctor/Nurses
- Social Worker/Geriatric Care Manager
- Chaplain/Spiritual care
- Volunteers

If we look at Palliative Care as a wheel, all members of the team, except for the geriatric care manager, are the spokes. Geriatric care managers (GCMs) act as the hub of this Palliative Care team. Beside family, care managers assess and oversee the needs of clients. GCMs are in the primary position to know when changes to a client's well being occur because we maintain records of their medications, their illnesses, and how they were treated. When medical support is needed, GCMs make the necessary doctor and specialist appointments. When therapies are needed, GCMs make sure the necessary assessments are made: neuro-psych exams, MRI, x-rays, blood work and analysis. GCMs are the front line of communication with client, family members, medical professionals, care providers, and spiritual support. It is their job to maximize the quality of life of the client and to help prepare them for the last part of their life.

How clients die has changed drastically over the last 50 years. Very few deaths are sudden; most die from on-going chronic illnesses. With advances in life-saving techniques, our clients are living longer with chronic illness. Geriatric care managers provide the support necessary to meet client and their family's medical, emotional, and spiritual needs with information and advocacy.

Geriatric care managers are able to help families prepare Advanced Directives for health care and finances. Society tends to avoid subjects of death and dying, creating barriers to conversation and counseling people who are facing

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long-term chronic illness or life-threatening illnesses. But death is the end of the road for all of us. By their communication to all parts of the team, GCMs have the unique understanding of the trajectory of an illness and are able to communicate all information to the client and their families. Then they are able to make sure that clients get what services they need. Their job is to make sure home care providers, health care professions, and all specialists are in place.

Basing decisions on client's goals, determined through the process of having completed all Advanced Directives, the palliative care team is able to make informed decisions based on the goal to improve their client's quality of life, minimizing pain and suffering. Once goals are clear, providing comfort in a non-judgmental, respectful, and hopeful way insures goals will be accomplished.

Geriatric care managers are also on the lookout for the signs and symptoms that the client is declining. Signs may be as subtle as increased sleep or disorientation or decreased communication and food/liquid intake. GCMs understand illness trajectory, and by keeping close communication with the client's health professionals, GCMs help clients and families make the most informed decisions. GCMs recognize when hospice is needed and initiate these conversations with family members in a timely manner. Most people wait too long to obtain hospice services, missing out on the wonderful services hospice provides. We may help all involved understand hospice is not about giving up hope but about maintaining dignity, quality of life, and expect pain and symptom management.

GCMs help families ease into the last stages of life. We help family members stay connected and alleviate, by providing clear information, the fear of the unknown. There are many barriers to quality end-of-life care. In his discussion of barriers, Dr. Ira Byock described the ways in which a GCM is the perfect person to lead clients toward better

openly discuss their questions and express fears. By discussing all that is important, GCMs are reinforcing the hope that all important things will be accomplished. Strength and hope springs from a group of people working together towards a common goal.

Disease progression and increased disability are what GCMs

are best at assessing, and they are experts at finding daily life solutions. As illness progresses, questions change. Does our client now need assistance with bathing, toileting, and transportation? Does he/she need to see a specialist, clergy, or physical therapist to maintain the highest level of independence?

***Disease progression and increased disability are what GCMs are best at assessing, and they are experts at finding daily life solutions. As illness progresses, questions change.***

care. Physicians and the medical profession, in general, have too little time to discuss the day to day challenges clients with chronic or progressive illness face. GCMs have the time to make sure that clients have all the information from primary care physicians and specialists needed to make informed decisions and understand all their options for care. They also are committed to explore whatever questions the client and family members may have and are in the position, with the aid of signed medical releases, to discuss and research the answers to those questions.

GCMs with the goal of complete communication and resolution may set up family meetings that involve important family members, the client and key medical professionals. The goal of the meeting would be to discuss treatments, side effects and probable outcomes. GCMs make sure the important questions get answered: How will this treatment/medication/technique improve my illness prognosis? What are the side effects? Will these treatments extend my life? Will these treatments cause pain or discomfort? By creating a family meeting everyone is able to

Would durable medical equipment aid movement and insure safety? GCMs know how to direct support and focus on the daily needs of clients and their families.

GCMs will also be on the lookout for anticipatory grief and caregiver burnouts. We know how to assess for caregiver burden, help loved ones cope with caregiver stress, emotion and grief, and arrange for respite support care. GCMs are trained to recognize the anger and loss and provide support by suggesting grief counseling and support groups. We are experts at referring clients and family members to support services based on the client's illness and finding subsidies for family members in need of caregiver support.

Geriatric care managers may also assist family members in setting up informal care for their seriously and chronically ill loved ones through organization like Share the Care [www.sharethecare.org](http://www.sharethecare.org) and Lotsa Helping Hands, [www.lotsahelpinghands.org](http://www.lotsahelpinghands.org). Friends and neighbors, based on their available time and their strengths, are able

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## **Palliative Care and Geriatric Care Managing**

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to choose from a range of tasks and responsibilities. The GCM or a family member acts as a captain and schedules others to accomplish the necessary tasks and responsibilities.

When clients are chronically ill and in the hospital, they find that their primary care physicians are replaced by hospitalists (physicians who manage clients in the hospital) and oncologists. In many circumstances, family members and GCMs are the only consistent care providers throughout the course of an illness. Because care managers are usually with clients from the onset of illness, clients come to have trust and confidence in their care. Physicians and medical support may change and often the care manager is the only person, other than family, who is a consistent member of the care team.

Since most GCMs work with the client from the beginning of illness, they are unique in having a long and broad range view of the final stage of a client's life. They have compiled historical information in the form of initial assessments and medical records. Not all medical care professionals will have access to this information. The GCM may act as an anchor in the sea of many on-going changes.

Geriatric care managers are also in a position to help families find meaning, work towards resolution, and make important connections during the final stage of clients' lives. But they might also be the necessary gatekeepers when there are too many or unwanted visitors. GCMs can assist clients and their loved ones recall pleasant memories suggesting the use of music, photographs, or life review. Life review provides the opportunity for a client or family to achieve

resolution and celebration, affirmation, hope, and personal growth in the final years. It provides an opportunity for one to make sense of the life he or she has lived. Dr. Ira Byock discussed the four things that matter most to say:

1) Please forgive me 2) I forgive you 3) Thank you 4) I love you.

Sometimes clients and families are so overwhelmed with illness and care providing that they are not able to see the "forest from the trees." As part of the team, but not a family member, the care manager is able to model and introduce comforting solutions.

In addition to introducing life review and life stories, there are also ethical wills in which clients discuss and leave in writing important thoughts and legacies. After death, GCMs may assist family members with funeral arrangements, memorial planning, and celebrations of life.

GCMs might also help connect family member to valuable bereavement groups.

The goals of care at the final stage of life are the successful completion of legal and financial affairs, completion of relationships, whether through reconciliation or closure. GCMs assist clients in gaining meaning to their lives, simply by asking the right questions and listening to the answers.

Palliative care alleviates suffering and improves the quality of remaining life. Its goal is to enhance comfort – isn't that the primary job for all GCMs? In dealing

with elders who are facing chronic or life-threatening illness, the goals of life prolonging vs. palliative care is not an either/or choice. There is no curative treatment for chronic illness or old age. Life prolonging and comfort measures can exist together, improving the quality of life for our clients and their families.

Once clients and family members are fully informed, they are able to make treatment decisions and are given the tools to handle life's transitions. GCMs provide advocacy and coordination, all of which are time intensive. Geriatric care managers help families obtain the best needed service and support. GCMs are the leaders of the client's palliative care team.

I hope to give to the world some of what was given to my family: comfort, dignity and a greater

understanding and acceptance of the last stages of life.

*Since most GCMs work with the client from the beginning of illness, they are unique in having a long and broad range view of the final stage of a client's life.*

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*for over two years. Gwen recently co-authored a chapter on death and dying in the publication Care Managers: Working with the Aging Family.*

# The Beneficial Effects of Life Story and Legacy Activities

By Pat McNeas

Personal historians—those of us who help others tell or write their life stories, their family stories, or their organization’s stories—know firsthand how powerful the experience can be for everyone involved. We know, and research increasingly tells us, that life story writing and reminiscence can improve the mood and quality of life for adults with more years behind than ahead of them. This is true for both healthy and unhealthy adults, but especially for the adults most likely to require the services of geriatric care managers.

In research on “dignity therapy” funded by the Canadian Cancer Society, palliative care expert Harvey Chochinov (2005) studied the effect of asking 100 terminally ill cancer patients from Canada and Australia about what issues mattered most to them or what they would most want to be remembered about their lives. His researchers learned that this 30-to-60-minute therapy session significantly reduced both suffering and depression. Few drug-based therapies can lessen a person’s “distress about death or reinforce their sense of worth as they near death,” observed Chochinov, a professor at the University of Manitoba and a researcher at CancerCare Manitoba. His study shows that “this relatively simple and straightforward psychotherapy can help patients attain the sense of

peace they need to die with dignity.” In short, health care professionals working with cancer patients near the end of life should be asking, “Tell me about your life.”

I am helping J, a retired business executive, tell his life story. Reminiscence is important in his family, and macular degeneration limits his ability to see photos and text, and Alzheimer’s disease limits his wife’s ability to remember people

*I am helping J, a retired business executive, tell his life story. Reminiscence is important in his family, and macular degeneration limits his ability to see photos and text, and Alzheimer’s disease limits his wife’s ability to remember people and events.*

and events. In addition to a print memoir for the family, we may create a video slide show, with most of the narrative in J’s voice, from what he tells me in interviews. J will be fully involved in the process.

This is not just nostalgia for nostalgia’s sake. At least two studies (Woods 2007; Allen 2008) found that such legacy activities have a beneficial therapeutic effect for both patients and caregivers. “I have been informed by the families of clients who have later been diagnosed with dementia,” writes personal historian Mary O’Brien Tyrrell (2008), “that the nursing assistants or family members often spend some of their visiting time with the elder, reading their memoir aloud; this has the dual

benefit of calming the elder and helps the staff get to learn about the person in their care.” The finished memoir has a powerful effect both on the elder’s self-esteem and on the family members’ esteem for the elder, says Tyrrell.

## The “Summing Up” Phase of Life

Fifteen years ago, when I wrote a history of J’s firm, I asked him to tell me the story of his life and he said no. But now he’s ready. He’s in that “summing up” phase of life that Gene D. Cohen (Director of the Center on Aging, Health and Humanities at George Washington University) says emerges most often from our late sixties into our eighties or beyond. In this phase,

says Cohen, people are reexamining and assessing their lives, looking back not only at what happened but at what they learned from it. As “keepers-of-the-culture, people who reach this phase begin to share their lessons and fortunes through autobiography and personal story telling, philanthropy, community activism, volunteerism and other forms of giving back.” They are also often motivated to develop creative new strategies for dealing with “unresolved conflicts and unfinished business” (Cohen 2007).

As recently as 50 years ago, “people believed that reminiscing was a sign of senility—what we now

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call Alzheimer's disease," wrote Robert N. Butler (Kunz 2007). After working with healthy volunteers for 11 years, in 1961 Butler "postulated the existence of the life review as a normal function of the later years and not a pathological condition. Memories, reminiscence, and nostalgia all play a part in the process. Far from living in the past or wandering, as was thought, older people were engaged in the important psychological task of coming to terms with the life they had lived. They sought to make amends for acts of omission and commission, resolve conflicts, and reconcile alienated relationships."

Although some aspects of brain function decline with age, writes Cohen, the "older brain is more resilient, adaptable, and capable than we thought." When we're young, for example, we tend to favor one side of the brain over the other. In the second half of life we tend to integrate the hemispheres, essentially "moving to all-wheel drive." Autobiography, because it engages both sides of the brain, is like "chocolate for the brain," says Cohen. Moreover, as we age, we have a stronger impulse to tell our life story. We may not tell that story any better than a younger person would, but we are more motivated to do so—not only because storytelling and reminiscence are part of the natural work of elders, but also because they "become appealing ways of giving back—sharing what we have learned" (Cohen 2007).

## The New Fields of Reminiscence Therapy and Personal History

Exasperated by elders who tell stories of the old days over and over, adult children may be reassured to learn that recapitulating the story of their life is the task both of seniors and of people who are dying—and that that task can be made easier.

An academic conference held in 1995 led to the formation of the International Institute for Reminiscence and Life Review, an academically based organization that has helped increase interest in incorporating reminiscence and life review activities into the care and treatment of older adults. "The known advantages of doing such work," wrote John A. Kunz (2007), "include improving the attitudes of younger adults toward older adults and vice versa, finding meaning in life, improving problem-solving skills, assisting with the grief process, increasing emotional support, strengthening self-esteem, decreasing depression and anxiety, and developing interventions for individuals with dementia."

The Association of Personal Historians, which also came into being in 1995, was launched by 15 people who were trying to make a living helping ordinary people record or write their life stories. Statesmen and celebrities had long engaged the services of professional writers to help them with their memoirs. APH's members (now numbering 670) sought to bring such services to a broader public. Celebrities were welcome, but so was Aunt Minnie.

The least complex project is the oral history, which may be audio only, or print, with interview transcripts edited for narrative flow, often illustrated with photos. Next is the as-told-to memoir, based on interviews and presented in the voice of the narrator (Aunt Minnie, in our example), though it may also incorporate material from journals, letters, and other documents. A third

option is a biography of Aunt Minnie, a story told about her – or about Aunt Minnie and her husband or family, or the company she founded because she had to feed the family. The biography told by the outside writer is especially helpful when Aunt Minnie's memories are sketchy, in which case the personal historian gathers material from others and

from old diaries, letters, and other resources.

New technologies make it easy to "self-publish" a printed book or mount a story on a website, though many families order handsomely designed and bound books issued in private printings as small as one copy. A rapidly growing number of personal historians create audio or video histories

*When we're young, for example, we tend to favor one side of the brain over the other. In the second half of life we tend to integrate the hemispheres, essentially "moving to all-wheel drive."*

or tributes instead—the videos sometimes illustrated with photos and sound, including recordings and videos of people telling stories, sometimes a montage of stills with narration and reminiscence in one or more voices.

## Life Story Writing and Reminiscence Groups

For adults who are up to it, life story writing or reminiscence can be a social activity that increases the social connections equally important to well-being. James Birren (1992), author of a useful text for guided autobiography groups, encourages leaders to assign a theme and a list of questions, send participants home to write, and then return to share what they wrote the following week. Often these groups are run from senior centers, faith communities, or writers'

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centers, and there is much to be said for cross-generational workshops (which mine are). Something about reading stories aloud—about being heard—seems to encourage frankness and bonding and to nourish everyone’s spirits.

## Working with Patients at the End of Life

Increasing numbers of personal historians are helping the dying record their stories or write ethical wills, whether as paid professionals, hospice volunteers, or mentors and consultants to family members and friends. Ethical wills (or “legacy letters”) are loving testaments in which one generation shares life experiences and lessons learned with the next. Barry Baines, a family physician and medical director of a home-based hospice, has done as much as anyone to revive the old Jewish tradition of the ethical will (see examples on his website). It is easier to work with patients when they’re in the community, he says, before they sign up for hospice, when they’re often severely depleted. Many hospice patients die not long after enrolling in hospice, and of those who live longer, many have advanced dementia. Yet this is the population with the greatest need to create such documents, so many hospices are training their volunteers to help.

“Ideally we should see life stories as ‘works in progress’ and record them long before hospice is needed,” says Linda Blachman, author of *Another Morning: Voices of Truth and Hope from Mothers with Cancer*, “but critically ill people can summon remarkable focus and energy to complete

what is considered an important developmental task of dying: reviewing one’s life, harvesting it for meaning, and passing on nuggets of wisdom and messages of love.”

Families who come to visit patients who are dying often feel awkward. They want to be there, or feel they should be, but they don’t really know what to do or discuss. Providing an activity that gets everyone involved increases the connection between patients, caregivers, and family members.

For over a decade, Blachman directed the nonprofit Mothers Living Stories Project, which trained

*The people who are trained to help should be able to listen well and gently elicit stories and messages. They should be close enough to the dying person to engender trust and yet distant enough to contain their emotions while facilitating the process.*

“volunteer listeners” to record the life stories and legacies of young mothers living with cancer. In her private practice as a personal historian, Blachman has helped families identify a friend or family member who can be flexibly available to a hospice patient and is willing to receive brief training for, and mentoring through, the process of recording a story or legacy.

The people who are trained to help should be able to listen well and gently elicit stories and messages. They should be close enough to the dying person to engender trust and yet distant enough to contain their emotions while facilitating the process. Blachman believes that working with the dying requires the ability to offer compassionate presence and be with suffering, which relies heavily on the interviewer’s willingness to face her own

experiences and emotions surrounding suffering, loss, illness, and death and to “walk her talk” by recording her own story and legacy.

“We scribe and polish for the patient whatever story, letter, or memory they want to share,” says personal historian Rebecca Stimson, who participates in a Michigan hospice program called Tuesdays Writers, after the Mitch Albom book, *Tuesdays with Morrie*. “But we don’t polish them so much that they aren’t recognizable as the patient’s words.”

One of Stimson’s most challenging assignments was to help B, a 55-year-old African American woman in a marginal neighborhood, craft a message for her children. “We always say something on the pages we write to indicate who we are and the circumstances under which we are doing what we are doing,” says Stimson. “I said, ‘These are B’s words, delivered to her children.’ Given her circumstances—the

drug addiction, the alcoholism, the educational deprivation—it had to be in B’s words, so her children could hear her voice and message. B said, ‘I just want everyone to get along.’ And her instructions were specific: ‘Don’t have babies with every man you meet.’ She was concerned that, without her oversight, her daughters would go down the same path she did, and she wanted a better life for them.” When a social worker delivered the document, B started to cry, saying, “Finally I have something I can give my family.”

“You don’t always get to talk to the hospice patient again,” says Stimson. “Sometimes they’re gone before you’ve finished. When you can talk to them, you see this joy and relief on their face. It is clearly such a gift to them to talk about themselves, their family, and what’s on their mind. I assume it’s because this stranger

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cares about them in this unexpected way and then turns around and gives them the gift of their story, their feelings, their emotions, in print. I don't know if it seems unexpected because they didn't know this kind of service was available, to talk with someone and review their life, or because it's a stranger. It's interesting that they open themselves up so much to someone they don't know at what is, to me, an extraordinarily private time. From my perspective as a writer, it's a really spiritual experience, and rewarding like nothing else that I have ever done."

The messages the dying leave are often poignant in unexpected ways. The family of a woman who was dying from a diseased liver hired personal historian Susan Rothenberg to do an oral history with the woman, partly to give them all something else to think about besides her illness. Asked what lessons she wanted to leave for her grandchildren, the woman told Susan, "Only worry about things you can do something about. My liver is gone. I need a new one, but I'm too old and too sick to get one, and anyway, I think it should go to a younger person. But one of my granddaughters is going to have a bat mitzvah and another is getting married and I don't know what I'm going to wear to either celebration. That worries me."

## Practical Considerations with Legacy Videos

Increasingly, hospices are encouraging legacy videos. "Personally, I'm glad I don't have videotapes of my mother and father as hospice patients," says Stimson. "I worked a long time to get those images out of my head and remember them as lively, vital people. And I think that's the benefit of the written word: That's about when they were lively and vital.

You have these stories from when life was rich and blood was coursing through their veins and they were at their best. I think putting words on paper, formalizing memories and experiences, has a value to people that we can't know. As a tribute, it's more than a trophy, more than a dinner party, more than a photograph. It's their words. And you don't need a piece of technology to give you access to it."

But some clients cherish those final videos, particularly if they capture the final thoughts and wishes of adults who won't see their children or grandchildren grow up. Vickie Holland has done about a dozen "life legacy" videos for patients at the Northcare Hospice, in North Kansas City, Missouri, in addition to life stories she does for private clients. "Initially, I was hesitant to volunteer for this project," says Holland. "It sounded like it could be depressing, but I have found it to be the opposite. I believe the video plays a big role in wrapping up their end-of-life preparation. They have to talk to family members about the stories they want to include and again when they gather photos. The video just wraps things up with a bow for them."

Personal historian Dan Curtis did a series for the National Film Board of Canada, Bearing Witness, following three individuals at the end of their lives. He is currently heading up a pilot project to provide Legacy Audio services for patients registered with hospice in Victoria, British Columbia. He has learned in working with people toward the end of their life that "things don't always work out in a nice, neat, orderly fashion. They may say, 'Let's do something

tomorrow,' and tomorrow they're not physically up to it. You must have immense patience and ability to go with the flow. You must be sensitive to their time and how they're feeling. Sometimes you realize after 15 minutes they are beginning to lose it, so you say, 'I think maybe we'd better stop here.' You have to deal with what's happening right in front of you, instead of thinking, My job is to get some kind of life story."

Many patients are not up to many hours of interviews. They may be able to cope with only two or three hours, in which case you really need to talk about what it's important to them to leave behind. "It may be they have things they really want to say to their children or grandchildren," says Curtis. "They may not have time

***"They may not have time to reminisce about Aunt Bessie." Aware of the patient's vulnerability, you must quickly identify their needs, agenda, and physical limitations.***

to reminisce about Aunt Bessie." Aware of the patient's vulnerability, you must quickly identify their needs, agenda, and physical limitations.

And not everyone is interested in leaving such a legacy. "Often it's the family members who want something done, not necessarily the patients," says Curtis. Curtis and the volunteers he trains leave a one-page description of their pilot program with hospice patients. About a third agree to participate, which is similar to the ratio in a program conducted at two universities (Allen 2008). Another third of the patients seem to feel that if they participate, "It's over. The curtains are going to close." So they say, "I'm not quite ready for this now."

"For some patients," says Curtis, "if you don't get them at the right window of opportunity, there

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## The Beneficial Effects of Life Story and Legacy Activities

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are just too many other issues going on—medications, pain management, family issues—and adding one more thing doesn't seem appropriate. Some people just don't see the value to it. Their view is, my family knows who I am; I don't need to say anything more. And finally, let's face it, in some families, there's no love lost between parent and child so they really don't want to do anything."

Still, most individuals want to tell their stories and leave something behind, given the opportunity, and they usually need help.

Carolyn, a woman who had battled cancer for eight years, asked Dan Curtis to help her create a video ethical will. He taped two hours, some of it with Carolyn watching her kids play soccer, walking with her family on the beach, and decorating the Christmas tree. They edited it down to an hour, adding photographs and Carolyn giving instructions to her daughters: "I won't be there when you start dating. I won't be there when you get married. These are some of the things I want to tell you that I believe it's important that you do with your life." It was her way of leaving behind a kind of instruction book. "She had a chance to show it to her husband and daughters about a month before she died," says Curtis, "and told me 'Poof. Now I can go.'"

And a month later she did.

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