

Journey To Life's End: A Traveler's Guide
by Susan Keller, M.A., M.L.I.S
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About the Author

Susan Keller has worked professionally as a public interest planner and network developer, responsible for “engineering change” since the mid-1970s. She began her career with the Library Council of Metropolitan Milwaukee assisting librarians to develop programs to better serve the information needs of all library users in a four-county region. Since then, working as the Executive Director/Principal Planner of the Community Network for Appropriate Technologies, Susan has done work of a similar nature in the fields of affordable housing, the arts, appropriate technology, resource conservation, and elder care.

She has a Master’s Degree in Library and Information Science from the University of Wisconsin-Milwaukee and a Master’s Degree in Management from Sonoma State University, Rohnert Park, California. Susan and her husband John live in Sonoma County, CA where they operate their family-owned custom woodworking business.

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Preface

For several years, in order to afford my work as a consumer advocate, I worked part-time as a gardener to make ends meet. My clients were elderly people living in a rural neighborhood on the edge of a small town. The yards and gardens I tended were connected by foot paths and dirt roads. We all knew each other and so became a garden club of sorts with my time shared as the hired help.

It was there, living and working in that neighborhood, that I had the good fortune to be with several elderly friends as they traveled the journey to life's end. Much to our satisfaction, we were able to figure out how things worked and how to proceed as nature ran its course. We built upon experiences shared and resources available in the community. What appeared to be insurmountable hurdles became great challenges to overcome, with each achievement toward peace and comfort a major victory.

Knowledge gained during that time and since, convinced me that we as a society had failed seriously in our ability to care for our aging and dying. Few seemed to know or care about tending to the person as a person, learning what mattered to them most of all, and helping them to get along as best they could given their health situation, their values and resources available to them.

Sometime later, while working on elder care issues, I discovered that the stories from my days with the garden club had great value and meaning for others as they faced life's end with family members, friends or alone. With the encouragement and support of these folks, the Community Network began work needed to create the Journey Project. A group of professionals and elders, known for their wisdom and compassion, was assembled to provide needed support and assistance. *Journey to Life's End: A Traveler's Guide* is the result.

Part One clarifies the origins of the work and the credentials of

those responsible for its creation. Part Two presents successful journeys of people who had the good fortune to live the end of their lives as they had done through all the years before - doing the best they could, working with what they had, knowing when to hang on and when to let go. Part Three presents the reader with ways to help insure that life's end is of one's own choosing, consistent with one's wishes. Legal documents essential to plan and secure matters related to health care and the disposition of property are clearly explained, with actual forms included. True stories are included to add meaning and value. . . .

The work is unique for the nature of travel explored. Be it for oneself, a family member or a friend *Journey to Life's End* intends to help guide people as they pursue quality of life through its remaining time.

Susan Keller
November 14, 1996

Introduction

Within these anecdotes of peaceful aging and dying is a story just as inspiring. Susan Keller, a social activist, now middle aged, is a woman who considers it her good fortune that she always has had elders among her closest companions.

Susan's career as a public interest planner, and her life focus as a person seeking justice and giving appropriate help has led her into the lives of those around her. When the going got tough for friends and neighbors, and life's end started closing in - Susan used her organizing talents and compassion to help alleviate problems in the best possible way. This took wisdom, research and time. Somehow, Susan consistently found the right working combinations, without sacrificing balance and flow in her own life and work.

Now, through The Community Network Journey Project, Susan's personal encounters are being put to additional service in *Journey to Life's End: A Traveler's Guide*. Susan skillfully weaves together her own experiences with state-of-the-art research, professional expertise, and stories of others. She offers people new ways to consider the journey to life's end, a journey that we all must travel eventually. The route, as to any mysterious province, requires guidance over the rough spots so that people can arrive with grace, dignity and a minimum of pain and suffering. Susan's

contribution is this important guide book, inspired by her own life.

Written by Gloria Potter, a friend who respects the need for maps, admires map-makers, and loves the challenge of preparing for a trip.

Excerpts from Chapter 1. Successful Journeys

My friend was terrified when, after a long and healthy life, he was abruptly faced with life's end. Together we came to terms with the encroaching life-threatening condition and made plans for the inevitable. This happened to me not once, but several times in the course of a few short years and provided me with some of the most rewarding experiences I have known.

The stories that follow are the stories of elderly neighbors, friends and family. For most of these folks, I was also their gardener. But for the vexing ailments of aging, all were well in mind, body and spirit when I began working with and for them. Each one eventually encountered failures in health that led to their dying. Along the way, I assisted them to resolve caregiving needs as they arose. Learnings I gained while traveling the journey to life's end with this circle of friends, provide the foundation for this work. Emily Sage is a pseudonym.

Jake

Jake was devastated when he told Emily that he finally knew what was causing an annoying numbing sensation in his limbs. A neurologist had determined it was Lou Gehrig Disease, one of the most debilitating diseases of them all. Jake told Emily that the doctor said nothing could be done; he had at best two years to live. Broken hearted, they hugged and wept as they left his garden and went into Emily's home nearby for a cup of coffee.

It was agreed then and there that Jake would live out his life in his own home, and that Emily would help in any way that she could. First, they demystified the disease by learning all they could about it. Emily actively participated in a support group of folks sharing learnings and working together to do needed problem solving. The support group was invaluable and made everything else so much easier. It was like being given a road map. Emily and Jake

learned what to expect and how to prepare for probable developments. They discovered that sustaining quality of life was indeed quite possible, in spite of great odds.

Jake died 18 months later at 89 years of age resting in his easy chair, proud as he could be. Although he was just “skin and bones,” he could walk to the bathroom with a helping hand even on the morning of his death. He was well in mind and spirit to the end.

With the assistance of an innovative holistic health practitioner, Jake had managed to stave off loss of speech, respiratory problems, constipation and immobility. Key elements of his care included sound nutrition, and simple head to toe stress reduction and muscle toning exercises he could do in his easy chair. Daily outings to a chaise lounge in the garden allowed his spirit to soar "out into the wild blue yonder", as he assured Emily it was doing again just hours before he died.

When Jake's respiratory system finally did fail, a home hospice nurse was there to guide the way. Via telephone conference call from her office 20 miles away, she advised Jake and Emily regarding the morphine prescribed by his physician. The nurse told Jake how the medication would affect him, how best to take it, and how to use it appropriately in order to allow him to live out his dying hours comfortably and consciously at home with friends, as he so willed. He died peacefully less than 36 hours later.

Anna

Anna was a gentlewoman in her 70s whose husband Arthur was a spry 90 year old. Together they grew most of their fruits and vegetables on their country property. Jake and Emily lived nearby and were dear friends.

One day Anna fell going out to the garden. She became preoccupied with learning what had caused her to fall. In the course of a variety of examinations she acquired the flu, which led to pneumonia and hospitalization. Soon after, in a rather confused state of mind, Anna found herself placed in a nursing home.

Her husband, Arthur, called to ask Emily to look in on Anna as he feared she was having a mental and nervous breakdown. Emily found Anna tied with restraints into a wheelchair. She was extremely distressed by the fact that her son - a prominent

businessman - was insisting Anna stay in the nursing home. With a bit of reminiscing about the many years Emily and Anna were neighbors, and the shar-

ing of some stress reduction techniques that Emily knew, Anna was able to calm down and achieve a peaceful state of being by bedtime that evening.

Anna's son was so amazed by what he witnessed, that he hired Emily to work with Anna a few hours a day to help his mother "settle in." What the son didn't understand was that Anna was not about to settle in. She was going to go home and Emily would help her do just that.

After a few weeks of daily visits from Emily, which included outings into the community, Anna was well on the road to being her freestanding, independent self. She threatened to divorce her husband Arthur if he didn't take responsibility to bring her back home where she belonged. Their son signed an order forbidding the nursing home to permit anyone to take his mother outside of the home as Emily had been doing. And he fired Emily. Emily's response was to remind him that she was Anna's friend and neighbor and would continue to visit her.

With the help of the *Ombudsman Program** for patient rights, Anna prepared a *Durable Power of Attorney for Health Care* clarifying her wishes regarding any future care she would need. She was able to return home within a month. A woman came three times a week to help with household chores and stroll the neighborhood with Anna who used a walker.

Six months later Anna became ill again. This time she went to a residential care home she had learned about through the *Ombudsman Program*. It was a special place that allowed its residents to live life's end within the care facility, if that was the resident's desire. Anna died comfortably within a week from dehydration caused by her refusal to eat or take in fluids of any kind. Her caregivers honored her wish that she be allowed to die naturally, as was stated in her *Durable Power of Attorney for Health Care*.

*** *Italics* are used to indicate resources of value that will be clarified in detail further along in this work**

Norman

Within months after Emily began gardening for Norman, he became seriously ill. To her dismay, she learned he had cancer of the liver which had been in remission for some time. Weeks before they had worked together splitting more than a cord of firewood. He was “strong as an ox” for his 80+ years.

Suddenly, in only a matter of a few weeks, Norman no longer had even the strength to go outside. Together with his frail wife Louise, they pondered his fate, and hers. The hospital where Norman went for care was more than an hour's drive away and impossible for Louise to visit. Norman was dying and he wanted to die at home. So, together, that's what they agreed to accomplish with Emily in the lead.

A hospital bed set up in the living room worked well, as did the potty chair kept close at hand for convenience and to preserve precious energy. From his hillside view he could see out over the river and farmlands to the ocean far beyond. A visiting nurse came twice a week and the Council on Aging brought "Meals-on-Wheels" Monday through Friday. Norman and Louise managed right up to the end with a little assistance from neighbors and friends who provided a helping hand, love and home cooking to keep them going.

One morning Emily's husband came with her to help get Norman up, as he had become unable to get up without help. They found Louise sitting beside Norman's bed grieving. Norman had died peacefully in his sleep during the night, less than three months after the return of his cancer, with his dear wife beside him holding his hand.

Louise

After Norman's death, Louise who was nearly 90 years old, lost the will to live. The loss of her husband, coupled with constant pain caused by osteoporosis, was too much for her to bear. When Emily came to work after Norman's death Louise was so sad. She would tell Emily often that all she wanted to do was die. Emily told her she believed that Louise could do just that if she put her mind to it. Emily encouraged her to delegate all her responsibilities to people she could trust, so that Louise could be free to disengage completely and achieve the peace of mind needed to die willfully, without resorting to drastic measures.

Soon a man began coming regularly to manage Louise's financial

affairs, doing such things as preparing tax forms, paying bills, and managing her income. He came from the bank where Louise had worked as a secretary for 45 years. Next followed a woman who came to clean, cook and make the needed preparations for live-in help. Louise completed a *Nomination of Conservator* form designating an elderly neighbor and trusted friend.

Shortly thereafter, Louise was hospitalized briefly for what friends thought may have been a stroke. She returned home in a wheelchair with a live-in helper, to live out her remaining days. She always had a pleasant healthy glow whenever Emily would visit, but she never spoke another word. Louise died peacefully in her own bed, as she had willed, within one year of Norman's death. Before Louise became ill, she gave Emily two of her most treasured possessions: Arthur's gold penknife and the bible Louise's parents had given her as a young girl back near the turn of the century.

Aunt Ruthie Emily's aunt died less than six months after she entered the County Home. All those who visited her, including the priest who delivered the eulogy at her funeral, spoke of the grace, dignity, courage and peace she brought to her dying. The same lady Emily found terrified by the social pressure to trust the end of her life to the medical establishment and its technical fixes - had truly lived her dying naturally, as she chose to do. What warriors each and every one of these people were. Emily remains very close to them even now, years after their deaths. There would be a big void in her life without them. Their spirits indeed live on, and Emily enjoys their company often, much to her delight. Guardian angels? Perhaps. It just may be so.

Excerpt from Chapter Two: Life's Learnings Applied
an interview with a a well-known Bay Area octogenarian.

". . . Her life's work was helping those in need to get out of crisis and make their lives better. Never married, she devoted extraordinary time tending to the well-being of the poor, the elderly, and the homeless. She served as a social worker from the days of the Great Depression until her retirement. Since then, she has continued her work caring for the community in remarkable ways too numerous to mention.

Now wheelchair bound - disabled by a crippling stroke and advanced diabetes - she lives in her own home together with her pets, assisted by caregivers who drop in on a regular basis to lend a helping hand. Whenever the need arises or an opportunity

presents itself, she eagerly ventures out into the community.

Her home was built by her family around the turn of the century. Here she was raised by her aunt and uncle after becoming an orphan at a very young age . . . As we visit, the cat settles close by on the dining room table between us. An old dog effectively guards the door left unlocked so visits and business can proceed even though she can no longer answer the door during the day when she's home alone.

A poster of an American Indian tacked on her bedroom door, catches the eye. It reads:

When you have cut down all of the trees
And killed off all of the buffalo
And taken the last fish from the river,
Then I hope you can eat all your money.

Mohawk Woman to Teddy Roosevelt

Though physically disabled with the weight of years and illness, her mind is still sharp despite a nagging problem of forgetting people names. Her eyes twinkle like a child's when she's at her happiest. She raps the table to punctuate critical points. She types notes on an old cast iron Remington resting against the outer edge of a place mat which marks the spot at the table where she spends most all her days.

Ever so thoughtfully, she shares her views on aging in hopes of helping others to maintain quality of life as they age and live life's ending. Clara is a pseudonym.

On Growing Old

Susan Keller: *What insight can you share as to how you've been able to grow old, managing your life and ever-increasing handicaps so very well? How do you view growing old now that you are at this stage of your life?*

Clara: First of all, I don't look at it in those terms. I look at it like, "Gee, here I am and I've got to get dressed, I've got to get this and do that. How can I do it?" So I decide what I need and that's how I get by. I don't think of it as age. . . I have to do some trial and error myself. I have to see what I can do with what I have.

You see, all of my life, I've always done it this way. I always have

gone so far with something and if it didn't work, I pulled back and tried it another way. Because there isn't any other way for me to get by. It's only that I know if I can't get along doing this and being aged, then I will do it another way. And if I can't, well then I can't. . . What I am saying is that the process of how I've always gone about things has worked very successfully all the rest of my life. And so it should work now as well.

Susan: *The whole issue of death and dying is such a monumental part of life, yet few can or will talk about it. Why do you think it is that way?*

Clara: It seems important but none of us want to talk about something that frightens us and is threatening to others. But some of us are more accustomed to talking things over. . . I'm used to it, just more accustomed to this way of dealing with people and speaking my mind. It is because of how I am as a person.

In society where addressing the matter of death and dying is a big problem, it is because of how society deals with the whole matter. To change that, people have to make up their mind they are going to change, and you have to be in a position where you are going to make some changes in yourself.

. . . I deal with death and dying in the same way I have dealt with issues all of my life. . . It is a selfish thing when people won't face up to the reality. It short changes them and comes back around to get them. You just have to keep working with them, teaching and learning one on one.

Making the Difference: Actions of value

Susan: *If you could say something to help elderly people who are in poor health and facing the end of their life, what would you say?*

Clara: Communication is vital! To the elderly, I would say: "We are all going to die someday. You better think about what will happen when you die. You don't want to talk about it, but do remember we are all going to be that way someday and we must think about it." Some just won't think about it and to them I would say: "If you can't do that, fine, but you know it makes it hard on your children. Just think about it and try to make it easier . . ."

If we could get people to be more receptive and open to conversation about death and dying, the end of their life would be

so much more comfortable and satisfying . . . If they have never come out and faced this, you know they will get in a jam. You just have to keep working with them and try to help them see how they could do things a different way . . .

In America, I think we are disadvantaged regarding health care because we have always given over our medical care to the doctors. Generally speaking, we never had the opportunity to learn and experience holistic, natural ways to care for our health. If we get sick, we go to the doctor and do as the doctor says. And then of course, there is the health insurance industry. They tightly control the options we have available to us by what they will pay for in terms of health care.

As for myself, I came from a family who didn't listen to doctors as normal procedure. So I learned from my family that doctors aren't always right and that my own judgment and wisdom has great value also in pursuit of health and well-being. For me, I weigh my doctors advice along with my own values, knowledge and experience. . . .

Excerpts from Chapter: Managing Pain and Suffering

Pain Management

Professionals specialized in pain management, agree that 95% - 98% of all pain can be effectively treated, including side effects such as nausea and fatigue. Other commonly accepted understandings among professionals include the knowledge that:

- Pain is more easily treated before extreme pain has a chance to set in.
- Pain can usually be kept under control without clouding a person's consciousness.
- People can lessen the need for medication and surgery by using a variety of alternative pain management techniques such as rest, meditation, hypnosis, massage, acupressure, visualization, and touch therapy.
- Serious illness is not necessarily a physically, emotionally and

financially devastating experience.

- For most near end of life, quality of life is more important than quantity of life.

In recent years, pain management centers have been established across the country to assist people in identifying and managing root causes of pain. Simultaneously, medical professionals are beginning to challenge the dominance of science and technology in the field of health care. More and more people are questioning the wisdom and humanness of depending on technology to prolong life's end: all too often done without regard for the well-being of patient and family, and the inordinate expense that results.

Palliative care, also known as comfort care, is emerging as a realistic treatment option for anyone with advanced progressive disease. Palliative care is defined as comprehensive care aimed at quality of life for patient and family when cure is no longer the focus. Control of pain and other symptoms, as well as attention to psychological and spiritual issues is paramount. Gradually, it is being accepted in the United States as a field of medicine, supported by our academic institutions - as it is in England where the modern day hospice movement has its roots. Likewise, hospice service is flourishing in communities across America, with over 2,000 hospice programs now existing nationwide. . .

. . . Resources of Value

Learn what resources exist to help you and use them. . . Gather information about your illness, how it will progress, and your treatment options. Determine the kind of care and help you will need. Make contact with the many different agencies that exist to help people like yourself. Find out how they can help, and share with them your needs and worries. A lot of emotional and mental anguish can be resolved this easily.

According to the Director of Professional Services for a countywide home hospice service, the only people now empowered to find their way around in the medical system are professionals. She advises that people need to:

- know their rights
- learn what all the choices are

- learn how to ask the right questions
- be empowered to stand up for themselves
- identify alternative treatments
- learn to care for themselves.

It is important to get clarity about what really matters to you and then go after it. Get a friend to help if you aren't able. With very little time and a few phone calls you can make a remarkable difference. This point is well made by the true story that follows.

Upon learning that Jake had Lou Gehrig's Disease, his friend Emily immediately went to the library to learn about the disease and resources that could be helpful. A few phone calls later, Jake and Emily knew that nutrition and exercise were key and that he could lose his ability to speak early on. And so, they acted accordingly.

Creative cooking greatly boosted calorie intake as appetite decreased. Voice therapy overcame slurred speech. Stress reduction freed up energy needed to read and move about a bit. As Jake's caregiver, Emily participated in a support group that provided firsthand contact to cutting-edge researchers and an opportunity to share with others their success stories. Fear was rarely known thereafter. Jake died a peaceful natural death in his own home, well in spirit to the end.

What Emily learned along the way with Jake, and with several others close to her who have died - or are dying - is invaluable to know. *The intensity of pain and suffering one experiences, is directly related to the level of knowledge, skill and humanity those who share caregiving responsibilities bring to the task.* The lack of these attributes can cause people to suffer greatly. With a little effort, good planning and responsible action, this need not be.

Excerpts from Chapter Titled: Essential Papers: An Overview

Essential papers are the directives legally required to transfer responsibility for one's person and/or property to another person or legal entity. These papers, which professionals generally refer to as "advance directives," include:

- Advance Health Care Directive
(Durable Power of Attorney for Health Care)

- Nomination of Conservator
- Hospital or Non-hospital Do Not Resuscitate (DNR)
- Durable Power of Attorney for Finances
- Will and/or Living Trust

Also essential is a notebook or letter of instruction to cover related matters including business and personal affairs. For some papers it may be necessary to have signatures verified by a notary public.

Ideally, a person's essential papers should all fit neatly together, like tiles in a mosaic. When viewed altogether, they should present the complete picture of how a person would like their personal and financial matters to be handled should they become incapacitated or die. No ambiguity should remain regarding one's intentions and desires when these papers are done properly and all the appropriate conversations are completed with the physician, family members, spiritual counselors and legal advisors.

Having one's papers in order is key to achieving peace of mind and quality of life to its end. It helps to insure a smooth transition of personal and business affairs by providing the legal means to guide this stage of life and events which follow. And, it makes it so much easier for the one whose life is ending and those who are left to pick up the pieces, finalize details and carry on. With business settled, people can be present in the moment to share in the experience of life passing, with less worry and strife.

(This chapter goes on to explain and clarify) the different papers one must consider when planning the journey to life's end. Stories are included to help the reader understand the value of these papers and the choices that must be made when getting these papers in order.

End of excerpts from book.