

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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www.caremanager.org



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

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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The Beneficial Effects of Life Story and Legacy Activities

By Pat McNeese

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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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.

Writer-editor Pat McNees, vice president of the Association of Personal Historians and author of Building Ten at Fifty: 50 Years of Clinical Research at the NIH Clinical Center, is currently writing a history of the Department of Psychiatry at the University of Maryland School of Medicine. She edited the anthology Dying: A Book of Comfort and co-edited the anthology My Words Are Gonna Linger: The Art of Personal History. She teaches Life Stories and Legacy Writing at the Writer's Center in Bethesda, MD. You can find useful links on this subject at: www.patmcnees.com (see Storycatching) www.comfortdying.com

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